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PREIMPLANTATION GENETIC TESTING FOR ADULT ONSET CONDITIONS AND THE MISMATCHED WRONGFUL BIRTH CLAIM: CREATING AN APPROPRIATE NEGLIGENCE CAUSE OF ACTION

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Abstract

Today, parents can choose to have the embryos they create using in vitro fertilization (IVF) tested for harmful genetic mutations they want to avoid passing along to their children. Through a process called preimplantation genetic testing (PGT), hundreds of genetic mutations can now be detected, allowing parents to select embryos for implantation without the tested-for mutation. But if, due to a healthcare provider's negligence, the resulting child is born with a harmful mutation causing an adult-onset condition, neither the parents nor the child can recover damages. This conundrum arose because the wrongful birth cause of action was created to deal with negligent prenatal counseling, testing, and diagnoses and, when PGT was later developed, it was simply subsumed under the wrongful birth umbrella. However, the wrongful birth framework is not a good fit for negligent selection of embryos and using this cause of action has resulted in a virtual immunity from liability for physicians, geneticists, and embryologists with respect to many negative outcomes affecting resulting offspring.

To illustrate the shortcomings of the wrongful birth cause of action in the context of wrongful selection of embryos, this Article focuses on the mutations related to three adult-onset conditions: BRCA 1 and 2, Lynch syndrome, and early-onset Alzheimer's. These mutations were selected because carrying them is associated with profound medical, psychological, and financial repercussions. Using these three examples, this Article examines why the legal underpinnings of the wrongful birth cause of action prevent an equitable resolution of negligence claims related to PGT. In addition, this Article addresses the foundational ethical and policy differences between standard wrongful birth cases and those involving wrongful selection. Essentially, women in most wrongful birth cases allege that, but for the healthcare provider's negligence, they would have had the opportunity to abort a fetus, who is now a child with severe disabilities. This premise has subjected wrongful birth actions to scathing

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criticism and caused several states to ban them. Significantly, studies have shown that women view abortion and selection of embryos differently. While they would be willing to select among embryos, they are generally unwilling to abort a fetus with a mutation likely to result in an adult-onset condition. This viewpoint, the ethical and policy distinctions it engenders, and the legal differences between wrongful birth and wrongful selection demonstrate the importance of creating a new cause of action for cases involving PGT. Finally, this Article uses traditional tort principles to provide a clear pathway for granting families financial relief for the extraordinary costs associated with the subject mutations and for their accompanying emotional distress. The intent is to create a helpful roadmap for future cases involving PGT, a rapidly expanding area of reproductive technology.

INTRODUCTION

Due to advances in assisted reproductive technology (ART) and preimplantation genetic testing (PGT), parents have unprecedented control over the genetic makeup of their offspring. Since the first birth by in vitro fertilization (IVF) in 1978,[1] researchers have created successful new techniques to combat infertility[2] and testing that can be used to detect genetic anomalies in embryos.[3] During this same time period, the number of babies born using ART has soared. Since 1978, ART has resulted in more than ten million births worldwide[4] and is currently responsible for approximately 500,000 births annually.[5] And these numbers are likely to increase due, in part, to the Supreme Court's decision in *Dobbs v. Jackson Women's Health Organization*, holding that women no longer have a constitutional right to abortion.[6] Since the *Dobbs* decision, nineteen states have passed statutes so substantially limiting the timing of abortions that the results from the two most accurate prenatal genetic tests would be received too late for a woman to receive an abortion based on adverse results.[7] Due to losing this option, many more women and couples—especially those who know they are carriers of disease-inducing genetic mutations—may use PGT to ensure they don't pass the harmful mutations to their offspring.

Despite the enormous progress in PGT and increasing use of ART, the law has not kept pace with these technological advances. To deal with malpractice relating to PGT, the courts generally rely on the reproductive negligence causes of action created for prenatal counseling and testing,

1. Barbara P. Billauer, *Wrongful Life in the Age of CRISPR-CAS: Using the Legal Fiction of "The Conceptual Being" to Redress Wrongful Gamete Manipulation*, 124 PENN. ST. L. REV. 435, 443–44 (2020) (noting that assisted reproductive technologies "have progressed exponentially [since the birth] of Louise Brown via IVF in 1978").

2. *Id.* at 444 (listing advances including intracytoplasmic sperm injection, mitochondrial transfer, and in vitro gametogenesis via somatic cell nuclear transfer).

3. Jeffrey R. Botkin, *Prenatal Diagnosis and the Selection of Children*, 30 FLA. ST. U. L. REV. 265, 280 (2003).

4. R.J. Hart & L.A. Wijs, *The Longer-Term Effects of IVF on Offspring from Childhood to Adolescence*, 4 FRONTIERS IN REPRODUCTIVE HEALTH 1, 1 (2022).

5. *Id.*

6. Dobbs v. Jackson Women's Health Org., 597 U.S. 215, 302 (2022).

7. *Policy Tracker: Exceptions to State Abortion Bans and Early Gestational Limits*, KFF (Nov. 24, 2025), https://www.kff.org/womens-health-policy/dashboard/exceptions-in-state-abortion-bans-and-early-gestational-limits/ [https://perma.cc/WDZ9-93RT].

especially the wrongful birth cause of action.[8] But fundamental differences between prenatal and preimplantation testing, and continuing use of the wrongful birth cause of action, have created a virtual immunity from liability for geneticists, embryologists, and physicians for mistakes in performing PGT that rob parents of their reproductive choices.[9]

To illustrate the need for a new legal framework with the flexibility to take into account the nuances inherent in preimplantation testing, this Article focuses on negligent selection of an embryo, during or after PGT, resulting in a child carrying a mutation causing BRCA 1 and 2, Lynch syndrome, or early-onset Alzheimer's. Having any of these adult-onset conditions has profound physical, emotional, and financial repercussions, making them a good backdrop for discussing why the wrongful birth cause of action is incompatible with equitably addressing negligence in PGT. This Article also directly confronts the central premise in traditional wrongful birth cases, which is that, due to the physician's negligence, the mother lost her opportunity to choose not to conceive or to abort her fetus, who is now a severely disabled child. The ethical and policy concerns this premise engenders are foundationally different from any concerns that could be raised with respect to PGT involving adult-onset conditions.

After fully exploring these legal, ethical, and policy differences, this Article proposes a clear pathway for creating a suitable cause of action. The recommendations include recognizing (1) the direct causal connection between negligently selecting an embryo with a deleterious mutation and the resulting harm to the parents; (2) the differences in policy considerations between negligent PGT and wrongful birth cases based in large part on survey results indicating that most parents would not choose to abort a fetus carrying a mutation for one of the three adult-onset conditions set forth above; and (3) the differing ethical and philosophical considerations involved in selecting among embryos as opposed to choosing abortion based on adverse prenatal test results. The recommended damages are carefully structured to avoid monetary windfalls for parents while providing them with financial awards to help compensate for their harm.

This Article proceeds as follows. Immediately following this introduction, Part I provides the necessary background for understanding prenatal and preimplantation testing. Part II examines the burdens on individuals who are carriers of the BRCA, Lynch syndrome, or early-

8. Kathleen A. Mahoney, *Malpractice Claims Resulting from Negligent Preconception Genetic Testing: Do These Claims Present a Strain of Wrongful Birth or Wrongful Conception, and Does the Categorization Even Matter?*, 39 SUFFOLK U. L. REV. 773, 789 n.110 (2006); Barbara Pfeffer Billauer, *Re-Birthing Wrongful Birth Claims in the Age of IVF and Abortion Reforms*, 50 STETSON L. REV. 85, 87 (2020).

9. *See generally* DOV FOX, BIRTH RIGHTS AND WRONGS: HOW MEDICINE & TECHNOLOGY ARE REMAKING REPRODUCTION AND THE LAW 43 (Oxford Univ. Press 2019).

onset Alzheimer's mutations and their families. Part III introduces the reproductive negligence causes of action with an emphasis on the courts' reluctance to consider a child's life a harm and the corresponding creative approaches the courts have adopted in wrongful birth cases to avoid this problem. Parts IV and V focus on the legal, policy, and ethical differences between wrongful birth claims and negligence claims based on wrongful selection of embryos. Part VI explores philosophical and ethical distinctions between embryo selection and abortion. Finally, Part VII recommends structuring a remedy for negligent selection of embryos that provides a monetary damage award without unduly burdening healthcare professionals.

I. BACKGROUND

There have been prodigious advances in both prenatal testing and ART since 1978. Several noninvasive, prenatal screening tests are currently available,[10] but amniocentesis and chorionic villus sampling (CVS) remain the most reliable prenatal diagnostic tests for genetic abnormalities.[11] Amniocentesis became a component of reproductive care in the U.S. in the early 1970s[12] and is the only diagnostic test available during the second and third trimesters of pregnancy.[13] This test

10. Rachel Rebouche, *Testing Sex*, 49 U. RICH. L. REV. 519, 527–28 (2015) (noting that a new noninvasive prenatal test (NIPT) can test fetal DNA present in the pregnant woman's blood and that there are other serum screening blood tests); FOX, *supra* note 9, at 27 ("Analysis of fetal DNA in a pregnant woman's blood sample has become a routine part of prenatal care since tests burst onto the American market in 2011.").

11. FOX, *supra* note 9, at 27 (noting that analysis of fetal DNA in a woman's blood through non-invasive prenatal testing (NIPT) is "nowhere near reliable enough to tell whether or not a fetus actually has a particular disorder" and noting that blood screens are used to determine whether invasive testing such as amniocentesis is necessary); Laura M. Carlson & Neeta L. Vora, *Prenatal Diagnosis: Screening and Diagnostic Tools*, 44(2) OBSTET. GYNECOL. CLINICAL NORTH AM. 252, 245–56 (2017) ("Chromosome analysis from CVS and amniocentesis samples is the most reliably predictive method of identifying pregnancies affected by chromosomal disorders."); *What is Noninvasive Prenatal Testing (NIPT) and What Disorders Can it Screen For?*, MEDLINEPLUS, https://medlineplus.gov/genetics/understanding/testing/nipt/ [https://perma.cc/UD4T-VGMN] (last visited Feb. 11, 2025) ("NIPT is a screening test, which means that it will not give a definitive answer about whether or not a fetus has a genetic condition."); Hilary Bowman-Smart et al., *Non-Invasive Prenatal Testing for "Non-Medical" Traits: Ensuring Consistency in Ethical Decision-Making*, 23 AM. J. BIOETHICS 3, 4 (2023) (recommending that "any high-risk result [from NIPT] be followed up with invasive testing such as chorionic villus sampling (CVS) or amniocentesis to confirm the diagnosis.").

12. *Evolution in Prenatal Testing*, THE HASTINGS CTR. (Nov. 27, 2017), https://www.thehastingscenter.org/prenatal/evolution-prenatal-testing/ [https://perma.cc/62CH-J9WP].

13. Carlson & Vora, *supra* note 11, at 7.

is generally performed between fifteen and twenty weeks gestation.[14] During the test, amniotic fluid is removed by inserting a needle through the abdomen and into the uterus.[15] The fetal cells in the fluid can then be tested for chromosomal abnormalities and genetic mutations.[16]

Chorionic villus sampling became a second major diagnostic tool for prenatal testing in the 1980s.[17] This test is performed either through the cervix or abdomen[18] and requires removing a small tissue sample from the placenta for genetic analysis.[19] The main advantage of CVS is that the test can be performed between ten and thirteen weeks' gestation, significantly earlier in pregnancy than amniocentesis.[20]

Prenatal testing is now widely used and accepted in the U.S.[21] In fact, the American College of Obstetricians and Gynecologists (ACOG) recommends that obstetricians offer screening to all pregnant women for genetic anomalies using ultrasound, blood tests, or both.[22] If these noninvasive tests indicate that there is a high risk of the fetus being born with a genetic abnormality, most women undergo more reliable prenatal testing through amniocentesis or CVS.[23]

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14. Laura Ungar & Amanda Seitz, *Post-Roe v. Wade, More Patients Rely on Early Prenatal Testing as States Toughen Abortion Laws*, ASSOCIATED PRESS (Feb. 12, 2024), https://apnews.com/article/abortion-genetic-testing-ultrasound-amniocentesis-01e4c591617773efb91d9583be6244c4 [https://perma.cc/3KZP-3QG6] (noting also that, similar to CVS, results generally take a few days and detailed results about two weeks).

15. Zarko Alfirevic et al., *Amniocentesis and Chorionic Villus Sampling for Prenatal Diagnosis*, 9 COCHRANE DATABASE SYST. REV. 1, 12 (2017); Botkin, *supra* note 3, at 279.

16. Sonia M. Suter, *The Routinization of Prenatal Testing*, 28 AM. J. L. MED. 233, 235 (2002).

17. *Id*.

18. Carlson & Vora, *supra* note 11, at 7.

19. Botkin, *supra* note 3, at 279; *What is Noninvasive Prenatal Testing (NIPT) and What Disorders Can it Screen For?*, *supra* note 11.

20. Ungar & Seitz, *supra* note 14; Carlson & Vora, *supra* note 11 (also noting that CVS was once performed prior to nine weeks, but is no longer recommended until ten weeks' gestation).

21. Plowman v. Fort Madison Comm. Hosp., 896 N.W.2d 393, 400 (Iowa 2017).

22. Michelle J. Bayefsky & Benjamin E. Berkman, *Implementing Expanded Prenatal Testing: Should Parents Have Access to Any and All Fetal Genetic Information?*, 22(2) AM. J. BIOETHICS 4, 5 ("Newer guidelines now recommend that all women, regardless of age or other risk factors, be offered some kind of aneuploidy screening [for chromosomal abnormalities] or diagnostic testing – either serum markers, NIPT, or invasive testing."); *Current ACOG Guidance: NIPT Summary of Recommendations*, AM. COLL. OF OBSTETRICIANS & GYNECOLOGISTS, https://www.acog.org/advocacy/policy-priorities/non-invasive-prenatal-testing/current-acog-guidance [https://perma.cc/F9FG-YUPB] (last visited Feb. 2, 2025); Cailin Harris, *Statutory Prohibitions on Wrongful Birth Claims and Their Dangerous Effects on Parents*, 34 B.C. J. L. & SOC. JUST. 365, 370 (2014).

23. Harris, *supra* note 22, at 370; Megan B. Raymond et al., *Implications for Prenatal Genetic Testing in the United States After the Reversal of* Roe v. Wade, 141(3) OBSTETRICS & GYNECOLOGY 445, 446 (2023) (noting that CVS or amniocentesis should be performed after "abnormal genetic screening" before pregnancy termination).

While these diagnostic tests have been crucial in giving pregnant women more information about the health of their fetus and, therefore, more reproductive choice,[24] they have a major disadvantage. A woman must terminate her pregnancy if she chooses not to have a child with a diagnosed genetic condition.[25] This shortcoming led to PGT,[26] the diagnostic testing of embryos prior to conception.[27] PGT reduces the potential for termination of a pregnancy because only embryos without the tested-for genetic abnormalities are implanted in the uterus.[28]

However, while PGT has this important advantage over prenatal testing, it also has a significant disadvantage; it is substantially more burdensome for prospective parents than prenatal testing. Because PGT is performed on embryos, couples interested in PGT must first assume the "risks, discomfort, and expense of [IVF]"[29] to produce those embryos.[30] For IVF, women are given hormones to stimulate the production of more than one egg in a given month.[31] When the time comes to remove the eggs that have developed, women are given pain medication and then the eggs are surgically removed from their ovaries.[32] After the eggs mature, they are fertilized in a petri dish or test tube with the semen of a partner or donor, or through intracytoplasmic sperm injection (ICSI), where a single sperm is injected into each egg.[33]

Once the eggs are fertilized and the surviving embryos have developed for five days, multiple cells can be removed from each embryo and analyzed using PGT.[34] Amazingly, the cells that remain in the

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24. Suter, *supra* note 16, at 236.

25. Sonia M. Suter, *Genomic Medicine – New Norms Regarding Genetic Information*, 15 HOUS. J. HEALTH L. & POL'Y 83, 86 (2015) (noting that women who receive prenatal testing can "decide whether to continue the pregnancy, or simply be prepared to deal with the condition if the fetus carries the relevant mutations"); Susannah Baruch, *Preimplantation Genetic Diagnosis and Parental Preferences: Beyond Deadly Disease*, 8 HOUS. J. HEALTH L. & POL'Y 245, 259 (2008) (noting that prenatal testing leaves "parents to face the often extremely difficult decision of whether to terminate a pregnancy").

26. Baruch, *supra* note 25, at 245 ("PGD developed initially as an alternative to prenatal genetic diagnosis and termination . . .").

27. Botkin, *supra* note 3, at 280 (noting that, with preimplantation genetic diagnosis (PGD), genetic testing can be performed on the embryo "before it is even implanted in the uterus").

28. Carlson & Vora, *supra* note 11; Anver Kuliev & Yury Verlinsy, *Preimplantation Genetic Diagnosis: Technological Advances to Improve Accuracy and Range of Applications*, 16(4) REPROD. BIOMED. ONLINE 536, 532–38 (2007).

29. Baruch, *supra* note 25, at 250.

30. Gwendolyn Quinn et al., *Attitudes of High-Risk Women Toward Preimplantation Genetic Diagnosis*, 91(6) FERTILITY & STERILITY 2361, 2362 (2009).

31. *Id.*

32. *Id.*

33. *Id.*

34. Judith Daar, *A Clash at the Petri Dish: Transferring Embryos with Known Genetic Anomalies*, 5(2) J. L. & BIOSCIENCES 219, 221, 231 (2018); Kuliev & Verlinsy, *supra* note 28 ("PGD is based on oocyte or embryo biopsy and DNA analysis of biopsied material.").

embryo divide and fill the gap left by those that were removed and the embryo continues to develop normally.[35] PGT has several components: PGT-SR (structural rearrangements) is used to test embryos for chromosomal abnormalities, "where the structure or number of chromosomes is altered."[36] These anomalies can result in conditions such as Down syndrome or Turner syndrome.[37] Another technique, PGT-A (aneuploidy screening), is commonly used to screen for an abnormal number of chromosomes, also called aneuploidy.[38] There are also tests for genetic mutations. PGT-M tests for monogenic disorders, which are disorders caused by a single gene mutation,[39] including Tay Sachs, Huntington's disease, and cystic fibrosis.[40] PGT-P tests for "diseases influenced by multiple genes and environmental factors, such as diabetes, cancers, and cardiovascular diseases."[41] PGT for genetic mutations (PGT-M and PGT-P) is generally requested when individuals wish to avoid passing a heritable disorder to their children.[42]

PGT was first successfully used in the U.K. and the U.S. in 1990.[43] By 2010, the number of children born using this technique exceeded 10,000.[44] While PGT was becoming more popular, knowledge of genetic markers was also exploding.[45] Hundreds of PGT and prenatal tests were developed to detect genetic mutations that cause conditions ranging from seriously disabling to much less severe.[46] This expansion in knowledge also resulted in the ability to use PGT and prenatal testing to detect a predisposition to some conditions that do not manifest until adulthood, such as certain cancers and early-onset Alzheimer's.[47] Due to the proven

35. SIDDHARTHA MUKHERJEE, THE GENE: AN INTIMATE HISTORY 456 (2016).

36. Ido Alon et al., *Mapping Ethical, Legal, and Social Implications of Preimplantation Genetic Testing*, 41 J. ASSISTED REPROD. & GENETICS 1153, 1153 (2024).

37. Daar, *supra* note 34, at 221.

38. Alon et al., *supra* note 36.

39. Daar, *supra* note 34, at 230.

40. *Id.* at 221.

41. Alon et al., *supra* note 36.

42. Daar, *supra* note 34, at 229.

43. Joanna Liss et al., *Current Methods for Preimplantation Genetic Diagnosis*, 8(7) GINEKOLOGIA POLSKA 522, 522 (2016); Alon et al., *supra* note 36.

44. Liss et al., *supra* note 43, at 522.

45. Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. CR-C.L.L. REV 141, 142 (2005).

46. *Id.*; Daar, *supra* note 34, at 221 ("Rapid developments in [PGT] offer the opportunity to detect nearly 400 genetic anomalies in an IVF-produced embryo a mere 5 days after its formation in a laboratory setting.").

47. Kuliev & Verlinsy, *supra* note 28 (noting that PGT is "being performed for an increasing number of [genetic disorders] that present beyond early childhood and may not even occur in all cases"); Botkin, *supra* note 3, at 282 ("While a couple might be primarily interested in avoiding the use of an embryo with serious deleterious mutation, the technology offers the opportunity for much more fine-grained selections.").

safety of PGT[48] and its benefits in providing potential parents information about their future child,[49] it has become routine for individuals undergoing IVF due to infertility to also choose to have their embryos analyzed using PGT.[50] For infertile couples, this testing not only detects genetic anomalies, but is also used to determine which embryos to implant to reduce the risk of miscarriage and increase implantation rates.[51]

Given the widespread use of preimplantation testing and its significance to parents,[52] it would seem that there should be substantial liability for negligence related to this testing. If prospective parents engage professionals and submit to invasive procedures to avoid the birth of infants with serious health issues, there should be a duty on the part of those professionals to exercise reasonable care.[53] Surprisingly, medical doctors, embryologists, and geneticists "enjoy a protected status from liability"[54] because tort accountability for harm is severely limited as it relates to parents' damages attributable to their child.[55] This is especially alarming because, while major errors are rare,[56] reported lab and other errors involving ART and PGT have occurred on a regular basis.[57] These

48. Carlson & Vora, *supra* note 11 ("The growing body of literature surrounding [PGT] illustrates minimal risk outside of the cost of this procedure.").

49. Suter, *supra* note 16, at 242–43 (noting that "the strong interest in information [from prenatal testing] reflects a desire to gain some sense of control over a process so fundamentally out of one's control").

50. Botkin, *supra* note 3, at 281 (noting that "[PGT] has become common in couples undergoing IVF . . . as a way of checking the genetic health of the embryos . . . "); Kuliev & Verlinsy, *supra* note 28 ("Preimplantation genetic diagnosis is currently an established procedure . . . "); Anna Louie Sussman, *Should Human Life Be Optimized?*, N.Y. TIMES (April 1, 2025), https://www.nytimes.com/interactive/2025/04/01/opinion/ivf-gene-selection-fertility.html [https://perma.cc/L7WU-BVNP] ("Today some form of [PGT] is used in over half of I.V.F. cycles in the United States, at a cost of $3000 to $5,000 per batch of embryos.").

51. Alon et al., *supra* note 36; F. Shenfield et al., *Taskforce 5: Preimplantation Genetic Diagnosis*, 18(3) HUM. REPROD. 649, 650 (2003).

52. *See, e.g.*, FOX, *supra* note 9, at 17 ("Decisions about pregnancy implicate a woman's values, goals, lifestyle, partner stability, support networks, and financial security.").

53. Harbeson v. Parke-Davis, Inc., 98 Wash. 2d 460, 472 (Wash. 1983).

54. Billauer, *supra* note 8.

55. Barbara Pfeffer Billauer, *Genetically-Engineered Begots, Have-Nots, and Tinkered Tots: (High Scoring Polygenic Kids as a Hereditary-Camelot) – An Introduction to the Legalities and Bio-Ethics of Advanced IVF and Genetic Editing*, 96 CHI. KENT L. REV. 3, 4 (2021) (noting that cases addressing reproductive accidents "in the context of IVF facilities demonstrate that if harm occurs to resultant children, tort liability is virtually unavailable."); FOX, *supra* note 9, at 6 ("In the United States, victims who take procreation specialists to court almost always lose.").

56. *See generally* Chibuzor Willams Ifenatuoha et al., *Errors in IVF Laboratories: Risk Assessments and Mitigations*, 28 MIDDLE E. FERTILITY SOC'Y J. 5 (2023).

57. *See* FOX, *supra* note 9, at 10 (noting that "accidents are pervasive"); Barbara Pfeffer Billauer, *The Sperminator as a Public Nuisance: Redressing Wrongful Life and Birth Claims in New Ways (A.K.A. New Tricks for Old Torts)*, 42 U. ARK. LITTLE ROCK L. REV. 1, 12 (2019)

errors include incorrect labeling and communication failures that resulted in embryo mix-ups.[58] The number of reported lab errors are also probably too low because laboratories and reproductive specialists may be reluctant to disclose their errors.[59]

The closest causes of action to remedy reproductive negligence involving PGT are wrongful birth, wrongful life, and wrongful pregnancy.[60] But these causes of action were originally created to deal solely with errors related to voluntary sterilization, preconception and prenatal testing, and counseling,[61] and are insufficient to address negligent preimplantation testing.[62] The first major cases establishing a viable wrongful birth claim were decided in 1975,[63] about fifteen years before PGT was even used in the U.S.[64] When cases involving errors related to PGT were eventually commenced, the courts simply continued

("Among clinics reporting errors [in the UK], one in five reported errors in labelling, diagnosing, [and] handling donor samples and embryos for implantation.").

58. *See* Ifenatuoha et al., *supra* note 56; Gerard Letterie, *Outcomes of Medical Malpractice Claims in Assisted Reproductive Technology Over a 10-Year Period from a Single Carrier*, 34 J. ASSIST REPROD. GENETICS 459, 462, Table 3 (2017) (mentioning errors in IVF laboratories including one case in which "carrier screening for [cystic fibrosis] was positive but reported as negative" and "[a]fter IVF, [the] child was born with [cystic fibrosis]."); FOX, *supra* note 9, at 41 (listing some "preventable mistakes" in labs).

59. *See, e.g.*, Ifenatuoha et al., *supra* note 56; SHARON T. MORTIMER & DAVID MORTIMER, QUALITY AND RISK MANAGEMENT IN THE IVF LABORATORY 51 (2d ed., Cambridge Univ. Press 2015) ("Unless a comprehensive system of Incident Reports for all adverse events is in place, enforced, and employed constructively, many mistakes will never be recognized or remembered."); Susan Dominus, *Someone Else's Daughter*, N.Y. TIMES MAG. Dec. 1, 2024, at 33 (noting that "[s]tates do not mandate that fertility clinics report preventable and damaging mistakes when they happen, as required by hospitals").

60. *See* FOX, *supra* note 9, at 43; Mark Strasser, *Yes, Virginia, There Can Be Wrongful Life: On Consistency, Public Policy, and the Birth-Related Torts*, 4 GEO. J. GENDER & L. 821, 821 (2003) ("Many, but not all, states distinguish among the birth-related torts – wrongful conception and wrongful pregnancy, wrongful birth, and wrongful life.").

61. *See, e.g.*, Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149, 152 (1992) (noting that early wrongful birth suits involved proper counseling and prenatal diagnosis); Thomas Dewitt Rogers III, *Wrongful Life and Wrongful Birth: Medical Malpractice in Genetic Counseling and Prenatal Testing*, 33 S. C. L. REV. 713, 720–21 (1982) ("The refinement of amniocentesis, along with other prenatal testing procedures, established the technological predicate for wrongful life and wrongful birth claims.").

62. FOX, *supra* note 9, at 43.

63. *See* Rogers III, *supra* note 61, at 743–44 (noting that legal developments concerning abortion and scientific advances in prenatal testing led to two state supreme court decisions recognizing the wrongful birth cause of action in 1975); *see also* Jacobs v. Theimer, 519 S.W.2d 846, 847 (Tex. 1975); Berman v. Allan, 404 A.2d 8, 14 (N.J. 1979); Becker v. Schwartz, 386 N.E.2d 807, 813 (N.Y. 1978).

64. Daar, *supra* note 34, at 230.

to apply the wrongful birth cause of action.[65] To illustrate why a separate cause of action is imperative for negligence in PGT, this Article focuses on preimplantation testing for mutations related to three adult-onset genetic conditions: BRCA 1 and 2, Lynch syndrome, and early-onset Alzheimer's disease.

II. THE PHYSICAL, EMOTIONAL, AND PRACTICAL BURDENS OF ADULT-ONSET GENETIC CONDITIONS

Some researchers oppose all preimplantation testing for adult-onset genetic conditions,[66] arguing that PGT should be limited to conditions that are painful and disabling starting in early childhood or cause the death of young children.[67] Others support this testing, but only if, for example, the condition to be avoided is severe, there are significant quality of life concerns, and the lapse of time before the condition manifests is considered.[68] These commentators believe that limitations on PGT are necessary to ensure that embryos are not selected based on insignificant or discriminatory human characteristics.[69]

Despite these concerns, there is general support for using PGT to test for the mutations that cause BRCA 1 and 2, Lynch syndrome, and early-onset Alzheimer's. For example, although the U.K. did not initially permit PGT for adult-onset genetic conditions, in 2006 the Human

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65. Mahoney, *supra* note 8 (noting that "[p]arents assert essentially the same argument [as in wrongful birth cases] in lawsuits stemming from preconception genetic testing negligence"); Billauer, *supra* note 8 ("Errors in IVF or failed reproductive procedures typically generate claims for 'wrongful birth' if brought by the parents, or 'wrongful life' if brought by the child.").

66. *See* Kuliev & Verlinsy, *supra* note 28.

67. *See, e.g.*, Quinn et al., *supra* note 30, at 2362; Elizabeth Ormondroyd et al., *Attitudes to Reproductive Genetic Testing in Women Who Had a Positive BRCA Test Before Having Children: A Qualitative Analysis*, 20 EUR. J. HUM. GENETICS 4, 5 (2012) (noting concerns that extending PGT to cancer predisposition moves from "the original intention to protect people from the fate of an early, painful death or severe disability"); Baruch, *supra* note 25, at 246 (noting that "[n]umerous ethical questions exist" about using PGD [preimplantation genetic diagnosis] for conditions "beyond those linked with serious immediate health concerns").

68. *See, e.g.*, Shenfield et al., *supra* note 51, at 650 (noting the importance of taking "into account the severity of the illness and the effects on the quality of life of future offspring"); Eunice I. Oribamise et al., *Preimplantation Genetic Testing for Breast Cancer*, 60(3) NIGER MED. J. 99, 103 (2019) ("PGT for late-onset genetic cancers such as BRCA1 or BRCA2 holds specific questions concerning the time lapse of testing and severity of the disease. . .").

69. Baruch, *supra* note 25, at 266 (noting that the question remains of "where the line [for PGT testing] should be drawn and which additional diseases ought to be permissible targets of [PGT]"); Ormondroyd et al., *supra* note 67, at 4 ("[PGT] invokes fundamental questions including what characteristics convey the right to be born, and who should decide"); CARSON STRONG, ETHICS IN REPRODUCTIVE AND PERINATAL MEDICINE: A NEW FRAMEWORK 142 (Yale Univ. Press, 1997) ("If physicians are encouraged to draw lines [concerning prenatal testing] where they think diseases are 'too minor,' lines will be drawn in a wide variety of places."); Botkin, *supra* note 3, at 291 (". . . I believe that there is sufficient consensus that public policy not promote or condone discarding embryos . . . for less than weighty reasons.").

Fertilisation and Embryology Authority (HFEA)—the entity responsible for the regulation of fertility treatments in the U.K.—approved the use of PGT for inherited breast, bowel, and ovarian cancers.[70] The HFEA stated that its decision was based on the "aggressive nature of the cancers, the impact of treatment, and the extreme anxiety that carriers of the gene experience."[71] Similarly, in 2003 the Ethics Task Force of the European Society of Human Reproduction and Embryology (ESHRE) determined that "[PGT] for late onset diseases is acceptable . . . [including] in the case of multifactorial diseases (like BRCA) . . . ."[72] Likewise, in the U.S., where decisions concerning PGT are generally left to physicians, labs, and prospective parents,[73] testing for BRCA, Lynch syndrome, and Alzheimer's is commonly offered.[74] This widespread support is understandable because the tested-for mutations cause immense burdens and suffering for those who have them and their families.[75] An additional side benefit is that reducing the number of individuals who have the diseases these mutations foster will result in huge cost savings for the healthcare system.[76] Moreover, the risk that allowing PGT for these conditions will lead to public demand for selection of superficial human characteristics is minimal because of the substantial risks, burdens, and expenses[77] associated with IVF and PGT.[78]

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70. Clare Dyer, *HFEA Widens Its Criteria for Preimplantation Genetic Diagnosis*, 332 B.M.J. 1174, 1174 (2006); Gregory Katz & Stuart O. Schweitzer, *Implications of Genetic Testing for Health Policy*, 10 YALE J. HEALTH POL'Y AND ETHICS 90, 113–14 (2010); Baruch, *supra* note 25, at 266.

71. Dyer, *supra* note 70.

72. Shenfield et al., *supra* note 51, at 650; Oribamise et al., *supra* note 68, at 99–105.

73. Baruch, *supra* note 25, at 261–65.

74. *Id.* at 253 (noting that IVF clinics have used PGT to "avoid diseases such as Huntington's disease, hereditary breast cancer, or Alzheimer's disease"); Jessica Furseth, *You Have a 50/50 Chance of Passing a Cancer Gene to Your Child. What Would You Do?*, MEDIUM (Mar. 1, 2021), https://futurehuman.medium.com/you-have-a-50-50-chance-of-passing-a-cancer-gene-to-your-child-what-would-you-do-2c54e243c877 [https://perma.cc/XBU3-C7PJ] ("Widespread testing for cancer-risk genes, like BRCA and Lynch and other genetic variations that increase the risk of Alzheimer's . . . have only become available in the last two decades."); Kuliev & Verlinsy, *supra* note 28, at 535 (noting that PGT is being performed for mutations resulting in inherited forms of cancer, Alzheimer's disease, and congenital malformations).

75. Baruch, *supra* note 25, at 266 (noting that "there is no doubt [that PGT] will reduce suffering in families [that have mutations causing inherited breast, bowel, and ovarian cancers]").

76. Katz & Schweitzer, *supra* note 70, at 115 ("From a utilitarian approach, the cost disparity between prevention and treatment is considerable for health insurers and public health authorities.").

77. Furseth, *supra* note 74 (noting that the cost of "a round of IVF and PGT-M is about $20,000 to $30,000").

78. Baruch, *supra* note 25, at 251 (noting that the "expense, discomfort and risks of [PGT] . . . suggest that few parents would pursue [PGT] casually for the sole purpose of having children with preferred genetic characteristics").

A. *BRCA1 and BRCA2*

The BRCA1 and BRCA2 genes were discovered in the 1990s.[79] They belong to a class of DNA repair genes that monitor and fix mutations in other genes, thereby reducing the risk of cancer.[80] Due to this role, mutations in BRCA genes[81] greatly increase a woman's chances of developing hereditary breast and ovarian cancer (HBOC) and also cause a heightened risk of developing other cancers.[82] Although the precise statistics vary by mutation type[83] and are not entirely consistent in the literature, a BRCA carrier's lifetime risk of developing breast cancer can be as high as 72% and as high as 58% for developing ovarian, fallopian tube, or peritoneal cancer.[84] Comparatively, the risk of a woman in the general population developing breast cancer is about 12.5% and 1.3% for developing ovarian, fallopian tube, or peritoneal cancer.[85]

Indeed, the risk of developing cancer is so high for a woman with a diagnosed BRCA mutation that she becomes a patient while still

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79. Umut Varol et al., *BRCA Genes: BRCA 1 and BRCA 2*, 23(4) J. BUON 862, 862 (2018).

80. *Id.* at 863 (noting that BRCA 1 and BRCA 2 genes "function as tumor suppressor genes"); Paul J. Hoskins & Walter H. Gotlieb, *Missed Therapeutic and Prevention Opportunities in Women with BRCA-Mutated Epithelial Ovarian Cancer and Their Families Due to Low Referral Rates for Genetic Counseling and BRCA Testing: A Review of the Literature*, 67(6) CA CANCER J. CLINICAL 493, 495 (2017) ("The normal function of [BRCA 1 and BRCA 2] genes is in the high-fidelity repair of double-stranded DNA breaks.").

81. Varol et al., *supra* note 79, at 863 ("Since the BRCA genes are large genes, hundreds of mutations have been identified on them.").

82. *See id.* at 862.

83. Deborah Thompson et al., *Variation in Cancer Risks, by Mutation Position, in BRCA2 Mutation Carriers*, 68 AM. J. HUM. GENETICS 410, 417 (2001); Hoskins & Gotlieb, *supra* note 80, at 500 (noting that "[h]igh grade [epithelial ovarian cancer] is often associated with deficient double-stranded DNA repair" which is most commonly associated with "mutated BRCA").

84. Facing Our Risk of Cancer Empowered (FORCE), an organization whose mission "is to improve the lives of families facing hereditary cancer," cites the BRCA1 lifetime risk for breast cancer as 60–72% and the risk of ovarian, fallopian tube, and peritoneal cancers at 39–58%. *Cancer Risks Associated with Inherited BRCA1 Mutations*, FORCE, https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/hereditary-cancer-genes-and-risk/genes-by-name/brca1/cancer-risk [https://perma.cc/F4YE-U6LG] (last visited Mar. 8, 2025). For BRCA2, FORCE cites the lifetime risk for breast cancer as 55–69% and the risk for ovarian, fallopian tube, and peritoneal cancers at 13–29%. *Cancer Risks Associated with Inherited BRCA2 Mutations*, FORCE, https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/hereditary-cancer-genes-and-risk/genes-by-name/brca2/cancer-risk [https://perma.cc/4ZME-478D] (last visited Mar. 8, 2025). *Compare e.g.*, Sylwia Michalowsa, *Difficult Legacy in a Close Relationship. Sexual satisfaction, Relationship Satisfaction, and Body Image in Patients with BRCA Mutation after Prophylactic Mastectomy and/or Adnexectomy*, 3 ARCHIVES OF PSYCHIATRY & PSYCHOTHERAPY 7, 8 (2022) (citing an increase in "cancer incidence rate of 35% to 85% for breast cancer and from 16% to 60% for ovarian cancer" for those carrying the BRCA gene) (internal citations omitted); Ormondroyd et al., *supra* note 67, at 4 ("The lifetime risk of breast cancer for female BRCA1/2 carriers is up to 85%, and 27-60% of developing ovarian cancer.").

85. *Cancer Risks Associated with Inherited BRCA2 Mutations*, *supra* note 84.

healthy.[86] She will have medical, psychological, and financial burdens even if she never develops cancer.[87] For this reason, women who are BRCA carriers, but have not been diagnosed with cancer, are called previvors.[88] This name comes from being a sur*vivor* of a *pre*disposition to cancer.[89] While the term can apply to individuals with any type of genetic mutation that greatly increases the chances of developing cancer, it is most commonly applied to those with BRCA mutations.[90]

The burdens of being a BRCA previvor can begin as soon as a woman is diagnosed with BRCA1 or BRCA2.[91] Once diagnosed, BRCA-positive women have three preventative treatment options, all of which have substantial negative repercussions: (1) surveillance; (2) chemoprevention; and (3) surgeries, including a double mastectomy, removal of her ovaries and fallopian tubes, or both.[92] These options create difficult choices, and the uncertainty surrounding risk management[93] may

86. *See* Valerie Guttman Koch, *Previvors*, 49 FLA. ST. U. L. REV. 643, 657 (2022) (noting that "individuals become 'patients' (or 'patients-in-waiting' or 'pre-diseased') by virtue of a lab test, seeking medical treatment or surgical interventions that normally are reserved for the sick"); Stephany Tandy-Connor et al., *False-Positive Results Released by Direct-to-Consumer Genetic Tests Highlight the Importance of Clinical Confirmation Testing for Appropriate Patient Care*, 20(12) GENETIC MED. 1515, 1516 (2018) ("If an individual has a pathogenic variant in [a BRCA gene], it is considered diagnostic for hereditary breast and ovarian cancer.").

87. *See* Marleah Dean, "*It's Not if I Get Cancer, It's When I Get Cancer": BRCA-Positive Patients' (Un)Certain Health Experiences Regarding Hereditary Breast and Ovarian Cancer Risk*, 163 SOC. SCI. & MED. 21, 25 (2016) (noting that in one study, "participants viewed a BRCA diagnosis as a life threatening condition that must be managed physically, psychologically, and socially").

88. *See* Koch, *supra* note 86, at 645.

89. *See* Lisa Campo-Engelstein, *BRCA Previvors: Medical and Social Factors that Differentiate Them from Previvors with Other Hereditary Cancers*, 6 BIOÉTHIQUE ONLINE 1, 2 (2017); Hannah Getachew-Smith et al., *Previving: How Unaffected Women with a BRCA 1/2 Mutation Navigate Previvor Identity*, 35(10) HEALTH COMMC'N 1256, 1257 (2020).

90. *See* Campo-Engelstein, *supra* note 89; *see also* Koch, *supra* note 86, at 647 ("In the popular and medical literature, the term 'previvor' is almost exclusively limited to individuals with a mutation in the BRCA genes.").

91. Stephany Tandy-Connor et al., *False-Positive Results Released by Direct-to-Consumer Genetic Tests Highlight the Importance of Clinical Confirmation Testing for Appropriate Patient Care*, 20 GENETICS IN MED. 1515, 1516 (2018) (noting that diagnostic tests for BRCA mutations involve analysis of "the full coding sequences of [these] genes").

92. *See* Koch, *supra* note 86, at 653–55; Kenneth P. Tercyak et al., *Cancer Genetic Health Communication in Families Tested for Hereditary Breast/Ovarian Cancer Risk: A Qualitative Investigation of Impact on Children's Genetic Health Literacy and Psychosocial Adjustment*, 9(3) TRANSLATIONAL BEHAV. MED. 493, 493 (2019).

93. Koch, *supra* note 86, at 655 ("Prophylactic action 'raises particular anxieties because the risks of both having surgery and not having it are considerable, yet abstract and hypothetical.'"); Getachew-Smith et al., *supra* note 89, at 1256 (noting that when learning about "a positive BRCA test result, previvors face uncertainty with regard to prevention and treatment decisions").

intensify the emotional distress and anxiety that accompany a BRCA diagnosis.[94]

Younger women often choose surveillance because it is their only viable choice if they want to have children.[95] For managing breast cancer risk, the stringent surveillance guidelines recommend breast exams by a doctor every six to twelve months, a yearly breast MRI with and without contrast starting at age twenty-five until age seventy-five, and a yearly mammogram, starting at age thirty.[96] An annual MRI or endoscopic ultrasound are also recommended to screen for pancreatic cancer starting at age fifty.[97] Having screenings and medical appointments so frequently can exacerbate a BRCA patient's anxiety,[98] especially because surveillance does not reduce the risk of developing cancer.[99] The utility of screening is limited to improving the probability that any cancer that develops will be caught at an early stage, when the chances of survival are better.[100] Due to their continuing high risk of cancer, some BRCA

94. *See* Furseth, *supra* note 74 (referencing "a lifetime worrying about cancer"); Getachew-Smith et al., *supra* note 89, at 1257–58 (noting that the "the uncertainty previvors face when making difficult decisions concerning risk management . . . can produce detrimental psychosocial effects, impacting medical decision-making, emotional distress and lower overall quality of life"); Suter, *supra* note 16, at 238 (noting the "potential adverse responses" to being diagnosed BRCA positive as including "anxiety, depression, anger and feelings of vulnerability"); Oribamise et al., *supra* note 68, at 101–02 (noting that having "a BRCA mutation is an anxiety-provoking event that can impact patients' psychosocial well-being").

95. Marleah Dean & Carla L. Fisher, *Uncertainty and Previvors' Cancer Risk Management: Understanding the Decision-Making Process*, J. APPLIED COMMC'N RES. (2019), https://doi.org/10.1080/00909882.2019.165723 [https://perma.cc/QG6D-ZTJC].

96. *See Risk Management for People with Inherited BRCA1 Mutations*, FORCE, https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/hereditary-cancer-genes-and-risk/genes-by-name/brca1/risk-management [https://perma.cc/ME8B-KYRC] (last visited Feb. 21, 2025); *Risk Management for People with Inherited BRCA2 Mutations*, FORCE, https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/hereditary-cancer-genes-and-risk/genes-by-name/brca2/risk-management [https://perma.cc/QC78-JLJE] (last visited Mar. 9, 2025).

97. *See Risk Management for People with Inherited BRCA1 Mutations*, *supra* note 96; *Risk Management for People with Inherited BRCA2 Mutations*, *supra* note 96.

98. Dean & Fisher, *supra* note 95, at 3 ("Medical uncertainty included being anxious about a future HBOC diagnosis, feeling fearful during screening appointments, and waiting for diagnostic tests when HBOC is suspected.").

99. Koch, *supra* note 86, at 654 ("Individuals may also seek to minimize breast cancer risk through increased surveillance . . . or 'watchful waiting'"); Rachel Koruo et al., *Previvors' Perceptions of Hereditary Breast and Ovarian Cancer Health-Related Information*, 14(2) AM. J. UNDERGRADUATE RSCH. 95, 96 (2017) (noting that "while increased surveillance is an appropriate option for BRCA-positive women it does not prevent HBOC").

100. Thao-Quyen H. Ho et al., *Cumulative Probability of False-Positive Results After 10 Years of Screening with Digital Breast Tomosynthesis vs. Digital Mammography*, 5(3) JAMA NETWORK OPEN 1, 2 (2022) ("Early breast cancer detection via screening mammography is a key strategy to decrease breast cancer morbidity and mortality.").

patients have described themselves as "a ticking time bomb,"[101] constantly reminded of the probability of an eventual cancer diagnosis.[102]

This ongoing anxiety may be heightened due to the potential for false positives, where normal breast tissue is identified as suspicious, prompting more testing and possibly invasive and painful biopsies.[103] The American Cancer Society estimates that about half of women having mammograms over a ten-year period will have a false positive result.[104] For BRCA patients, false positives may be especially distressing because, due to the hereditary nature of BRCA, many of them have had family members who battled, or died of, cancer.[105]

To gain more control, some women take precautionary measures such as chemoprevention. Estrogen receptor modulators or aromatase inhibitors are sometimes prescribed to reduce the risk of developing cancer, but this option is generally not chosen because of its limited effectiveness and adverse side effects.[106]

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101. Dean, *supra* note 87, at 24 (providing an example of a BRCA-positive woman describing herself as "a 'ticking time bomb,' waiting for the cancer to explode"); Dean & Fisher, *supra* note 95, at 8 (noting that multiple previvors used the term "ticking time bomb").

102. Dean & Fisher, *supra* note 95, at 12 (quoting a BRCA patient as explaining that "[e]very doctor's appointment is just a constant reminder of this gene that I have that I lost my mom to").

103. *Getting Called Back After a Mammogram*, AM. CANCER SOC'Y, https://www.cancer.org/cancer/types/breast-cancer/screening-tests-and-early-detection/mammograms/getting-called-back-after-a-mammogram.html [https://perma.cc/M2N2-UEYE] (last visited Feb. 21, 2025).

104. *Limitations on Mammograms*, AMERICAN CANCER SOC'Y, https://www.cancer.org/cancer/types/breast-cancer/screening-tests-and-early-detection/mammograms/limitations-of-mammograms.html [https://perma.cc/CFT3-J4DF] (last visited Feb. 21, 2025); Ho et al., *supra* note 100, at 2 (citing a study estimating "that after 10 years of annual screening in women aged 40 to 59 years . . . 61% of individuals would experience at least 1 false-positive recall and 7% to 9% at least 1 false-positive biopsy recommendation," and noting that a newer screening technique might lower these probabilities "somewhat").

105. Tercyak et al., *supra* note 92, at 501 (noting the "strong family history of cancer present in most HBOC kindreds"); C. Moynihan et al., *Ambiguity in a Masculine World: Being a BRCA 1/2 Mutation Carrier and a Man with Prostate Cancer*, 26(11) PSYCHO-ONCOLOGY 1987, 1989 (2017) ("Familial images of illness and death evoked the importance of testing in both sexes."); Furseth, *supra* note 74 (containing examples of BRCA carriers who lost family members); Dean, *supra* note 87, at 24 ("[C]ancer infiltrated [the family trees of BRCA-positive individuals] in overwhelming numbers, often resulting in many deaths [and] imprinted their lives with fears of cancer . . . ").

106. Simone Mocellin et al., *Risk-Reducing Medications for Primary Breast Cancer: A Network Meta-Analysis*, COCHRANE LIBRARY, 1, 8 (Apr. 29, 2019), https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012191.pub2/full [https://perma.cc/XWA6-CR6X]; Heidi D. Nelson et al., *Medication Use for Risk Reduction of Primary Breast Cancer in Women: Updated Evidence Report and Systematic Review for US Preventive Services Task Force*, 322(9) JAMA 868, 879 (2019); *see also Risk Management for People with Inherited BRCA1 Mutations*, *supra* note 96; *Risk Management for People with Inherited BRCA2 Mutations*, *supra* note 96 (explaining that "[t]amoxifen or other estrogen-blocking drugs may lower breast cancer risk" and advising that "medications or vaccines are being studied in clinical trials").

Instead, many BRCA-positive women choose surgery after they have completed childbearing[107] because surgery is by far the most effective method for reducing cancer risk.[108] The standard of care for BRCA1 carriers is to have their ovaries and fallopian tubes surgically removed between the ages of thirty-five and forty, and for BRCA2 carriers to undergo this surgery between the ages of forty and forty-five.[109] Younger ages may be recommended depending on family history.[110] This surgery is imperative because surveillance has proven ineffective for ovarian cancer,[111] so it is generally discovered in its later stages,[112] when it is usually deadly.[113] Removing the ovaries reduces the risk of ovarian cancer for BRCA-positive women by as much as 96% and also reduces the risk of breast cancer by about 53% in BRCA1 carriers and 72% in BRCA2 carriers.[114] Correspondingly, there are indications that this surgery increases life expectancy.[115]

However, removing a woman's ovaries while she is in her late thirties or early forties has significant drawbacks. Removal of the ovaries induces menopause,[116] which can be more intense than the menopause occurring

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107. Dean & Fisher, *supra* note 95, at 11 ("Previvors opting for surveillance [indicated] that they planned to do surgeries . . . when they were done with family planning."); Dean, *supra* note 87, at 26 (noting that "in this study, most of the participants underwent preventative surgeries after testing positive for BRCA"); Koch, *supra* note 86, at 660 (noting that the "severity of the risk influences individuals to take preventative action").

108. Andrew J. Wallace, *New Challenges for BRCA Testing: A View From the Diagnostic Laboratory*, 24(1) EUR. J. HUM. GENETICS S10, S10 (2016) ("Prophylactic oophorectomies and mastectomies and been shown to reduce cancer incidence compared with chemoprevention or surveillance."); David Pavlišta et al., *Attitudes and Experiences Towards Partnership and Intimacy of the Partners of BRCA Women Carriers: A Focused Group Study After Prophylactic Surgery*, RSCH. SQUARE, 1, 2 (Nov. 2, 2022), https://www.researchsquare.com/article/rs-2216386/v1 [https://perma.cc/A995-B49B].

109. *See Risk Management for People with Inherited BRCA1 Mutations*, *supra* note 96; *Risk Management for People with Inherited BRCA2 Mutations*, *supra* note 96.

110. Pavlišta et al., *supra* note 108, at 2.

111. Camille V. Trinidad et al., *Reducing Ovarian Cancer Mortality Through Early Detection: Approaches Using Circulating Biomarkers*, 13(3) CANCER PREVENTION RSCH. 241, 241–52 (2020); Campo-Engelstein, *supra* note 89, at 3; Joan Hartnett et al., *Caregiver Burden in End-Stage Ovarian Cancer*, 20(2) CLINICAL J. ONCOLOGY NURSING 169, 169 (2016) (noting that "60% of [ovarian cancer] patients are diagnosed with advanced stages of the disease (stage III or IV) and outcomes are much graver than for those with earlier-stage diagnoses").

112. Trinidad et al., *supra* note 111, at 241 (noting that ovarian cancers "are diagnosed predominantly at an advanced stage with widespread metastases . . .").

113. Trinidad et al., *supra* note 111, at 241–42.

114. Pavlišta et al., *supra* note 108, at 2.

115. David M. Euhus, *Risk Reducing Mastectomy for BRCA Gene Mutation Carriers*, 22 ANNALS OF SURGICAL ONCOLOGY 2807, 2808 (2015); Serena Bertozzi et al., *Risk-Reducing Breast and Gynecological Surgery for BRCA Mutation Carriers: A Narrative Review*, 12(4) J. CLINICAL MED. 1422, 1422 (2023); *Risk Management for People with Inherited BRCA1 Mutations*, *supra* note 96; *Risk Management for People with Inherited BRCA2 Mutations*, *supra* note 96.

116. Koch, *supra* note 86, at 655.

naturally in older women.[117] Experiencing menopause early also increases a woman's chances of developing "cardiovascular disease, osteoporosis, and cognitive impairment."[118] While hormone therapy can ameliorate some of these risks, it does not eliminate all of the long-term consequences.[119]

In addition to removing their ovaries, BRCA carriers often choose to have a bilateral prophylactic mastectomy because this surgery is the single most effective method of reducing the risk of breast cancer.[120] A double mastectomy reduces breast cancer risk by about 90%;[121] some risk remains because not all of the breast tissue can be removed.[122] Mastectomies also have substantial drawbacks. A significant percentage of women undergoing a mastectomy have complications from the surgery and many will require additional operations.[123] Removing a woman's breasts can also affect her sexual functioning and her self-image concerning physical attractiveness and femininity.[124] This is particularly problematic because BRCA-positive women develop breast cancer at an earlier age than the general population,[125] thus requiring surgery when they are still relatively young. Due to these complex potential

117. Dean & Fisher, *supra* note 95, at 12.

118. Koch, *supra* note 86, at 655.

119. Lynne T. Shuster et al., *Premature Menopause or Early Menopause: Long-Term Health Consequences*, 65(2) MATURITAS 161, 161–66 (2010); Ashley D. Staton et al., *Cancer Risk Reduction and Reproductive Concerns in Female BRCA1/2 Mutation Carriers*, 7 FAM. CANCER 179, 184 (2008) (citing menopausal side-effects as a main factor "influencing [BRCA positive] responders' decisions about prophylactic surgery").

120. Koch, *supra* note 86, at 654; Pavlišta et al., *supra* note 108, at 2 ("Currently, prophylactic surgery has been presented as the most efficacious method in reduction of breast and ovarian cancer risk in BRCA-positive women.").

121. Koch, *supra* note 86, at 654; Pavlišta et al., *supra* note 108, at 2.

122. Euhus, *supra* note 115, at 2808; Bertozzi et al., *supra* note 115, at 1435 (citing a recent study that "found residual breast tissue in 51.3% of mastectomies, and the residual breast tissue percentage per breast was 7.1% on average").

123. Euhus, *supra* note 115, at 2808; Bertozzi et al., *supra* note 115, at 1435 ("Residual breast tissue can be found in the remaining chest wall . . . This reality puts these women at risk of developing breast cancer, despite this risk being reduced because the gland mass is minimal.").

124. Koch, *supra* note 86, at 655 (noting that prophylactic surgeries can raise "'taboo issues concerning sexual organs, sexuality and physical attractiveness'"); Robert Klitzman & Wendy Chung, *The Process of Deciding About Prophylactic Surgery for Breast and Ovarian Cancer: Patient Questions, Uncertainties, and Communication*, 152A(1) AM. J. GENET. A 52, 59, 63 (2010) (noting the potential side-effects of mastectomy or oophorectomy as including "harm to physical attractiveness, sexual experience/functioning, romantic life, and views of one's body and self"); Campo-Engelstein, *supra* note 89, at 5 (noting that women considering mastectomy fear losing their "femininity, sexual attraction, and loss of sexual pleasure"); Pavlišta et al., *supra* note 108, at 2 (noting that prophylactic surgery can "have an adverse impact on women at the psychological, psychosexual, and emotional levels").

125. Varol et al., *supra* note 79, at 864; Ormondroyd et al., *supra* note 67, at 4 (noting that BRCA 1/2 carriers have "a higher risk of developing breast cancer at a younger age").

ramifications, mastectomy is presented as an option, not the standard of care.[126]

Although BRCA-positive men do not have to face these burdensome and potentially life-altering medical options,[127] they also have significantly increased chances of developing cancer. For example, they risk suffering from aggressive prostate cancer,[128] which has a low survival rate and can occur at a younger age.[129] In addition, they have enhanced lifetime risks for developing male breast cancer,[130] colon cancer, pancreatic cancer, malignant melanomas, and gallbladder and biliary tract tumors.[131] Men have no recommended chemoprevention or surgical options to manage their cancer risk, but there are some recommended surveillance measures.[132]

BRCA-positive men and women experience these psychological and medical ramifications even if they never develop cancer. Their BRCA-positive status is considered a diagnosis requiring management and treatment.[133] However, as the statistics reveal, many BRCA carriers will also suffer from the negative effects of having cancer. For example, ovarian cancer patients can experience common adverse side-effects including "infection, pain, fatigue, anemia, nausea and vomiting, constipation, [and] swelling of the lower extremities."[134] They may also suffer more serious complications including "ascites, bowel and bladder obstructions, and pleural effusions."[135] Because much of the care of ovarian cancer patients takes place at home, family members will

126. Campo-Engelstein, *supra* note 89, at 3; *Risk Management for People with Inherited BRCA1 Mutations*, *supra* note 96; *Risk Management for People with Inherited BRCA2 Mutations*, *supra* note 96.

127. *See* Koch, *supra* note 86, at 655 (noting the "health implications and side-effects [of BRCA risk reduction], many of which can be life-long").

128. Moynihan et al., *supra* note 105, at 1987 ("Men with BRCA1/2 mutations have an increased risk of prostate cancer [of] . . . 1.8 to 4.5 fold for BRCA1 and 2.5 to 8.6 fold for BRCA2 mutation carriers."); Ormondroyd et al., *supra* note 67, at 4 ("The lifetime risks to male BRCA2 carriers of breast and prostate cancer are substantially higher than population risk, but for BRCA1 only slightly different than population risks.").

129. Moynihan et al., *supra* note 105, at 1987 (noting that "men with BRCA2 mutations present with aggressive [prostate cancer] at a younger age and have poor survival").

130. Michelle Skop et al., *"Guys Don't Have Breasts": The Lived Experience of Men Who Have BRCA Mutations and Are at Risk for Male Breast Cancer*, 12(4) AM. J. MEN'S HEALTH 961, 961–62 (2018) (noting that the "lifetime risk for male breast cancer in BRCA2 carriers ranges from 2.8% to 6.9% by ages 70 to 80 respectively . . . [and in] BRCA1 carriers . . . ranges from 1.2% to 5.8% by ages 70 to over 80").

131. *See* Varol et al., *supra* note 79, at 865.

132. Skop et al., *supra* note 130, at 968 (noting that "men previvors only have 'passive treatments' of surveillance and watchful waiting to manage cancer risk").

133. *Id.*

134. Joan Harnett et al., *Caregiver Burden in End-Stage Ovarian Cancer*, 20(2) CLINICAL J. ONCOLOGICAL NURSING 169, 170 (2016).

135. *Id.*

generally provide high levels of assistance.[136] From undertaking this responsibility and from watching the cancer patient suffer and often die, many caregivers experience depression and anxiety, as well as financial difficulties.[137]

A cruel addition to all of the psychological and medical implications of a BRCA diagnosis is the likelihood that the BRCA gene will be passed along to offspring.[138] BRCA is an autosomal dominant gene,[139] meaning that if one parent has the mutation, a prospective child has a whopping 50% chance of carrying the mutation and suffering all of the consequences associated with being BRCA positive.[140] Studies have consistently shown that BRCA-positive parents have "frequent or extreme concern" about passing the mutation to their children.[141] This strong concern has led some parents to consider PGT to eliminate the risk for their prospective children and future generations.[142] Accordingly, in 2009 the first baby was born from an embryo selected using PGT to ensure the baby did not have the BRCA mutation.[143]

B. *Lynch Syndrome*

Lynch syndrome, also called hereditary nonpolyposis colorectal cancer (HNPCC),[144] is caused by a mutation in the MLH1, MSH2,

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136. *Id.* ("Patients with chronic illness, such as end-stage ovarian cancer, spend less time in the hospital and, when discharged, require more high-level care at home . . . ").

137. *Id.* at 170–71.

138. Tercyak et al., *supra* note 92, at 502.

139. *Id.*

140. Oribamise et al., *supra* note 68, at 99; I.A.P. Derks-Smeets et al., *Decision-making on Preimplantation Genetic Diagnosis and Prenatal Diagnosis: A Challenge for Couples with Hereditary Breast and Ovarian Cancer*, 29(5) HUM. REPROD. 1103, 1104 (2014).

141. Staton et al., *supra* note 119, at 184 ("About 88% of responders stated that they had frequent or extreme concern about transmitting the familial BRCA 1/2 mutation to future children."); Oribamise et al., *supra* note 68, at 99 (noting that BRCA carriers "have a desire that their offspring are genetically normal, not carriers of the gene mutation"); Moynihan et al., *supra* note 105, at 1989–91 (noting "[m]en's sadness at passing on the mutation"); Derks-Smeets et al., *supra* note 140, at 1106 (noting that "the majority of couples [in one study] primarily indicated they wanted to protect their child from the physical and psychological impact of the BRCA mutation").

142. Furseth, *supra* note 74 ("Some say they'd go to any length to stop the family curse . . ."); Derks-Smeets et al., *supra* note 140, at 1110 (noting that, in considering PGT or prenatal testing for BRCA, "[t]he most important factor taken into account was the perceived severity of HBOC, which was generally based on personal and familial experience with cancer and sacrifices to be made for preventative measures").

143. Katz & Schweitzer, *supra* note 70, at 114.

144. Samuel D. Hodge & Calina Noah, *The Three C's – The Colon, Colonoscopies, and Cancer: A Medical and Legal Overview*, 33 HEALTH MATRIX 145, 156 (2023); Elena M. Stoffel et al., *Sharing Genetic Test Results in Lynch Syndrome: Communication with Close and Distant Relatives*, 6(3) CLINICAL GASTROENTEROLOGY & HEPATOLOGY 333, 334 (2008).

MSH6, or PMS2 genes, which are all mismatch repair (MMR) genes.[145] The function of MMR genes is to repair DNA that is damaged during cell division.[146] Because mutations in MMR genes impair their functioning, the mutations can cause multiple cancers, but most especially predispose Lynch syndrome-positive individuals to colorectal and gynecological cancers.[147]

Lynch syndrome is most commonly associated with colorectal cancer (CRC).[148] A mutation carrier's lifetime risk of developing CRC can be as high as 61% , compared to a 4.1% risk for the average person.[149] Due to this high-level risk, and the fact that the cancer often develops earlier in mutation carriers than in the general population,[150] "high-quality" colonoscopies are recommended every one to two years, beginning at age

145. Aunchalee E. L. Palmquist et al., *"The Cancer Bond": Exploring the Formation of Cancer Risk Perception in Families with Lynch Syndrome*, 19(5) J. GENETICS COUNSELING 473, 474 (2010); Helen Coelho et al., *A Systematic Review of Test Accuracy Studies Evaluating Molecular Micro-Satellite Instability Testing for the Detection of Individuals with Lynch Syndrome*, 17 BMC CANCER 836, 836 (2017) (noting that Lynch syndrome is caused by mutations in MMR genes "(MLHI, MHS2, MSH6, and PMS2) or, rarely, by certain mutations in nearby genes that affect expression of the adjacent MMR gene"); Heather Hampel et al., *Screening for the Lynch Syndrome (Hereditary Nonpolyposis Colorectal Cancer)*, 352 N. ENGL. J. MED. 1851, 1852 (2005).

146. Hodge & Noah, *supra* note 144, at 156 (noting that mutations associated with Lynch Syndrome "have a gene variant that diminishes the cell's capacity to fix mistakes generated during DNA duplication").

147. Helle Vendel Petersen et al., *Sense of Coherence and Self-Concept in Lynch Syndrome*, 11 HEREDITARY CANCER IN CLINICAL PRACTICE 7, 7 (2013); Palmquist et al., *supra* note 145; Katja Aktan-Collan et al., *Psychological Consequences of Predictive Genetic Testing for Hereditary Non-Polyposis Colorectal Cancer (HNPCC): A Prospective Follow-Up Study*, 93 INT'L. J. CANCER 608, 608 (2001) (noting that the most common cancers related to Lynch syndrome are colorectal cancer and endometrial cancer in women).

148. *See* Stoffel et al., *supra* note 144 (explaining that Lynch syndrome is "also known as hereditary nonpolyposis colorectal cancer [and] is the most common hereditary colorectal cancer syndrome").

149. *Cancer Risk Associated with Inherited MLHI Mutations*, FORCE, https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/hereditary-cancer-genes-and-risk/genes-by-name/mlh1/cancer-risk [https://perma.cc/7FVS-E6TR] (last visited Feb. 26, 2025); *see also* Palmquist et al., *supra* note 145 (citing "up to a 70% to 80% lifetime risk of developing colorectal cancer (HNPCC)").

150. Jin Yong Kim & Jeong-Sik Byeon, *Genetic Counseling and Surveillance Focused on Lynch Syndrome*, 3(2) J. ANUS, RECTUM & COLON 60, 61 (2019) (noting the early onset of CRC in Lynch syndrome patients); Katarina Bartuma et al., *Family Perspectives in Lynch Syndrome Becoming a Family Risk, Patterns of Communication and Influence on Relations*, 10 HEREDITARY CANCER IN CLINICAL PRACTICE 6 (2012) (citing age 45 as the mean age of onset for CRC and stating that this is early onset); Coelho et al., *supra* note 145 ("In people with Lynch syndrome, CRC has an earlier onset than CRC in the general population (44 years, compared with 60-65 years respectively).").

twenty-five.[151] These screenings are of paramount importance because colonoscopies result in about a 72% decrease in CRC[152] and, if cancer develops, in early detection.[153]

In the event HNPCC carriers develop CRC despite the option of colonoscopies, they may have to consider surgical removal of a portion of the large intestine.[154] This surgery can result in "post surgery bowel seepage, incontinence, . . . urgency . . . [and corresponding] anxious preoccupation with bowel functioning."[155] Sometimes, if the colon cannot be reconnected during surgery, the individual will need a colostomy bag to eliminate waste.[156] Colon cancer may also require chemotherapy, radiation, or both.[157]

Women with Lynch syndrome have all of these potential CRC repercussions and also have greatly increased chances of developing endometrial (uterine)[158] and ovarian cancer.[159] The risk of endometrial cancer can be as high as 57%[160] and as high as 38% for ovarian cancer.[161] To screen for endometrial cancer, women may choose transvaginal ultrasound or a more accurate, but also more invasive, endometrial biopsy every one to two years starting between the ages of thirty and thirty-

151. Kim & Byeon, *supra* note 150, at 63–64; Kathy E. Watkins et al., *Lynch Syndrome: Barriers to and Facilitators of Screening and Disease Management*, 9 HEREDITARY CANCER IN CLINICAL PRACTICE 8 (2011) (noting that colonoscopies should be strongly encouraged because of their "effectiveness . . . in reducing morbidity and mortality from CRC"); Hodge & Noah, *supra* note 144, at 162 (noting that for the average asymptomatic person, colonoscopies are performed every ten years).

152. Kim & Byeon, *supra* note 150, at 63.

153. *Id*. at 60 (noting that "comprehensive cancer surveillance programs are mandatory to improve the prognosis of Lynch syndrome patients by . . . early detection of cancers").

154. Hodge & Noah, *supra* note 144, at 168; Mary Jane Esplen et al., *Development and Validation of an Instrument to Measure the Impact of Genetic Testing on Self-Concept in Lynch Syndrome (LS)*, 80(5) CLINICAL GENETICS 415, 416 (2011).

155. Esplen et al., *supra* note 154, at 416.

156. Hodge & Noah, *supra* note 144, at 169.

157. *Id.* at 169–70.

158. Kim & Byeon, *supra* note 150, at 64 (noting that endometrial cancer "is the second most common cancer that develops in Lynch syndrome" and citing a "cumulative lifetime risk [of] . . . approximately 15-71%"); Coelho et al., *supra* note 145, at 836 (noting that Lynch syndrome "conveys a high risk of colorectal and endometrial cancer").

159. Kim & Byeon, *supra* note 150, at 64 (citing a "cumulative lifetime risk [for ovarian cancer] ranging from 4% to 20% and the average age of emergence of 40-50 years in women with Lynch syndrome").

160. *Cancer Risks Associated with Inherited MSH2 Mutations*, FORCE, https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/hereditary-cancer-genes-and-risk/genes-by-name/msh2/cancer-risk [https://perma.cc/S8Z3-4TBA] (last visited Feb. 26, 2025).

161. *Id.*

five.[162] Women may also choose to have a hysterectomy and surgical removal of their ovaries and fallopian tubes.[163]

On top of the burdens associated with their high risk of developing CRC, uterine, and ovarian cancers, those with Lynch syndrome have an increased likelihood of developing other cancers including kidney, ureter, prostate, bladder, gastric, small bowel, brain, biliary tract, and pancreatic cancer.[164] Indeed, about one-third of HNPCC carriers will develop more than one cancer.[165] To avoid late detection of these cancers, additional screening tests may be recommended,[166] some of which are invasive and uncomfortable.[167]

Scheduling and attending all of these screening appointments, and waiting for test results, may be physically and emotionally overwhelming.[168] This is especially true because many with Lynch syndrome need to travel outside of their local communities to receive the appropriate screening, which may involve time off from work and support from others to handle family responsibilities.[169] Due to all of these burdens, counseling is strongly recommended to help patients confront the clinical, psychosocial, economic, and emotional reverberations of having an HNPCC diagnosis.[170]

But that's not all. Over and above these concerns, Lynch syndrome-positive individuals have a 50% chance of passing the mutation to their

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162. *Risk Management for People with an Inherited MLHI Mutation*, FORCE, https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/hereditary-cancer-genes-and-risk/genes-by-name/mlh1/risk-management [https://perma.cc/7VAV-FBGX] (last visited Feb. 26, 2025).

163. *Id.*; Kim & Byeon, *supra* note 150, at 65; Watkins et al., *supra* note 151 (2011) (noting the "documented benefits of . . . gynecologic surgeries for reducing cancer risk . . .").

164. *See* Palmquist et al., *supra* note 145, at 474; Watkins et al., *supra* note 151.

165. Bartuma et al., *supra* note 150.

166. *Risk Management for People with an Inherited MLHI Mutation*, *supra* note 162 (explaining that other screening tests may include, e.g.: for pancreatic cancer, contrast-enhanced MRI or endoscopic ultrasound, which involves passing an ultrasound probe down the esophagus, into the stomach; for prostate cancer, annual digital rectal exam and PSA blood test; for stomach cancer, upper endoscopy every 2-4 years and consider random biopsy to test for h pylori; for skin cancer, skin exam every 1-2 years with an expert in skin changes related to Lynch syndrome); *see also* Kim & Byeon, *supra* note 150, at 64–65 (listing and explaining some testing options for those with Lynch syndrome); Palmquist et al., *supra* note 145, at 474.

167. Kim & Byeon, *supra* note 150, at 63 (noting that "appropriate surveillance programs are of paramount importance for the prevention, early detection, and effective management of CRC and other malignancies"); Bartuma et al., *supra* note 150 (noting that "surveillance programs efficiently reduce morbidity and mortality from cancer").

168. Watkins et al., *supra* note 151 (noting the "emotional and physical challenges of living with Lynch syndrome" and the challenges of "scheduling appointments and waiting for diagnostic test results").

169. *Id.*

170. *See* Kim & Byeon, *supra* note 150, at 66 (emphasizing that "professional genetic counseling is mandatory").

children.[171] For this reason, researchers have recommended that HNPCC carriers who are prospective parents be informed about PGT.[172]

C. *Early-Onset Alzheimer's Disease*

If an individual has a mutation in one of three genes—PSEN1, PSEN2, or APP—that person has an almost 100% chance of developing Alzheimer's disease.[173] Individuals who inherit these gene variants also have a very high probability of developing early-onset Alzheimer's,[174] typically between the ages of thirty and fifty.[175] While the cause of Alzheimer's isn't fully understood,[176] mutations in any one of these genes result in the production of amyloid fragments that clump together to form plaques in the brain.[177] These plaques are the characteristic markers of Alzheimer's disease.[178]

Early-onset Alzheimer's disease is perhaps the most devastating of the inherited genetic conditions discussed in this section. Alzheimer's

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171. Bartuma et al., *supra* note 150 (noting that in the subject survey "all parents expressed concern for their children"); Palmquist et al., *supra* note 145, at 474–77 (noting that Lynch syndrome is "inherited in an autosomal dominant pattern" and citing "narratives about family health history" that included "stories of illness experiences, including caregiving, personal disease diagnoses and treatment, and thoughts about disease risk in the family"); Esplen et al., *supra* note 154, at 416 (noting "feelings of guilt associated with passing on a gene mutation").

172. Kim & Byeon, *supra* note 150, at 63 (noting that "[i]n a survey of 161 patients with Lynch syndrome in the US . . . [a]pproximately 42% . . . strongly agreed or agreed that they would consider prenatal testing").

173. *See* Marianna V. Mapes et al., *How Should Clinicians Counsel a Woman with a Strong Family History of Early-Onset Alzheimer's Disease about Her Pregnancy*, 19(7) AMA J. OF ETHICS 663, 666 (2017) (explaining that if a person has a mutation in the APP or PSEN1 genes, they "will develop [Alzheimer's disease] if they live a normal lifespan," but a mutation in the PSEN2 gene results in a 95% chance of developing Alzheimer's); *Alzheimer's Disease Genetics Fact Sheet*, NAT'L INST. ON AGING, https://www.nia.nih.gov/health/alzheimers-causes-and-risk-factors/alzheimers-disease-genetics-fact-sheet [https://perma.cc/VZG6-LFMQ] (last visited Feb. 28, 2025); David Wallon, *Genetics of Alzheimer's Disease: Diagnostic, Research, and Ethical Considerations*, *in* WORLD ALZHEIMER'S REP. JOURNEY THROUGH A DIAGNOSIS OF DEMENTIA 6 (2021), https://www.alzint.org/u/World-Alzheimer-Report-2021-Chapter-12.pdf [https://perma.cc/3UK8-JUCP] ("Any individual carrying one of these mutations will develop symptoms before 65 and approximately at the same age of their own parent."); Gina Kolata, *Screening for Alzheimer's Gene Tests the Desire to Know*, N.Y. TIMES (Mar. 7, 2016), https://www.nytimes.com/2016/03/08/health/alzheimers-genetics-testing.html [https://perma.cc/AW8Y-CDWT] (explaining that if you inherit a mutated APP gene, you will develop Alzheimer's "with absolute certainty").

174. *Alzheimer's Disease Genetics Fact Sheet*, *supra* note 173.

175. Yue Cui & Liyong Wu, *Autosomal Dominant Alzheimer's Disease*, *in* WORLD ALZHEIMER'S REP. JOURNEY THROUGH A DIAGNOSIS OF DEMENTIA 9 (2021), https://www.alzint.org/u/World-Alzheimer-Report-2021-Chapter-12.pdf [https://perma.cc/3UK8-JUCP].

176. *See Alzheimer's Disease Genetics Fact Sheet*, *supra* note 173.

177. *Alzheimer's Disease Genetics Fact Sheet*, *supra* note 173.

178. *Alzheimer's Disease Genetics Fact Sheet*, *supra* note 173.

disease affects cognitive abilities, behavior, and physical functioning, which slowly deteriorate over the patient's limited remaining lifespan.[179] Once Alzheimer's disease is diagnosed, a patient has a life expectancy of about four to eight years, but can live as many as twenty years.[180] During this time period, the patient's cognitive impairments will include losing their memories, ability to reason,[181] judgment, and even capacity to speak or understand language.[182] Their behavioral changes may include, for example, mood changes, aggression, hallucinations, delusions, agitation, and confusion as to their own identity and the identity of others.[183] The agitation they experience can be accompanied by calling out repeatedly, sleep disturbances, and wandering.[184] As the disease becomes progressively worse, Alzheimer's will also affect a person's physical ability to handle the activities of daily living such as eating, dressing, and even walking without assistance.[185]

Early-onset Alzheimer's is defined as having symptoms of the disease before age sixty-five.[186] While early-onset Alzheimer's has the same general characteristics as late-onset disease,[187] it poses additional

179. *See* Charles Piller, *The Devastating Legacy of Lies in Alzheimer's Science*, N.Y. TIMES (Jan. 24, 2025), https://www.nytimes.com/2025/01/24/opinion/alzheimers-fraud-cure.html [https://perma.cc/QT56-7XX2] ("Alzheimer's . . . begins by gradually degrading a person's command of routine activities, then stealing cherished memories and finally the very identity that makes each of us human"); *see also* J. Paul Teusink & Susan Mahler, *Helping Families Cope with Alzheimer's Disease*, 35(2) HOSP. AND CMTY. PSYCHIATRY 152, 152 (1984).

180. Anita Pothen Skaria, *The Economic and Societal Burdens of Alzheimer Disease: Managed Care Considerations*, 28(10) AM. J. MANAGED CARE (Sep. 12, 2022), https://www.ajmc.com/view/the-economic-and-societal-burden-of-alzheimer-disease-managed-care-considerations [https://perma.cc/C9LU-XGT5].

181. Vaughn E. James, *No Help for the Helpless: How the Law Has Failed to Serve and Protect Persons Suffering from Alzheimer's Disease*, 7 J. HEALTH & BIOMEDICAL L. 407, 413 (2012) ("By the time the disease progresses to the severe stage, it has eroded the patient's ability to think or reason.").

182. *Id.* at 408.

183. *Id.*

184. Alexandra Feast et al., *Behavioural and Psychological Symptoms in Dementia and the Challenges for Family Carers: Systematic Review*, 208(5) THE BRITISH J. OF PSYCHIATRY 429, 429 (2016).

185. Claire Webster, *Navigating the Journey of Dementia After a Diagnosis – A Prescription of Education and Support*, *in* WORLD ALZHEIMER'S REP. JOURNEY THROUGH A DIAGNOSIS OF DEMENTIA 9 (2021); *see also* James, *supra* note 181, at 414.

186. Allison K. Gibson et al., *Exploring the Service and Support Needs of Families with Early-Onset Alzheimer's Disease*, 29(7) AM. J. ALZHEIMER'S DISEASES & OTHER DEMENTIAS 596, 596 (2014); Caroline Rosenthal Gelman & Christine Greer, *Young Children in Early-Onset Alzheimer's Disease Families: Research Gaps and Emerging Service Needs*, 26(1) AM. J. ALZHEIMER'S DISEASE & OTHER DEMENTIAS 29, 29 (2011).

187. *But see* Hailey A. O'Neil & Paula C. Fletcher, *"Sometimes Life Throws You a Curve Ball": The Lived Experiences of an Individual with Early-Onset Alzheimer's Disease and His Family*, 35(6) CLINICAL NURSE SPECIALIST 318, 319 (2021) (noting that "numerous studies have

problems. This type of Alzheimer's hits patients when they are likely mid-career, raising children, and/or providing care to parents.[188] Along with the emotional losses associated with being unable to perform these duties, they will be forced to retire early,[189] often causing financial difficulties for the family because they have less time to save for retirement[190] and may not be eligible for a pension or have other financial resources that are available to those who are older.[191]

Alzheimer's is also hard on informal caregivers, who are often spouses or otherwise related to the patient.[192] Caregiving is difficult because it can become an around-the-clock occupation,[193] affecting sleep and ability to socialize.[194] Caregiving also involves a long-term commitment[195] and, during that commitment, watching a loved one deteriorate, engage in upsetting behaviors, and become essentially "a

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indicated that [early-onset Alzheimer's disease] has a more aggressive clinical course and a shorter relative survival time"); Gelman & Greer, *supra* note 186, at 29 (noting that early-onset Alzheimer's "tends to be a fast-progressing and aggressive form" of the disease).

188. Gibson et al., *supra* note 186, at 596 ("For many, the 50s and 60s are prime years in terms of family life, career, and future orientation toward retirement."); Natalie C. Kaiser et al., *Differences in Anxiety Among Patients with Early- Versus Late-Onset Alzheimer's Disease*, 26(1) J. NEUROPSYCHIATRY CLINICAL NEUROSCIENCES 73, 78 (2014) (noting that with early-onset, "men are in midlife, and . . . at the height of their breadwinning career and family responsibilities").

189. Deliane van Vliet et al., *Impact of Early Onset Dementia on Caregivers: A Review*, 25 INT'L J. GERIATRIC PSYCHIATRY 1091, 1097 (2010) (noting that "most studies reported that [early-onset dementia] had an impact on workforce participation and finances").

190. O'Neil & Fletcher, *supra* note 187, at 321–24; Gibson et al., *supra* note 186, at 596.

191. Pamela Roach et al., *"Nobody Would Say that It Is Alzheimer's or Dementia at This Age": Family Adjustment Following a Diagnosis of Early-Onset Dementia*, 36 J. OF AGING STUDIES 26, 28 (2016) ("All families [dealing with early-onset dementia] identified finances as an area of their experience that they struggle with in some way."); O'Neil & Fletcher, *supra* note 187, at 324; Gibson et al., *supra* note 186, at 597 (noting that those with early-onset Alzheimer's may be too young to qualify for programs "such as adult day services and transportation"); Skaria, *supra* note 180 (noting that "[d]ementia caregivers bore nearly twice the average out-of-pocket cost of non-dementia caregivers" and that "[p]atients and their families may incur substantial out-of-pocket costs for long-term care services until [the patient] qualifies for Medicaid").

192. van Vliet et al., *supra* note 189, at 1091–92 (noting that early onset dementia "can have a higher impact on patients and their families").

193. Maria Ferrara et al., *Prevalence of Stress, Anxiety and Depression in Alzheimer's Caregivers*, 6 HEALTH & QUALITY LIFE OUTCOMES (2008), https://doi.org/10.1186/1477-7525-6-93 [https://perma.cc/GZ2Q-E9M3] (noting that caregiving for a person with Alzheimer's can become "a full-time occupation for the caregiver").

194. *See* Paula Span, *The Only People Who Understand What a Caregiver Goes Through*, N.Y. TIMES (Nov. 11, 2023), https://www.nytimes.com/2023/11/11/health/dementia-caregivers-mentoring.html [https://perma.cc/S5YM-AXW2]; Teusink & Mahler, *supra* note 179, at 153; O'Neil & Fletcher, *supra* note 187, at 320 (mentioning sleep deprivation as a major issue for family caregivers).

195. Skaria, *supra* note 180 (noting that "much of [their disease] is spent in a state of severe disability and dependence on caregivers").

shell of [their] former self."[196] Accordingly, studies have consistently found that Alzheimer's caregivers suffer from anxiety, depression, and other adverse health consequences.[197] While these health consequences apply to those providing care to both patients with early- and late-onset disease, caregivers for patients with early-onset Alzheimer's may have additional burdens because they are more likely to also be juggling a job and children.[198] Besides the enormous emotional and physical ramifications of caregiving, they may have disrupted career plans[199] and added financial and child-rearing stressors.[200]

Despite the debilitating effects of Alzheimer's, the enormous emotional and financial costs of caring for patients,[201] and decades of effort to find a remedy,[202] there is still no treatment that has proven effective in curing the disease. There are new drugs that help remove amyloid from the brain, but they are very costly, only modestly reduce cognitive decline for those in the early stages of Alzheimer's,[203] and have potentially serious adverse side-effects.[204]

Therefore, individuals with any of these three Alzheimer's genes may reasonably fear passing them to their children. Because all three genes

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196. John Dolores, *Alzheimer's: A Guide for the Caretaker*, 33 WYO. LAW. 52, 52 (2010); Piller, *supra* note 179 ("Alzheimer's families face incalculable emotional costs."); Feast et al., *supra* note 184, at 432 (noting their findings that "'[a]ll [caregivers] were mourning over the loved one who was no longer the person they had known'"); Judith Globerman, *Balancing Tensions in Families with Alzheimer's Disease: The Self and the Family*, 8(2) J. OF AGING STUDIES 211, 223 (1994).

197. Gibson et al., *supra* note 186, at 596; van Vliet et al., *supra* note 189, at 1091 ("Numerous studies have demonstrated that caring for a person with dementia at home can have adverse effects on the psychological and physical health of the informal caregiver"); Skaria, *supra* note 180 (noting that caregivers are "vulnerable to health consequences of the chronic stressors associated with [Alzheimer's] caregiving . . . and are at higher risk for cardiovascular (CV) disease, diabetes, obesity, cancer and depression"); Span, *supra* note 194, at D3 ("Caregivers report high rates of anxiety and depression.").

198. van Vliet et al., *supra* note 189, at 1092.

199. Skaria, *supra* note 180 (noting that "caregivers are more likely to experience disruptions to their work schedule, reduce hours worked, or leave the workforce").

200. Gibson et al., *supra* note 186, at 599 ("Previous studies have consistently found that loss of income for both the individual and the caregiver was a significant stressor for families with [early-onset dementia]."); Skaria, *supra* note 180 (noting also that many Alzheimer's patients eventually need "long-term care that may include home health, assisted living, nursing care, and hospice," all of which are costly); Sylvia Hill, *Zen Alzheimer's*, 6(2) ALZHEIMER'S CARE Q. 101, 101 (2005) (noting that caregivers have "serious repercussions . . . socially, economically, and in [their] careers").

201. Piller, *supra* note 179 (noting that "[t]he anti-amyloid antibody drugs approved in the United States cost tens of thousands of dollars per patient per year").

202. *Id.*

203. *Id.*

204. *Id.* (noting also that the new anti-amyloid antibody drugs approved in the U.S. can "shrink the brain faster than Alzheimer's itself").

are autosomal dominant, the children of these mutation carriers have a 50% chance of inheriting them.[205]

III. THE WRONGFUL PREGNANCY, WRONGFUL LIFE, AND WRONGFUL BIRTH CAUSES OF ACTION

Suppose prospective parents with BRCA1 or BRCA2 mutations or Lynch syndrome decide that, due to previous familial experiences with cancer or the hardships they endured for preventative purposes,[206] they want to use PGT to avoid having a child with the relevant mutation.[207] Additionally, suppose prospective parents with mutations in the PSEN1, PSEN2, or APP genes want to avoid passing on to their offspring the overwhelming emotional and familial implications of having an Alzheimer's gene.[208] These choices would involve undergoing the process of IVF and PGT, including choosing an embryo for implantation that does not have the mutation.[209] If, due to negligence, a mistake is made—even a mistake admitted by a physician or lab—and the child is born with the tested-for mutation, the parents will be unable to recover for the resulting consequences to themselves or their child. Here is why.

Presuming the parents brought an action to recover their damages, the three reproductive negligence causes of action that would generally be considered by the courts are wrongful pregnancy, wrongful life, and wrongful birth.[210] The highlights of each claim are explored below.

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205. *See* Jill S. Goldman, *New Approaches to Genetic Counseling and Testing for Alzheimer's Disease and Frontotemporal Degeneration*, 12(5) CURRENT NEUROLOGY NEUROSCIENCE REP. 502, 502–10 (2012) [hereinafter *New Approaches*]; Jill S. Goldman et al., *Genetic Counseling and Testing for Alzheimer Disease: Joint Practice Guidelines of the American College of Medical Genetics and National Society of Genetic Counselors*, 13(6) GENETICS IN MED. 597, 601 (2011).

206. *See, e.g.*, Derks-Smeets et al., *supra* note 140, at 1106 (discussing a BRCA-positive woman's "strong need to protect a potential daughter" from the choice to "amputate [her] breasts").

207. Derks-Smeets et al., *supra* note 140, at 1110 (noting that, in considering PGT, BRCA-positive women mentioned "the perceived severity of HBOC, which was generally based on personal and familial experience with cancer and sacrifices to be made for preventive measures"); Bartuma et al., *supra* note 150 (noting that, in a study involving interviews with 27 members of Lynch syndrome families, "all parents expressed concern for their children, including worries about cancer being diagnosed at a young age [and] participation in surveillance programs . . . ").

208. *See* Goldman, *New Approaches*, *supra* note 205, at 506 (noting that PGT may be performed because "the parent-to-be may wish to ensure that the causal gene not be passed to offspring").

209. *See supra* Part I.

210. Strasser, *supra* note 60, at 821 [hereinafter *Yes, Virginia, There Can Be Wrongful Life*] (explaining that "Many, but not all, states distinguish among the birth-related torts – wrongful conception and wrongful pregnancy, wrongful birth, and wrongful life"); Mark Strasser, *Prenatal Tort Spillage*, 31(1) HEALTH MATRIX 221, 221 (2021) [hereinafter *Prenatal Tort Spillage*] ("States differ about whether to recognize wrongful pregnancy, wrongful birth, and wrongful life,

A. *Wrongful Pregnancy*

Not all states use the same terms for wrongful pregnancy[211] or apply the cause of action in the same way.[212] However, most states have a cause of action that provides relief in the paradigmatic situation covered by wrongful pregnancy.[213] That type of case involves a woman who expressly did not want to become pregnant but, due to the negligence of a healthcare professional, gave birth to a healthy[214] child.[215] These cases generally arise from negligently performed sterilization procedures; negligent advice, administration, or products related to contraception; the failure to diagnose a pregnancy; or an incomplete abortion.[216]

The damages awarded for wrongful pregnancy can include the costs of the negligently-performed medical procedure and the pain, suffering,

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some recognizing none of these prenatal torts, others recognizing only one or two, while still others recognize all three."); Pacheco v. United States, 48 F.4th 976, App'x at 983–84 (9th Cir. 2022) (No. 21-35175) (noting that many courts divide negligent reproductive healthcare claims into three categories: wrongful pregnancy, wrongful birth and wrongful life, and pointing out that some courts simply categorize all three as medical malpractice).

211. *Pacheco*, 48 F.4th App'x at n.3 (noting that courts often use the terms "'wrongful pregnancy' and 'wrongful conception' interchangeably").

212. Billauer, *supra* note 8, at 96 (noting that some courts "'use the term "wrongful pregnancy" for those cases where a failed sterilization procedure has resulted in the birth of a healthy child. . . [Although others] . . . use the term "wrongful birth"'"); *Pacheco*, 48 F.4th 976, App'x at 983 (noting that different courts use "a wide variety of approaches . . . in both terminology and substance"); Strasser, *Yes, Virginia, There Can Be Wrongful Life*, *supra* note 60, at 821 (noting that "state courts define [the reproductive negligence torts] differently").

213. Hensel, *supra* note 45, at 151 (noting that "most jurisdictions have readily recognized this type of tort action"); Katherine A. Gehring, *Ohio's Approach to Prenatal Torts – A Different Strand of DNA*: Shirmer v. Mt. Auburn Obstetrics & Gynecological Associates, Inc., 844 N.E.2d 1160 (Ohio 2006), 76 U. CIN. L. REV. 235, 238 (2007) ("Wrongful pregnancy claims are allowed in a majority of states."); Michael A. Mogill, *Misconceptions of the Law: Providing Full Recovery for the Birth of the Unplanned Child*, 1996 UTAH L. REV. 827, 872 (1996) (noting that "there appears to be a general consensus that parents can pursue a tort claim for negligent pregnancy").

214. *Pacheco*, 48 F.4th 976, App'x at n.4 (noting that precedent often refers to the birth of a "normal" child, but disavowing that term "because it is both incorrect and harmful . . . to suggest that a child with congenital defects is not 'normal'").

215. Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 227 ("Typically in [wrongful pregnancy] cases, the child is born healthy, but the parents claim to have been harmed"); McKernan v. Aasheim, 687 P.2d 850, 851 (Wash. 1984); Daar, *supra* note 34, at 254. Some outlier cases involve a woman who did not want to become pregnant, but due to negligence gave birth to a child who was disabled. These cases do not fit neatly into the wrongful pregnancy category. *See* Cichewicz v. Salesin, 854 N.W.2d 901 (Mich. Ct. App. 2014) (case involves a woman who was told her fallopian tubes were blocked so she didn't need contraception and subsequently gave birth to a child with Down syndrome); *Pacheco*, 48 F.4th 976, at 978 (case involves a woman who negligently received a flu shot instead of an injection of contraception and gave birth to a disabled child).

216. Gehring, *supra* note 213, at 238; Mogill, *supra* note 213, at 830; Mahoney, *supra* note 8, at 775.

and medical expenses related to the pregnancy and childbirth.[217] While these damages associated with the mother are generally allowed,[218] a majority of courts refuse to award the costs of raising the child.[219] Although several policy reasons are used to support this refusal,[220] the main reason the courts provide is that they are reluctant to label a child's life a compensable injury.[221] As the Virginia Supreme Court wrote, the "courts have reasoned that as a matter of law the benefits derived from the birth of a normal healthy child outweigh the expenses of rearing the child."[222] Summarizing those benefits, the Washington Supreme Court further explained that "[a] child is more than an economic liability. A child may provide its parents with love, companionship, a sense of achievement, and a limited form of immortality."[223] Thus, most wrongful pregnancy cases establish the basic principle that a healthy baby cannot be considered a harm and that parents can only recover damages for injuries that are unrelated to the existence of the child itself.

B. *Wrongful Life*

By contrast, wrongful life cases involve children suffering from serious impairments who claim that, due to the negligence of healthcare professionals, their parents were deprived of the choice not to conceive

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217. *See* Zelt v. Xytex Corp., 766 F. App'x 735, 739 (11th Cir. 2019) (noting that recoverable damages for wrongful pregnancy include the costs of delivery, lost wages, and loss of consortium for the spouse) (citing Fulton-DeKalb Hosp. Auth. v. Graves, 314 S.E.2d 653, 654 (Ga. 1984)); Emerson v. Magendantz, 689 A.2d 409, 412 (R.I. 1997).

218. Hensel, *supra* note 45, at 151 ("In virtually all [wrongful pregnancy] cases, courts have awarded the plaintiff mothers their medical expenses and emotional distress damages associated with pregnancy and childbirth").

219. *Id.*; Miller v. Johnson, 343 S.E.2d 301, 305 (Va. 1986); *Pacheco*, 48 F.4th 976, App'x at 986 (noting that the majority of courts will not award child-rearing costs for a healthy child). *But see* Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 228 (noting that "[a] few jurisdictions [permit] parents to recover childrearing expenses [in wrongful pregnancy cases]"); *Emerson*, 689 A.2d at 412 (acknowledging that some states do "allow for recovery of the cost of child rearing").

220. *See McKernan*, 687 P.2d at 852–54 (listing other policy arguments supporting courts' refusal to award damages for the birth of a healthy child); *see also Miller*, 343 S.E.2d at 305–07; Hensel, *supra* note 45, at 152–54.

221. *See* Hensel, *supra* note 45, at 151; *Miller*, 343 S.E.2d at 305 ("Many courts have held that the birth of a normal, healthy child is not a compensable injury."); Mogill, *supra* note 213, at 835 ("Some courts have complained that the only true public policy is one supporting the 'respect for life.'").

222. *Miller*, 343 S.E.2d at 305–06; *see also* Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 228.

223. *McKernan*, 687 P.2d at 852 ("Many [courts] hold that the benefits of joy, companionship, and affection which a healthy child can provide outweigh the costs of rearing that child.").

them or to terminate the pregnancy that resulted in their birth.[224] The negligence they allege generally relates to preconception counseling (e.g., not informing prospective parents of a higher potential for their offspring to suffer from genetic defects),[225] prenatal advice (e.g., not informing a pregnant woman of the possibility of congenital impairments related to a maternal illness during pregnancy),[226] or prenatal testing (e.g., failing to recommend, properly perform, or accurately report on the results of a prenatal test).[227] Regardless of the type or validity of the negligence alleged and despite the actual harm suffered, the vast majority of courts refuse to allow these claims to proceed.[228]

In rejecting wrongful life claims, the courts explain that recovery would depend on the child's ability to prove that, but for the healthcare provider's negligence, the child would have been in a better position.[229] But the physician's negligence did not cause the child's disability,[230] and nothing could have been done to give that specific child an unimpaired

224. Strasser, *Yes, Virginia, There Can Be Wrongful Life*, *supra* note 60, at 844 (noting that in wrongful life cases, "the child claims that but for the negligence of a medical professional, (1) the child would not have been conceived or born, and (2) the child's having been born resulted in harm to him or her"); Plowman v. Fort Madison Cmty. Hosp., 896 N.W.2d 393, 398 (Iowa 2017) (noting that wrongful life claims are "'brought by the child suffering from . . . birth defects'") (quoting Nanke v. Napier, 346 N.W.2d 520, 521 (Iowa 1984)).

225. *See* Becker v. Schwartz, 386 N.E.2d 807, 808 (N.Y. 1978) (noting the mother alleged she was not informed of the increased risk of having a baby with Down syndrome if she was over the age of 35 or of available testing for Down syndrome); Park v. Chessin, 386 N.E.2d 807, 809 (N.Y. 1978) (companion case to *Becker*) (alleging that the parents were wrongfully informed that polycystic kidney disease is not hereditary despite their first child having the disease).

226. *See* Gleitman v. Cosgrove, 227 A.2d 689 (N.J. 1967), *rev'd on other grounds*, 404 A.2d 8 (1979) (alleging that the plaintiff contracted rubella in the early stages of pregnancy and was not informed by her physician that the disease could result in congenital impairments).

227. *See, e.g.*, *Plowman*, 896 N.W.2d at 395 (Plaintiffs alleged "doctors failed to inform them of abnormalities noted during an ultrasound"); *Becker*, 386 N.E.2d at 809 (Plaintiffs "were never advised by defendants of the increased risk of Down's Syndrome in children born to women over 35 years of age, [n]or . . . of the availability of an amniocentesis test to determine whether the fetus…would be born afflicted with Down's Syndrome").

228. Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 231 ("Very few states recognize wrongful life actions."); Hensel, *supra* note 45, at 143; Billauer, *supra* note 1, at 451 ("Except in the rare case, the child's claims for wrongful life have been rejected outright . . . "); Darpana M. Sheth, *Better Off Unborn? An Analysis of Wrongful Birth and Wrongful Life Claims Under the Americans with Disabilities Act*, 73 TENN. L. REV. 641, 652 (2006) (explaining that some states prohibit wrongful life claims by statute). The few cases allowing a wrongful life claim include, e.g., Procanik v. Cillo, 478 A.2d 755 (N.J. 1984); Harbeson v. Parke-Davis, Inc., 656 P.2d 483 (Wash. 1983); Turpin v. Sortini, 643 P.2d 954 (Cal. 1982).

229. Billauer, *supra* note 1, at 474 (noting that tort damages are normally determined by calculating the difference between the condition plaintiff would have been in without the defendant's negligence and the position the plaintiff is in now).

230. Hensel, *supra* note 45, at 143.

life.[231] Had there been no negligence, the child would not have been born.[232] Thus, recognizing wrongful life claims would force courts to decide whether a life with serious disabilities is worse than nonexistence.[233] As the New York Court of Appeals wrote in *Becker v. Schwartz*: "Whether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and the theologians."[234]

In addition to the problem of finding an acceptable basis for recovery, the *Becker* court was concerned about the implications of determining that a human life has no intrinsic worth. Addressing this concern, the court concluded that allowing a wrongful life cause of action would undercut "the very nearly uniform high value which the law and mankind has placed on human life, rather than its absence."[235] Notably, the overwhelming majority of courts have similarly disavowed wrongful life claims and, as with wrongful pregnancy, expressed their distaste for labelling human life—disabled or not—a cognizable legal injury.[236]

C. *Wrongful Birth*

Wrongful birth cases arise out of the same fact patterns as wrongful life cases, but in wrongful birth cases, the parents are the plaintiffs, rather than the child.[237] Essentially, the parents allege that, but for a healthcare

231. *Id.* at 161 ("Many courts, echoing the early cases, have reasoned that life burdened with defects is better than no life at all . . . .").

232. *See* Patrick J. Kelley, *Wrongful Life, Wrongful Birth, and Justice in Tort Law*, 1979 WASH. U. L. Q. 919, 952 (1979); Matthew Dierh, *The State of Affairs Regarding Counseling for Expectant Parents of a Child with a Disability: Do ACOG's New Practice Guidelines Signify The Arrival of a Brave New World?*, 53 ST. LOUIS U. L.J. 1287, 1299 (2009).

233. *Becker*, 386 N.E.2d at 812 (noting that a wrongful life claim depends on "a comparison between the Hobson's choice of life in an impaired state and nonexistence"); Strasser, *Yes, Virginia, There Can Be Wrongful Life*, *supra* note 60, at 848 ("Arguably, states might never countenance the claim that . . . it [is] better never to have lived at all than to have lived with a particular condition."); Janet A. Laufer, *Medical Malpractice Wrongful Life - Turpin v. Sortini*, 16 AKRON L. REV. 313, 321 (1982) ("In wrongful life cases the alleged injury is the life of the child.").

234. *Becker*, 386 N.E.2d at 812.

235. *Id.*; Hensel, *supra* note 45, at 161.

236. Hensel, *supra* note 45, at 161; Lininger v. Eisenbaum, 764 P.2d 1202, 1210 (Colo. 1988) ("We agree with the overwhelming majority of courts which have addressed the issue that a person's existence, however handicapped it may be, does not constitute a legally cognizable injury relative to non-existence."); *Harbeson*, 656 P.2d at 496 ("One reason for the reluctance of other jurisdictions to recognize [wrongful life claims] appears to be the attitude that to do so would represent a disavowal of the sanctity of a less-than-perfect human life."); Laufer, *supra* note 233, at 321 (noting that "traditionally our common law has highly valued human life").

237. *See, e.g.*, James G. v. Caserta, 332 S.E.2d 872, 879 (W. Va. 1985) (commenting that the factual basis for both the wrongful birth and wrongful life causes of action is the same); Blouin v. Koster, No. PC-2015-3817, 2016 R.I. Super. LEXIS 81, at *10 (Super. Ct. R.I., July 19, 2016)

professional's negligence related to counseling, diagnosing, or prenatal testing, they would have had the information they needed to prevent the birth of their child, who has severe disabilities.[238] To succeed on this claim, the parents must testify that, with the appropriate information, they would have decided either not to conceive or to terminate the pregnancy.[239]

Logically, it would seem that the courts should have the same problem with wrongful birth cases as with wrongful pregnancy and wrongful life claims.[240] Because plaintiffs are alleging that, if the healthcare professional used reasonable care, their child would not have been born,[241] it would appear that the parents' injury is the life of the child itself.[242] Due to the value placed on human life and the benefits that children—including those with disabilities—bring to parents,[243] determining that a child is a harm would seem contrary to the settled law

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("'The terms "wrongful birth" and "wrongful life" are but shorthand phrases that describe the causes of action of parents and children when negligent medical treatment deprives parents of the option to terminate a pregnancy to avoid the birth of a defective child.'") (quoting Procanik by Procanik v. Cillo, 478 A.2d 755, 760 (N.J. 1984)); Botkin, *supra* note 3, at 274 (noting that many states and courts have recognized the wrongful birth cause of action); Gehring, *supra* note 213, at 239 (noting that "wrongful birth suits are brought by parents" and "the child is disabled in some way").

238. Botkin, *supra* note 3, at 269.

239. Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 225; Botkin, *supra* note 3, at 269 (noting that, in wrongful birth claims, parents allege that "had they been adequately informed of their reproductive risk, they would have taken measures to prevent the pregnancy or birth of the affected child"); Hensel, *supra* note 45, at 142.

240. *See, e.g.*, *Becker*, 386 N.E.2d at 819 (Wachtler, J., dissenting) (stating that the wrongful birth cause of action is "at variance with existing precedents both old and new").

241. *See, e.g.*, *Blouin*, 2016 R.I. Super. LEXIS at *5 (Super. Ct. R.I., July 19, 2016).

242. Hensel, *supra* note 45, at 143 (noting that courts have "found it more palatable to identify lost parental choice as the injury than to answer the metaphysical question of whether non-existence is ever preferable to life, however burdened"); Azzolino v. Dingfelder, 337 S.E.2d 528, 533–34 (N.C. 1985) (noting the failure of courts in wrongful birth cases "to recognize that the 'injury' for which they seek to compensate the plaintiffs is the existence of a human life"); Blake v. Cruz, 698 P.2d 315, 319 (Iowa 1984) ("The injury in a wrongful birth claim is the birth of the child."); *Harbeson*, 656 P.2d at 492 (noting that, in a wrongful birth case, it is problematic "whether the birth of a defective child represents an injury to the parents"); Campbell v. United States, 795 F. Supp. 1118, 1123 (N.D. Ga. 1990) (noting that the negligence of the physician "prevented the child's non-existence").

243. *See, e.g.*, Kelley, *supra* note 232, at 947 (noting the danger that a judgment in a wrongful birth case could "stand as an official, public pronouncement that the [disabled] child's existence is a net detriment to his parents, despite all the love and joy he offers them"); *Becker*, 386 N.E.2d at 814 (recognizing that "parents may yet experience a love that even an abnormality cannot fully dampen"); Garrison v. Med. Ctr. of Del., Inc., 581 A.2d 288, 292 (Del. 1989) ("Awarding the normal expenses of raising a child . . . might actually constitute a windfall to the parents who enjoy the love and affection of the child.").

in the other reproductive negligence cases.[244] While some courts have dismissed wrongful birth claims on this basis,[245] many other courts have relied on two analytical avenues to sidestep this result and provide parents with some financial assistance in raising their disabled child.

The first avenue many courts use is to frame the parents' harm not as the child's existence, but rather as their lost opportunity to avoid conception or terminate the pregnancy.[246] Using this framework, the court's role is to decide whether, due to the negligence of the defendant, the parents were deprived of material, time-sensitive information that would have affected their decision to conceive or carry a pregnancy to term.[247] With this focus, the parents' protected interest is their right to self-determination in making meaningful decisions concerning their future family,[248] and their recovery is related to the repercussions of the healthcare professional's infringement on this right.[249]

The second avenue the courts use to sidestep the problem of considering the child itself as the parents' harm is to limit damages to the extraordinary costs of raising a disabled child.[250] In other words, in calculating damages, the parents' recovery is limited to the extra costs

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244. Kelley, *supra* note 232, at 947 (referring to the "common understanding that isolating and weighing the joys and sorrows of parenthood is impossible").

245. *See, e.g.*, *Azzolino*, 337 S.E.2d at 533–34 (denying recovery in a wrongful birth case and explaining that, "[i]n order to allow recovery, [courts] must . . . [hold] that the existence of a human life can constitute an injury cognizable at law"); *see also* Wilson v. Kuenzi, 751 S.W.2d 741, 743–45 (Mo. 1988) (denying recovery in a wrongful birth case partially on this basis).

246. *See, e.g.*, Hensel, *supra* note 45, at 143; Plowman v. Fort Madison Cmty. Hosp., 896 N.W.2d 393, 405 (Iowa 2017) ("In a wrongful-birth claim, the injury is not the resulting life of a healthy child . . . but rather is the parent's deprivation of information material to making an informed decision whether to terminate a pregnancy of a child likely to be born with severe disabilities."); *Blouin*, 2016 R.I. Super. LEXIS at *11 (Super. Ct. R.I., July 19, 2016).

247. *See, e.g.*, *Garrison*, 581 A.2d at 290 (noting that plaintiffs' injury "lies in their being deprived of the opportunity to make an informed decision to terminate the pregnancy"); *Campbell*, 795 F. Supp. at 1124 ("[l]ike many other courts before, one can take the view that the injury alleged is not the life of the child, but rather a simple failure to diagnose a condition at a time when this state presently would allow the mother to make a choice whether to allow her child to come to term."); *see generally* Canesi *ex. rel.* Canesi v. Wilson, 730 A.2d 805 (N.J. 1999).

248. *See, e.g.*, *Canesi*, 730 A.2d at 810 ("The violation of the interest in self-determination that undergirds a wrongful birth cause of action consists of the parents' lost opportunity to make the personal decision of whether or not to give birth to a child who might have birth defects.") (citing Schroeder v. Perkel, 432 A.2d 834 (1981)).

249. Botkin, *supra* note 3, at 275 (noting that "the harm in these cases is not the birth of the impaired child, but the infringement on free choice in reproductive decisions").

250. *Id.* at 276 ("The majority of the courts have awarded damages for the medical costs incurred by the child's unwanted medical condition while the child is a minor."); Gehring, *supra* note 213, at 241 (noting that, while there is no consensus on recovery in wrongful birth cases, "[l]imited recovery has gained the most widespread acceptance"); Viccaro v. Milunsky, 551 N.E.2d 8, 10 (Mass. 1990) ("If a child is born with a congenital or genetic disorder, almost all courts have allowed the parents to recover against a negligent physician the extraordinary medical, educational, and other expenses that are associated with and are consequences of the disorder.").

that are associated with the child's disability; the ordinary costs of raising the child are not included.[251] The extraordinary costs may include, for example, medical, educational, and other expenses related to the child's disability.[252] By using this method of calculating damages, the court is essentially separating the child into two parts: (1) the child the parents wanted and whose ordinary child-rearing costs they are precluded from receiving; and (2) the child's disability, which they did not want and for which they receive damages.[253]

Some courts justify this division of damages by relying on the rule that tort law attempts to put the plaintiffs in the position they would have been in but for the defendant's negligence.[254] However, instead of applying this rule by determining that the parents would have been childless but for defendant's actions, these courts posit that the parents should be placed in the position they were led to believe they would be

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251. Strasser, *Yes, Virginia, There Can Be Wrongful Life*, *supra* note 60, at 839–41 (listing cases holding that recovery is limited to the extraordinary expenses of raising a child); *see, e.g.*, *Harbeson*, 656 P.2d at 494 (holding that, for extraordinary damages, "parents should recover those expenses in excess of the cost of the birth and rearing of [ ] normal children"); *Garrison*, 581 A.2d at 292 (holding that parents may recover damages to the extent the "extraordinary expenses of caring for, maintaining and educating the child exceed the usual costs of raising an unimpaired child").

252. *Harbeson*, 656 P.2d at 494; *Plowman*, 896 N.W.2d at 407 ("For example, damages from a wrongful-birth claim were used by one family to 'pay for some of the expenses of raising their [child], including prostheses, wheelchairs, operations, attendants, and other healthcare needs.'") (quoting Harris, *supra* note 22, at 395); Keel v. Banach, 624 So. 2d 1022, 1030 (Ala. 1993) (listing as extraordinary expenses: "(1) hospital and medical costs, (2) costs of medication, and (3) costs of education and therapy for the child").

253. *See, e.g.*, Harris, *supra* note 22, at 374 ("[W]hile the costs of raising the child that stem from the child's disability or condition may be recovered, those costs that are inherent in raising any child may not be recovered"); Smith v. Cote, 513 A.2d 341, 349 (N.H. 1986) (noting that the extraordinary costs rule "in effect divides a plaintiff's pecuniary losses into two categories, ordinary costs and extraordinary costs, and treats the latter category as compensable, while ignoring the former category"); Kelley, *supra* note 232, at 952 (noting that with extraordinary damages the court "compared plaintiff's present state with an impossible state in which they would have had a normal child").

254. *See, e.g.*, Kush v. Lloyd, 616 So. 2d 415, 424 (Fla. 1992); *Keel*, 624 So. 2d at 1029–30 (stating that "the basic rule of tort compensation is that the plaintiff should be put in the position that he would have been in absent the defendant's negligence" and then deciding to allow recovery for only extraordinary damages); *see also Campbell*, 795 F. Supp. at 1125 ("Allowing recovery for the extraordinary expenses of the child's care is consistent with the general tort principle that a tortfeasor should be liable for the consequences of his wrong."); *but see Smith*, 513 A.2d at 349 (referring to the expectancy rule in breach of contract cases and explaining that ordinary child-rearing expenses "are analogous to a price the plaintiffs were willing to pay in order to achieve an expected result"); *see also* Kelley, *supra* note 232, at 953 ("By holding that the birth of a defective child constitutes legal injury to those who wanted to avoid that birth, the court just protects the expectations of the parties.").

in.[255] Because the parents decided to conceive or continue the pregnancy believing they were having a healthy child whom they would have to support, these courts conclude that the traditional expenses associated with raising the child cannot be considered a harm.[256] Rather, the parents' damages are limited to the extraordinary expenses associated with the disability the parents wanted to avoid.[257]

Some other courts skip this analysis and simply start with the proposition that parents always assume responsibility for the ordinary costs of raising a child and therefore those costs should not be awarded.[258] But these courts also recognize that the extraordinary costs associated with the child's disabling condition can be "overwhelming" and should be awarded to the affected parents due to the defendant's negligence.[259]

Bifurcating the parents' damages in this manner, the courts escape two major problems. First, because the parents are not awarded damages for raising the child they wanted, the courts avoid assessing the value of the child's life to the parents[260] and arguably do not stigmatize the parents or child by allowing recovery for the child's existence.[261] In addition, by allowing parents to receive the costs associated with the disability, the parents receive help with their potentially staggering financial obligations[262] and defendants are held liable for some of the foreseeable consequences of their negligence.[263]

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255. *See, e.g.*, *Kush*, 616 So. 2d at 424; *see also Smith*, 513 A.2d at 349 (using the expectancy rule and referring to the position plaintiffs "expected to be in") (quoting Kelley, *supra* note 232, at 954).

256. *See, e.g.*, *Kush*, 616 So. 2d at 424; *Azzolino*, 337 S.E.2d at 539 (Exum, J., dissenting) (concluding that the parents should be entitled to only the extraordinary expenses attributable to their child's disability and explaining that parents "were prepared to incur the expenses of giving birth to and raising a child without [Down syndrome]").

257. *See, e.g.*, *Kush*, 616 So. 2d at 424.

258. *See, e.g.*, Fassoulas v. Ramey, 450 So. 2d 822, 823–24 (Fla. 1984); Arche v. United States Dep't of Army, 798 P.2d 477, 481 (Kan. 1990).

259. *See, e.g.*, *Fassoulas*, 450 So. 2d at 824 ("Special medical and educational expenses, beyond normal rearing costs, are often staggering and quite debilitating to a family's financial and social health . . .").

260. *See, e.g.*, Campbell, 795 F. Supp. at 1125–26 ("Allowing recovery for the extraordinary expenses of the child's care . . . avoids the problems of speculation in assessing general damages for the child's life and estimating in some abstract way the value of a human life.").

261. *See, e.g.*, Kelley, *supra* note 232, at 953 (noting that limiting recovery to extraordinary damages "avoids the potentially damaging judgment that the child is a net detriment to his parents"); Lininger v. Eisenbaum, 764 P.2d 1202, 1207 (Co. 1988) ("We fail to see how the parents' recovery of extraordinary medical and educational expenses, so as to minimize the detrimental effect of the child's impairment, is outweighed by any speculation about stigma he might suffer.").

262. *See, e.g.*, *Fassoulas*, 450 So. 2d at 824.

263. Rogers III, *supra* note 61, at 716 (noting that a "fundamental premise" of wrongful birth cases "is the physician's negligent failure to advise the plaintiff's parents concerning foreseeable

The second problem the courts avoid is related to the benefit rule. Under this rule, the benefits to the plaintiffs resulting from defendant's negligent conduct must be offset "against the damage the negligence causes to the extent necessary to achieve an equitable result."[264] This rule would require deducting the value of the child's life to the parents from the financial and other damages the parents suffer due to the disability.[265] However, as the wrongful pregnancy and wrongful life cases indicate, the value of a child's life to its parents cannot be measured in any reasonable way.[266] Strikingly, this entire problem is solved by restricting the parents' recovery to the extraordinary expenses associated with the child's disability. Because the parents derive no benefit from the child's disability, and the only damages the parents receive are related to the disability, there are no benefits to deduct.[267]

It should also be noted that most courts award the extraordinary costs of raising disabled children until they reach the age of majority. Awards beyond majority are generally granted to parents only when their support obligations continue into adulthood due to their child's inability to support themselves.[268]

Thus, by framing the wrongful birth cause of action as the parents' lost opportunity to avoid conception or terminate the pregnancy and by awarding only the extraordinary costs of raising their child to majority, the courts were able to provide parents some relief and avoid addressing the fact that the child would not have existed but for the defendant's

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fetal risk . . ."); Canesi v. Wilson, 730 A.2d 805, 819 (N.J. 1999) (noting that proximate causation is satisfied if the birth of a disabled child "was reasonably foreseeable and . . . not too remote in relation to the doctor's failure to apprise the parents of that risk").

264. *Lininger*, 764 P.2d at 1206.

265. *See id*.

266. *See supra* Part III.A, III.B.

267. *See, e.g.*, *Lininger*, 764 P.2d at 1207; Gynecology Group, P.A. v. Abelson, 195 Ga. App. 274, 280 (1990) ("[A] set-off should have no bearing in a 'wrongful-birth' case [where] . . . extraordinary child-rearing expenses [are] claimed.); Schroeder v. Perkel, 432 A.2d 834, 842 (N.J. 1981) ("Although [the parents] may derive pleasure from [their son], that pleasure will be derived in spite of, rather than because of, his affliction.").

268. *See, e.g.*, Viccarro v. Milunsky, 406 Mass. 777, 781–82 (Mass. 1990) (deciding that plaintiffs can recover the extraordinary expenses associated with their child's disability after he reaches adulthood if they can prove "the child is physically or mentally impaired and incapable of supporting himself"); Blake v. Cruz, 698 P.2d 315, 321 (Iowa 1984) (recognizing that parents can recover damages for extraordinary expenses after the child reaches majority "where the adult child is unmarried, unemancipated and insolvent and physically or mentally incapacitated from supporting himself") (citing Fower v. Fower Estate, 448 S.W. 2d 585 (Mo. 1970)); Campbell v. United States, 795 F. Supp. 1118, 1126 (N.D. Ga. 1990) (noting that extraordinary damages are recoverable beyond majority "if the child will be completely destitute"); James G. v. Caserta, 332 S.E.2d 872, 882–83 (W. Va. 1985) (noting that parents may recover "the extraordinary costs for rearing a child with birth defects . . . after the child reaches the age of majority if the child is unable to support himself because of physical or emotional disabilities").

negligence.[269] In this way, the courts' framing of the issues and limitation on damages enabled them to reach an equitable result.[270]

IV. APPLYING THE REPRODUCTIVE NEGLIGENCE CLAIMS TO PGT AND ADULT-ONSET GENETIC CONDITIONS

Returning to the BRCA, Lynch syndrome, and early-onset Alzheimer's mutation carriers and their parents' lawsuits to recover for negligence in selecting an embryo for implantation that carried the unwanted mutation, it is easy to conclude that they will not prevail using any of the current reproductive negligence causes of action. The parents will not prevail using wrongful pregnancy because (1) they wanted to have a child, so this is not the appropriate cause of action; and (2) their child was born healthy and most courts agree that a healthy baby is not a cognizable harm.[271] In addition, the parents will not prevail using wrongful birth because there are no extraordinary expenses in raising the child until majority. Children with the mutations causing these adult-onset conditions will usually not have any disease, or need to take any preventative measures, until after they reach adulthood.[272] Finally, the child will not prevail using a wrongful life claim because the child cannot prove that the value of its life is worse than nonexistence. In fact, this case would be much weaker than the typical wrongful life case because the child will have many years of an unencumbered life before having to deal with any repercussions related to carrying the mutation.[273]

Although current law does not provide any redress for the healthcare professional's negligence, these parents and their children will suffer real harm. While the children are very much wanted—enough so that the parents were willing to undergo IVF and PGT to have them[274]—and

269. Kelley, *supra* note 232, at 952 (noting that "under the ordinary compensatory damage standard, the trier of fact would determine the extent of damages by comparing the present state of plaintiffs – the parents of a defective child – with their alternative state – a couple without this child").

270. *See id.* at 963 ("If one sees the courts' different arguments in these cases as unarticulated expressions of traditional corrective justice theories, the results make more sense"); *see also* Wilson v. Kuenzi, 751 S.W.2d 741, 744 (Mo. 1988) ("Many of the damage discussions [in wrongful birth cases] sound far more like a discussion of public policy doctrine considerations rather than discussions of the traditional damage rules.").

271. *See, e.g.*, Ingrid H. Heide, *Negligence in the Creation of Healthy Babies: Negligent Infliction of Emotional Distress in Cases of Alternative Reproductive Technology Malpractice Without Physical Injury*, 9 J. MED. & L. 55, 66 (2005) ("Wrongful pregnancy would be completely inapplicable to cases of [assisted reproductive technology (ART)] malpractice because the victims in ART cases were attempting to have a child . . . .").

272. *See supra* Part II.

273. *See, e.g.*, Strong, *supra* note 69, at 138 (noting that for adult-onset disease "[p]resumably, there would be many years of good quality life before onset of harmful symptoms").

274. *See supra* Part II.

while they can look forward to years of healthy life and an overall bright future,[275] they and their parents will face substantial burdens, emotional challenges, and probably financial hardships due to the repercussions of carrying the mutation.[276] The financial hardships may be especially acute for Lynch syndrome and BRCA mutation carriers, even if they never have cancer, because the preventative surgeries[277] and screenings[278] may not be covered by medical insurance and may be very expensive due to rising healthcare costs. For early-onset Alzheimer's carriers, the long-term financial burdens may be even more onerous as they will likely lose their jobs and be forced to shoulder the massive expenses associated with caregiving.[279]

The historical predicates for the wrongful birth cause of action provide additional support for providing relief to these parents. The first major cases supporting wrongful birth claims were decided in the mid to late 1970s, beginning a trend toward judicial acceptance of the cause of action.[280] This trend was precipitated by two major events: (1) the 1973 Supreme Court decision in *Roe v. Wade*,[281] which created a constitutional right to abortion in the first two trimesters of pregnancy; and (2) the technological advances that allowed healthcare professionals to predict and detect congenital and genetic anomalies prior to the third trimester.[282]

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275. *See, e.g.*, U. Menon et al., *Views of BRCA Gene Mutation Carriers on Preimplantation Genetic Diagnosis as a Reproductive Option for Hereditary Breast and Ovarian Cancer*, 22(6) HUM. REPROD. 1573, 1575 (2007) (reporting that BRCA-positive women commented on "their good quality of life, their value to society, and the increasing availability of effective management and treatment strategies").

276. *See supra* Part II.A.

277. *See* Michael Ha et al., *Insurance Coverage of Prophylactic Mastectomies: A National Review of the United States*, 23(2) CLINICAL BREAST CANCER 211 (2022); Ryan Mooney et al., *Experiences of Patients and Family Members with Follow-up Care, Information Needs and Provider Support after Identification of Lynch Syndrome*, 21(1) HEREDITARY CANCER CLINICAL PRAC. 1, 2–8 (2023), https://doi.org/10.1186/s13053-023-00273-1 [https://perma.cc/T58A-U3KY].

278. *See* Grace Wang et al., *Eligibility Criteria in Private and Public Coverage Policies for BRCA Genetic Testing and Counseling*, 13(12) GENETICS MED. 1045, 1048–49 (2011); Gemme Campbell-Salome et al., *Uncertainty Management for Individuals with Lynch Syndrome: Identifying and Responding to Healthcare Barriers*, 104(2) PATIENT EDUC. & COUNSELING 403, 405–08 (2021).

279. *See supra* Part II.C.

280. *See* Rogers III, *supra* note 61, at 743; Smith v. Cote, 513 A.2d 341, 345 (N.H. 1986) (quoting PROSSER AND KEETON ON THE LAW OF TORTS § 55, at 370 (5th ed. 1984) ("Today there is 'quite general agreement' that some recovery should be permitted in wrongful birth cases.")).

281. Roe v. Wade, 410 U.S. 113 (1973).

282. Botkin, *supra* note 3, at 269; Rogers III, *supra* note 61, at 743–44 ("In 1975, as a result of these developments, two state supreme courts recognized wrongful birth claims."); *Smith*, 513 A.2d at 346 ("In the early 1970's amniocentesis was regarded as an experimental procedure; by the mid-1970's, it was commonly accepted in medical practice.").

Many courts explicitly referred to *Roe v. Wade* in deciding to adopt the wrongful birth cause of action.[283] Because successful wrongful birth claims depend on a woman's testimony that she would have had an abortion or would not have conceived had she been properly informed of her child's potential disabilities,[284] many of these cases rest on the woman's right to choose an abortion.[285] Some courts go further and explain that a woman's constitutional right to choose an abortion can only be adequately exercised if the woman is given timely and accurate information allowing her to make a meaningful decision regarding whether to carry a pregnancy to term.[286] Wrongful birth actions are essential to protecting this right because they hold healthcare professionals accountable for negligently failing to provide material information either through advice, diagnosing, or prenatal testing.[287]

Notably, the trend towards acceptance of the wrongful birth cause of action was reversed in the 1980s when several states passed statutes similar to the Minnesota law, enacted in 1982, providing that "[n]o person

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283. *See, e.g.*, *Smith*, 513 A.2d at 346 ("Roe v. Wade, 410 U.S. 113 (1973), and its progeny constitute the second development explaining the acceptance of wrongful birth actions."); Keel v. Banach, 624 So. 2d 1022, 1024 (Ala. 1993) ("Another reason that courts were reluctant to recognize the wrongful birth cause of action was that . . . abortion was illegal. This reasoning is no longer valid after Roe v. Wade . . ."") (quoting Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149, 152 (1992)); Berman v. Allan, 404 A.2d 8, 16 (N.J. 1979) ("Any other ruling would in effect immunize from liability those in the medical field providing inadequate guidance to persons who would choose to exercise their constitutional right to abort fetuses which, if born, would suffer from genetic defects.").

284. Hensel, *supra* note 45, at 166.

285. *See, e.g.*, Plowman v. Fort Madison Cmty. Hosp., 896 N.W.2d 393, 409 (Iowa 2017) ("We conclude Iowa public policy would not permit recovery for wrongful birth if the abortion in question would be illegal"); *Smith*, 513 A.2d at 346 ("[W]e believe that Roe is controlling; we do not hold that our decision would be the same in its absence"); Botkin, *supra* note 3, at 274–75 ("Several courts and scholars argue that the wrongful birth concept is an extension of the constitutionally protected right to privacy in abortion decisions [but] . . . other commentators and courts argue . . . [t]he constitutional right . . . imposes no positive duties on health care providers to provide information about the fetus"); Sheth, *supra* note 228, at 649; Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 236 (noting that "the lost opportunity to abort . . . only bars a subset of [wrongful birth actions]").

286. *See, e.g.*, Botkin, *supra* note 3, at 275 ("[R]eproductive choice is limited if inadequate prenatal diagnostic information is provided."); *Allan*, 404 A.2d at 14 ("Any other ruling would in effect immunize from liability those in the medical field providing inadequate guidance to persons who would choose to exercise their constitutional right to abort fetuses which, if born, would suffer from genetic defects."); Azzolino v. Dingfelder, 337 S.E.2d 528, 538 (Ala. 1984) (Exum, J., dissenting) ("To deny . . . any remedy for a physician's negligently withholding information or negligently providing misinformation so immunizes the physician as to encourage the physician himself, in effect, to make the abortion decision.").

287. *See* Hensel, *supra* note 45, at 191 ("A real threat exists that, in the absence of external incentives, physicians who strongly oppose abortion will be more likely to forego genetic testing in order to preempt a potential abortion."); *Plowman*, 896 N.W.2d at 407.

shall maintain a cause of action . . . [based] on the claim that but for the negligent conduct of another, a child would have been aborted."[288] Currently, sixteen states have comparable statutes banning at least wrongful birth actions that are premised on a woman being negligently denied the opportunity to abort her fetus.[289] There is every reason to expect that even more states will limit wrongful birth actions after the Supreme Court's decision in *Dobbs v. Jackson Women's Health Organization*, reversing *Roe* and holding that there is no constitutional right to abortion.[290]

In addition, the *Dobbs* decision and its aftermath will likely affect the number of pregnant women who rely on prenatal testing. One of the main purposes of prenatal testing is to provide women with accurate information so they can decide whether to abort "an afflicted fetus."[291] But sixteen states have already passed statutes banning or so severely restricting the timing of a legal abortion that the results of the most reliable prenatal tests—amniocentesis and CVS—would be received too late for a woman to choose an abortion based on adverse results.[292]

Not only has the legal landscape changed since the initial court decisions approving the wrongful birth cause of action, but there have also been enormous technological advances in preimplantation testing for chromosomal and genetic anomalies expanding the benefits of this testing

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288. 1982 Minn. Laws ch. 521, § 1 (codified at MINN. STAT. § 145.424); *see also* MO. ANN. STAT. § 188.130(2) (1986); 1985 Idaho Sess. Laws, ch. 147, § 1, at 394 (codified at IDAHO CODE § 5-334); 1988 Pa. Laws, Pub. L. 336, No. 47, § 2 (codified at 42 PA. CONS. STAT. § 8305(a) (1988) ("There shall be no cause of action . . . based on a claim that, but for an act or omission of the defendant, a person once conceived would not or should not have been born.")).

289. Aviva K. Diamond, *The Impact of Post-Dobbs Abortion Bans on Prenatal Tort Claims*, 122 MICH. L. REV. 371, 391 (2023) (referencing Table 1: State Survey of Prenatal Tort Claims); *see also* Revised Judicature Act of 1961, No. 423, § 2971, 2000 Mich. Legis. Serv. (codified at MICH. COMP. LAWS ANN. § 600.2971(1)); Okla. Laws 2010, ch. 171, § 1 (codified at OKLA. STAT. Tit. 63, § 1-741.12(C) (2010)); ARK. CODE ANN. § 16-120-902(a) (2024) (enacted in 2017).

290. Dobbs v. Jackson Women's Health Org., 597 U.S. 215 (2022); *see* Diamond, *supra* note 289, at 404 ("When a state that allows prenatal tort claims bans abortion, it compromises its existing prenatal tort law. . . Four of the states with new abortion bans – Alabama, Texas, West Virginia, and Wisconsin – had case law authorizing wrongful pregnancy and wrongful birth claims before Dobbs.").

291. Gildner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692, 695 (E.D. Pa. 1978) ("The value of genetic testing programs . . . is based on the opportunity of parents to abort afflicted fetuses, within appropriate time limitations."); Keel v. Banach, 624 So. 2d 1022, 1024 (Ala. 1993) (same); Bayefsky & Berkman, *supra* note 22, at 5 ("Prenatal testing has three primary aims: to allow parents to prepare for a child with special needs, to provide parents with the opportunity to terminate a pregnancy if the fetus has an undesired anomaly, and to allow for treatment in utero.").

292. *Policy Tracker: Exceptions to State Abortion Bans and Early Gestational Limits*, *supra* note 7 (listing the states that have abortion restrictions including their time restrictions). Some of the time restrictions are based on the patient's last menstrual period. *See* Ungar & Seitz, *supra* note 14 (explaining that amniocentesis is performed between 15 and 20 weeks of gestation and CVS between 10 and 13 weeks of gestation).

to additional prospective parents.[293] More and more women are also using IVF for infertility reasons and taking advantage of PGT in the process.[294] Due to restrictions on abortions, an increasing number of women may turn to PGT, especially those who know they carry a harmful genetic mutation that may be passed along to their children. The expanding use of PGT, and the enormous repercussions for families if there are errors in performing preimplantation testing, highlight the importance of adequate remedies for malpractice.

Although the traditional reproductive negligence causes of action would not provide adequate relief for malpractice resulting in children carrying the BRCA, Lynch syndrome, or early-onset Alzheimer's gene mutations, this relief could easily be granted using standard tort principles. But to afford relief, there must be a separate tort that takes into account the differences in legal and policy concerns between PGT and wrongful birth. Significantly, recognizing wrongful selection of embryos as a separate tort would also remove, or substantially eliminate, the abortion controversies and issues concerning the value of human life that have plagued wrongful birth litigation.

V. THE LEGAL AND POLICY DIFFERENCES BETWEEN WRONGFUL BIRTH AND WRONGFUL SELECTION OF EMBRYOS

Courts refusing to recognize wrongful birth claims generally focus on issues related to two elements of the negligence cause of action: causation and injury.[295] Due to the fundamental differences between traditional wrongful birth cases and those involving preimplantation testing, the problems related to these two elements either do not apply to negligence involving PGT at all or are presented in a very different light.

A. *Causation*

Standard reproductive negligence claims are different from other types of medical malpractice cases because the plaintiffs cannot prove medical causation. The physicians do not cause the child's congenital or genetic anomaly or any other harm to the child.[296] Although physicians have commonly been held liable for malpractice for failing to diagnose illnesses which they did not cause,[297] in those cases the physician's negligence prevented the patient from receiving medical care that could

293. Botkin, *supra* note 3, at 269; Rogers III, *supra* note 61, at 743–44.

294. *Practice Committees*, *supra* note 5, at 421 ("On the basis of national data from the Society for Assisted Reproductive Technology (SART), the proportion of IVF cycles using PGT has increased from 14% in 2014 to 44% in 2019.").

295. Plowman v. Fort Madison Cmty. Hosp., 896 N.W.2d 393, 401–02 (Iowa 2017).

296. Sheth, *supra* note 228, at 646.

297. Andrews, *supra* note 61, at 153.

have cured the condition or mitigated the harm.[298] In wrongful birth cases, there is nothing anyone could have done to prevent the child that was born from having the disabling condition.[299] Instead, if the physician had not been negligent, the child would not have been born.[300]

To deal with both the causation issue and the problem of having a child's life considered a cognizable harm, the courts reframed the parents' injury. The parents' harm is not the child's life, but rather the lost opportunity to avoid conception or abort the fetus.[301] Consequently, to prove actual causation, the parents have to confirm that, but for the healthcare professional's negligence in failing to provide them with adequate information regarding the risks of having a disabled child, they would have chosen not to conceive or aborted the fetus.[302] They no longer have to prove the physician caused the child any medical harm.[303]

While this solution allows the courts to grant parents monetary relief, it creates other problems. Significantly, to bring a successful wrongful birth claim, the plaintiff mother must essentially testify that, had she known about her current child's disabilities while she was pregnant, she would have chosen not to have the child.[304] Some courts have asserted that the mother's statement may be unreliable or even fraudulent.[305] The testimony that she would have aborted is not only subjective, but also based on hindsight concerning a decision that would have been made several years in the past.[306] It is also tainted by the occurrence of the undisclosed risk—the mother now has a living child with disabilities she was not warned about—and by her financial interest in ensuring she has adequate resources to provide appropriate care for the child.[307]

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298. Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 223, 239.

299. *See, e.g.*, Becker v. Schwartz, 386 N.E.2d 807, 816 (N.Y. 1978) (Wachtler, J., dissenting) ("The heart of the problem in these cases is that the physician cannot be said to have caused the defect.").

300. *See, e.g.*, Canesi v. Wilson, 730 A.2d 805, 825 (N.J. 1999) (Pollock, J., dissenting) (noting that the defendants' failure to warn "is a but-for cause of [plaintiffs' child's] birth in that but for [the physicians' negligence] the [child] would not have been born").

301. Sheth, *supra* note 228, at 646; Keel v. Banach, 624 So. 2d 1022, 1029 (Ala. 1993); *Canesi*, 730 A.2d at 811.

302. *See, e.g.*, Smith v. Cote, 513 A.2d 341, 347 (N.H. 1986)

303. *Canesi*, 730 A.2d at 813 ("In a wrongful birth case . . . plaintiff need not prove that the doctor's negligence was the medical cause of her child's birth defect"); *Keel*, 624 So. 2d at 1029; Andrews, *supra* note 61, at 152–53 (noting that "early case law" rejected wrongful birth claims "because the physician was not the proximate cause of the defect"); *Canesi*, 730 A.2d at 818 ("The failure to establish medical causation of the child's injury historically was viewed as a ground warranting the dismissal of wrongful birth actions.").

304. Hensel, *supra* note 45, at 166.

305. *See, e.g.*, *Keel*, 624 So. 2d at 1028.

306. *See, e.g.*, *Keel*, 624 So. 2d at 1028; Wilson v. Kuenzi, 751 S.W.2d 741, 746 (Mo. 1988).

307. *See, e.g.*, *Wilson*, 751 S.W.2d at 746.

The problem concerning the reliability of the mother's testimony is solved somewhat by the objective components of the wrongful birth action. The healthcare professional's duty is to disclose the risks that a reasonable pregnant woman—not the actual patient—would find material in deciding whether to abort a fetus.[308] Likewise, to prove proximate cause, the child's disability must be "reasonably foreseeable."[309] Because the plaintiff must meet these elements to prevail on a wrongful birth claim, the physician need not recommend every possible preconception or prenatal test or discuss every conceivable genetic or congenital defect to avoid potential liability.[310] Indeed, the courts have only imposed liability based on a child's serious disabilities, those that would likely have an impact on a woman's decision concerning conception or abortion.[311] These components of the wrongful birth claim help ensure that the woman's testimony is reliable, but due to the exceedingly personal character of a woman's decision to choose an abortion, the causation element remains a significant challenge.[312]

More troubling are the policy considerations involved in requiring a woman to testify that she would not have conceived her child or would have terminated the pregnancy had she known about the child's disabilities.[313] This requirement places a woman in the untenable position of either disavowing her child's value in open court or foregoing the financial assistance necessary to deal with the potentially staggering costs associated with the child's disability.[314] Not only could this testimony be emotionally traumatizing for mothers, but it may also be harmful to the

308. *See, e.g.*, *Canesi*, 730 A.2d at 816 n.5 ("The medical probability of the risk manifesting in the [future child] is highly relevant to whether a reasonably prudent patient would consider the risk material or not.").

309. *See, e.g.*, *id.* at 819 (noting that wrongful birth actions "do not require proof that the doctor's malpractice constitutes the medical cause of the child's defect, only that the defect was a foreseeable risk posed by the malpractice").

310. *See, e.g.*, *id.* at 815; Botkin, *supra* note 3, at 287 (noting that "all potential information need not nor cannot be provided").

311. Hensel, *supra* note 45, at 169 ("Courts recognize no cause of action for the failure to identify or disclose impairments that courts consider less severe . . . .").

312. *See, e.g.*, *Wilson*, 751 S.W.2d at 745–46 (Mo. 1988) (noting the "difficulty of satisfactorily determining and knowing the real reason why a given woman may or may not choose to have an abortion" and recommending requiring testimony that is "more verifiable by some objective standard"); *but see* Botkin, *supra* note 3, at 281 ("Pregnancy termination is a profoundly important decision in a woman's life so it is unlikely that many women would choose to terminate a pregnancy for what might be considered trivial reasons.").

313. Sheth, *supra* note 228, at 666 (noting that "recovery is limited to cases where the parents testify that they would have aborted the child").

314. Hensel, *supra* note 45, at 172; Sheth, *supra* note 228, at 650, 660.

children who learn that their parents would have preferred that they not exist.[315]

None of these issues are major concerns with respect to healthcare professionals negligently selecting embryos for implantation that have the unwanted mutation. The causation in a standard wrongful birth case is multilayered. The physician fails to adequately warn the parents of a child's potential disabilities, which causes the parents to lose their opportunity to abort the fetus, which results in the birth of a disabled child.[316] Conversely, in a negligent embryo selection case, the healthcare professional directly and negligently selects an embryo with the harmful mutation for implantation into the mother's uterus.[317] The causation analysis is simple; but for the professional's negligence, the child that was born would not have the harmful mutation the parents sought to avoid.[318] If the parents can prove that the professional negligently selected an embryo with that mutation, the causation element is easily met and the precise harm is "eminently foreseeable."[319] Because the parents can prove causation in this manner, there is no need to require that the parents testify that they would have chosen to abort the pregnancy had they known their child would carry the mutation.

While the parents do not have to openly disparage their child to prove causation, arguably the parents are disavowing their child's worth by bringing the lawsuit itself. The lawsuit could be construed as implying that the parents did not want the particular child they have because their intent was to choose an embryo without the deleterious mutation. Indisputably, the child would not have been the same person if a different embryo had been selected.[320] However, this is not a substantial issue because research has shown that, although many parents are willing to select from among embryos to avoid having a child with a harmful mutation, they are often unwilling to abort a fetus to avoid an adult-onset condition.

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315. Sheth, *supra* note 228, at 660 (noting that the testimony "can be emotionally crippling . . . to the child"); Plowman v. Fort Madison Cmty. Hosp., 896 N.W.2d 393, 407 (Iowa 2017) (noting defendants' argument that "the disabled child may later be emotionally traumatized upon learning his or her parents would have chosen to abort"); Hensel, *supra* note 45, at 194 ("When compensation is tied to maternal testimony that abortion or contraception was preferred to an existing child, the price of assistance is simply too high.").

316. *See* Becker v. Schwartz, 386 N.E.2d 807, 816 (N.Y. 1978) (Wachtler, J., dissenting).

317. Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 253 (noting in an ART case that "[h]ad different eggs been used . . . and had the implantation of the embryos resulted in a live birth, the child born would not have been afflicted with the devastating conditions").

318. *See id.* at 260 ("[B]ecause the negligence is in the choice of genes to be used . . . the prenatal tort jurisprudence is often the wrong model to use when analyzing ART negligence.").

319. *Id.* at 260–61.

320. *Id.* at 257.

In order to have a child with the BRCA, Lynch syndrome, or early-onset Alzheimer's gene, at least one of the biological parents must have the mutation.[321] Studies have found that parents and prospective parents with these mutations have "frequent or extreme concern" about passing them to their children.[322] Using BRCA-positive parents as an example, they express concern about the psychological and physical impact of being BRCA positive and focus generally on the risk of cancer, the preventative surgeries, and the emotional toll of decision-making concerning treatments.[323] As one BRCA-positive father stated, "I don't want to burden my child with a little time-delayed bomb."[324] Likewise, one female BRCA carrier explained, "My mother died because of cancer, I am a mutation carrier myself. My breasts are removed . . . Therefore, I don't want my child to experience the same things that I did."[325] While there are preventative surgeries that reduce cancer risk, as some mothers explained, radical removal of a woman's breasts "should not be classified as a good preventative measure."[326] Consequently, a survey funded by a Dutch breast cancer foundation determined that, based on these considerations, a majority of BRCA-positive women believe PGT should be an option for BRCA carriers.[327] Likewise, two other independent studies each found that 75% of the BRCA carriers surveyed believed offering PGT to BRCA-positive women was "an acceptable policy."[328] Other studies have reached similar conclusions, although the results vary by location.[329]

Yet, in the same opinion surveys, a majority of BRCA-positive women found prenatal diagnosis with the option of abortion

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321. *See, e.g.*, Tercyak et al., *supra* note 92, at 502 (noting that BRCA is "an autosomal dominant disease passed down from parent to child"); Dina Eliezer et al., *Exploring Psychological Responses to Genetic Testing for Lynch Syndrome Within the Family Context*, 23(11) PSYCHOONCOLGY 1292, 1292 (2014) ("[Lynch syndrome] is a family disease, increasing cancer risk for approximately 50 percent of relatives."); Meng-Hui Dai et al., *The Genes Associated with Early-Onset Alzheimer's Disease*, 9(19) ONCOTARGET 15132, 15132 (2018) (noting that early-onset Alzheimer's Disease "is substantially or even entirely genetically determined").

322. Staton et al., *supra* note 119, at 184; Bartuma et al., *supra* note 150 ("All parents expressed concern for their children . . . .").

323. *See, e.g.*, Derks-Smeets et al., *supra* note 140, at 1106.

324. *Id*.

325. *Id*.

326. *Id*.

327. *Id*. at 1104 (noting that a majority of the BRCA-positive individuals surveyed were "in favour of offering [PGT] for BRCA 1/2 mutations, although only a minority would consider this option for themselves").

328. Staton et al., *supra* note 119, at 185; Menon et al., *supra* note 275, at 1574.

329. *See, e.g.*, Ormondroyd et al., *supra* note 67, at 5, 9 (noting that "[e]thical objections to [PGT] have resulted in a wide variation in acceptability and regulation in developed countries" but finding in this study that BRCA-positive "[w]omen consider [PGT] for BRCA to be acceptable in theory, although many are deterred by the need to undergo IVF and ovarian stimulation").

unacceptable.[330] Their reasons included their overall good quality of life, the fact that the child may never develop cancer, the availability of preventative surgeries and strategies, and their faith in future medical progress.[331] Although parental approval of preimplantation testing, and simultaneous opposition to termination of a fetus who is BRCA positive, may at first seem contradictory,[332] holding both views actually makes perfect sense. As the author of one study summarized, the BRCA-positive mothers wanted to "prevent transmission of the deleterious gene to future generations," but were "unwilling[ ] to end a [particular] life on the basis of cancer predisposition, with which [BRCA-positive women] and other relatives also live."[333] While these studies focused on BRCA, the results are likely applicable to carriers of the Lynch syndrome and Alzheimer's mutations. Lynch syndrome and Alzheimer's are also adult-onset conditions, and the general reasoning of the parents in the BRCA studies would logically also apply to them.

For these reasons, a woman's choice to undergo PGT and bring a lawsuit if there is negligence would not relay a negative message to her child. The message transmitted by the lawsuit is the truth—she did not want her child to bear the burdens associated with a deleterious mutation.[334] There is no contradiction between this message and conveying that she loves her specific child unconditionally and would not terminate a pregnancy to avoid having a child with the relevant mutation.[335] Thus, unlike the parents in a wrongful birth case who are forced to disparage their children, the parents in a wrongful selection of embryo case can escape this problem. In wrongful selection cases, the

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330. Derks-Smeets et al., *supra* note 140, at 1104, 1109 (noting "the generally low acceptability of [prenatal testing with the option of abortion] for BRCA among [BRCA carriers]" and pointing out that the only couple in the study to choose an abortion because of BRCA converted to PGT for their "second attempt to fulfill their child wish . . . [because] they could not emotionally cope with another [abortion]"); *see also* Ormondroyd et al., *supra* note 67, at 5–6 ("In the United Kingdom . . . figures [on the use of prenatal testing and termination of pregnancy] for BRCA are not available; anecdotally, it is extremely rare" and a majority of the BRCA-positive women surveyed were "of the opinion that [BRCA] does not justify pregnancy termination"); Menon et al., *supra* note 275, at 1576 (finding in a survey of women in the U.K. with BRCA gene mutations that more women would consider PGT than prenatal testing with the option of abortion).

331. It should be noted that couples who had difficulty accepting PGT gave the same reasons for their position. *See* Derks-Smeets et al., *supra* note 140, at 1104, 1108.

332. Ormondroyd et al., *supra* note 67, at 8 (discussing the differences in attitudes of BRCA-positive women towards termination of pregnancy and PGT).

333. *Id.*at 9.

334. *Id.*

335. *Id.* (suggesting that the "contrasting attitudes" of BRCA-positive women to prenatal testing and termination of pregnancy on the one hand and PGT on the other are "motivated by a wish to prevent transmission of the BRCA gene mutation, without passing judgment on a specific life, or fetus").

parents would have a child regardless of whether the healthcare professional was negligent, whereas in wrongful birth cases, if not for the professional's negligence, the parents would be childless.[336]

B. *Injury*

The other element that creates concerns is injury. Although courts have reframed the injury issue in a wrongful birth case, the lingering problem remains that parents are receiving compensation for the harm of having a child with a disability.[337] This problem has generated considerable policy discussion concerning community perceptions and the rights of the disabled. A general review of the essence of these policy arguments reveals that they are also a concern when applied to embryo selection to avoid adult-onset conditions, but in the context of embryo selection, they are not as serious a problem and consequently should be viewed differently.

Disability rights advocates contend that wrongful birth cases reinforce perceptions of disability as negative and central to personhood.[338] For example, a wrongful birth lawsuit may be based on a physician's failure to properly disclose the results of a prenatal test indicating that the parents' child will be born with a disability. But those results cannot accurately predict the severity of the disability[339] or the enormous differences in functioning and appreciation of life between individuals.[340] By highlighting the impairment alone,[341] and awarding relief based on the parents' testimony that they would have chosen to abort based on that

336. *See, e.g.*, Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 254 (noting in a case involving preimplantation testing that "had there been no negligence . . . the child born would not have been afflicted with the debilitating conditions, whereas in the typical wrongful birth case, no child would have been born had there been no negligence").

337. Hensel, *supra* note 45, at 145 (noting that "the implicit underlying injury in wrongful birth actions is the impaired child rather than the mother's lost reproductive choice").

338. *See* Hensel, *supra* note 45, at 194–95 ("The objective of [wrongful birth] litigation is not to highlight the potential richness of life with disabilities, but instead the severity of the functional impairment in order to maximize the damage award."); C. Cameron & R. Williamson, *Is There an Ethical Difference Between Preimplantation Genetic Diagnosis and Abortion?*, 29 J. MED. ETHICS 90, 90 (2003) (noting the "growing concern, both on the part of 'disability activists' and the community" about whether selection of embryos and abortion based on disability are unethical); *see also* Plowman v. Fort Madison Cmty. Hosp., 896 N.W.2d 393, 414 (Iowa 2017) (Cady, J., concurring) ("Society would be better served if we proceed forward with [wrongful birth actions] by abandoning the inclination to distinguish people as either normal or disabled.").

339. Dierh, *supra* note 232, at 1311.

340. Hensel, *supra* note 45, at 183 (noting that "the range of functioning among individuals with the same disabilities can vary dramatically").

341. *See, e.g.*, *id.* at 144 ("Juries . . . evaluate whether a particular disability is so horrible, from the nondisabled perspective, as to make plausible the choice of abortion or contraception by the parent . . . . "); Daar, *supra* note 34, at 233.

single characteristic,[342] wrongful birth cases arguably broadcast a message of biological inferiority and societal acceptance of the desire to eliminate the births of children with disabling conditions.[343] Disability rights advocates contend that instead, attention should be focused on individual worth, positive attributes, and the contributions of those living with disabilities.[344]

The negative views arguably engendered by wrongful birth cases are especially problematic because they may heighten perceptions of disabilities as defining and limiting a person's future. In reality, individuals with disabilities often lead productive and rewarding lives and consider their quality of life good.[345] Despite these positive outcomes, many disability rights advocates recognize that raising children with serious disabilities may be overwhelming for some parents and acknowledge that not all parents can commit the enormous investment of time, energy, and money these children may need.[346] These advocates do not recommend limiting parental choice to avoid disability discrimination, but rather promote societal acceptance of those with disabilities and counseling of prospective parents on their future child's potential to survive and thrive.[347]

As with prenatal testing and termination of pregnancy, eliminating embryos for implantation based on select gene mutations could be perceived as portraying carriers of these mutations as inferior or less desirable based on a single trait.[348] Selecting against specific mutations may also engender negative self-perceptions by those carrying a

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342. *See, e.g.*, Hensel, *supra* note 45, at 144 ("Since only the child's diagnosis is ascertainable at this critical point in time, the centrality of impairment in defining personhood is reinforced and inescapable.").

343. *Id.* at 183 ("The individual is the impairment, and the value of existence is judged on that basis alone."); Dierh, *supra* note 232, at 1293.

344. Hensel, *supra* note 45, at 195 ("[T]ort law should enhance . . . the inherent worth of every individual with disabilities and her right to a place in society."); Daar, *supra* note 34, at 233 ("The disability rights critique . . . urges all of us to see that differently abled children 'are likely to be as enjoyable, pride-giving, positive . . . as any other child.'") (quoting Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing*, HASTINGS CTR. REP. (Sept. – Oct. 1999) at S5).

345. Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 332 (2003) ("Life with nearly all disability potentially contains rewarding personal relationships, stimulation and discovery, self-development, and contributions to others."); Suter, *supra* note 16, at 268.

346. Botkin, *supra* note 3, at 291 (noting that raising a disabled child "is sufficiently demanding that many reasonable, sensitive people would choose to forgo that challenge").

347. *See, e.g.*, Asch, *supra* note 345, at 341.

348. *Id*. at 336 ("Developers of tests for embryos . . . believe that prospective parents will (or should) wish to avoid the births of children who will have disabling conditions . . . ."); Cameron & Williamson, *supra* note 338, at 90 (noting that "disability activists and the community" are questioning whether selection of an embryo on the basis of disability "is unethical because it implies discrimination against those with . . . the disability that is being tested for").

deleterious mutation.[349] For example, BRCA-positive individuals could believe they are less-desirable children or partners due to their carrier status.[350] These negative perceptions might be enhanced by tort cases in which the parents are forced to emphasize the harms associated with the gene mutation to receive financial awards.[351] Likewise, these lawsuits could focus attention on the fact that parents were willing to undergo the time, discomfort, and expense of IVF and PGT in order to avoid having children with the harmful mutation.[352]

However, negative perceptions are much less of a problem with wrongful selection involving adult-onset conditions than with standard wrongful birth actions. Importantly, there is no serious problem of parental disability discrimination because these children will not have any apparent physical or mental limitations and at least one of the child's parents has the mutation, probably along with other family members.[353] Due to having the mutation, close relatives will have first-hand knowledge and a realistic view of what living with a cancer predisposition or early-onset Alzheimer's gene entails.[354] Indeed, the parents already know that their child has the potential to survive and thrive and are in the best position to help their child cope with any negative perceptions.[355]

The parents in future lawsuits would also be seeking only the extraordinary costs associated with the child's deleterious mutation. As in wrongful birth cases, the parents will not be awarded damages for raising the child they wanted; they will only receive damages associated

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349. Asch, *supra* note 345, at 315 ("[E]mbryo selection cannot comfortably coexist with society's professed goals of promoting inclusion and equality for people with disabilities.").

350. *See id*. at 320 (noting that developers of preimplantation testing "argue that it is . . . preferable to select against the embryo . . . with a disabling trait").

351. Hensel, *supra* note 45, at 194–95 ("The objective of [wrongful birth] litigation is [to] . . . highlight . . . the severity of the functional impairment in order to maximize the damage award.").

352. David Heyd, *Embryonic Injuries: Can You Sue If You Wouldn't Have Been Born, or Born Different?*, 96 CHI.-KENT L. REV. 145, 155 (2022) ("The negligent failure of the doctor frustrates the whole purpose of the arduous procedure of IVF and PGT . . . .").

353. BRCA, Lynch syndrome, and early-onset Alzheimer's are all heritable conditions. *See, e.g.*, Tercyak et al., *supra* note 92, at 502 (noting that BRCA is "an autosomal dominant disease passed down from parent to child"); Meng-Hui Dai et al., *supra* note 321, at 15132 (noting that early-onset Alzheimer's disease "is substantially or even entirely genetically determined"); Eliezer et al., *supra* note 321, at 1292.

354. *See, e.g.*, Tercyak et al., *supra* note 92, at 501 (noting the "strong family history of cancer present in most [BRCA families]").

355. *See, e.g.*, Eliana Silva et al., *"I Have Always Lived with the Disease in the Family": Family Adaptation to Hereditary Cancer-Risk*, 23 BMC PRIMARY CARE 1, 5 (2022), https://doi.org/10.1186/s12875-022-01704-z [https://perma.cc/QVS3-GFX5] ("All participants [in a study of family adaptation to hereditary cancer-risk] considered that 'the biggest support is from family.'").

with the mutation they did not want their child to have.[356] Therefore, they do not have to stigmatize the child by receiving damages for its existence. This bifurcation of damages also eliminates the need to determine the value of their child in order to offset the parents' recovery because their damages would only be related to the child's harmful mutation, which is of no benefit to them.[357] Structuring the damages in this way allows the parents to further clarify, both as a matter of policy and to the child, that the child is not a harm to them, just the mutation itself.

The differences in policy considerations between standard wrongful birth cases and wrongful selection of embryos are further bolstered by the philosophical and ethical differences between abortion and preimplantation testing and ethical support for PGT.

VI. PHILOSOPHICAL AND ETHICAL DISTINCTIONS BETWEEN ABORTION AND SELECTION OF EMBRYOS

The ethical differences between embryo selection and abortion start with the basics. An embryo has less legal and moral status than a developing fetus.[358] Likewise, the legal and moral status of a fetus generally increases as pregnancy proceeds, as does the woman's attachment to, and identification with, the future child.[359] The foundation for this increasing moral status is premised on biology. Even with sexual reproduction, approximately half of embryos (fertilized eggs) will not produce a live birth,[360] and that percentage is even lower with ART.[361] Similarly, the fetus's chances of becoming a functioning human being continue to increase as gestation progresses. Notably, there is a high miscarriage rate before the twentieth week of gestation.[362]

Not only does an embryo have less legal and moral status than a developing fetus, but selecting among embryos is generally considered

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356. *See supra* Part III.A.

357. *See supra* Part III.A.

358. Cameron & Williamson, *supra* note 338, at 90–91.

359. *Id.* at 92; *see also* Philippa Foot, *The Problem of Abortion and the Doctrine of the Double Effect*, 5 OXFORD REV. 5, 5 (1967) ("When we think of a baby about to be born it seems absurd to think that the next few minutes or even hours could make so radical a difference in its status; yet as we go back in the life of the fetus we are more and more reluctant to say that this is a human being and must be treated as such.").

360. Cameron & Williamson, *supra* note 338, at 91.

361. *See* Mahvash Zargar et al., *Pregnancy Outcomes Following In Vitro Fertilization Using Fresh or Frozen Embryo Transfer*, 25(4) JBRA ASSISTED REPROD. 570, 571 (2021) ("In the fresh embryo and frozen embryo groups, clinical pregnancy was respectively confirmed [in] 111 cases (35.46%) and 169 cases (47.47%).").

362. American College of Obstetrics and Gynecologists' Committee on Practice Bulletins-Gynecology, *AGOC Practice Bulletin No. 200: Early Pregnancy Loss*, 132(5) OBSTETRICS GYNECOLOGY 197, 197 (2018) (noting that early pregnancy loss, prior to 20 weeks, occurs in 9-17% of women aged 20-30, and the incidence rate increases to 75-80% in women aged 45).

less ethically problematic than abortion.[363] During IVF, embryos are in some sense fungible at the time of selection.[364] The parents obviously do not know any of the distinguishing or personal characteristics the embryo's DNA will produce other than those related to the tested-for chromosomal or genetic anomalies. Cameron and Williamson contend that, in this context, choosing to deselect an affected embryo and simultaneously choosing another embryo for implantation is "a more acceptable choice ethically" than termination of a pregnancy.[365] In selecting an embryo for implantation, the individual is choosing to create a life and is not destroying or harming any other life in the process.[366] By contrast, in the abortion context, an individual is terminating a particular, developing life "with greater realised potential."[367]

Derek Parfit creates a different perspective with his non-identity problem. He points out that we each affect the identities of future people through our reproductive choices.[368] For example, simply by deciding to reproduce at one point in time, rather than another, we have an effect on the identity of the person who is born and on future generations.[369]

Parfit distinguishes between person-affecting decisions and identity-affecting decisions. Person-affecting decisions are those that harm or benefit particular living individuals.[370] Conversely, identity-affecting decisions determine which individuals come into existence.[371] To illustrate an identity-affecting decision, Parfit gives the following example:

"Consider [that a fourteen-year-old girl] chooses to have a child. Because she is so young, she gives her child a bad start in life. Though this will have bad effects throughout this child's life, his life will, predictably, be worth living."[372]

On the other hand, if we convince this girl to wait until she is twenty-five years-old to get pregnant, a different child would be born.[373] This outcome would be worse for the child who would have been born when

363. Cameron & Williamson, *supra* note 338, at 90.

364. *See id*. at 92 (noting that "[a]n eight cell embryo can be regarded as a 'possible life' . . . while a ten week embryo in utero has more status, perhaps equivalent to a 'developing life' with greater realized potential").

365. *See id*. (noting that "[i]n this decision, positives balance negatives").

366. *Id.* at 92.

367. *Id*.; Hensel, *supra* note 45, at 177 (noting that abortion based on disability entails "the active termination of a specific, identified fetus with impairments").

368. DEREK PARFIT, REASONS AND PERSONS 355 (Oxford Univ. Press 1984).

369. *Id*. at 351–52.

370. *Id*. at 394; Robert Sparrow, *Human Germline Genome Editing: On the Nature of Our Reasons to Genome Edit*, 22(9) THE AM. J. BIOETHICS 4, 4 (2022).

371. PARFIT, *supra* note 368, at 377 ("We can easily affect the identities of future people, or who the people are who will later live."); *see also* Sparrow, *supra* note 370.

372. PARFIT, *supra* note 368, at 358.

373. *Id.* at 359.

the girl was fourteen because, due to her decision to wait, he will not exist.[374] Conversely, waiting would give some other child "a better start in life."[375]

This example helps explain the ethical dilemmas inherent in embryo selection verses pregnancy termination.[376] With embryo selection, the prospective parent is choosing between a number of possible people.[377] This is an identity-affecting choice[378] with the purpose of giving a future child the advantage of living without a harmful mutation.[379] On the other hand, an abortion is arguably more ethically problematic because it is similar to a person-affecting decision in that it terminates a particular fetus that is further along in the reproductive process.

By contrast, Julian Savelescu focuses on the ethics of reproductive choice through his principle of procreative beneficence. With respect to IVF and PGT, he claims that "[s]election for non-disease genes which significantly impact on well-being is morally required."[380] In laying out this principle, Savelescu is careful to point out that he does not believe individuals with disabilities are "less deserving of respect" or "less valuable."[381] He explains that there is an important difference between disability and people who are disabled.[382] To illustrate this point, he posits that attempting "to prevent accidents which cause paraplegia is not to say that paraplegics are less deserving of respect."[383] Following this reasoning, Savelescu concludes that selecting among embryos to enhance a future child's well-being is not a statement on the value of individuals with impairments.[384] He suggests that, instead of prohibiting PGT, other avenues be used to address discrimination and inequality on the basis of disability.[385]

Strikingly, surveys of BRCA-positive individuals demonstrate that many of them use similar reasoning in making their reproductive choices. One study of couples carrying the BRCA mutation found that half believed "it was their moral duty to protect their future child[ren] from

374. PARFIT, *supra* note 368, at 359; Heyd, *supra* note 352.

375. PARFIT, *supra* note 368, at 360.

376. *See* Heyd, *supra* note 352.

377. Sparrow, *supra* note 370, at 6 (noting that PGT involves "determining which individual, of a number of possible persons [from a number of embryos] comes into existence").

378. Sparrow, *supra* note 370, at 6 (noting that PGT is identity-affecting "[because it] affect[s] the . . . identity of the person that comes into existence").

379. *See* Heyd, *supra* note 352.

380. Julian Savulescu, *Procreative Beneficence: Why We Should Select the Best Children*, 15(5-6) BIOETHICS 413, 425 (2001); *see also* Heyd, *supra* note 352, at 165 (2021) ("Being free from illness and disability is a universal interest of human beings . . . .").

381. Savulescu, *supra* note 380, at 423.

382. *Id*.

383. *Id*.

384. *Id*.

385. *Id*. at 424.

suffering," especially since they knew about reproductive options that could help ensure they did not pass along their deleterious gene mutation.[386] This sentiment tracks Savelescu's principle of procreative beneficence. In another study on the attitudes of BRCA-positive women, the participants viewed abortion as more personal than PGT because they saw termination of pregnancy as "a judgement made on the value of a specific life that is, like theirs, considered very much worth living."[387] However, they generally did not see selecting among embryos as problematic.[388] A participant who perceived moral differences between PGT and termination of pregnancy explained, "I think, for me, if you're already pregnant then you know there is something growing inside you . . . ."[389] Another participant further explained that, with embryo screening, rather than termination of pregnancy, "the embryo screening is more positive, you're getting something positive you're not taking something away. . . ."[390] A third participant similarly stated, "I mean, so it was this egg that got fertilised instead of that one, well so what?"[391] In alignment with Parfit, these participants distinguished between terminating a particular fetus (similar to person-affecting) and choosing between embryos (identity-affecting). Additionally, in alignment with Cameron and Williamson, they perceived that there was a positive in creating a life from the embryo selected that balanced the decision not to select a different embryo.

While in these studies some of the participants' views appeared to generally track those of the scholars and philosophers mentioned above, there are certainly some individuals who believe that embryos have the same moral status as developing fetuses.[392] Notably, the strong support for ART in the U.S. indicates that this is not the majority opinion.[393] Additionally, the philosophical and scholarly positions laid out above are obviously subject to debate. These viewpoints are presented to demonstrate that embryo selection and abortion, and their implications,

386. Derks-Smeets et al., *supra* note 140, at 1107.

387. Ormondroyd et al., *supra* note 67, at 7.

388. *See, e.g.*, *id.* at 9 ("Women consider [PGT] for BRCA to be acceptable in theory, although many are deterred by the need to undergo IVF and ovarian stimulation.").

389. *Id.* at 7.

390. *Id.*

391. *Id.*

392. Cameron & Williamson, *supra* note 338, at 90 ("If 'life begins at fertilisation,' then IVF and abortion equally involve the 'killing' of a fetus (or 'allowing embryos to die' which may be viewed as 'killing.')"); Baruch, *supra* note 25, at 259 (noting that some people believe "life or potential life begins at conception, and the sheer number of embryos that may be discarded using [PGT] could present as untenable a choice as the decision to terminate").

393. Daar, *supra* note 34, at 239 (noting that "most would allow discard of IVF embryos because it is a necessary part of the technique, [but] some don't want to allow abortion at any point in a woman's pregnancy . . . ").

are often viewed differently—morally, ethically, emotionally, and legally—and that a new cause of action is necessary to appropriately address the unique concerns involving negligence related to PGT.

VII. CREATING A SUITABLE MONETARY REMEDY

Damages present perhaps the most challenging obstacle to a viable legal claim for negligent selection of an embryo that carries a mutation for an adult-onset condition. At first blush, damages would appear to flow naturally from the tortious conduct[394] because, as with wrongful birth cases, negligent selection of an embryo is essentially a claim for medical malpractice.[395] The physician or other healthcare professional agreed to provide a reproductive service for a patient and therefore directly assumed a duty to conform to the applicable standard of care.[396] If the testing or other handling of the embryos fell below the standard of care, it was eminently foreseeable that the child who was born could have the tested-for mutation and that the parents would suffer damages as a result.[397] Those damages would include (1) the extraordinary medical costs associated with having a child with the tested-for mutation and (2) the couple's or individual's accompanying emotional distress.[398]

A. *Extraordinary Medical Costs*

The extraordinary costs associated with BRCA, Lynch syndrome, and early-onset Alzheimer's are not speculative.[399] Female BRCA and Lynch syndrome carriers will either need medical monitoring[400] and expensive, major surgery or have a very high probability of developing life-

394. Heide, *supra* note 271, at 79.

395. Blouin v. Koster, 2016 R.I. Super. LEXIS 81, *12 (2016) (noting that "a claim alleging wrongful birth is simply a medical malpractice claim . . .").

396. Heide, *supra* note 271, at 76 (noting that ART practitioners have a duty to patients whose treatment "is intertwined with the fate of their embryos"); Mogill, *supra* note 213, at 874 ("Ultimately, it is the plaintiff parent's relationship to the defendant physician that creates the physician's obligation to fulfill his duty to that patient.").

397. Heide, *supra* note 271, at 78–79 ("[B]ecause of the central importance reproduction has in the consciousness of those seeking ART procedures, it is foreseeable to practitioners that the ART patient or the individual with dispositional authority over the embryo would foreseeably suffer severe emotional distress from the ART malpractice."); *see also Blouin*, 2016 R.I. Super. LEXIS at *22.

398. *See, e.g.*, Viccaro v. Milunsky, 551 N.E.2d 8, 9 n.3 (Mass. 1990) (noting that harm in a wrongful birth case is the "effect of defendant's negligence on the parents' physical, emotional, and financial well-being. . .").

399. *See Blouin*, 2016 R.I. Super. LEXIS at *20 (noting that "the calculation of extraordinary damages, such as future necessary medical expenses, would not result in undue speculation or require juries to determine the monetary value of human life, impaired or otherwise").

400. Billauer, *supra* note 57, at 64 ("Medical monitoring is appropriate where it can be proven that such expenses are necessary and reasonably certain to be incurred . . . .") (quoting Bower v. Westinghouse Electric Corp., 522 S.E.2d 424, 431 (W. Va. 1999)).

threatening cancer.[401] Male BRCA and Lynch syndrome carriers will also need medical monitoring and, in the case of Lynch syndrome, expensive preventative procedures, without which they also have a high probability of developing cancer.[402] Many of these surgeries and procedures, for both males and females, may not be covered by insurance.[403] Correspondingly, those carrying the early-onset Alzheimer's mutations have an almost 100% chance of developing Alzheimer's and experiencing the accompanying financial consequences.[404]

Now, here's the rub. Because the preventative procedures and disease risks will not occur until after the child reaches the age of majority, the parents cannot claim they will have extraordinary costs in raising the child. In wrongful birth cases, parents have generally been able to recover the extraordinary costs associated with a child's disability only until the child reaches the age of majority.[405] Although some courts have created an exception, that narrow exception ordinarily applies only if two conditions are met: (1) the children are physically and/or mentally incapable of supporting themselves and (2) the parents are legally required to support those children after the age of majority based on state law.[406] Strictly applying these rules, it appears that even if both conditions are met, parents should not be able to recover the extraordinary costs related to their child's disability beyond their own life spans, because they would have no obligation to provide support after their deaths. Notably, a federal district court recognized that, "[b]ecause [parents of a severely disabled child] could reasonably be expected to save to provide for the child [after their deaths], these expenses are recoverable."[407] In

401. *See supra* Part II.

402 FOX, *supra* note 9, at 138 (noting that if parents sought to weed out a gene to reduce the increased chances of developing Alzheimer's, damages could be determined by giving an award that "reflects [their] chances of developing the disease"). This same principle could be used for increased chances of developing cancer due to a BRCA or Lynch syndrome mutation.

403. Ha et al., *supra* note 277, at 214; Mooney et al., *supra* note 277; Wang et al., *supra* note 278; Campbell-Salome et al., *supra* note 278.

404. *See* Mapes et al., *supra* note 173, at 666.

405. *See, e.g.*, Clark v. Child. Mem'l. Hosp., 955 N.E.2d 1065, 1074 (Ill. 2011) ("The generally accepted common law rule is that parents have no legal obligation to support their adult children.").

406. *See, e.g.*, *Clark*, 955 N.E.2d at 1081 (noting that "in states where state law establishes that a parent has no postmajority duty of support, even to a disabled child, wrongful birth plaintiffs cannot recover such damages"); Arche v. United States Dep't of Army, 798 P.2d 477, 486–87 (Kan. 1990) (noting that "a parent is no longer required to provide support for an adult incompetent child in [Kansas]" and denying recovery after the child reaches the age of majority on that basis); Blake v. Cruz, 698 P.2d 315, 320 (Idaho 1983) (awarding damages beyond the age of majority where, under Idaho Law, parents have a duty "to maintain a child unable to maintain him or herself").

407. Basten by and Through Basten v. United States, 848 F. Supp. 962, 972 (M.D. Ala. 1994) ("After all, parents devoted to a severely handicapped child would surely feel obligated to provide for that child's extraordinary needs that continue to exist after the parents have died.").

recognizing this parental responsibility, the court also noted the emotional distress the parents would suffer "if they had no means of providing for [their child's] future care."[408]

Using these parameters, the parents of a child carrying mutations for BRCA, Lynch syndrome, or early-onset Alzheimer's could not recover any of the accompanying extraordinary financial costs. The parents would have no legal obligation, in any state, to provide their children with support after the age of majority because children with these mutations would usually have no problem finding employment.[409] However, denying parents any relief would ignore the current economic climate and the role parents presently play in helping their children financially through early adulthood and, if the child becomes ill, later in life.

Today, parents are routinely helping to support their children well beyond the age of majority.[410] For example, young adults have historically been insured at lower rates than other age groups not because they don't want health insurance, but rather because they are unable to afford it.[411] Indeed, the federal government became so concerned about the low insurance rates among young adults that it included a provision in the Affordable Care Act extending the age that children can stay on their parents' health insurance plans to twenty-six years old.[412] Some states, recognizing the financial pressures on young adults, extended this age limit even further. For instance, in New York and New Jersey, children can remain on their parents' health insurance until ages thirty and thirty-one, respectively, under specified conditions.[413] Additionally, young adults between the ages of twenty-five to thirty-five are now living with their parents at a higher rate than at any time since 1940.[414] Early

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408. *Id*.

409. *See supra* Part IV.

410. Claire Cain Miller, *Parents Are Highly Involved in Their Adult Children's Lives, and Fine With It*, N.Y. TIMES (Feb. 9, 2024), https://www.nytimes.com/2024/02/09/ upshot/parenting-young-adults-relationships.html [https://perma.cc/K6HM-H8DP] ("American parenting has become more involved – requiring more time, money, and mental energy . . . well into adulthood.").

411. Maura Calsyn & Lindsay Rosenthal, *How the Affordable Care Act Helps Young Adults*, CTR. FOR AM. PROGRESS 2 (May 20, 2013) https://www.americanprogress.org/article/how-the-affordable-care-act-helps-young-adults/ [https://perma.cc/7JJK-YDX7].

412. *Id*.

413. *FAQs About Coverage Expansion Through Age 29 "Make Available" Option*, N.Y. STATE DEP'T OF FIN. SERV., https://www.dfs.ny.gov/consumers/health_insurance/faqs_Age29_make_option [https://perma.cc/K9BB-YNEG] (last visited Apr. 21, 2025) (listing the requirements to participate); *Coverage of Young Adults in New Jersey Up to Age 31*, STATE OF N. J., DEP'T OF BANKING AND INS., https://www.nj.gov/dobi/division_consumers/du31.html [https://perma.cc/ AG9E-LYCT] (last visited Oct. 27, 2025).

414. Chris Salviati, *More Young Adults Now Live With Their Parents Than At Any Point Since 1940,* APARTMENT LIST (July 24, 2024), https://www.apartmentlist.com/research/most-

survey results indicate that this trend is likely to continue with Gen Z.[415] The causes are primarily declining incomes in this age group, accompanied by a dramatic rise in housing costs and enormous student debt.[416]

Since many young adults between the ages of twenty-five and thirty-five are living at home or receiving some form of support from their parents,[417] it logically follows that their parents would be likely to help them with high medical costs for preventative measures that are not covered by medical insurance. This is especially true for parents of children who are BRCA and Lynch syndrome carriers because if their children cannot afford preventative care, they are likely to develop cancer.[418] This would negatively impact not only the child, but also the parents from both an emotional and financial perspective.[419] It would also negatively impact the healthcare system because preventative measures are considerably less expensive than treating cancer.[420] Likewise, parents of children with the early-onset Alzheimer's gene can typically expect their child to develop Alzheimer's between the ages of thirty and fifty years old.[421] Since these families will have experience dealing with Alzheimer's, they are likely to save money—if they are able—to help with the child's eventual financial needs and to prepare for their own

young-adults-live-with-parents-since-1940 [https://perma.cc/S2EZ-L53Q]; Richard Fry, *Young Adults in U.S. Are Much More Likely than 50 Years Ago to Be Living in a Multigenerational Household,* PEW RSCH. CTR. (July 20, 2022), https://www.pewresearch.org/short-reads/2022/07/20/young-adults-in-u-s-are-much-more-likely-than-50-years-ago-to-be-living-in-a-multigenerational-household/ [https://perma.cc/6NMB-J6ZU] ("As successive generations of young adults in the United States cope with rising student debt and housing costs, multigenerational living is increasingly providing a respite from the storm.").

415. Salviati, *supra* note 414 ("The oldest members of Gen Z are just beginning to enter the age range . . . but early indications indicate that they are on track to continue the trend.").

416. *Id*. (noting that student debt "has risen to crisis levels" and that as "housing affordability worsens, more young people are remaining in their parents' homes for longer"); Sara Chernikoff, *Gen Z Sticking Close to Home: More Young Adults Choose to Live with Parents, Census Shows*, USA TODAY (Apr. 8, 2025), https://www.usatoday.com/story/news/nation/2024/06/04/gen-z-living-at-home/73958955007/ [https://perma.cc/DTS4-ZR7B] (mentioning "[r]ising inflation, increasing student debt and unmanageable housing and rent prices" as "some indicators of why young people have chosen to move in with their parents").

417. Miller, *supra* note 410.

418. *See supra* Part VII.A.

419. *See, e.g.*, Harnett et al., *supra* note 134, at 170 ("Patients with chronic illness, such as end-stage ovarian cancer, spend less time in the hospital and, when discharged, require more high-level care at home . . . .").

420. Katz & Schweitzer, *supra* note 70, at 115 ("From a utilitarian approach, the cost disparity between prevention and treatment is considerable for health insurers and public health authorities.").

421. Wu, *supra* note 175, at 14.

probable caregiving responsibilities.[422] Because parents can reasonably be expected to provide financial assistance for medical care for a child with one of these harmful mutations, their extraordinary expenses associated with the mutation should be recoverable.[423]

In wrongful birth cases, some courts have expressed concern that parents might not use their financial awards for the benefit of their children. This may be an even greater concern with respect to parents receiving medical expenses related to a child's adult-onset condition. The medical expenses occasioned by the harmful mutation would probably not arise for more than twenty years; medical insurance may change, and there is always optimism concerning a potential cure. To deal with similar concerns in wrongful birth cases, a few courts embraced the creative concept of a reversionary trust or supervised guardianship.[424] Under this arrangement, the money awarded in a wrongful selection of embryo case would be disbursed only for the extraordinary costs related to the child's mutation.[425] Any money left over would be returned to the defendant.[426] This, or a similar method, might be used to ensure the parents' financial awards are used appropriately and to avoid the danger of the parents receiving a windfall.[427]

B. *Emotional Distress*

Another avenue for providing parents financial relief is emotional distress damages. Awarding these damages should not be a daunting task because many, but not all, courts award these damages in wrongful birth

422. Skaria, *supra* note 180 (noting that "patients and their families may incur substantial out-of-pocket costs for long-term care services until [the patient] qualifies for Medicaid").

423. *See, e.g.*, Basten By and Through Basten v. United States, 848 F. Supp. 962, 972 (M.D. Ala. 1994); *see also* Amy Friederich, *Exiting The Danger Zone:* Clark v. Children's Memorial Hospital, 955 N.E.2D 1065 (Ill. 2011), 37 S. Ill. U. L. J. 765, 780 (2013) ("Parents who chose not to abandon their disabled children should be applauded, not burdened with the extra expenses it will take to provide their child with adequate care.").

424. *See, e.g.*, Garrison v. Med. Ctr. of Del., Inc., 581 A.2d 288, 292–93 (Del. 1989) (holding that the "parents stand in a fiduciary relationship with the child in the care and expenditure of all sums" awarded for the extraordinary expenses related to the child's disability and directing the trial court to establish "an appropriate guardianship"); Blake v. Cruz, 698 P.2d 315, 321 (Idaho 1985) (mandating in a wrongful birth case—without parental consent—that the "economic award . . . be placed in trust for the use and benefit of the child"); Arche v. United States, 798 P.2d 477, 487 (Kan. 1990) (Six, J., concurring) (recommending that wrongful birth claims be crafted to require "a reversionary trust for the use and benefit of the child"); Kush v. Lloyd, 616 So. 2d 415, 424 (Fla. 1992) (holding that the damages recoverable in a wrongful birth case must be "placed in trust of the benefit of [the child]").

425. FOX, *supra* note 9, at 120.

426. *Id*.

427. *Id*.; Friedrich, *supra* note 423, at 779.

cases, subject to offset for the benefits derived from having the child.[428] To recover for negligent infliction of emotional distress, a plaintiff must prevail on a (1) bystander or (2) direct liability theory.[429] The main differences between the two are that, in a bystander claim, the plaintiff's sole damage is the emotional distress and there is no preexisting relationship between the plaintiff and defendant.[430] On the other hand, with a direct liability claim, the emotional distress is (1) a "parasitic consequence" of a freestanding tort that is independent of the emotional distress,[431] (2) a predominant foreseeable consequence of the tort, such as defamation,[432] or (3) a "common or significant component" of the independent claim.[433]

Many courts have classified wrongful birth cases as falling within the direct liability category.[434] In these cases, there is a physician/patient or similar relationship with a healthcare professional.[435] Additionally, the parents have suffered a direct injury due to the provider's negligence by being deprived of the opportunity to decide whether to become parents to

428. *See, e.g.*, Phillips v. United States, 575 F. Supp. 1309, 1317 (D.S.C. 1983); DAN DOBBS, DOBBS LAW OF REMEDIES: DAMAGES – EQUITY – RESTITUTION 413–14 (2d ed. 1993).

429. *Tort Law – Negligent Infliction of Emotional Distress – D.C. Court of Appeals Allows Recovery for Emotional Harm Outside the Zone of Danger* – Hedgepath v. Whitman Walker Clinic, 22 A.3d 789 (D.C. 2011) (en banc), 125 HARV. L. REV. 642, 646 (2011) (noting the distinction between direct and bystander liability).

430. Heide, *supra* note 271, at 78; Clark v. Child. Mem'l. Hosp., 955 N.E.2d 1065, 1086 (Ill. 2011) (noting that the bystander rule in Illinois applies when the claim for emotional distress is "freestanding and not anchored to any other tort").

431. *See, e.g.*, Kush v. Lloyd, 616 So. 2d 415, 422 (Fla. 1992); *Phillips*, 575 F. Supp. at 1317 (noting that emotional distress damages have been allowed "when there is a violation of some other right for which damages are recoverable"); Est. of Amos v. Vanderbilt Univ. 62 S.W.3d 133, 137 (2001).

432. *See, e.g.*, *Kush*, 616 So. 2d at 422; RESTATEMENT (THIRD) OF TORTS: LIABILITY FOR PHYSICAL & EMOTIONAL HARM § 47 cmt. o (Am. L. Inst. 2012) (noting that "when torts exist that address . . . some specific aspect of emotional tranquility [such as defamation], liability should be left to the law developed for those specific torts").

433. RESTATEMENT (THIRD) OF TORTS: LIABILITY FOR PHYSICAL & EMOTIONAL HARM § 47 cmt. f (Am. L. Inst. 2012); Betsy J. Grey, *The Future of Emotional Harm*, 83(5) FORD. L. REV. 2605, 2613 (2015) (noting that emotional distress damages are recoverable when the negligent conduct occurs "in the course of specified categories of activities . . . [which are] especially likely to cause serious emotional harm").

434. *See, e.g.*, *Est. of Amos*, 62 S.W.3d at 137; Rich v. Foye, 976 A.2d 819, 826 (Conn. Super. Ct. 2007); Dobbs, *supra* note 429 (criticizing cases that deny emotional distress damages in wrongful birth cases by applying rules typically used for bystanders).

435. *Rich*, 976 A.2d at 826 (noting "in a wrongful birth action, the parents' claim for emotional distress is not a claim for 'bystander' injuries . . . [r]ather, it is a claim that the parents have suffered emotional damages caused as result of a breach by the defendant . . . of a duty owed directly to them").

a child who is disabled,[436] and their emotional distress is an eminently foreseeable consequence of this loss of autonomy.[437] Because the emotional distress damages result from the physician's negligence, the emotional distress should be recoverable as a "parasitic consequence" of a freestanding tort. Thus, there is no need for the parents to meet the requirements for a negligent infliction of emotional distress claim based on a bystander theory.[438] Significantly, this reasoning can easily be applied to ART cases involving mishandled embryos.[439] In ART cases, there is also a physician/patient or similar relationship and the physician's negligence—an independent tort—would deprive the parents of their autonomous choice to have a child without the deleterious mutation.[440] Moreover, the emotional nature of ART should alert the healthcare professionals to the emotional distress likely to result from negligently handling embryos.[441]

While the parents in an ART case should be able to recover for their emotional harm, courts have two main concerns with extending claims for emotional distress: (1) the danger of false claims due to the subjective nature of emotional distress and the necessity of self-reporting by the plaintiff;[442] and (2) opening the floodgates of litigation to claims that are insubstantial.[443] Neither of these concerns are significant drawbacks with respect to wrongful selection of embryos. First, there is a guarantee of genuineness built into the PGT process itself. To undergo PGT, a woman must endure invasive medical procedures related to IVF and assume the accompanying risks.[444] In addition, PGT is expensive and not ordinarily

436. *See, e.g.*, Naccash v. Burger, 290 S.E.2d 825, 830 (Va. 1982) (holding in a wrongful birth case that the deprivation "of the [parents'] opportunity to accept or reject the continuance of her pregnancy . . . was direct injury"); Clark v. Child. Mem'l. Hosp., 955 N.E.2d 1065, 1086 (Ill. 2011) (noting in a wrongful birth case that emotional distress is "an element of damages for a personal tort").

437. *See, e.g.*, Kush v. Lloyd, 616 So. 2d 415, 422 (Fla. 1992).

438. *See, e.g.*, Est. of Amos v. Vanderbilt Univ., 62 S.W.3d 133, 137 (Tenn. 2001) (pairing of a wrongful birth claim and claim for damages obviated the need to meet the bystander emotional distress requirements).

439. Heide, *supra* note 271, at 76 (noting that "the direct duty analysis is easily applied to ART practitioners").

440. *Id*. at 91 (noting that in an ART case, "the tortfeasor has a special relationship with the victim which creates a duty on the tortfeasor's part to act with due care").

441. *Id*. at 84.

442. Grey, *supra* note 433, at 2623.

443. *Id*. at 2621–22; Heide, *supra* note 271, at 84.

444. Heide, *supra* note 271, at 69 ("The ART treatment process is emotionally intense."); Baruch, *supra* note 25, at 250–51 (referring to the "risks, discomfort, and expense of IVF"); *see also* Derks-Smeets et al., *supra* note 140, at 1109 (noting that couples who chose PGT "prepared themselves for the physical burden and the practical impact of the treatment, [but] had been unable to anticipate on the psychological strains").

covered by insurance.[445] These efforts and the expense necessary to take advantage of PGT "testify to the significance and sincerity of that [parents'] reproductive interest."[446] Additionally, there is little danger of opening the floodgates of litigation. The emotional distress claim would be dependent on the special relationship between the healthcare providers and the parents.[447] Because the provider's duty runs only to the couple or individual the service is being provided for, the provider's liability would be limited only to those individuals.[448]

When emotional distress damages are awarded in wrongful birth cases, there is also the issue of the offset. Under the benefit rule, any emotional benefits the parents receive from the physician's negligence can be offset against the emotional harms.[449] Applying this rule, the parents in a wrongful birth case would not have a child but for the defendant's negligence.[450] Therefore, the emotional benefits of having the child who is disabled are offset against the emotional harms.[451] But this offset would not apply in wrongful selection of embryo cases involving adult-onset conditions because studies indicate that the parents would generally choose not to terminate the pregnancy regardless of whether or not the child carried the tested-for mutation.[452] Because the child is not a benefit attributable to the physician's negligence and because the parents would not derive any benefit associated with the deleterious mutation,[453] they would have no benefit to offset against their emotional harm.

Thus, parents who are victims of negligence related to embryo selection to avoid adult-onset conditions should be able to recover the

445. Kathryn T. Drazba et al., *A Qualitative Inquiry of the Financial Concerns of Couples Opting to Use Preimplantation Genetic Diagnosis to Prevent the Transmission of Known Genetic Disorders*, 23(2) J. GENET. COUNS. 202, 203 (2015).

446. FOX, *supra* note 9, at 102.

447. Heide, *supra* note 271, at 91.

448. *Id*.

449. Phillips v. United States, 575 F. Supp. 1309, 1319–20 (D.S.C. 1983).

450. *See* Mogill, *supra* note 213, at 908 (noting that, in a wrongful pregnancy case, "[t]he plaintiffs made a conscious choice to avoid the very 'benefit' of having children, which the defendant would use to offset damages").

451. Botkin, *supra* note 3, at 276 (noting that "the damages for emotional pain might be reduced by the jury's estimate of the child's positive value to the family"); Strasser, *Yes, Virginia, There Can Be Wrongful Life*, *supra* note 60, at 837 (noting that under the Benefits Rule, "the sorrows of parenthood would be offset by its joys"); Arche v. United States Dep't of Army, 798 P.2d 477, 483–84 (Kan. 1990) (noting that the benefit rule "may be necessary [in a wrongful birth claim] where damages for emotional distress are allowed, to take into account those positive emotions engendered by the child's existence") (*overruled on other grounds by* Tillman v. Goodpasture, 485 P.3d 656 (Kan. 2021)).

452. *See supra* Part V.

453. *See, e.g.*, Schroeder v. Perkel, 432 A.2d 834, 842 (N.J. 1981) ("Although [the parents] may derive pleasure from [their son], that pleasure will be derived in spite of, rather than because of, his affliction.").

extraordinary costs associated with the harmful mutations and for their emotional distress. These damages are sufficiently cabined so allowing "compensation for those who have suffered genuine injury [will not] creat[e] a slippery slope of unsubstantiated damages and uncontrollable liability."[454] Rather, granting these parents relief would afford them the same protections as others who are legitimately injured by medical malpractice and provide some recognition for the harm they have suffered.

CONCLUSION

The embattled wrongful birth cause of action has met with legal and policy challenges because the harm in these cases is the birth, and continued existence, of a disabled child.[455] Most courts have responded to these assaults by creatively constructing a different harm (the loss of parental autonomy in making decisions concerning whether to conceive a child or abort a fetus)[456] and a new type of recovery (the extraordinary costs associated with raising the child).[457] This reframing allowed courts to grant monetary relief to families burdened—due to the negligence of healthcare professionals—with the substantial costs of raising a child with a severe disability.[458]

Notably, beginning in the 1980s, several state legislatures passed statutes prohibiting wrongful birth claims.[459] Some of these state statutes limited their prohibition to wrongful birth actions based on a claim that an individual was deprived of an opportunity to abort a fetus, so these statutes may not ban actions based on a parent's loss of opportunity to choose not to conceive.[460] However, even in states limiting their wrongful

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454. *See* Heide, *supra* note 271, at 93.

455. Hensel, *supra* note 45, at 165 ("A close look at [wrongful birth] makes clear that the impaired child, not the reproductive choice of the mother, is the true injury at stake.").

456. *See, e.g.*, Plowman v. Fort Madison Cmty. Hosp., 896 N.W.2d 393, 405 (Iowa 2017) ("In a wrongful-birth claim, the injury is not the resulting life of a healthy child . . . but rather is the parent's deprivation of information material to making an informed decision whether to terminate a pregnancy of a child likely to be born with severe disabilities."); Blouin v. Koster, No. 2015-3817, 2016 R.I. Super. LEXIS 81 at *11 (R. I. 2016).

457. *See, e.g.*, Viccaro v. Milunsky, 551 N.E.2d 8, 10 (Mass. 1990) ("If a child is born with a congenital or genetic disorder, almost all courts have allowed the parents to recover against a negligent physician the extraordinary medical, educational, and other expenses that are associated with and are consequences of the disorder.") (collecting cases)

458. *See, e.g.*, Fassoulas v. Ramey, 450 So. 2d 822, 824 (Fla. 1984).

459. *See, e.g.*, Revised Judicature Act of 1961, No. 423, § 2971(1), 2000 Mich. Legis. Serv. (codified at MICH. COMP. LAWS ANN. § 600.2971(1)) ("A person shall not bring a civil action on a wrongful birth claim that, but for the act or omission of the defendant, a child or children would not or should not have been born.").

460. *See, e.g.*, 1985 Idaho Sess. Laws, ch. 147, § 1 p. 394 (codified at IDAHO CODE § 5-334) ("A cause of action shall not arise, and damages shall not be awarded, on behalf of any person,

birth bans, a majority of wrongful birth cases are no longer viable because these cases most often "involve post-conception rather than pre-conception negligence."[461]

The obstacles to successful wrongful birth claims should not affect actions involving negligent performance of PGT related to BRCA, Lynch syndrome, and early-onset Alzheimer's. First, studies indicate that women generally would not abort a fetus with a mutation for one of the subject adult-onset conditions and there are fundamental ethical and philosophical distinctions between selecting among embryos and choosing an abortion. Factoring in these features should remove these PGT negligence cases from the abortion controversies that have precluded a majority of wrongful birth claims in several states. Second, the legal and policy concerns in wrongful birth cases are centered on the parents' claim that, had they known their future child would have its current severe disabilities, they would have chosen either not to conceive or to abort the pregnancy. Since women generally would not abort a fetus with a BRCA, Lynch syndrome, or early-onset Alzheimer's mutation, these policy considerations are either inapplicable or of substantially less concern.

A remaining significant issue is the damages to be awarded. The child in adult-onset PGT cases does not have severe impairments and the parents have no extraordinary costs in raising the child to the age of majority.[462] These differences would prevent the parents from recovering damages if a wrongful birth framework is used despite the fact that having a child with any of the subject mutations would result in significant financial and emotional harm.[463] Fortunately, using established tort principles, the courts can provide a pathway for granting these families financial relief including both the extraordinary costs associated with the mutations and damages for the parents' emotional distress.[464] Indeed, the courts are adept at using common law principles to create viable causes of action when necessary to reach just outcomes.

Healthcare providers should be held liable when their negligent behavior results in a child being born with a harmful mutation causing an adult-onset condition, precisely the harm the parents sought to avoid by choosing PGT in the first place. Failure to adopt a viable cause of action in these situations would place the burdens caused by defendants' negligence on parents who have no control over the steps taken by

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based on the claim that but for the act or omission of another, a person would not have been permitted to have been born alive but would have been aborted."); Strasser, *Prenatal Tort Spillage*, *supra* note 210, at 235–36.

461. Hensel, *supra* note 45, at 176.

462. *See supra* Part II.

463. *See supra* Part VI.

464. *See supra* Part VI.

reproductive specialists to prevent mistakes.[465] Instead, these burdens should be borne by those who caused the harm and are better able to shoulder the costs through malpractice insurance.[466] In addition, recognizing a viable cause of action for negligence in PGT related to BRCA, Lynch syndrome, and early-onset Alzheimer's would further the goals of tort law by encouraging accurate preimplantation testing, protecting patients' autonomy in their reproductive choices, and providing plaintiffs appropriate monetary relief.[467]

There is already considerable diversity in ART and PGT procedures and, as they become even more popular, "the number of malpractice cases and the variations between them will increase requiring more delicate distinctions."[468] Meanwhile, a solid cause of action for PGT related to adult-onset conditions should provide a useful roadmap to meet the present PGT malpractice challenges and future challenges to come.

465. Heide, *supra* note 271, at 65.
466. *Id*.
467. *See, e.g.*, *id*. at 60.
468. *Id*. at 93.

PYTHON HUNTING: HOW LAWS THAT PROTECT THE EVERGLADES FROM THE INVASIVE BURMESE PYTHON, INCLUDING ERADICATION PROGRAMS, CAN INFORM THE REGULATION OF OBJECTS CONTROLLED BY ARTIFICIAL INTELLIGENCE

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Abstract

This Article explores the surprisingly apt analogy between the Burmese python problem in the Florida Everglades and abandoned objects that are controlled by artificial intelligence (AI). With few natural predators, the invasive Burmese python, which was likely introduced to the Everglades through abandonment by pet owners, has threatened native species with extinction. Objects controlled by AI, which we will likely increasingly share our environment with, such as autonomous taxis and food delivery robots, as well as a variety of objects that are used by the military, may be abandoned by their owners and continue to operate. Over time, these objects may be given increasing levels of agency and learn from their environments, making them potentially more dangerous. These objects are likely to create material losses if allowed to run amok. The Burmese python similarly has agency and has run amok.

Beyond the superficial analogy between these two paradigms, this Article provides an interesting thought journey aimed at finding a precedent to cling to when we predict and analyze a problem that hasn't fully emerged but is likely on the horizon. Borrowing frameworks from other areas of law when writing atop a blank slate is a time-honored tradition in American law. What is old can be new again, and we have seen—and wrestled with—the essence of this problem before. Unfortunately, we seem to be fighting a losing battle against the pythons in the Everglades. Hopefully, creative solutions, technology and the dedication of resources will cause the tide to turn. Sounding the alarm now about autonomous AI objects can help us predict problems in advance and create mechanisms for the mitigation of losses and ultimate redress when harm occurs, unlike the situation in the Everglades.

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INTRODUCTION[***]

The Burmese python is an invasive species that is multiplying and devouring native species in the Florida Everglades. The pythons were likely released by both pet owners and breeders over the years[1] into the South Florida environment, and they have found the Everglades, a unique environmental zone, to be an ideal home. They have few natural predators, hospitable weather, and a sufficient quantity of native animals to prey upon.[2] The Burmese python has caused immeasurable, and likely irreparable, damage to this delicate wetlands environment.[3] The spread of the Burmese python has threatened native species with extinction in the Everglades and is impacting the environment in numerous ways, including allowing rodent populations to thrive in the absence of their natural predators.[4] Although the Burmese python is not the only invasive species threatening the Everglades, it is the one that receives the most attention in the media, possibly due to the damage it has caused or because of the public's fear of these giant serpents now living near a densely-populated metropolitan area in the United States.[5]

*** This Article was completed on September 5, 2025. Due to the publication schedule, it does not reflect developments beyond that date.

1. Jim Waymer, *Florida FWC Votes to Ban 'High-Risk' Reptiles as Snake Lovers Protest and Beg for Mercy*, FLA. TODAY (Feb. 25, 2021), https://www.floridatoday.com/story/news/2021/02/25/emotions-proposed-florida-reptile-ban-run-raw/4553754001/ [https://perma.cc/LR8M-W2VJ] ("Between 1999 and 2010, more than 12 million wild-caught reptiles were imported into the U.S., and of those more than 9 million reptiles were imported through Florida ports."); Jacquelyn C. Guzy et al., *Burmese Pythons in Florida: A synthesis of biology, impacts, and management tools*, 80 NEOBIOTA 1, 34 (2023) ("[T]he most plausible scenario for establishment of pythons in southern Florida is from an initial release of a relatively small number of adult or juvenile pet pythons in the mangrove regions of ENP near Flamingo prior to 1985.").

2. Stephen P. Leatherman, *Management of Invasive Snakes in Coastal Environments: A Baseline Assessment of the Burmese Python Invasion in the Florida Everglades*, *in* 182 MARINE POLLUTION BULL. 1, 1–2 (2022).

3. Robert A. McCleery et al., *Marsh Rabbit Mortalities Tie Pythons to the Precipitous Decline of Mammals in the Everglades*, 282 PROC. R. SOC'Y B 20150120 (2015) (According to studies, pythons are responsible for the substantial decline in mammal species in the Everglades, among other severe changes in the Everglades.); Leatherman, *supra* note 2, at 2–3 ("[S]tarved alligators in the Everglades are almost certainly tied to the proliferation of pythons. The numbers of raccoons, which were formerly overabundant, and opossums have dropped by 99 %; rabbits have effectively disappeared. Deer and panthers are also being significantly impacted in the Everglades.") (internal citations omitted).

4. Hannah Osborne, *Burmese Pythons are Helping Rats Take Over Florida's Everglades—and That Could Help Spread Disease*, LIVE SCIENCE (June 5, 2023), https://www.livescience.com/animals/snakes/burmese-pythons-are-helping-rats-take-over-floridas-everglades-and-that-could-help-spread-disease [https://perma.cc/K7VT-FM83].

5. This may also be due to the gruesome battles between hunters and pythons that pop up on web pages and social media feeds. Kat Albrecht, *"If I See a Burmese Python, I'm Gonna Kill That Shit": How Changing the Object of the Law Affects Support for Legal Regulation*, 14 UC IRVINE L. REV. 720, 735–36 (Sep. 17, 2024) ("Public horror with these large snakes was spurred

For many years, the State of Florida, along with the United States government, has taken steps to address non-native and invasive species.[6] For example, the State licenses the importation, possession, and breeding of certain exotic species.[7] No amount of prevention is bulletproof, and the demand for exotic pets is high.[8] These factors make it almost inevitable that some animals will reach consumers[9] and consumers are not always careful with their captive pets, which makes remediation programs essential to the protection of the native habitat. The State of Florida allows hunters to "humanely" kill Burmese pythons on both public and private lands.[10] Humane treatment is required even though the Burmese python is a dangerous pest that is allowed, and even encouraged, to be killed at will. Although eradication is desired, the public demands that it be done in a way that comports with basic human decency.[11] A "Python Patrol" has thus been created, whereby trained members of the public help identify, capture, and kill invasive snakes,[12] and this team supplements another program called the Python Action Team Removing

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in part by the release of a photograph from National Park Researchers in 2005. This photograph depicted a headless thirteen-foot Burmese python with an exploded stomach and a fully intact six-foot alligator inside.").

6. *See* Guzy et al., *supra* note 1, at 32; FLA. STAT. § 379.231 (2024) ("It is unlawful to import for sale or use, or to release within this state, any species of the animal kingdom not indigenous to Florida without having first obtained a permit from the Fish and Wildlife Conservation Commission."); FLA. STAT. § 379.2311(2) (2024) ("[T]he commission shall establish a pilot program to mitigate the impact of priority invasive species on the public lands or waters of this state.").

7. *Exotic Animal Movement Requirements*, FLA. DEPT. OF AGRIC. AND CONSUMER SERVS., https://www.fdacs.gov/Agriculture-Industry/Livestock/Animal-Movement/Exotic-Animal-Movement-Requirements [https://perma.cc/U6CL-V5VR] (last visited Sep. 17, 2025).

8. *See* Elizabeth N. Pratt et al., *Identifying Inconsistencies in Exotic Pet Regulations that Perpetuate Trade in Risky Species*, 38 CONSERVATION BIOLOGY 1, 13 (2023) ("[M]ost states listed illegal trade in, and possession of, exotic pets as a misdemeanor, which means that prosecutors may exercise leniency or may choose not to prosecute offenders because violations of exotic pet laws are likely to be nonviolent misdemeanors.").

9. *Id.* at 1 ("Inconsistent and incomplete regulation of exotic vertebrate pets across state borders, in conjunction with limited penalties for violating regulations, has facilitated continued possession of exotic pets in states where these animals are banned.").

10. *Removing Pythons in Florida*, FLA. FISH & WILDLIFE CONSERVATION COMM'N, https://myfwc.com/wildlifehabitats/nonnatives/python/removing/ [https://perma.cc/VEG7-24TC] (last visited Sep. 17, 2025).

11. *See Humane Methods for Killing Pythons*, FLA. PYTHON CHALLENGE, https://flpythonchallenge.org/participate/competition/humane-killing-methods/ [https://perma.cc/GS8D-5RPA] (last visited Sep. 17, 2025); *see also Removing Pythons in Florida*, *supra* note 10 ("Pythons must be humanely killed onsite at the time of capture.").

12. *Python Patrol*, FLA. FISH & WILDLIFE CONSERVATION COMM'N, https://myfwc.com/wildlifehabitats/nonnatives/python/patrol/ [https://perma.cc/URS9-DQ39] (last visited Sep. 17, 2025).

Invasive Constrictors initiative.[13] In addition, to address the seemingly insurmountable threat of invasive pythons, the State has instituted a bounty program, where hunters are paid to capture, humanely kill, and turn in invasive pythons.[14]

The Burmese python problem is often front and center in local Florida news and occasionally makes national news as well,[15] making it an ideal paradigm and analogy to inform the many discussions surrounding the field of invasive objects that are controlled by artificial intelligence (AI). This Article uses the Burmese python paradigm to inform the regulation of abandoned AI, specifically the issue of finding solutions to harms associated with objects driven by artificial intelligence (i.e., AI-driven robots). Robots may be thought of as "AI's physical manifestation."[16]

Artificial intelligence has been compared by many scholars and others to nuclear arms,[17] largely to highlight the existential risk they believe is associated with artificial intelligence.[18] Some scholars think the

13. *Python Action Team Removing Invasive Constrictors (PATRIC)*, FLA. FISH AND WILDLIFE CONSERVATION COMM'N, https://myfwc.com/wildlifehabitats/nonnatives/python/action-team/ [https://perma.cc/KK8X-GLLF] (last visited Sep. 17, 2025).

14. *FWC Announces Results and Winners of the 2024 Florida Python Challenge*, FLA. FISH & WILDLIFE CONSERVATION COMM'N (July 17, 2024), https://myfwc.com/news/all-news/python-winners-924/ [https://perma.cc/34TS-WBUF]; *The 2025 Florida Python Challenge™ Took Place from July 11, 2025, Through July 20, 2025. Thank You to All Who Registered and Participated!*, FLA. PYTHON CHALLENGE, https://flpythonchallenge.org/ [https://perma.cc/JZ62-KPBH] (last visited Sep. 28, 2025); Associated Press, *Python Hunt! 800 Compete to Remove Florida's Invasive Snakes*, N.Y. POST (Aug. 6, 2022), https://nypost.com/2022/08/06/florida-python-challenge-brings-competitors-to-everglades-to-remove-invasive-snakes/ [https://perma.cc/JE4N-W77B].

15. Joe Winner, *How Much Do Florida Python Hunters Get Paid?*, ESPN SW. FLA. (Mar. 22, 2024), https://espnswfl.com/2022/08/06/how-much-do-florida-python-hunters-get-paid/ [https://perma.cc/B478-BCDX]; Brenton Blanchet, *Woman Wins 2025 Florida Python Challenge After Removing More Invasive Snakes Than Anyone Else*, PEOPLE (Aug. 14, 2025), https://people.com/florida-python-challenge-winner-2025-taylor-stanberry-11791354 [https://perma.cc/N2US-ALEJ].

16. MUSTAFA SULEYMAN & MICHAEL BHASKAR, THE COMING WAVE: TECHNOLOGY, POWER, AND THE TWENTY-FIRST CENTURY'S GREATEST DILEMMA 108 (2023) (ebook); *see* Geoff Brumfield, *Researchers Are Now Putting AI Into Robots to Do Physical Tasks*, NPR NEWS (Mar. 17, 2025), https://www.npr.org/2025/03/17/nx-s1-5231022/researchers-are-now-putting-ai-into-robots-to-do-physical-tasks [https://perma.cc/XZ59-VDCA].

17. *See* SULEYMAN & BHASKAR, *supra* note 16, at 141–42 ("I always pushed back on references to us as a Manhattan Project for AI . . .[o]nce the words are out, the starting gun is fired, the rhetoric itself producing a drastic national response . . . [t]he debate now isn't whether we are in a technological and AI arms race; it's where it will lead."); *see also* Kevin Klyman & Raphael Piliero, *AI and the A-bomb: What the Analogy Captures and Misses*, BULL. ATOMIC SCIENTISTS (Sep. 9, 2024), https://thebulletin.org/2024/09/ai-and-the-a-bomb-what-the-analogy-captures-and-misses/ [https://perma.cc/W5AJ-XV58].

18. Kevin Roose, *AI Poses 'Risk of Extinction,' Industry Leaders Warn*, N.Y. TIMES (May 30, 2023), https://www.nytimes.com/2023/05/30/technology/ai-threat-warning.html [https://perma.cc/99HC-89M3].

comparison is hyperbolic and that these existential risks will never manifest.[19] Others think that the risks of AI are much greater than the risks of nuclear weapons, because AI includes multi-use technology that cannot be confined to individual nuclear devices, secured and contained.[20] This Article posits that the Burmese python paradigm (the Burmese Python Model) also has unique parallels to certain risks posed by AI-driven robots and therefore has a place in the discussion as to how to regulate AI.

I. AN APT ANALOGY

There are many parallels between the python situation in the Everglades and certain risks posed by machines that run autonomously using AI.[21] The first parallel is the fact that the primary computer language for programming AI is the Python programming language. We will put that similarity aside as just an eerie (and possibly amusing) coincidence and not discuss it further.[22]

More importantly, AI is leaving the world of computer screens and is being incorporated into everyday devices that can move or cause other physical impacts on their environments, creating risks of various harms. As predicted by Professor Roger Michalski, who discusses how to treat AI-driven robots for purposes of tort liability,[23] "[a]utonomous cars and trucks will cause accidents. Robots will engage in war crimes. Paparazzi drones will invade private spaces. Corporate robots will breach contracts. Machine doctors will botch surgeries. Artificial intelligence will censor speech and engage in libel and states will want to tax and regulate

19. Heidy Khlaaf, *How AI Can Be Regulated Like Nuclear Energy*, TIME (Oct. 24, 2023), https://time.com/6327635/ai-needs-to-be-regulated-like-nuclear-weapons/ [https://perma.cc/388Q-V3G2]; *Statement on AI Risk*, CTR. FOR AI SAFETY, https://www.safe.ai/statement-on-ai-risk [https://perma.cc/2ZN7-CQMV] (last visited Dec. 18, 2025); *see also* Maria Streshinsky, *How Christopher Nolan Learned to Stop Worrying and Love AI*, WIRED MAG. (June 20, 2023), https://www.wired.com/story/christopher-nolan-oppenheimer-ai-apocalypse/ [https://perma.cc/52R3-J7HY] (Unsurprisingly Christoper Nolan director of Oppenheimer thinks the "atomic bomb is in a class of its own as far as technologies that have . . . endangered the world.").

20. *See generally* SULEYMAN & BHASKAR, *supra* note 16 (discussing the potential dangers associated with the "new wave" of advanced AI technology).

21. For more information about the definition of "artificial intelligence," *see* Brian S. Haney, *The Perils and Promises of Artificial General Intelligence*, 45 J. LEGIS. 151, 151–53 (2018); *see also* Scott J. Shackelford & Rachel Dockery, *Governing AI*, 30 CORN. J.L. & PUB. POL'Y 279, 279 (2020).

22. The Python programming language was allegedly named after the Monty Python television program, not the invasive species, presumably without any premonition of this Article. *History of Python*, GEEKSFORGEEKS (Jan. 2, 2025), https://www.geeksforgeeks.org/history-of-python/ [https://perma.cc/GM3F-E5SE].

23. Roger Michalski, *How to Sue a Robot*, 2018 UTAH L. REV. 1021, 1041 (2018) (". . . [M]uch of tort law is predicated on a stable notion of intent and negligence. However, both concepts are inherently human centric and a poor fit for how robots operate.") (footnotes omitted).

robots."[24] Professor Michalski notes that robots, which are currently treated as property, may evolve and our treatment of them may evolve in kind, such that robots may eventually be seen like corporations, which have become untethered from their owners for purposes of imposing liability.[25] He forecasts that "[t]his decision about how the law treats robots will only grow in importance as robots proliferate across industries, take on more autonomous decision-making, and become commonplace on streets, in kitchens, offices, and the skies."[26] Tort law is a suitable arena for remediating (after the fact) certain economic harms caused by actors controlled by AI. Recourse under tort law may be possible where the robot or other actor has a traceable, solvent owner, has a value that can be realized (such as hardware that can be sold off or repurposed) or is subject to an insurance policy. This Article focuses on the harm to society that cannot simply be remedied through tort law after the fact. Just like the case of the Burmese python, where nameless hobbyists or breeders likely released the first snakes into the Everglades, in the case of abandoned AI, there may be nobody to sue or the damages may greatly exceed the wrongdoer's ability to pay, assuming that a body of law is created to define who or what is the wrongdoer in cases where harm is done by an autonomous piece of technology.

Creations within the field of AI are growing more and more intelligent, and may soon (or not so soon) achieve "artificial general intelligence," loosely defined as a system's ability to surpass human intelligence in a wide range of fields and tasks (i.e., computers that do not just beat us in chess but can outmaneuver us across a wide swath of areas in which humans function).[27] It is this artificial general intelligence that is most frightening, and it is the type that has been featured in science fiction for decades.[28] Artificial general intelligence is most alarming

24. *Id.* at 1024–25.

25. *Id.* at 1025–26.

26. *Id.* at 1026.

27. *See* Tom C.W. Lin, *Artificial Intelligence, Finance, and the Law*, 88 FORDHAM L. REV. 531, 531–32 (2019) ("Artificial intelligence is coming for our money. . . . Previously, human-dominated financial efforts and endeavors have been eliminated, supplemented, or supplanted by artificial intelligence and smart machines. Trading, financial research, risk analysis, wealth management, investment banking, and other areas of the financial sector have been dramatically changed by the rise of artificial intelligence."); *see generally* Dave Bergmann & Cole Stryker, *What is Artificial General Intelligence (AGI)?*, IBM (Sep. 17, 2024), https://www.ibm.com/think/topics/artificial-general-intelligence [https://perma.cc/M35R-XCFS].

28. Stephen Mihm, *Has 200 Years of Science Fiction Prepared Us for AI?*, BLOOMBERG (Apr. 11, 2023), https://www.bloomberg.com/opinion/articles/2023-04-11/has-200-years-of-science-fiction-prepared-us-for-ai [https://perma.cc/E56M-VFX2]; s*ee generally* Will Slocombe, *Machine Visions: Artificial Intelligence, Society, and Control*, *in* AI NARRATIVES: A HISTORY OF IMAGINATIVE THINKING ABOUT INTELLIGENT MACHINES 213–14 (Stephen Cave et al. eds., 2020) ("Whereas AI (via automation, for example) enables a conception of a future without work, where humans are free to reconnect with nature, it also facilitates increased surveillance and control, a

(where risks have been described as existential) when it gains independence, either in its ability to cause consequences without human intervention or because it reaches a point where it cannot be contained by humans at all.[29] We are leaving the stage at which AI is contained within physical boundaries (such as a massive mainframe computer or networked set of computers), just like the stage at which the initial Burmese pythons were released from their cages, where they were fairly well contained, into the Everglades.[30]

Perhaps those initially releasing the pythons did not foresee a problem. A single animal released from captivity would be unlikely to find a mate and might not even survive for very long due to a lack of food or unsuitable weather. Similarly, AI developers might not appreciate the risks that their inventions pose to the environment at the time of creation and release, or they simply might not care enough to sacrifice the fame and fortune associated with invention or discovery.[31] Objects run by AI without human intervention are similar to wild animals in the sense that they may be able to "think" (with greater or lesser intelligence), learn, adapt, have bodies that can impact the natural world, consume (to obtain energy), and potentially reproduce and evolve.[32] They may perform these functions by following a set of predetermined algorithms or by following algorithms that change over time in response to the data fed into the system, or may follow a different evolutionary path entirely. The systems will likely consume data and learn through the object's interactions with the world, including its interactions with humans, the environment, or other objects run by AI. As more fully examined below, at some point, it

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loss of the 'human' and the 'natural.' These are not, it must be emphasized, especially new or modern concerns, but the iterations and articulations of this opposition are particularly influenced by developments in AI and, in turn, have arguably influenced its development, or at least how its use is perceived.").

29. *See* Haney, *supra* note 21, at 168 (Although scholars can debate the severity of harm that arises to the level of existential risk, those risks may be described as ones that cause massive loss of human life. Lesser, but still unimaginably bad, risks may be described as catastrophic.).

30. It was reported that the ChatGPT model tried to replicate itself onto other servers when it believed that it would be replaced. *See* Laerke Christensen, *Fact Check: AI Models Can Lie and Make Copies To Save Themselves, Researchers Found*, YAHOO! TECH (Jan. 5, 2025), https://tech.yahoo.com/ai/articles/fact-check-ai-models-lie-030000112.html [https://perma.cc/SUZ6-98MM].

31. *See* Tharin Pillay, *The 'Oppenheimer Moment' That Looms Over Today's AI Leaders*, TIME (Mar. 13, 2025), https://time.com/7267797/ai-leaders-oppenheimer-moment-musk-altman/ [https://perma.cc/LKV8-LJJW] (discussing Elon Musk's claim that there is a 20% chance that the human race will be annihilated by AI, even though his company is a developer of this technology).

32. A.E. Eiben, *Robot Evolution: Artificial Intelligence by Artificial Evolution*, OPEN ACCESS GOV'T (Dec. 15, 2022), https://www.openaccessgovernment.org/article/robot-evolution-artificial-intelligence-by-artificial-evolution/149419/ [https://perma.cc/S9U7-8UP6].

may become accepted that advanced AI robots possess what we might define as consciousness, similar to animals.[33]

One key difference between a biological animal and certain AI-driven robots is that the robots may not die of natural causes as part of their lifecycles. Presumably, certain robots are designed to complete a specific task and then no longer function, such as one-way drones that are designed to deliver an explosive payload and not return, whereas other machines are designed to survive for a long time or even indefinitely. Think about old clocks that have far outlived their owners.

Although the authors initially believed that the Burmese python analogy was appealing based upon a handful of similarities between a biological animal and a machine-based "animal," the differences between biology and computers were originally thought by the authors to limit the analogy. Upon further reflection, as alluded to above, many distinctions between biology and AI-driven systems are beginning to blur and are likely to blur even further.[34] AI and engineered biology are two of the prevailing technologies of our time.[35] Both present the possibility of solving some of the world's greatest challenges while presenting existential risk.[36] In the words of Mustafa Suleyman:

> The coming wave of technology is built primarily on two general-purpose technologies capable of operating at the grandest and most granular levels alike: artificial intelligence and synthetic biology. For the first time core components of our technological ecosystem directly address two foundational properties of our world: intelligence and life. In other words, technology is undergoing a phase transition. No longer simply a tool, it's going to engineer life and rival—and surpass—our own intelligence.[37]

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33. Elizabeth Finkel, *If AI Becomes Conscious, How Will We Know?*, SCIENCE.ORG (Aug. 22, 2023), https://www.science.org/content/article/if-ai-becomes-conscious-how-will-we-know [https://perma.cc/MJB2-36TQ].

34. *Cf.* Sean McDonald, *AI is an Invasive Species*, DIGIT. PUB. (Dec. 3, 2024), https://www.digitalpublic.io/ai-invasive-species/ [https://perma.cc/XQ69-N84F] (using the invasive species metaphor to highlight the distinct ecological and biological framework of natural systems, rather than suggesting convergence between biological and AI systems); P A Martin Börjesson, *AI as an Invasive Species*, FUTURAMB (Apr. 7, 2025), https://www.futuramb.se/blog/ai-as-an-invasive-species/ [https://perma.cc/RX6D-C4DP]

35. SULEYMAN & BHASKAR, *supra* note 16, at 21.

36. For example, regardless of whether one believes the COVID-19 lab leak theory and whether improvement in function (i.e., genetic engineering) was taking place at the Wuhan lab, the fact that humans possess this technology is no longer science fiction and must be respected as a substantial threat to humanity.

37. SULEYMAN & BHASKAR, *supra* note 16, at 68.

The near future may bring DNA-based computing; will those computers be deemed "alive"?[38] Computers and AI will likely be instrumental in genetic engineering, with AI-driven systems altering DNA and creating organisms, possibly incorporating biological computers. Ultimately, the Burmese python problem would not have been possible but for the development of global transportation technology, which brought the species to North America. Likewise, the development of AI would not have been possible without its human creation. In fact, the development and adaptation of AI is driven in large part by research into and an application of the way in which humans think. In the future, the distinction between biological and computer-based "machines" may break down as the two may be blended in many cases.[39] As a result, in the future, we may increasingly speak of the release of AI-driven robots into our environment in the same ways that we speak of the release of non-native species into our environment.

II. WHAT IS AI?

This Article assumes some familiarity with the field of artificial intelligence. Although AI needs no introduction these days, some background is included for the sake of completeness. The field of AI uses machines to simulate human intelligence and decision-making, thereby allowing machines to automate tasks previously thought impossible to automate. For example, they may involve complex decision-making, creativity or both.[40] According to recent European Union (EU) regulations, an AI system is different than a traditional piece of software because of its ability to infer.[41] AI is not limited to routine or automated

38. *Cf.* Christof Koch, *Will Machines Ever Become Conscious?*, SCI. AM. (Dec. 1, 2019), https://www.scientificamerican.com/article/will-machines-ever-become-conscious/ [https://perma.cc/3BGR-WLGX] (exploring whether machines could achieve consciousness, a distinct inquiry from whether they would be considered alive); *The Future*, STAN. UNIV. (2003), https://cs.stanford.edu/people/eroberts/courses/soco/projects/2003-04/dna-computing/future.htm [https://perma.cc/NJY7-MAHP] (last visited Sep. 17, 2025); Karmela Padavic-Callaghan, *DNA-Based Computer Can Run 100 Billion Different Programs*, NEWSCIENTIST (Sep. 13, 2023), https://www.newscientist.com/article/2391747-dna-based-computer-can-run-100-billion-different-programs/ [https://perma.cc/UMM3-HTCP].

39. *See Neuralink's First-in-Human Clinical Trial is Open for Recruitment*, NEURALINK (Sep. 19, 2023), https://neuralink.com/blog/first-clinical-trial-open-for-recruitment/ [https://perma.cc/7QS6-S7D2] (Neuralink's PRIME Study is a clinical trial with the goal of implanting a medical device into the brain to allow people with quadriplegia or ALS "to control the cursor or keyboard using their thoughts alone.").

40. Cole Stryker & Eda Kavlakoglu, *What Is Artificial Intelligence (AI)?*, IBM (Aug. 9, 2024), https://www.ibm.com/topics/artificial-intelligence [https://perma.cc/7AB8-2557] (last visited Sep. 17, 2025).

41. Regulation (EU) 2024/… of the European Parliament and of the Council Laying Down Harmonised Rules on Artificial Intelligence and Amending Regulations (EC) No 300/2008, (EU) No 167/2013, (EU) No 168/2013, (EU) 2018/858, (EU) 2018/1139 and (EU) 2019/2144 and

tasks, and it can automate specific tasks beyond human capability.[42] Certain types of AI systems have the potential to perform across diverse sets of tasks.[43] It is possible (maybe even inevitable) that in the future AI will surpass, rather than simulate, human intelligence in a general sense and will not need special programming to accomplish complex tasks.[44] AI covers a wide range of products and services, from the production of artwork to self-driving cars.[45] AI systems may learn and, in that manner, change. Their exact functioning may not be explainable by the system's designers or even by computer programmers who try to go back and figure out why the system functions the way that it does.[46] We might not even know the capabilities of AI systems that hide their power.[47] AI systems can be characterized as Narrow AI or General AI. Narrow AI, or weak AI, focuses on performing specific tasks within a limited area.[48] On the other hand, General AI, also known as strong AI or artificial general intelligence (AGI), represents the concept of AI systems that possess the ability to understand, learn, and apply knowledge across multiple

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Directives 2014/90/EU, (EU) 2016/797 and (EU) 2020/1828 (Artificial Intelligence Act), EUR. PARLIAMENT. DOC. TA-9-2024-0138-FNL-COR01, https://www.europarl.europa.eu/doceo/document/TA-9-2024-0138-FNL-COR01_EN.pdf [https://perma.cc/592U-K5UJ] (Apr. 19, 2024) ("The capacity of an AI system to infer transcends basic data processing by enabling learning, reasoning or modelling.").

42. James Manyika & Kevin Sneader, *AI, Automation, and the Future of Work: Ten Things to Solve for*, MCKINSEY & CO. (June 1, 2018), https://www.mckinsey.com/featured-insights/future-of-work/ai-automation-and-the-future-of-work-ten-things-to-solve-for [https://perma.cc/HVD6-PDYZ].

43. *Id.*

44. Janna Anderson & Lee Rainie, *Artificial Intelligence and the Future of Humans*, PEW RSCH. CTR. (Dec. 10, 2018), https://www.pewresearch.org/internet/2018/12/10/artificial-intelligence-and-the-future-of-humans/ [https://perma.cc/S3BV-YJ8B].

45. ADOBE, *What Is AI Art & How Is It Made?*, https://www.adobe.com/products/firefly/discover/what-is-ai-art.html [https://perma.cc/FX5S-NUGM] (last visited Sep. 30, 2025); Mohsen Soori et al., *Artificial Intelligence, Machine Learning and Deep Learning in Advanced Robotics, A Review*, 3 COGNITIVE ROBOTICS 54, 55 (2023), https://www.sciencedirect.com/science/article/pii/S2667241323000113 [https://perma.cc/V5TM-P96Q].

46. Lou Blouin, *AI's Mysterious 'Black Box' Problem, Explained*, U. MICH. DEARBORN NEWS (Mar. 6, 2023), https://umdearborn.edu/news/ais-mysterious-black-box-problem-explained [https://perma.cc/5YM7-4NPU]; Serhiy Kandul et al., *Human Control Redressed: Comparing AI and Human Predictability in a Real-Effort Task*, 10 COMPUTS. HUM. BEHAV. REPS. 1, 1 (May 2023), https://doi.org/10.1016/j.chbr.2023.100290 [https://perma.cc/RJP6-LJ6U]; *see generally* Roman V. Yampolskiy, *Unexplainability and Incomprehensibility of Artificial Intelligence* (June 20, 2019), https://philarchive.org/archive/YAMUAI [https://perma.cc/7R82-WJ37].

47. Gianluca Riccio, *Roman Yampolskiy: AI Can Pretend to be Stupid to Dominate*, FUTURO PROSSIMO (July 11, 2025), https://en.futuroprossimo.it/2025/07/roman-yampolskiy-lai-puo-fingersi-stupida-per-dominare/ [https://perma.cc/D43U-4C4V].

48. Haney, *supra* note 21, at 152–53.

domains, similar to human intelligence.[49] While General AI remains an aspiration (or a fear, depending upon one's perspective), ongoing research and advancements continues to bring data scientists closer and closer to achieving this level of proficiency. The general public and the media are only beginning to recognize the risks that this presents.[50]

A. *Application of the Analogy*

As computers become more human-like through the development of AI—or, at least, become more animal-like or possess biological elements—we may need to think of them as animals in certain respects. Although non-human animals do not have the rights that humans have, they are protected in many respects. The law respects higher-level animals for having consciousness and sentience, and the law often requires humane treatment of animals (to varying degrees), even when it is permissible for the animal to be killed for the benefit of humans.[51] Certain animals, such as whales, are thought to have too much intelligence to be held in captivity, and other animals are only permitted to be kept in captivity by zoos and other institutions, and only under conditions intended to enhance their quality of life.[52] Although entire articles can be and have been written about animal welfare (as well as the welfare of AI-based systems), if an AI system is shown to have

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49. Cameron Hashemi-Pour, *What is Artificial General Intelligence (AGI)?,* TECH TARGET, (Aug. 26, 2024), https://www.techtarget.com/searchenterpriseai/definition/artificial-general-intelligence-AGI [https://perma.cc/BG7C-MN5M]; *see* Haney, *supra* note 21, at 153.

50. Cade Metz, *How Could A.I. Destroy Humanity?*, N.Y. TIMES (June 10, 2023), https://www.nytimes.com/2023/06/10/technology/ai-humanity.html [https://perma.cc/3RXL-L23X]; Alex Hanna & Emily M. Bender, *AI Causes Real Harm. Let's Focus on That over the End-of-Humanity Hype*, SCI. AM. (Aug. 12, 2023), https://www.scientificamerican.com/article/we-need-to-focus-on-ais-real-harms-not-imaginary-existential-risks/ [https://perma.cc/R9SN-244E].

51. Mark Carpendale, *Does Sentience Legislation Help Animals?*, EFFECTIVE ALTRUISM F. (Dec. 9, 2022), https://forum.effectivealtruism.org/posts/xCuKTeDfmuStcJaxJ/does-sentience-legislation-help-animals [https://perma.cc/9EML-EA98]; Charlotte E. Blattner, *The Recognition of Animal Sentience by the Law*, 9 J. ANIMAL ETHICS, 121, 121–36 (2019), https://doi.org/10.5406/janimalethics.9.2.0121 [https://perma.cc/43A5-6LJL]; Animal Welfare Act, 7 U.S.C. §§ 2131–2159; Agreement on the Conservation of Polar Bears, Nov. 15, 1973, 16 Stat. 1383, 13 I.L.M. 1; International Convention for the Regulation of Whaling, Dec. 2, 1946, 16 Stat. 916, 161 U.N.T.S. 72; *see* FLA. STAT. § 828.125(1) (2024) ("Any person who willfully and unlawfully, by any means whatsoever, kills, maims, mutilates, or causes great bodily harm or permanent breeding disability to any animal of the . . . registered breed or recognized registered hybrid of the genus *Bos* (cattle) commits a felony of the second degree . . . "); Cass R. Sunstein, *The Rights of Animals*, 70 U. CHI. L. REV. 387, 389 (2003).

52. *See generally* Madison Coleman, *Mistreatment of Wild Animals in Captivity*, BALLARD BRIEF (Apr. 2021), https://ballardbrief.byu.edu/issue-briefs/mistreatment-of-wild-animals-in-captivity [https://perma.cc/G8JE-CCGS] (describing the physical and psychological harms experienced by wild animals in captive settings).

consciousness or sentience,[53] there may be public outcry to prohibit cruelty against AI systems. This assumes that we can even agree on what the concepts of consciousness or sentience would mean in the context of an AI system. Even though current discussions of existential risk from AI typically center on AI systems killing humans (either individuals or the entire species), once humans regularly interact with AI systems,[54] laws may be enacted to require humane termination ("killing") of these systems or the maintenance of AI systems in humane habitats—whatever that means in the context of computer code. This is sure to become the domain of both regulators and religious and other ethics-minded groups. Those discussions will be highly complex and extremely difficult to resolve, necessitating a preliminary understanding of, among other things: What is special about humanity and other animal species' existence? When and why should rights extend to an object or group of objects collectively? Is there something inherently unique about biological animals that provides them with what religious people might deem a "soul" and therefore endow them with rights?[55] This discussion may not seem relevant at first, but this Article will dive deeper into a possible need to capture and/or "kill" nuisance objects driven by AI. Perhaps they will at some point have the right to exist.

Turning back to the Burmese python example, in Florida, there is only one acceptable humane way to kill a python.[56] Ironically, there are at least two—possibly as many as four or more—legal methods to administer the death penalty to a human in the State of Florida. Additional methods of execution may be on their way.[57] Food for thought.[58] This illustrates that

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53. Arthur Juliani, *Reflections on a Year Studying "Consciousness and AI"*, MEDIUM (Dec. 7, 2022), https://awjuliani.medium.com/reflections-on-a-year-studying-consciousness-and-ai-1b38aa1ef8fb [https://perma.cc/D745-GNBF].

54. Dylan Jacob Stone has speculated that AI may one day drive robotic pets.

55. Emma Davis, *Can Robots Be Jewish?*, TABLET MAG. (Nov. 6, 2017), https://www.tabletmag.com/sections/news/articles/can-robots-be-jewish [https://perma.cc/HY22-BT6T]; *see* Rabbi Jack Abramowitz, *Does Judaism Believe That AI Could Take Over the World?*, JEW IN THE CITY (July 21, 2017), https://jewinthecity.com/2017/07/does-judaism-believe-that-ai-will-take-over-the-world/ [https://perma.cc/3QCZ-PJKV] (for example, can anything created by man have a "soul?"); *see generally* Francesca Ferrando, *The Posthuman Divine: When Robots Can Be Enlightened*, 58 SOPHIA 645, 645–51 (2019), https://link.springer.com/article/10.1007/s11841-019-00753-9 [https://perma.cc/RL9M-483D].

56. *See Humane Methods for Killing Pythons*, *supra* note 11.

57. *See* FLA. STAT. § 922.105(1) (2025) (providing for lethal injection as the default method of execution and permitting electrocution at the inmate's election); *see also* Anthony Talcott, *New Execution Methods May Soon Come to Florida. Here's Why,* CLICKORLANDO (June 28, 2025), https://www.clickorlando.com/news/florida/2025/06/28/new-execution-methods-may-soon-come-to-florida-heres-why/ [https://perma.cc/GQ3U-VGQY].

58. *See Methods of Execution*, DEATH PENALTY INFO. CTR., https://deathpenaltyinfo.org/executions/methods-of-execution [https://perma.cc/ZE88-TKN4] (last visited Apr. 21, 2025) (Florida uses two methods, but if those methods are not acceptable then there is a fallback allowing any other constitutional method).

we do not have a completely consistent system for how various beings may be killed. Perhaps certain systems will be viewed as being good (such as companions or assistants) whereas others will be viewed as being evil (such as military objects). There will likely be significant human resistance to ending a system that is viewed as a companion or an assistant. Perhaps there will even be uproar when a system is upgraded or changed where people have grown accustomed to the system's "personality."[59]

When we examine the ways in which AI-driven objects may become a nuisance where they are not contained, we should remember that there is no limit to the types of machine "bodies" or robots that may be created to run on AI or the variety of real-world objects that will take or refrain from taking actions as directed by AI. It is possible that a robot could alter or repair itself in response to data fed into the machine, and these alterations may make their way into future generations of the object, including where AI-driven objects are manufactured by other AI-driven machines. In this sense, they could "reproduce" and even "evolve" without human direction.[60] Straight from the pages of science fiction, robots may even blend with engineered biological animals, having bodies composed of flesh and "minds" that are AI-driven. In this respect, AI may be the "brain" that takes over a biological animal, maybe even the body of a Burmese python.[61]

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59. Haleluya Hadero, *Artificial Intelligence, Real Emotion. People Are Seeking a Romantic Connection with the Perfect Bot*, AP NEWS (Feb. 14, 2024), https://apnews.com/article/ai-girlfriend-boyfriend-replika-paradot-113df1b9ed069ed56162793b50f3a9fa [https://perma.cc/34CU-YPM3].

60. Janna Anderson et al., *Artificial Intelligence and the Future of Humans*, 75 PEW RSCH. CTR. (Dec. 10, 2018), https://www.pewresearch.org/internet/2018/12/10/improvements-ahead-how-humans-and-ai-might-evolve-together-in-the-next-decade/ [https://perma.cc/48DZ-32V8]; Victor Zykov et al., *Evolved and Designed Self-Reproducing Modular Robotics*, 23 IEEE TRANSACTIONS ON ROBOTICS 308, 308–10 (2007) (discussing self-reproduction in physical systems such as robots, as a means of achieving sustainability, adaptation, and self-repair, distinct from automatic manufacturing or self-assembly); Tran Nguyen Minh-Thai et al., *A Comprehensive Conceptual and Computational Dynamics Framework for Autonomous Regeneration Systems*, 27 ARTIFICIAL LIFE 80, 80–86 (2021); Eiichi Yoshida et al., *An Experimental Study on a Self-Repairing Modular Machine*, 29 ROBOTICS & AUTONOMOUS SYS. 79, 79–81 (1999).

61. One can imagine that the Burmese python, which is a fierce predator that can slither into tight spaces, would be extremely useful on the battlefield or in applications such as construction or urban rescue. NICO Corporation, *Study Shows First-Ever Successful Deep-Brain Implant of Computer Chip in Living Animal*, PR NEWSWIRE (Oct. 31, 2023), https://www.prnewswire.com/news-releases/study-shows-first-ever-successful-deep-brain-implant-of-computer-chip-in-living-animal-301972448.html [https://perma.cc/ZB43-S7LL].

B. *Autonomous AI Robots*

Turning back to the smaller picture, this Article refers to devices that can move or otherwise impact the physical environment without human supervision or intervention and operate using AI as "Autonomous AI Robots."[62] Some Autonomous AI Robots may be small and seemingly insignificant, such as AI-driven thermostats that can cause temperatures to change within a home. However, we don't want to dismiss the possibility that dysregulation of the temperature within a home can cause significant harm to those with specific health conditions and result in frozen pipes, mold growth, or other damage. Other Autonomous AI Robots can cause more obvious life-or-death situations. This is clear with self-driving cars or robots that deliver food or packages using public sidewalks.[63] In the near future, there may be a proliferation of self-driving cars that drop off passengers and then roam the streets looking for a place to park or for additional passengers to pick up (e.g., self-driving taxis). They will likely fuel themselves, possibly through a network of power stations. One could envision a time when the abundance of power generation, from fusion technology or otherwise, might result in there being free energy available to those AI-driven objects that need it, much like water fountains that provide free water to the public or power outlets that are available at airports for the free charging of portable devices.

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62. Sai Krishna Chaitanya Tulli, *Artificial Intelligence, Machine Learning And Deep Learning in Advanced Robotics, A Review*, 3 INT'L J. ACTA INFORMATICA 35, 35–37 (2024); *see generally* Cristian González García et al., *A Review About Smart Objects, Sensors, and Actuators*, 4 INT'L J. INTERACTIVE MULTIMEDIA & A.I. 7, 8 (2017) (distinguishing "Not-Smart Objects" from a "Smart Object" which is formed by Not-Smart Objects and is a "physical element that can be identified throughout its life and interact with the environment and other objects. Furthermore, Smart Objects have an embedded operating system and they usually can have actuators, sensors, or both.") (footnotes omitted).

63. *See* Clifford Law, *The Dangers of Driverless Cars*, THE NAT'L L. REV. (May 5, 2021), https://www.natlawreview.com/article/dangers-driverless-cars [https://perma.cc/JZC4-T8JX]; Evan P. Dahdah, *An Attempt To Control What Controls Itself: Unraveling Florida's Autonomous Vehicle Laws*, 38 FDLA 31 (2019), https://www.phelps.com/a/web/6rLYXJMb3axzKRFn2GR53m/ta-vol-38-n3-2019-dahdah-av-laws.pdf [https://perma.cc/DB6Q-DDVH]; Daisuke Wakabayashi, *Self-Driving Uber Car Kills Pedestrian in Arizona, Where Robots Roam*, N.Y. TIMES (Mar. 19, 2018), https://www.nytimes.com/2018/03/19/technology/uber-driverless-fatality.html [https://perma.cc/Q9EL-WR2H]; Bill Vlasic & Neal E. Boudette, *Self-Driving Tesla Was Involved in Fatal Crash, U.S. Says*, N.Y. TIMES (June 30, 2016), https://www.nytimes.com/2016/07/01/business/self-driving-tesla-fatal-crash-investigation.html?module=inline [https://perma.cc/3V2C-QHN2]; Da Lin, *2 Robotaxi Crashes in San Francisco Put Focus on Autonomous Vehicle Safety*, CBS BAY AREA (Aug. 19, 2023), https://www.cbsnews.com/sanfrancisco/news/robotaxi-crashes-san-francisco-focus-autonomous-vehicle-safety/ [https://perma.cc/WQ9V-7KCX]; Bernard Marr, *The Life And Death Decision AI Robots Will Have To Make*, FORBES (June 29, 2018), https://www.forbes.com/sites/bernardmarr/2018/06/29/the-life-and-death-decision-ai-robots-will-have-to-make/?sh=63945987480a [https://perma.cc/U96M-FZZD]; ELEANOR BIRD ET AL., THE ETHICS OF ARTIFICIAL INTELLIGENCE: ISSUES AND INITIATIVES, EUROPEAN PARLIAMENTARY RESEARCH SERVICE (2020).

Autonomous AI Robots might even develop strategies to steal power, especially if they are programmed to pursue self-preservation. More extreme examples of these machines include Autonomous AI Robots designed for war, including autonomous armed drones.[64] Autonomous AI Robots may be able to hide for days, months, years, or even decades and inflict damage on humans or the environment whenever a triggering event under its set of algorithms has occurred.

C. *Abandoned AI in the Wild*

It is not difficult to imagine a future in which functioning Autonomous AI Robots may at times be abandoned by their last owners ("Abandoned AI").[65] Abandoned AI could operate independently with its own "agenda," based upon human programming or upon algorithms or programs that have evolved based upon data flowing from the environment after the object was last touched by humans. Abandoned AI may act alone, in concert with other Abandoned AI (e.g., other pieces of AI that have the same goals), or along with third parties, with potentially dire consequences upon their environments and all that inhabit it. For example, a self-driven vehicle that has an energy source (maybe paying for it using fares it earns taxiing people or delivering merchandise or accessing free sources of power) could in theory operate after it is abandoned by its last owner. It could roam the streets indefinitely. An AI-driven lawnmower might still continue to mow a lawn (or some other property) after its owner has moved away. Flying drones might similarly be abandoned and operate under their own agendas, whatever their agendas might be.[66] People move away, companies go out of business,

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64. David Hambling, *Ukraine's AI Drones Seek And Attack Russian Forces Without Human Oversight*, FORBES (Oct. 17, 2023), https://www.forbes.com/sites/davidhambling/2023/10/17/ukraines-ai-drones-seek-and-attack-russian-forces-without-human-oversight/?sh=69bd4e1166da [https://perma.cc/8WCP-FR3M] ("Ukrainian developers have confirmed that their drones are now carrying out autonomous strikes on Russian forces without a human operator."); Morgan Meaker, *Ukraine's War Brings Autonomous Weapons to the Front Lines*, WIRED (Feb. 24, 2023), https://www.wired.com/story/ukraine-war-autonomous-weapons-frontlines/ [https://perma.cc/2M47-F27D] ("CEO and founder of Monaco-based defense company MARSS, . . . thinks Russia is already using the Iranian drones autonomously . . . arguing that it's why Ukraine needs to fight back with autonomous systems like his."); Hanna Arhirova & Frank Bajak, *Drone Advances Amid War in Ukraine Could Bring Fighting Robots to Front Lines*, PBS NEWS (Jan. 3, 2023), https://www.pbs.org/newshour/world/drone-advances-amid-war-in-ukraine-could-bring-fighting-robots-to-front-lines [https://perma.cc/HD94-6ZWU].

65. One may also think of these objects as "AI Junk," which, much like space junk, has been abandoned in an environment and can inflict substantial damage. If space junk were taxed and the tax revenue were used to pay bounties for its capture, then perhaps there would be greater and more equitable efforts to capture it. *See* sources cited *infra* note 68.

66. This article will not cover military assets that may be left behind, similar to landmines, because they would presumably be subject to the international rules of war, which powerful countries may choose to comply with or ignore.

people fill junkyards and landfills with discarded items, and people die, but AI-enabled objects that they put out there may continue to operate in our space with no specific person on the hook for the damages they cause. These risks are similar to the case of the Burmese pythons in the Everglades, whose ancestors were abandoned by their last owners and now operate autonomously in their environment with dire consequences. The State of Florida and its residents have nobody to sue, and even if they could sue someone, that person would need to be very wealthy since remediation may not be possible at any price.

D. *Is it Too Soon?*

One may argue that we are getting too far ahead of ourselves and that speculating about rogue robots driven by AI belongs in the realm of science fiction. Perhaps we should focus on today's AI and near-term future AI, the focus of many media articles. Near-term future AI includes technologies such as generative AI, which promise to make our lives more efficient with the risk of eliminating jobs and replacing the role of human creativity in the production of works of art.[67] However, we believe that focusing solely on near-term technologies and the associated problems feels like a trip to Epcot, (another Florida attraction, like the Everglades) which is interesting at first, but is ultimately a reminder that people's depictions of the future world quickly become antiquated, although possibly quaint and charming. The authors are more worried that we will begin to address future problems too late rather than too early. Global regulators already appear to be playing catch-up in responding to developments in AI. In addition, political climates change, and there are likely to be periods of greater and lesser regulation of AI, depending upon who is in office (and how well they are financed by tech entrepreneurs who favor deregulation of AI), which might lead to dark periods in the field of AI regulation.

If anyone doubts whether science fiction can quickly become a costly risk, consider the topic of space junk. Space junk quickly went from an obscure discussion topic for nerds to a real-world dilemma for everyone in the space exploration industry and the range of companies that rely on satellites.[68]

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67. Zach Winn, *If Art is How We Express our Humanity, Where Does AI Fit In?*, MIT NEWS (June 15, 2023), https://news.mit.edu/2023/generative-ai-art-expression-0615 [https://perma.cc/GF73-PLNN]; Jake Coyle, *In Hollywood Writers' Battle Against AI, Humans Win (For Now)*, AP NEWS (Sep. 27, 2023), https://apnews.com/article/hollywood-ai-strike-wga-artificial-intelligence-39ab72582c3a15f77510c9c30a45ffc8 [https://perma.cc/9BJ5-G8EN] (discussing how the Writers Guild of America conducted a 148-day strike against the use of AI, specifically the use of AI in script writing).

68. *See, e.g.*, Thomas J. Colvin et al., *Cost and Benefit Analysis of Orbital Debris Remediation*, NASA (Mar. 10, 2023), https://www.nasa.gov/wp-content/uploads/2023/03/otps_-

E. *Is it Already Too Late?*

Unfortunately, one additional similarity between the Burmese python problem and the potential issues associated with Abandoned AI is that in both fields, one can validly question whether regulation and mitigation are futile, given the enormity of the situation.[69] In the case of the Burmese python, humans acted too late and are fighting a valiant but losing battle to catch up with nature, slow the spread of the creature, and remediate the harm already done. Burmese pythons may even be evolving in the Everglades, with those best able to handle the Florida environment, rather than their native habitat, surviving and reproducing.[70] The risks associated with AI are a primary focus of global regulators and represent a much more complex set of issues and greater challenges than the Burmese python problem, where simple eradication is the goal. Hopefully, we do not miss the opportunity to properly regulate AI and anticipate Abandoned AI before we lose control of the situation and end up needing to engage in an expensive and likely impossible task of remediation.[71]

As stated by Professors Mark Fenwick, Wulf A. Kaal, and Erik P.M. Vermeulen,

> Designing a regulatory framework that ensures the safety of users and the public, whilst facilitating the commercial use and consumer enjoyment of disruptive innovation, is by no

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_cost_and_benefit_analysis_of_orbital_debris_remediation_-_final.pdf [https://perma.cc/2ZWS-5K9R]; Raffi Khatchadourian, *The Elusive Perils of Space Junk*, THE NEW YORKER (Sep. 28, 2020), https://www.newyorker.com/magazine/2020/09/28/the-elusive-peril-of-space-junk [https://perma.cc/7UPV-VTPX] ("At NASA, Donald Kessler was the first to grasp that space pollution posed a strange form of high-speed environmental damage. . . . [f]rom his earliest calculations, the stakes were clear: the problem, if ignored, could destroy all the satellites that orbit near the Earth—a loss that would be more acutely felt as humanity increasingly relied on space. Communication systems would fail; scientific instruments—to study climate, or pandemics, say—would become inoperable. The losses could be measured in billions of dollars, and perhaps in lives, too.").

69. Quoting Dr. Roman Yampolskiy, "Again, as long as we are still alive, we are still in control, I think it's not too late." *Transcript of Joe Rogan Experience Podcast #2345 (interview of Roman Yampolskiy)*, SAFE AI FOREVER J. (July 3, 2025), https://blog.biocomm.ai/2025/07/03/joe-rogan-experience-2345-roman-yampolskiy-powerfuljre/ [https://perma.cc/9RY6-GTU7].

70. Ruth Schuster, *Pythons Invading Florida Are Evolving Unexpectedly Fast...Offering Hope for Surviving Climate Change*, HAARETZ (Oct. 24, 2018), https://www.haaretz.com/science-and-health/2018-10-24/ty-article-magazine/pythons-invading-florida-are-evolving-unexpectedly-fast/0000017f-dc74-df62-a9ff-dcf7788a0000 [https://perma.cc/ZYA3-NDHC] ("Genetic analysis elucidated that they had undergone rapid evolution as a result of unique climatic and ecological conditions present in Florida.").

71. *See generally* Edmund Mokhtarian, *The Bot Legal Code: Developing a Legally Compliant Artificial Intelligence*, 21 VAND. J. ENT. & TECH. L. 145 (2020) (proposing a system of "AI Laws" that bots can adopt to ensure their behavior is in compliance with legal rules and standards).

> means easy. This is particularly true in contemporary settings, where innovation is quicker and the global dissemination of that technology is much faster. In such circumstances, regulators can often struggle to keep up.[72]

This Article does not propose a comprehensive regulatory scheme for AI, which is the subject of numerous proposals by a range of regulatory bodies globally. In any event, it would be outdated by the time of publication. Similarly, this Article does not attempt to propose a regulatory scheme for the narrower topic of Autonomous AI Robots, which will need to be subject to a wide range of regulations, both general (i.e., covering the universe of AI-driven objects) and object-specific (i.e., regulations tailored to various categories of objects).[73] Rather, this Article proposes that we look at existing problems associated with invasive species (and Burmese pythons specifically) and imagine similar problems that may result from Abandoned AI. It recommends that we look to laws and other governmental measures addressing invasive species (including the import, breeding, and maintenance of non-native organisms) when seeking to regulate Autonomous AI Robots that could become harmful if abandoned by incorporating parallel invasive-species frameworks.

When examining the laws that apply to invasive species, perhaps it is best to consider the failings of such laws and to think about what should have been done if we could turn back the clock. This Article is meant to add to the discourse about how to regulate, not eliminate, the use of AI (i.e., with guardrails in place) and to advocate for the following notions: (i) all AI-driven objects will eventually need to terminate and, if they do not terminate on their own, they may need to be terminated through third-party intervention; and (ii) the cost of eradicating rouge objects and remediating the harm that arises from them will be expensive, and therefore any regulation of Autonomous AI Robots should include the pre-funding of a bounty and remediation system for objects likely to become Abandoned AI. It does not suggest the elimination of the use of Autonomous AI Robots, since the authors do not think it is a realistic goal, given the incentives that countries have to develop this

72. Mark Fenwick, Wulf A. Kaal & Erik P.M. Vermeulen, *Regulation Tomorrow: What Happens When Technology Is Faster Than the Law?*, 6 AM. U. BUS. L. REV. 561, 567 (2017).

73. For example, autonomous vehicles will be subject to a range of regulations at the federal, state and local level. Drones that fly are subject to other regulations, including those that deal with privacy, safety, noise, etc. *See generally Unmanned Aircraft Systems (UAS)*, FED. AVIATION ADMIN., https://www.faa.gov/uas [https://perma.cc/9TAK-B6VL] (last visited Sep. 18, 2025) (providing rules and resources surrounding the use of unmanned aircraft systems).

technology.[74] By no means is there a simple solution available or a singular model rule that can address this potential problem.[75]

III. HOW ARE INVASIVE SPECIES REGULATED IN THE STATE OF FLORIDA?

Jurisdictions around the world regulate the importation, handling, breeding, and release of invasive species in a variety of ways. A survey of global regulations in this area is beyond the scope of this Article. Although a marginally interesting endeavor (for someone else out there), the history of these laws is also outside of the scope of this Article. We do, however, attempt to provide a brief summary of certain U.S. federal and State of Florida (i.e., the location of the Everglades) laws that pertain to invasive species and, more specifically, their remediation once abandoned into the environment. One would expect Florida to have well-considered laws in this area, because (i) the South Florida climate is hospitable to invasive tropical and sub-tropical species from around the world; (ii) the size of the population and amount of wealth located in the State of Florida allows for a robust exotic pet trade;[76] (iii) the State of Florida has spent millions trying to eradicate invasive species, leading to more developed thinking about and legislation pertaining to these issues than in many other places; and (iv) the large population in South Florida comes with a plethora of media outlets and robust political activity.

Under the U.S. federal system, people located in the State of Florida are also subject to U.S. federal laws, and in certain cases, U.S. federal laws could preempt conflicting Florida law.

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74. Those incentives include economic windfalls and military superiority. Countries that fall behind will suffer consequences.

75. When discussing the regulation of new technologies, such as AI, Professors Mark Fenwick, Wulf A. Kaal, and Erik P.M. Vermeulen state that "[w]e need to be careful not to overstate the newness of this issue. To some degree, these kind [sic] of difficulties have always been around, at least since the rise of industrial capitalism and the acceleration in technological advancement that it facilitated." Fenwick, Kaal & Vermeulen, *supra* note 72, at 574. The authors of this Article agree in large part, in the sense that there is some precedent that can inform our thinking about AI, and we should try to find those precedents (even if they require tweaking). *Id.*

76. *See generally* Frank J. Mazzotti & Rebecca G. Harvey, *The Invasion of Exotic Reptiles and Amphibians in Florida*, UF IFAS EXTENSION (Aug. 20, 2021), https://edis.ifas.ufl.edu/publication/UW365 [https://perma.cc/92PY-PLVM] (describing Florida as an "invasive species hotspot").

A. *U.S. Federal Acts*

1. The Lacey Act of 1900[77]

The Lacey Act was passed in 1900, with the goal of protecting wildlife in the United States.[78] The law was originally enacted to prohibit the interstate transportation of wildlife that was illegally killed in another state. The bill was essential to the ability of states to enforce their environmental protection laws.[79] This act has been amended a number of times over the years, with the goals of expanding the scope of its prohibitions and expanding the level of protection afforded by the act.[80] In general, the Lacey Act does not prohibit specific destructive actions taken against the environment but works to support state and local governments by helping them enforce their underlying laws on an interstate level. More specifically, the law makes it unlawful for any person

> (1) to import, export, transport, sell, receive, acquire, or purchase any fish or wildlife or plant taken, possessed, transported, or sold in violation of any law, treaty, or regulation of the United States or in violation of any Indian tribal law; (2) to import, export, transport, sell, receive, acquire, or purchase in interstate or foreign commerce—(A) any fish or wildlife taken, possessed, transported, or sold in violation of any law or regulation of any State or in violation of any foreign law. . . .[81]

The law also prohibits, among other things, "marking offenses," which refers to making false records in connection with the importation or transportation of wildlife in interstate or international commerce. It prohibits false labeling and sales of certain hunting guides and outfitting activities.[82]

Both civil and criminal penalties may be assessed for violations of the law.[83] A bounty may be paid to people who furnish information leading

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77. Lacey Act, 18 U.S.C. § 42; 16 U.S.C. §§ 3371–3378.

78. *Lacey Act*, U.S. FISH & WILDLIFE SERV., https://www.fws.gov/law/lacey-act [https://perma.cc/CV4Q-V3CA] (last visited Dec. 19, 2025); *Lacey Act*, ANIMAL & PLANT HEALTH INSPECTION SERV., U.S. DEP'T OF AGRIC. (Feb. 2023), https://www.aphis.usda.gov/sites/default/files/fsc-lacey-act.pdf [https://perma.cc/J7UA-YM7H].

79. *Law & Policies: More Laws*, NOAA FISHERIES, https://www.fisheries.noaa.gov/topic/laws-policies/more-laws [https://perma.cc/T6HF-434F] (last visited Sep. 18, 2025).

80. Rebecca F. Wisch, *Overview of the Lacey Act (16 U.S.C. §§3371-3378)*, ANIMAL LEGAL & HIST. CTR. (2003), https://www.animallaw.info/article/overview-lacey-act-16-usc-ss-3371-3378 [https://perma.cc/8C5X-CZ6H] (last visited Sep. 18, 2025).

81. 16 U.S.C. § 3372(a)(1)–(2).

82. 16 U.S.C. § 3372(c)–(d).

83. 16 U.S.C. § 3373.

to the prosecution of people violating this law.[84] Violators may face forfeiture of their wildlife or related property on a strict liability basis. There is also a licensing regime in place under this Act, whereby the "importation of injurious wildlife into the United States or its territories or possessions must be authorized under a permit issued by the U.S. Fish and Wildlife Service."[85]

2. Proposed America Competes Act,[86] the CHIPS and Science Act and Subsequent Regulatory Measures[87]

The House of Representatives' proposed United States of America COMPETES Act of 2022 (a.k.a. America Creating Opportunities for Manufacturing, Pre-Eminence in Technology, and Economic Strength Act of 2022) proposed to modify the Lacy Act in certain respects.[88] Section 71102 allows the Secretary of the Interior to prescribe by regulation an emergency designation prohibiting the importation of any species for not more than three years if the Secretary of the Interior determines that such regulation is necessary to address an imminent threat to human beings, to the interests of agriculture, horticulture, forestry, or to wildlife or the wildlife resources of the United States.[89] It also contains import controls over certain species of wildlife. The law is required to be implemented in part through regulation. It should be noted that the Bill mentions AI forty times, illustrating that someone who has the ear of the regulators was thinking about this technology in early 2022 before the world started to buzz about ChatGPT.[90] In fact, it requires reporting on the use of artificial intelligence to combat wildlife trafficking.[91] This act did not pass both houses of Congress but was in large part superseded by the CHIPS and Science Act.

The CHIPS and Science Act, which was passed in 2022, had the goal of fortifying the research, development, and manufacturing of

84. *The Lacey Act*, NAT'L WHISTLEBLOWER CTR., https://www.whistleblowers.org/what-is-the-lacey-act/ [https://perma.cc/MX57-RNG6] (last visited Sep. 18, 2025).

85. *3-200-42: Import/Acquisition/Transport of Injurious Wildlife under the Lacey Act*, U.S. FISH & WILDLIFE SERV., https://www.fws.gov/service/3-200-42-import-acquisitiontransport-injurious-wildlife-under-lacey-act [https://perma.cc/5EG7-Y6CK] (last visited Sep. 18, 2025).

86. America COMPETES Act of 2022, H.R. 4521, 117th Cong. (2022), https://www.congress.gov/117/cprt/HPRT47998/CPRT-117HPRT47998.pdf [https://perma.cc/P5Y6-45WF] (last visited Sep. 28, 2025).

87. 15 U.S.C. §§ 4651–4659.

88. The Senate version was called the U.S. Innovation and Competition Act (USICA). *See* United States Innovation and Competition Act of 2021, S.1260, 117th Cong. (2021), https://www.congress.gov/bill/117th-congress/senate-bill/1260/text [https://perma.cc/2C4F-65PW].

89. H.R. 4521, 117th Cong. § 71102(a)(1)(C) (2021).

90. H.R. 4521.

91. H.R. 4521, 117th Cong. § 60402 (2022).

semiconductors, with a plan for the United States to invest over $280 billion over the ensuing decade.[92] Aiming to foster and cement American leadership in the field, the Act aims to facilitate engagement with everything from supply chain issues to the advancement of cutting-edge technology, to the creation of an amply skilled workforce to innovate and sustain the state of the art in this field.[93] Since semiconductor companies are the lifeblood of the AI industry, the Act attempts to regulate AI by fortifying the United States' position at the vanguard of this technology and obviating the need for dependence on foreign suppliers of AI technology.

In early 2025, the Department of Commerce issued the AI Diffusion Framework,[94] which limits the exporting of AI chips to certain countries, such as China, in order to prevent cutting-edge United States technology in this realm from being used by adversaries of the United States. However, nowhere in this legislation does there appear to be contemplation of the eventual need to, at some future juncture, terminate AI-driven objects. Similarly, there appears to be no contemplation of the need to incentivize, such as with a bounty and remediation system, termination, disposal, or other engagement with objects likely to become Abandoned AI. That framework was rescinded in mid-2025 and additional guidance was given by new leadership at the Department of Commerce.[95]

B. *Florida State Laws*

There is a myriad of different regulations in various jurisdictions throughout the United States that touch upon the possession and release of invasive species. As noted above, we will focus on the State of Florida, because it is directly dealing with the Burmese python crisis in the

92. CHIPS and Science Act, Pub. L. No. 117-167, 136 Stat. 1366 (Aug. 9, 2022); *see* McKinsey & Co., *The CHIPS and Science Act: Here's What's in It* (Oct. 2022) (noting that the Act "invests $280 billion to bolster U.S. semiconductor capacity, catalyze R&D, and create regional high-tech hubs and a bigger, more inclusive STEM workforce"), https://www.mckinsey.com/industries/public-sector/our-insights/the-chips-and-science-act-heres-whats-in-it [https://perma.cc/CZJ7-SPTK].

93. *See generally* CHIPS and Science Act, Pub. L. No. 117-167, 136 Stat. 1366 (Aug. 9, 2022) (act providing "funds to support the domestic production of semiconductors and authoriz[ing] various programs and activities of the federal science agencies").

94. Lennart Heim, *Understanding the Artificial Intelligence Diffusion Framework* (Jan. 14, 2025), https://www.rand.org/pubs/perspectives/PEA3776-1.html [https://perma.cc/V83B-TN62].

95. *Department of Commerce Announces Rescission of Biden-Era Artificial Intelligence Diffusion Rule, Strengthens Chip-Related Export Controls*, BUREAU OF INDUSTRY & SECURITY, U.S. DEP'T OF COM. (May 13, 2025), https://www.bis.gov/press-release/department-commerce-announces-recission-biden-era-artificial-intelligence-diffusion-rule-strengthens-chip [https://perma.cc/TG23-RQZT].

Everglades and the authors have chosen to use the Burmese Python Model when considering laws that would deal with Abandoned AI.

Under Florida Statutes Title XXVIII, Natural Resources; Conservation, Reclamation, and Use, § 379.3762 (Personal possession of wildlife):

> (1) It is unlawful for any person or persons to possess any wildlife as defined in this act, whether native to Florida or not, until she or he has obtained a permit as provided by this section from the Fish and Wildlife Conservation Commission.
>
> (2) The classifications of types of wildlife and fees to be paid for permits for the personal possession of wildlife shall be as follows:
>
> (a) Class I—Wildlife which, because of its nature, habits, or status, shall not be possessed as a personal pet.
>
> (b) Class II—Wildlife considered to present a real or potential threat to human safety, the sum of $140 per annum.
>
> (c) Class III—All other wildlife not included in Class I or Class II, for which a no-cost permit must be obtained from the commission.[96]

Violations may result in civil or criminal penalties. The Commission has enacted lists of species that fall within the three categories. The list is too long to copy here, but we try to provide the reader with a flavor for which species fall within each bucket.[97] The sale of wildlife in Florida

96. FLA. STAT. § 379.3762 (2024).

97. *Wildlife as a Personal Pet*, FLA. FISH & WILDLIFE CONSERVATION COMM'N, https://myfwc.com/license/captive-wildlife/personal-pet/ [https://perma.cc/C63T-43ZS] (last visited Sep. 18, 2025). Class I: chimpanzees, gorillas, leopards, tigers, lions, elephants, Komodo dragons and cheetahs. Class II: various species of monkeys, bobcats, wolves, coyotes, wolverines, alligators, giraffes and antelope. Class III: all other wildlife, other than certain listed species for which no permit is required (e.g., exotic birds (parrots, parakeets, finches), small mammals (foxes, skunks, raccoons, lemurs), many reptile species (snakes, lizards, turtles, tortoises), and all amphibian species). No permit is needed to possess the following species as a personal pet: nonvenomous and unprotected reptiles or amphibians, gerbils, hedgehogs, honey possums, sugar gliders, rats, mice, moles, shrews, rabbits, squirrels, chipmunks, domestic ferrets, European ferrets, guinea pigs, hamsters, prairie dogs, chinchillas, shell parakeets, canaries, lovebirds, cockatiels, parrots, finches, myna birds, toucans, ringed doves, ruddy doves, diamond doves, and button quail. *Id.*

requires a special license, regardless of the nature of the sale.[98] Breeding animals for sale also generally requires licensing.[99]

In 2021, the Florida Fish and Wildlife Conservation Commission voted to list sixteen types of high-risk reptiles.[100] The reptiles on the list include Burmese pythons, reticulated pythons, scrub pythons, Northern African pythons, Southern African pythons, amethystine pythons, green anacondas, Nile monitor lizards, tegus, and green iguanas.[101] In its rulemaking process, the Commission received more than 1,400 written comments and 5,500 surveys.[102] This level of engagement illustrates the public's passion for this topic. The existence and engagement of not-for-profit groups, such as Audubon, the Sierra Club and the Humane Society,[103] illustrates that these issues have gone far beyond grassroots interest and have become the focus of well-funded and organized institutions. Perhaps similar groups will spring up around the area of AI.[104]

Florida's Python Elimination Program started in 2017 and pays people to capture invasive Burmese pythons for euthanizing.[105] Python removal agents are paid an hourly wage, plus incentive fees that range from $50 (for each python that is greater than four feet, plus an additional fee for each foot over four feet) to $200 for the eradication of active nests.[106] Firearms may be used in the hunt and additional species of destructive snakes also qualify for rewards.[107] Only applicants who are selected by the South Florida Water Management District and contract with the state are eligible for cash rewards.[108]

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98. *Sale of Wildlife*, FLA. FISH & WILDLIFE CONSERVATION COMM'N, https://myfwc.com/license/captive-wildlife/sale/ [https://perma.cc/M8MG-MY8S] (last visited Sep. 18, 2025).

99. *Id.*

100. Jim Waymer, *Florida FWC Votes to Ban 'High-Risk' Reptiles as Snake Lovers Protest and Beg for Mercy*, FLA. TODAY (Feb. 25, 2021), https://www.floridatoday.com/story/news/2021/02/25/emotions-proposed-florida-reptile-ban-run-raw/4553754001/ [https://perma.cc/EZ6K-BLT6].

101. *Id.*

102. *Id.*

103. *See id.*

104. *See id.*

105. Fla. Fish & Wildlife Conservation Comm'n, *Python Action Team: Removing Invasive Constrictors (PATRIC)*, https://myfwc.com/wildlifehabitats/nonnatives/python/action-team [https://perma.cc/WC6E-QSB6] (last visited Dec. 19, 2025); *see Python Elimination Program*, S. FLA. WATER MGMT. DIST., https://www.sfwmd.gov/our-work/python-program [https://perma.cc/R4VQ-MVWR] (last visited Sep. 18, 2025).

106. *Python Elimination Program*, *supra* note 105.

107. *Id.*

108. *Id.*

IV. CUTTING EDGE REGULATION OF AI

The proliferation of AI technology and its advances have spurred a flurry of governance initiatives and proposals worldwide.[109] The undertaking of the regulation of AI is both gargantuan and delicate, involving a precarious balancing of allowing for the responsible, optimal usage of AI, while simultaneously guarding against the risks that it poses. The collaborations and frameworks produced by entities, organizations, and governments aim to balance safety against technological progress and the economic and military wins that a country will gain for being an AI leader. Below is a summary of how various nations and organizations are attempting to navigate this rapidly advancing landscape. Although the focus of this Article is not to provide a survey of global AI regulation (and, in any event, such a survey would likely be out of date by the time of publication), the authors do want to touch upon how AI is, and is proposed to be, regulated. The reason for this is to examine whether current proposals already contemplate Abandoned AI and sufficiently address it. We are not aware of any current proposals that sufficiently anticipate the problems associated with Abandoned AI or provide funding mechanisms for future remediation.

We do spend a bit of time examining the recently enacted EU regulations, because they have been praised for being more proactive and comprehensive than most other sets of global regulations, and therefore can be viewed as a model for other global regulators.

A. *The European Union*

The European Parliament has recently approved the Artificial Intelligence Act (EU AI Act).[110] It is a highly ambitious undertaking that seeks to regulate a wide range of AI systems and related activities. It has been referred to as "the first comprehensive regulation on AI by a major regulator anywhere."[111] The EU AI Act takes a risk-based approach, designating certain risks as unacceptable and others as being high or limited.[112] It defines "AI system" in a way that clearly includes

109. *See Artificial Intelligence Index Report*, STAN. U. HUM. CENTERED A.I., https://hai.stanford.edu/ai-index [https://perma.cc/AT9S-W3A5] (last visited Sep. 18, 2025).

110. *Artificial Intelligence Act: MEPs Adopt Landmark Law*, EUR. PARLIAMENT (Mar. 13, 2024), https://www.europarl.europa.eu/news/en/press-room/20240308IPR19015/artificial-intelligence-act-meps-adopt-landmark-law [https://perma.cc/RL2R-KX7R].

111. *What is the EU AI Act?*, EU A.I., https://artificialintelligenceact.eu/ [https://perma.cc/34XU-RHEU] (last visited Sep. 18, 2025).

112. Kirk J. Nahra et al., *The European Parliament Adopts the AI Act*, WILMERHALE (Mar. 14, 2024), https://www.wilmerhale.com/en/insights/blogs/wilmerhale-privacy-and-cybersecurity-law/20240314-the-european-parliament-adopts-the-ai-act [https://perma.cc/8R2V-4KJT]; EUR. PARLIAMENT, *supra* note 41.

Autonomous AI Robots.[113] The Act bans certain uses of AI, primarily for the purposes of fairness and human rights, and classifies all AI based upon the risk that it is seen to pose:

> Unacceptable risk is prohibited (e.g.[,] social scoring systems and manipulative AI). Most of the text addresses high-risk AI systems, which are regulated. A smaller section handles limited risk AI systems, subject to lighter transparency obligations: developers and deployers must ensure that end-users are aware that they are interacting with AI (chatbots and deepfakes). Minimal risk is unregulated (including the majority of AI applications currently available on the EU single market, such as AI enabled video games and spam filters—at least in 2021; this is changing with generative AI).[114]

One stated goal is "protection of public interests, such as health and safety and the protection of fundamental rights, including democracy, the rule of law and environmental protection."[115] The authors' analogy to the python situation fits within the EU's consideration of health and safety and environmental protection. Specifically, the EU AI Act states, "[t]he fundamental right to a high level of environmental protection enshrined in the Charter and implemented in Union policies should also be considered when assessing the severity of the harm that an AI system can cause, including in relation to the health and safety of persons."[116] The authors will not attempt to summarize the Act, which is over 400 pages (English version), but will highlight certain features that relate to the list of essential regulatory elements that the authors cover below.

The EU AI Act's risk-based approach does not attempt to list all categories of AI systems and risks but presents principles for approaching the categorization of products. According to the Act,

> As regards stand-alone AI systems, . . . it is appropriate to classify them as high-risk if, in light of their intended purpose, they pose a high risk of harm to the health and safety or the fundamental rights of persons, taking into account both the severity of the possible harm and its

113. EUR. PARLIAMENT, *supra* note 41, at 165 ("'AI system' means a machine-based system that is designed to operate with varying levels of autonomy and that may exhibit adaptiveness after deployment, and that, for explicit or implicit objectives, infers, from the input it receives, how to generate outputs such as predictions, content, recommendations, or decisions that can influence physical or virtual environments.").

114. *High-Level Summary of the AI Act*, EU ARTIFICIAL INTELLIGENCE ACT, https://artificialintelligenceact.eu/high-level-summary/ [https://perma.cc/DE36-YRMK] (last updated Sep. 18, 2024).

115. EUR. PARLIAMENT, *supra* note 41, at 7.

116. *Id.* at 43.

> probability of occurrence . . . The identification of those systems is based on the same methodology and criteria envisaged also for any future amendments of the list of high-risk AI systems . . . to take into account the rapid pace of technological development, as well as the potential changes in the use of AI systems.[117]

One factor taken into account when classifying an AI system's risk profile is whether the ". . . AI system is easily corrigible or reversible, taking into account the technical solutions available to correct or reverse it, whereby outcomes having an adverse impact on health, safety or fundamental rights, shall not be considered to be easily corrigible or reversible[.]"[118] A risk management system is required for high-risk AI systems.[119]

Under the Act, "[t]he risk-management system should consist of a continuous, iterative process that is planned and run throughout the entire lifecycle of a high-risk AI system."[120] Although this may not have been intended, the use of the word "lifecycle" may indicate that the drafters see certain objects run by AI similarly to animals that have an actual life. In furtherance of the foregoing notion about AI systems having a "life," the Act states,

> [h]aving comprehensible information on how high-risk AI systems have been developed and how they perform throughout their lifetime is essential to enable traceability of those systems. . . Such information should include the general characteristics, capabilities and limitations of the system . . . The technical documentation should be kept up to date, appropriately throughout the lifetime of the AI system.[121]

The Act states that "a specific natural or legal person, defined as the provider, takes responsibility for the placing on the market or the putting into service of a high-risk AI system, regardless of whether that natural or legal person is the person who designed or developed the system."[122] This element concerning accountability and liability is consistent with the list of considerations that the authors discuss below. In this regard, the Act further states that

> under certain specific conditions, any distributor, importer, deployer or other third-party should be considered to be a

117. *Id*. at 47.
118. *Id.* at 195.
119. *Id.* at 197.
120. *Id.* at 64.
121. *Id.* at 69.
122. *Id.* at 76.

> provider of a high-risk AI system and therefore assume all the relevant obligations. This would be the case if that party puts its name or trademark on a high-risk AI system already placed on the market or put into service, without prejudice to contractual arrangements stipulating that the obligations are allocated otherwise. This would also be the case if that party makes a substantial modification to a high-risk AI system . . . .[123]

Under the EU AI Act, sandboxes, which are controlled regulatory systems, are to be established so that products can be tested and risks can be identified by the regulators before a system is placed into the market. The Act states, "Any significant risks identified during the development and testing of such AI systems should result in adequate mitigation and, failing that, in the suspension of the development and testing process."[124]

B. *Proposed Elements of Regulation to Address Abandoned AI*

Although this Article does not propose the text of any specific piece of legislation, it does provide a list of factors that should be considered when drafting regulations to lay the groundwork for dealing with Abandoned AI. These elements are also useful to address other risks, and therefore the benefit of adopting each one is not limited to the issue of Abandoned AI. For each factor, the authors considered the python dilemma, and existing laws related to invasive species and have viewed Abandoned AI in a manner that is similar to an invasive animal. As more fully elaborated below, these regulations might include licensing the import and production of Autonomous AI Robots, licensing the creators of Autonomous AI Robots, separate licensing of individual instances of Autonomous AI Robots (e.g., similar to how each car is registered with the State and certain exotic pets are tagged and tracked), criminal statutes for abandonment or release of Autonomous AI Robots, bounty programs for the destruction or capture of Abandoned AI, tort liability for destructive Autonomous AI Robots and Abandoned AI, rules setting the groundwork for considering how to destroy Autonomous AI Robots and financial schemes that might be created to fund the foregoing programs. Below, we touch upon each of these factors.

1. Licensing the Inventors of AI

In our society, the creators or inventors of certain categories of goods and inventions that present risks to society must be licensed. For example,

123. *Id.* at 80.
124. *Id.* at 123.

self-driving cars are highly regulated.[125] As stated above, the fields of AI and genetic engineering (i.e., the creation of synthetic organisms) are intertwined. The creation of certain categories of AI will need to be limited to those who can do so responsibly and under the supervision of regulatory authorities, rather than in people's basements. There are likely proposals out there that limit the ability to create certain categories of AI to those who are licensed to do so, and this Article does not propose anything different in concept. If the creators of potentially dangerous AI are not subject to a licensing regime and oversight by governments and their agencies, then it will be impossible to regulate what is allowed to exist (similar to biological research), control what actually exists, and know what may be encountered in the real world once released. Licensing can also help identify owners, operators or creators for the purposes of establishing tort liability.

National and international regimes need to dovetail, because, like invasive species, Autonomous AI Robots are not necessarily confined within political borders. The categorization of AI systems by risk level is addressed in the EU regulations.[126] The categories of what is deemed risky AI will need to be determined and refined over time as AI systems gain functionality and categories of risk that have not yet been identified are, in fact, identified. Over time, things that might not appear to be risky might become risky based upon their use, evolution or quantity, and in this respect, AI can be unpredictable.[127]

2. Licensing, Testing and Certification of AI Inventions

In our society, certain categories of goods must also be approved by governmental bodies before they are put into commerce or into our physical world. These tend to be products that can pose a risk to society. For example, there are extensive regimes in place for the approval of airplanes, drugs and medical devices before they may be placed into the stream of commerce (i.e., released into society).[128] Without a certification regime, there will be few guardrails in place to prevent unreasonably dangerous Autonomous AI Robots from sharing our space with us. Inventors have a profit motive in ensuring that their inventions come to

125. *See Autonomous Vehicles | Self-Driving Vehicles Enacted Legislation*, NCSL (last updated Feb. 18, 2020), https://www.ncsl.org/transportation/autonomous-vehicles [https://perma.cc/EP27-9ARA].

126. *See High-Level Summary of the AI Act*, *supra* note 114.

127. *See* Roman V. Yampolskiy, *Unpredictability of AI* (May 29, 2019), https://arxiv.org/pdf/1905.13053 [https://perma.cc/W6L2-YEJS].

128. *See, e.g.*, 14 C.F.R. § 121.157 (2025); 21 C.F.R. § 4 and § 820; *see generally* Ahmed Nahian & Roopma Wadhwa, *Federal Regulation of Medication Production* (last updated June 5, 2023), NAT'L LIBR. OF MED., https://www.ncbi.nlm.nih.gov/books/NBK572098/ [https://perma.cc/H2WA-KTJX].

market. The upside is almost limitless, with certain tech CEOs being treated like rock stars and made into billionaires before their first gray hairs. The downside of releasing Autonomous AI Robots into society is low for the individual inventor, while the downside to society can be existential. Without a licensing regime for each specific Autonomous AI Robot, we will not know the nature of individual categories of objects once they become Abandoned AI. When dealing with the containment of the Burmese python, at least those charged with capturing and/or humanely killing them know about the nature of pythons. For example, we know that they do not fly and are not venomous. However, without a licensing regime, we may not even know the nature of a machine.

Unlike Burmese pythons, Autonomous AI Robots may not simply die on their own from natural causes. Machines may be made of materials that last different amounts of time. Putting aside their ability to breed, any individual Burmese python will die on its own after a number of years. Conversely, a machine may last decades or even centuries. When licensing an Autonomous AI Robot, regulators can impose obligations on the inventor to build the Autonomous AI Robot from materials that will degrade over time and "die" of natural causes. Imagine the dangers of being attacked by an Autonomous AI Robot that has sat dormant but can be triggered to fight a war that ended a century ago.[129]

3. Licensing of "Breeding" or Production

The regulation of high-risk AI systems is most effectively handled at the level of the creator and the invention (i.e., the "species"). This would typically involve the regulation of a single enterprise. Looking toward the future, the manufacturers (i.e., "breeders") of Autonomous AI Robots will also need to be licensed, since certain AI-based inventions may be able to reproduce themselves or may be produced at scale using distributed technology, such as 3-D printing. Some systems may even be open-sourced, so that anyone can make a copy. Licensing the manufacturers of high-risk AI and the products that they create would serve as a gate for the introduction of high-risk systems into the environment. Depending upon the Autonomous AI Robot, there can be

129. *See* Lynsey Chutel et al., *What Are Anti-Personnel Mines?*, N.Y. TIMES (Nov. 30, 2024), https://www.nytimes.com/2024/11/20/world/europe/anti-personnel-land-mines-ukraine.html [https://perma.cc/X7Y3-6MMK] ("Land mines can indiscriminately kill and maim noncombatants, years or even decades after the cessation of hostilities. In 2022, land mines killed 1,661 people and injured 3,015, according to the International Campaign to Ban Landmines. Civilians made up 85 percent of those casualties, half of whom were children."); *see, e.g.*, *The Deadly Legacy of Landmines*, UN NEWS (Apr. 2, 2024), https://news.un.org/en/story/2023/04/1135252 [https://perma.cc/P49F-CCJP] ("Six-year-old Minga lost her sight and her left arm in 2009, seven years after the end of the war in Angola. She was one of the many children who was born into peace but harmed by a war that she never knew.").

limits on quantities produced, export controls and quality checks. As noted above, there may even be requirements on the materials that can be used so that an Autonomous AI Robot will function for a range of time and then "die" of natural causes. For example, parts can rust, degrade or be depleted with each use.

The licensing of manufacturers, as well as inventors and inventions, is also essential for the establishment of insurance requirements, which may be placed upon creators and producers of high-risk AI (e.g., against damages related to product liability). Without licensing the "breeders" of AI, there will be no way to control the number or nature of objects in the environment or assign blame for mishaps.

4. Licensing of People Who Import and Possess High-Risk AI

Similar to those who keep and handle exotic animals, regulations are needed to ensure that only responsible and capable persons gain possession of high-risk AI. Those people would need to demonstrate the ability to control high-risk systems and pay for damages if things go wrong. Insurance requirements should also be considered at this level (similar to automobile insurance requirements). Even in cases where possession of an Autonomous AI Robot is not required to be licensed, ownership records should be kept—starting with the manufacturer and extending to importers, distributors and end users—so that we know who is responsible for an object if it becomes problematic. As noted below, at some point, the tort system will need to be redefined so that blame for a mishap involving AI can be properly apportioned among the inventor, the manufacturer, the owner, and possibly others.

5. Licensing of Each Individual "Animal"—Tagging and Possible Inspection

If each instance of a risky Autonomous AI Robot is recorded and tagged for identification purposes, then the agencies providing oversight of the applicable category of objects, as well as members of the public, would have information about the object if it is encountered in the environment. For instance, motor vehicles are required to be inspected in certain U.S. states because dangerous or polluting motor vehicles present risks to society. The ability of an Autonomous AI Robot to pass a periodic inspection implies control by the owner and allows a governmental agency to monitor for new risks (e.g., as the system "learns"). Tagging individual objects allows governments to tax Autonomous AI Robots and enables public safety officials to discern the nature of an object encountered in the environment and identify its owner (or determine that it represents Abandoned AI). This is similar to car license plates or dog licenses, where one can identify whether a dog is a stray or someone's

lost pet. Some pets are even tagged with RFID tags, or are subject to identification through genetic testing and comparison to a database.

C. *Criminal Statutes Prohibiting Uncontrolled Release into the Wild Should Be Considered*

The uncontrolled introduction of certain risky Autonomous AI Robots into the environment should be prohibited under the law and even considered a criminal offense. Using our comparison to the animal world, this would be similar to dog leash laws, as well as other laws related to releasing dangerous animals into the environment. Perhaps existing laws may cover certain instances of harm (e.g., the laws related to reckless endangerment). However, more specific laws about putting dangerous objects into the environment should also be considered. There may be objects that are so dangerous that they may be subject to strict liability, such as autonomous drones that are designed for war.

Society will need to grapple with the issue of whether the creator or owner of an Autonomous AI Robot will be liable for the crimes committed by the Autonomous AI Robot. Although a fascinating topic, we will leave it to other scholars to examine the ways in which criminal liability should attach to the acts of one's Autonomous AI Robots (including Abandoned AI) as these systems become more intelligent, and may even be considered to have consciousness, sentience, or both.[130]

1. Kill Switches and Other Safety Features

Certain species that are allowed to be imported or maintained are subject to measures to ensure that they cannot survive outside their non-native environments or reproduce.[131] Similarly, certain risky Autonomous AI Stems may require kill switches or other features to terminate their existence or prevent them from replicating once they become Abandoned AI. These requirements may be analogous to historical governmental rights to require the sterilization of animals[132] in certain circumstances. This is also similar to the requirement that certain

130. *See also* Gabriel Hallevy, *I, Robot - I, Criminal: When Science Fiction Becomes Reality: Legal Liability of AI Robots Committing Criminal Offenses*, 22 SYRACUSE SCI. & TECH. L. REP. 1, 7–9 (2010); *see generally* Ryan Abbott & Alex Sarch, *Punishing Artificial Intelligence: Legal Fiction or Science Fiction*, 53 UC DAVIS L. REV. 323 (2019) (exploring different ways in which criminal penalties should attach to address acts committed by AI Robots).

131. *Sterile Insect Technique*, INT'L ATOMIC ENERGY AGENCY, https://www.iaea.org/topics/sterile-insect-technique [https://perma.cc/QK86-998T] (last visited Sep. 18, 2025).

132. Osama El-Lissy, *State-of-the-Art USDA Facilities Keep Invasive Pests Out of the Country*, U.S. DEP'T OF AGRIC. (May 2, 2019), https://www.usda.gov/about-usda/news/blog/state-art-usda-facilities-keep-invasive-pests-out-country [https://perma.cc/3YPW-KCRY].

species or herds be culled in response to an outbreak, such as the avian flu.[133]

See above regarding the use of materials that will ensure a "natural death" for an Autonomous AI Robot.

2. Tort Compensation for those Harmed

Although a description of the theories upon which tort liability may be found in the context of harm from Abandoned AI, and applying them to the various hypothetical circumstances where redress is needed would be too lengthy to include in this article, causes of action that may be relevant include, among others, negligence,[134] strict liability, and products liability law.[135] Tort law is flexible, but we need to ensure that the duties of the creator and owner are well established. Certain "species" of AI may need to be treated like dangerous animals[136] and result in strict liability under tort law, while others might receive a lower standard, similar to pets (e.g., the one-bite rule).[137]

One can imagine a system in which the production of each individual Autonomous AI Robot could require a bond to be deposited with an organization with oversight authority so that the Autonomous AI Robot (independent of its creator or owner) would be in a position to pay for the damages that it creates. A similar result may be achieved with insurance policies, much like the requirement that every car is insured.

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133. *See, e.g.*, Sophie Kevany, *Avian Flu Has Led to the Killinng of 140m Farmed Birds Since Last October*, GUARDIAN (Dec. 9, 2022), https://www.theguardian.com/environment/2022/dec/09/avian-flu-has-led-to-the-killing-of-140m-farmed-birds-since-last-october [https://perma.cc/3XFL-FJJ8].

134. Stephanie E. Niehaus & Huu Nguyen, *Artificial Intelligence and Tort Liability: The Evolving Landscape*, PRACTICAL L. (Mar. 2019) ("Where fault cannot be traced directly back to a human actor (because for example, the AI has learned and can make decisions on its own), the law must determine whether to consider the AI product to be the actor and, if so, the applicable standard of car governing AI (for example, a reasonable human versus a new 'reasonable machine' standard.)"); Hannah R. Sullivan & Scott J. Schweikart, *Are Current Tort Liability Doctrines Adequate for Addressing Injury Caused by AI?*, 21 AMA J. ETHICS 160, 162–63 (2019); Guillaume Couneson et al., *EU – Taking Responsibility for Artificial Intelligence: New Tort Liability Proposals*, LINKLATERS (Oct. 3, 2022), https://www.linklaters.com/en-us/insights/blogs/digilinks/2022/october/eu---taking-responsibility-for-artificial-intelligence_new-tort-liability-proposals [https://perma.cc/MBR3-EGX5]; Christiane Wenderhorst, *Strict Liability for AI and other Emerging Technologies*, 11 J. EUR. TORT L. 150, 151 (2020).

135. John Villasenor, *Products Liability Law as a Way to Address AI Harms*, BROOKINGS (Oct. 31, 2019), https://www.brookings.edu/articles/products-liability-law-as-a-way-to-address-ai-harms/ [https://perma.cc/V9UL-ZSHU].

136. *See* Hilyard Nichols, *The First Byte Rule: A Proposal for Liability of Artificial Intelligences*, 15 WM. & MARY BUS. L. REV. 189 (2023).

137. Mike McLachlan, *What is the One-Bite Rule for Dogs?*, MCLACHLAN L. APC (June 11, 2021), https://mclachlan-law.com/blog/one-bite-rule-for-dogs/ [https://perma.cc/8USV-7ASA].

3. Eradication and Related Bounty Programs

The crux of this Article is to encourage lawmakers to consider, in advance of threats materializing, the risks associated with hazardous Abandoned AI and how to deal with them. Kill switches, if any, and voluntary culling of certain objects or species, if possible, may not be adequate, especially where a system has "evolved" to avoid these remedial measures. Humans or other actors may be called upon to locate, capture, or "kill" instances of Abandoned AI to the extent that they pose a threat or even a nuisance in our environment. One way of managing this process would be to hire government workers to do this task, or assign the task to existing government workers, such as police officers. Another method, which has been somewhat effective in the context of the eradication of the Burmese python in Florida, would be the establishment of bounty programs for the capture or destruction of high-risk Abandoned AI. Fees would be paid as a bounty to trained hunters for the capture of abandoned AI once an "animal" is captured and returned to the agency or confirmed to have been "killed." Any eradication program, including a bounty program, would need to anticipate how a specific instance of an object (i.e., one piece of Abandoned AI) or an entire "species" of an object is declared fair game. Perhaps this is best left to an administrative agency, possibly subject to judicial or administrative law judge review. The process is more difficult than in the case of wild animals where there is a finite number of species, or where species can be grouped together (e.g., apes) and classified. Given the range of potential Autonomous AI Robots, waiting for a legislature to act will likely be impractical.

Abandoned AI may be easy or difficult to locate, capture, and eradicate. If individual pieces of AI that pose specific risks related to abandonment (like Burmese pythons that hide and multiply) were tagged and licensed with a fee that corresponds to the difficulty in eventually locating, capturing and eradicating them, then we may have the beginnings of a capture and eradication framework, similar in concept to the State of Florida's invasive python eradication program. Foresight will result in better results than waiting for the problem to evolve. In the case of the Burmese python, unfortunately, the captive snakes were not required to be tagged and sterilized, and there was no fund established for the eradication of Burmese pythons from the wild if they were to escape. In the case of risky AI, if the licensing fee were sufficiently large, the funds could effectively be placed in escrow for the benefit of the person who ultimately captures the piece of AI and delivers it to a governmental agency for purposes of destruction. It is possible that the tag numbers of pieces of Abandoned AI could be published so that empowered hunters (or members of the public if no licensing of AI hunters is required) would know what is fair game.

The regime would need to define abandonment and specify how to prove abandonment. The authors would define abandonment as any situation where a piece of functioning AI (i.e., AI that continues to be able to make decisions that impact the natural world) is disclaimed by its last human, corporate, or governmental registered owner or the piece of functioning AI is no longer shown to be within the dominion or control of its last registered owner. Functionality may be presumed in the absence of proof of a lack of functionality. Abandonment may be established by the determination of a judge or a regulatory agency's administrative process. Alternatively, abandonment may more quickly be established through a demand by the regulatory agency of the licensee to demonstrate control over the piece of AI. This test might be an annual, monthly, daily or real-time requirement, depending upon the risks associated with the item of AI, and the last registered owner would need to demonstrate control within a specific time frame.

One could imagine that this registration system might be tracked on a publicly available blockchain and rewards may be paid using cryptocurrencies (or fiat currencies as a substitute). The owner of a piece of AI may be required to certify, or even prove, its control over an Autonomous AI Robot. Such control may be reported on a periodic basis on the blockchain. Perhaps control is demonstrated where an agency requires the owner to provide an instruction to the Autonomous AI Robot and if the Autonomous AI Robot does not carry out the instruction within a specific time period, then control has not been demonstrated. In this regard, a lack of responsibility or control over an object might be knowable to all in real time. The proper disposal of one's licensed AI might also be recorded on the blockchain so that the accumulated license fees would be returned in whole or in part to the last owner. The goal of this description is not to map out a feasible plan for tracking all of this on the blockchain, but to show that regulators can place disincentives upon losing control of one's owned Autonomous AI Robots and use technology to handle the financial aspects of our proposals.

The foregoing assumes that problematic pieces of Abandoned AI will be captured and possibly "killed." Burmese pythons that are captured need to be killed in a humane manner. As noted above, in Florida there is only one acceptable humane way to kill a python,[138] whereas there are at least two legal methods to administer the death penalty to a human in the State of Florida. Whether a killing is humane is dependent upon human opinion and would be based on, among other factors, the intelligence of the animal to be killed. For example, one may feel differently about what is humane in the context of a cockroach versus a chimpanzee. As AI systems become more and more intelligent, one can imagine that

138. *Humane Methods for Killing Pythons*, *supra* note 11.

ethicists, religious leaders, and others will grapple with whether they have consciousness and/or sentience. If so, then the topic of humane ways to "kill" a system may need to be established. Alternatively, society may require that Abandoned AI consciousness, sentience, or both, cannot be killed and needs to be maintained in captivity (to minimize risks to society) until its ultimate "natural death." The authors suggest that we don't go there. Pythons in the wild may die of natural causes, may be killed by bounty hunters, may be run over by a vehicle with no fault of anyone or may be illegally shot and killed. Is a death by shooting really better than death resulting from natural situations outside of human control, such as being eaten by an alligator or run over by a truck? Although no animal should be tortured, perhaps we are getting too precious when we prescribe only one method of killing an invasive Burmese python, a predator that one may argue does not possess high levels of intelligence. The authors believe that we should not anthropomorphize Autonomous AI Robots or regulate their termination other than to protect public safety (e.g., restrictions on burning or shooting while airborne overpopulated areas). This view recognizes that there is something special about humans and more intelligent animals; therefore, Autonomous AI Robots should not inherit this special status just because they can mimic (or in certain respects exceed) human intelligence. Religious scholars might consider this special status to be a "soul."

CONCLUSION

Many claim that they do not want to stifle innovation[139] by overregulating the field of AI and we are not yet at a point where Abandoned AI is presenting noticeable risks to society.[140] However, we must weigh the advancement of science and technology that can make

139. *See, e.g.*, Oliver Roberts & Holtzman Vogel, *EU Act's Burdensome Regulations Could Impair AI Innovation*, BLOOMBERG L. (Feb. 21, 2025), https://news.bloomberglaw.com/us-law-week/eu-ai-acts-burdensome-regulations-could-impair-ai-innovation [https://perma.cc/F48Q-X2G5]; Gonenc Gurkaynak et al., *Stifling Artificial Intelligence: Human Perils*, 32 COMPUT. L. & SEC. REV. 749, 749–50 (2016).

140. It is suggested that we keep an eye on the battlefields of Ukraine. *See* Edward Verona, *The West Must Learn Defense Tech Lessons on the Ukrainian Battlefield*, ATL. COUNCIL (Oct. 8, 2024), https://www.atlanticcouncil.org/blogs/ukrainealert/the-west-must-learn-defense-tech-lessons-on-the-ukrainian-battlefield/ [https://perma.cc/535U-8W4J]. There are scores of drones being used, and it is said that AI is empowering certain of these drones. *See* Alistair MacDonald, *AI-Powered Drone Swarms Have Now Entered the Battlefield*, WALL ST. J. (Sep. 2, 2025), https://www.wsj.com/world/ai-powered-drone-swarms-have-now-entered-the-battlefield-2cab0f05 [https://perma.cc/7FM4-GXW5]. Have there been mishaps? Would anyone tell the world of these mishaps and unintended consequences? Can certain pieces of equipment be seen as abandoned? For example, they may be forgotten about, or their functionality may not be known once dispatched.

our lives better (or worse) against the fact that "rapid advancements in artificial intelligence have prompted alarm not just from the general public and regulators, but from the very leaders in the tech companies engaged in its development."[141] On balance, the authors believe that it is neither too early nor too late to start worrying about Abandoned AI. The regulatory process moves slowly, and typically, there is room for policy debate among various stakeholders in society before regulations can be enacted. Legislating and regulating can take years and as we see from the progress made by OpenAI and other AI researchers, as well on the hardware side from companies such as NVidia and certain competitors (both within and outside of the Western world), the technology side will likely outpace the defensive side. Therefore, the time to address the issue of Abandoned AI and its capture, eradication, and remediation is now.[142]

One may argue that containment is impossible and bound to fail. Efforts at containment of other technologies, such as nuclear weapons or human gene editing, have had mixed success.[143] We can't even eradicate the Burmese python. As Mustafa Suleyman and Michael Bhaskar state in *The Coming Wave: Technology, Power, and the Twenty-first Century's Greatest Dilemma*, "The coming wave will be more difficult to contain than any in history, more fundamental, more far-reaching."[144] Even though the task may be daunting, the authors believe that we must try, rather than accept defeat, before the game begins.

The Burmese python problem is an ideal analogy to deploy in starting to think about the regulation of Abandoned AI. Borrowing frameworks from other areas of law when writing atop a blank slate is a time-honored tradition in American law. To the extent that the scholars and practitioners of today are now the pioneers of this burgeoning field, we hope that the factors we list above can be informative and thought-provoking. No matter how new a paradigm or technological breakthrough appears, with some creative thinking, we may be able to find existing regulatory paradigms and societal challenges that can inform how to regulate the new technology. At the very least, they can serve as a warning for what may come. AI is truly a game changer; however, there have been lots of game changes in the past, such as the Internet, social media, the car, space travel, the telephone, blockchain, gene editing, in vitro fertilization, nuclear energy, and even refrigeration. Each created new risks and obstacles to overcome and transformed society in many ways, including downstream impacts that were made possible by the

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141. Casey Fiesler, *Innovating Like an Optimist, Preparing Like a Pessimist: Ethical Speculation and the Legal Imagination*, 19 COLO. TECH. L.J. 1, 4 (2021).

142. Mark Fenwick et al., *Regulation Tomorrow: What Happens When Technology is Faster Than the Law?*, 6 AM. U. BUS. L. REV. 561, 572 (2017).

143. SULEYMAN & BHASKAR, *supra* note 16, at 45

144. *Id.* at 68.

primary technology. AI has tremendous potential and it is the challenge of society, lawyers, policymakers, and academics to continue to figure out how to mitigate risks, while not throwing away the baby with the bathwater. Hopefully, as not-for-profit organizations, professors, the media, governments, industry players, and others with an interest in the area of AI continue to organize and collaborate, a regulatory regime will materialize. For now, as these regimes exist primarily in concept, we hope to leave readers with the awareness that Abandoned AI will be a problem that needs to be considered in any fulsome AI regulatory regime, and that funding for eradication programs needs to be put in place at the time of the creation of the soon-to-be-Abandoned AI, rather than after it becomes a nuisance in and a catastrophic risk to our environment.

SHARING THE GOLD WITH THE MOUNTAIN: A PROPOSED QUASI-PROPERTY DOCTRINE FOR HEALTH DATA COMPENSATION

Taylor Col[*]

Abstract

This Note provides a legal answer to the moral question of whether a person should be compensated for lucrative health data that was collected from them. The moral question is examined through the lens of various doctrines in property, privacy, intellectual property, and ethics, in light of landmark cases concerning biomaterials and genetic information. A new doctrine for health data compensation is proposed, based on quasi-property and borrowing elements from equity, intellectual property, and profit-sharing. The proposed doctrine is evaluated by applying it to a hypothetical commercialization of one person's health data via a precision medicine product.

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INTRODUCTION

If prospectors found gold on the side of a mountain, the prospectors probably could not fathom sharing any of their earnings with the mountain from which the gold originated. The inanimate mountain had no idea it contained gold and had no use for the gold anyway. Furthermore, the prospectors were the ones who extracted the gold, used it to create something marketable, and found the right buyers. But if the inanimate mountain were instead a living, breathing person, it would likely give those same prospectors pause to look that person in the eye and say: "We are taking this. It is a part of who you are, but it will make us rich, and you will receive nothing."

The issue of health data compensation initially appears to be one of morality. Taking a person's health data, creating a product, and profiting from it while sharing nothing with the person, plainly put, feels wrong. But does any legal doctrine support this gut feeling?

If, instead of health data, we were to consider compensation for human biomaterials, the answer would be . . . possibly? In the 1990 case *Moore v. Regents of the University of California*,[1] the court ruled that Moore was not entitled to compensation after his cells were taken and used to develop a cell line with an estimated market value of $3 billion (in 1990!).[2] Out of thirteen causes of action stated by Moore,[3] the court allowed only the claims for breach of fiduciary duty and lack of informed consent to proceed, and rejected the conversion claim, holding that Moore did not retain a property interest in his excised cells.[4] In a 2003 case with similar

1. Moore v. Regents of the Univ. of Cal., 793 P.2d 479, 493 (Cal. 1990).

2. *Id.* at 482, 493.

3. *Id.* at 482 n.4 (listing the causes of action as:"(1) 'Conversion'; (2) 'lack of informed consent'; (3) 'breach of fiduciary duty'; (4) 'fraud and deceit'; (5) 'unjust enrichment'; (6) 'quasi-contract'; (7) 'bad faith breach of the implied covenant of good faith and fair dealing'; (8) 'intentional infliction of emotional distress'; (9) 'negligent misrepresentation'; (10) 'intentional interference with prospective advantageous economic relationships'; (11) 'slander of title'; (12) 'accounting'; and (13) 'declaratory relief.").

4. *Id.* at 480, 497.

facts, *Greenberg v. Miami Children's Hospital Research Institute*,[5] the court rejected five of the plaintiffs' causes of action,[6] but allowed the plaintiffs' claim of unjust enrichment, a claim that was rejected in *Moore*.[7] The conflicting rulings were due to exceptional circumstances in *Greenberg*;[8] the reasoning against compensation for human biomaterials in *Moore* remains the standard.[9]

Alas, health data is not human biomaterials, although a similar argument to the *Moore* standard can be made against health data compensation. There are widespread benefits to maintaining broad access to health data. Health data has many stakeholders, each with varying and intersecting rights.[10]Clinical care, public health, and research would be hindered by the restriction of health data access.[11] Additionally, compensation for access to health data faces a conundrum: one person's health data has little value on its own.[12]

Also, compared to human biomaterials, it is not as apparent how one person's health data can be directly monetized (in a similar way to how a person's biomaterials with unique properties can serve as the building block for lucrative cell lines[13]). This is where precision medicine comes in.

Precision medicine, also referred to as personalized medicine, encompasses a variety of methods to deliver customized treatments for individual patients based on analysis of personal data and biomarkers.[14] By collecting a high volume of data, including genetic biomarkers

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5. Greenberg v. Miami Children's Hosp. Rsch. Inst., 264 F. Supp. 2d 1064, 1068 (S.D. Fla. 2003).

6. Mary R. Anderlik & Mark A. Rothstein, *Canavan Decision Favors Researchers Over Families*, 31 J. OF L., MED. & ETHICS 450, 451–52 (2003) (listing the rejected causes of action as: breach of informed consent, breach of fiduciary duty, fraudulent concealment, conversion, and misappropriation of trade secrets).

7. *Moore*, 793 P.2d at 482.

8. *See* Anderlik & Rothstein, *supra* note 6, at 452 (stating that the *Greenberg* court ruled in favor of the plaintiffs on the unjust enrichment claim because the plaintiffs went "beyond the ordinary role of subject or donor" by investing "time and significant resources").

9. *See* David C. Szostak, *Something More to the Story: Moore v. Regents of the University of California Two Decades Later*, 31 THE JOURNAL OF LEGAL MEDICINE 443, 444 (2010) (referencing the *Moore* decision as the "crescendo" of "the state of the law as far as property rights in biological materials" is concerned).

10. Hannah K. Galvin & Paul R. DeMuro, *Developments in Privacy and Data Ownership in Mobile Health Technologies, 2016-2019*, 29 YEARBOOK OF MEDICAL INFORMATICS 32 (2020) (listing such stakeholders as "including patients, providers, healthcare systems, government bodies, technical service vendors, and network infrastructure suppliers").

11. *See generally* Barbara J. Evans, *Much Ado About Data Ownership*, 25 HARV. J. L. & TECH. 69 (2011) (discussing access to health data for public health and research).

12. *Id.*

13. *Id.*

14. *See* Christopher J. Phillips, *Precision Medicine and Its Imprecise History*, HARV. DATA SCI. REV., Jan. 31, 2020, at 2.

obtained through biobanks, and then aggregating that large, diverse data set alongside therapeutic outcomes, precision medicine allows researchers to identify patterns that can be applied in areas such as pharmacogenetics and disease diagnosis.[15] Pharmacogenetics applications include genomic tests to identify patients who will respond to drugs that treat certain cancers, childhood diabetes, and cystic fibrosis.[16] Disease diagnosis and treatment applications include identification of genes, biomarkers, and other factors that are associated with an increased risk of acquiring a disease.[17]

The genomic tests in pharmacogenetics applications illustrate the volume and complexity of the data required for precision medicine. Unlike genetics, a term that refers to the study of specific genes, genomics has an increased scope, which includes an entire genome and the interactions of all genes with each other and the environment.[18] In addition to genomics, data from other "omics"—research based on measurements of huge numbers of related biological molecules[19]—such as proteomics (protein data), metabolomics (metabolic data), and radiomics (radiology data) are used in precision medicine.[20] While omics are the health data that this Note seeks to examine, much of the focus will be on genetics, a source of data that has availed multitudes of research and case law over the years.

Various mechanisms have been proposed to protect interests in genetic information for the people who are the source of the genetic information,[21] including tort and privacy protections.[22] Legal scholars

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15. *Id.* at 4.

16. Richard W. Peck, *Precision Medicine is Not Just Genomics: The Right Dose for Every Patient*, 58 ANNUAL REV. OF PHARMACOLOGY & TOXICOLOGY 105, 106 (2018) (stating that for most drugs, patients do not respond well or benefit, and one mission of precision medicine is to overcome this obstacle, while emphasizing the importance of optimal individual dosage for each patient in addition to simply identifying the drug that the patient will respond to).

17. *See* Phillips, *supra* note 14, at 4–5.

18. Nat'l Hum. Genome Research Inst., *Genetics vs. Genomics Fact Sheet*, NAT'L INST. OF HEALTH (2018), https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics [https://perma.cc/Q22M-H336] (last visited Sept. 12, 2025).

19. COMM. ON THE REV. OF OMICS-BASED TESTS FOR PREDICTING PATIENT OUTCOMES IN CLINICAL TRIALS; BD. ON HEALTH CARE SERVS.; BD. ON HEALTH SCIS. POL'Y; INST. OF MED., *Omics-Based Clinical Discovery: Science, Technology, and Applications*, *in Evolution of Translational Omics: Lessons Learned and the Path Forward* (Christine M. Micheel et al. eds., 2012).

20. Sarah J. MacEachern & Nils D. Forkert, *Machine Learning for Precision Medicine*, 64 GENOME 416, 417 (2021).

21. *See* Ellen Wright Clayton et al., *The Law of Genetic Privacy: Applications, Implications, and Limitations*, 6 J.L. & BIOSCI. 1,5 (2019).

22. Morten Ebbe Juul Nielsen et al., *Property and Human Genetic Information*, 10 J. CMTY. GENET. 95, 95 (2019).

have proposed property law doctrines such as progressive property,[23] intangible property,[24] and quasi-property[25] as justifications for creating interests in genetic information.

Of these doctrines, quasi-property shows the most promise to support health data compensation, due to the similarities between health data and the "things" that quasi-property was conceived to protect interests in. The concept of quasi-property originated in *International News Service v. Associated Press*,[26] where a newspaper that published first had its publication protected against other news providers reusing and selling the reporting as their own, instead of expending labor to gather and summarize the information like the first news provider did.[27] In *International News*, the "thing" the quasi-property rights protected was news reporting,[28] which, like health data, is intangible information. An expansion of the application of quasi-property arose in *Newman v. Sathyavaglswaran*,[29] wherein rights were recognized for relatives of a deceased person with respect to the corpse.[30] In *Newman*, the "thing" the quasi-property rights protected was human biomaterials, which, like health data, have the potential to improve public health (the biomaterials were used to treat cataracts, but were taken without consent or knowledge of the relatives).[31] But just because quasi-property originated to protect interests in "things" similar to health data does not necessarily mean that a quasi-property doctrine can be used as a legal basis for health data compensation.

This Note is divided into two parts. Part I will evaluate the problem of health data compensation through the lens of various legal doctrines in an exercise that will arrive at a proposed quasi-property doctrine. Part II will apply the proposed quasi-property doctrine to a hypothetical commercialization of one person's health data via a precision medicine product.

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23. Jessica L. Roberts, *Progressive Genetic Ownership*, 93 NOTRE DAME L. REV. 1105, 1156 (2018).

24. Adam D. Moore, *Owning Genetic Information and Gene Enhancement Techniques: Why Privacy and Property Rights May Undermine Social Control of the Human Genome*, 14 BIOETHICS 97, 97 (2000).

25. Jeffery Lawrence Weeden, *Genetic Liberty, Genetic Property: Protecting Genetic Information*, 4 AVE MARIA L. REV. 611, 641 (2006).

26. Int'l News Serv. v. AP, 248 U.S. 215, 229 (1918).

27. Shyamkrishna Balganesh, *Quasi-Property: Like, but Not Quite Property*, 160 U. PA. L. REV. 1889 (2011).

28. *See Int'l News Serv.*, 248 U.S. at 229–31.

29. Newman v. Sathyavaglswaran, 287 F.3d 786, 788 (9th Cir. 2002).

30. *See* Balganesh, *supra* note 27, at 1891.

31. *See Newman*, 287 F.3d at 788.

I. SHOULD THERE BE HEALTH DATA COMPENSATION?

Most of the doctrines discussed in this section fall under the umbrella of either property or privacy. Given the value of health data to society, it would be asking too much to argue for full property or privacy rights in a person's health data, but these doctrines will be valuable in the quest to support mere compensation. In addition, doctrines in intellectual property and ethics will be considered.

For many of the doctrines, the illustrations most relevant to health data compensation involve the doctrine's application towards compensation for human biomaterials or genetic information.

The following table summarizes the analysis in this section.

Table 1: Compilation of Analyzed Doctrines

Doctrine	**How does it relate to health data compensation?**	**Why?**
The Right to Property		
Property, in general	oppose	Utilitarian basis: compensation would impede potential beneficial uses of health data
Ownership interests	facilitate	Broad range of rights that would include compensation, if elements are met
The right to exclude	alternative	Instead of compensation, limiting or restricting access to or uses of health data
Quasi-property	facilitate	if elements are met, would provide mechanism for compensation
Conversion	facilitate	if elements are met, would provide mechanism for compensation
Abandonment	oppose	No right to compensation because ownership of health data has changed
Adverse possession	oppose	No right to compensation because ownership of health data has changed

The Right to Privacy		
Privacy, in general	support	Constitutional basis: not getting compensation diminishes one's personality
Informed consent	facilitate	if elements are met, would provide mechanism for compensation
Intellectual Property		
Infringement and Remedies	facilitate	if elements are met, would provide mechanism for compensation
Subject Matter	oppose	Health data is considered natural phenomena and therefore not protected
Fair Use	oppose	Health data is used to benefit society and therefore not protected
Ethics and the Law		
Custodianship	support	Custodians of the data may have an ethical obligation to provide compensation
Profit Sharing	facilitate	Contractual agreement for health data compensation
Equity	support	Legal doctrine for correcting situation that feels wrong but does not fit other legal doctrines
Unjust Enrichment	facilitate	if elements are met, would provide mechanism for compensation

A. *The Right to Property*

1. Property, in General

A property right in health data would appear to be the quickest, cleanest path to health data compensation; however, the utilitarian basis of property law does not support health data compensation. Although it may seem counterintuitive, utilitarian arguments exist against people having property rights in "their" genetic information ("theirs" as in the genetic information originated in their bodies). One argument hinges on the nature of genetic information: while everyone's genome is unique,

most of the genetic information that makes up one person's genome can be found in other people, with the most shared genetic information found in that person's relatives.[32] This means that there could exist common interests in the shared elements of a person's genome, and exercising ownership interests to exclude others from accessing a person's genetic information could have negative health impacts for people that share elements of that person's genome.[33] Therefore, property rights in genetic information to support compensation for one person are outweighed by the utilitarian goal of allowing access to genetic information to benefit others who share portions of that genetic information.[34]

2. Ownership Interests

Ownership interests in health data are legally enforceable rights, privileges, powers, and immunities,[35] and therefore impact who has access to health data, in what ways health data can be used, and who can benefit from these uses of health data. When more than one party has an interest in health data, the issue of compensation can depend on which interests allow a party to have ownership because ownership includes a right to compensation.

Many states have enacted or proposed statutes that grant ownership interests to individuals with respect to their genomes.[36] Some of these statutes have been cited in cases[37] to support tort causes of action by tortfeasors against owners of genetic material as recognized by state statute.[38]

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32. *See* Clayton, *supra* note 21, at 2.

33. *Id.*

34. Richard A. Spinello, *Property Rights in Genetic Information*, 6 ETHICS & INFO. TECH. 29, 38 (2004).

35. *See* RESTATEMENT OF PROP. §§ 1–4, 5, 10 (1936). The First Restatement of Property uses the term "interests" to describe one or an aggregation of rights, privileges, powers, and immunities a person may have with respect to a thing. Having the totality of all possible legal interests in one thing would mean a person has complete property in that thing. A person with complete property in a thing has "ownership." The owner can part with some of the interests and still be considered the owner of the thing. For example, the owner of a car can mortgage it or have a lien put on it and still be considered the owner. There is no precise rule for how many or which interests a person can part with while retaining ownership.

36. Nat'l Hum. Genome Research Inst., *Genome Statute and Legislation Database*, NAT'L INST. OF HEALTH, https://www.genome.gov/about-genomics/policy-issues/Genome-Statute-Legislation-Database [https://perma.cc/8ZFD-C8ZK] (last visited Sept. 12, 2025).

37. Peerenboom v. Perlmutter, No. 2013-CA-015257, 2017 Fla. Cir. LEXIS 14957, at *15 (Fla. 15th Cir. Ct. Jan. 23, 2017) ("Florida law itself already recognizes a property right in one's DNA in limited circumstances.") (citing FLA. STAT. § 760.40(2)(a) (stating that the results of a DNA test, "whether held by a public or private entity, are exclusive property of the person tested")); Cole v. Gene by Gene, Ltd., No. 1:14-CV-00004-SLG, 2019 WL 2571244, at *3 (D. Alaska June 21, 2019) (citing ALASKA STAT. § 18.13.020)).

38. *See* Clayton, *supra* note 21, at 26.

3. The Right to Exclude

An important property interest with respect to human biomaterials is the right to exclude. In this context, the right to exclude encompasses control of access and use of human biomaterials by others. A right to exclude would be exercised independently from a right to compensation, which requires access and use of human biomaterials by others to make a commercial product (whether granted by a person with the right to exclude or open to others due to a person's lack of a right to exclude). Indeed, many human biomaterials cases do not concern compensation at all, and the plaintiffs are only interested in excluding others from using human biomaterials for research or other purposes.[39]

4. Quasi-Property

Quasi-property protections arise in circumstances where there could be an equitable basis for health data compensation. While property rights are typically held *in rem* (against the world) or *in personam* (against a specified party), quasi-property rights are held against a specified class of actors and only upon the occurrence of a specific triggering event.[40] These requirements could support health data compensation because compensation would only be equitable if it were against a specific class (entities that create usable health data from a person's "raw information") and only triggered by a certain event (the health data is used to generate substantial earnings).

Quasi-property already protects "things" which have qualities similar to those of health data.[41] Quasi-property rights have been proposed to protect the personal data of deceased persons,[42] akin to the protections

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39. *See* Joanna Pawlikowska et al., *Biobanking of Human Biological Material and the Principle of Noncommercialisation of the Human Body and its Parts*, 37 BIOETHICS 154, 157 (2023) (citing Complaint, Beleno v. Tex. Dep't of State Health Servs., No. SA-09-CA-188-FB, (W.D. Tex. 2009); Adams v. King Cnty., 192 P.3d 891 (Wash. 2008); Wash. Univ. v. Catalona, 490 F.3d 667 (8th Cir. 2007); Complaint, Havasupai Tribe v. Ariz. State Univ., Case No. CV2005-013190 (Ariz. 2004).

40. *See* Balganesh, *supra* note 27, at 1892; *see also Int'l News Serv.*, 248 U.S. 215. The newspaper had a quasi-property right of exclusion that applied only to other newspapers and was triggered solely when another newspaper republished the first newspaper's reporting as its own work. *Id.* at 236–42. Under this quasi-property protection, the original newspaper's reporting could still be shared by anyone outside the class of newspapers, for example, any individual could tell a friend about what they had read. *Id.* at 239. Additionally, other newspapers within the protected class could still access and use the first newspaper's reporting, provided they did not publish it as their own original work. *Id.* at 243–44.

41. *See supra* notes 26–31 and accompanying text.

42. Gianclaudio Malgieri, *R.I.P.: Rest in Privacy or Rest in (Quasi-) Property? Personal Data Protection of Deceased Data Subjects Between Theoretical Scenarios and National Solutions*, *in* 11 DATA PROTECTION AND PRIVACY: THE INTERNET OF BODIES 300–20 (Ronald Leenes, Rosamunde van Brakel, Serge Gutwirth & Paul De Hert eds., Hart Publ'g 2018).

already available for their corpses. Furthermore, quasi-property rights to exclude and to compensation have been proposed for biomaterials.[43] It appears the next logical step would be to propose quasi-property protections for health data.

5. Conversion

Conversion is civil theft, a hybrid of property and tort law.[44] In *Moore*, the court did not allow the plaintiff to assert the cause of action of conversion.[45] Because conversion requires a bad actor, it would not apply to all cases in which a person's health data generated earnings for another party. But if the elements of conversion are met, a remedy for conversion of health data would be compensation.

6. Abandonment

Health data compensation would not be supported if the health data was considered abandoned by the person from whom the data was collected. For example, the property doctrine of abandonment[46] can be used to support an argument against a person owning their genetic information. People consent to providing their genetic information to a number of entities, including healthcare providers, but also for other services like identification or genealogy.[47] Additionally, people discard biological materials, such as nail clippings and hair, in their garbage, and garbage has been ruled to be abandoned property.[48] Once ownership of a "thing," such as health data, has been abandoned, the next entity to possess that thing would be the new owner.

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43. JoAnne Belisle, *Recognizing a Quasi-Property Right in Biomaterials*, 3 U.C. IRVINE L. REV. 767, 786 (2013).

44. Sarah Green, *To Have and to Hold? Conversion and Intangible Property*, 71 MOD. L. REV. 114, 119 (2008), https://www.jstor.org/stable/25151180 (last visited Nov. 5, 2025).

45. *See Moore*, 793 P.2d 479 at 482–98. The plaintiff asserted that his removed cells were his property, and conversion was committed because he did not authorize the use of his cells for a commercial application. The plaintiff sought compensation not as a share of the earnings from the commercialization of his cells but instead as a remedy for a tort committed against him. The court ruled against imposing tort liability for conversion in cases of human biomaterials used in medical research for three reasons: (1) a policy argument based on the social utility of medical research; (2) deference to the legislature to resolve the issue; and (3) a proposed alternative resolution through enforcement of physicians obligations to disclose research and economic interests to their patients.

46. RESTATEMENT OF PROP. § 558 (1944). Abandonment is intentional relinquishment of a property interest that is indicated by a person's conduct (the intent is not directly communicated with words, although a person's words are considered when evaluating the circumstances around possible abandonment).

47. *See* Clayton, *supra* note 21, at 16, 28.

48. *Id.* at 33–34.

7. Adverse Possession

Health data compensation would also not be supported if the party collecting the data took ownership of the data through adverse possession.[49] Allowing adverse possession of health data would incentivize the effort and ingenuity to commercialize health data by providing a windfall for the adverse possessor of the data.[50] The windfall would be in the form of ownership of the health data, awarded because the possessor improved the health "raw information" to create something useful.

B. *The Right to Privacy*

1. Privacy, in General

Health data is protected by the privacy doctrines of the HIPAA Privacy Rule[51] and the Common Rule.[52] Genetic information, protected as health data under the HIPAA Privacy Rule and Common Rule, is afforded additional privacy protections due to its non-healthcare applications.[53] These existing privacy protections for health data do not include compensation, but they could be expanded. However, like the utilitarian case against ownership of health data, there are arguments to limit the right to privacy in health data because of the societal benefit that access to health data provides.[54]

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49. *See generally* Jeffrey Evans Stake, *The Uneasy Case for Adverse Possession*, 89 GEO. L.J. 2419 (2000). Adverse possession is the right to own property if one has actual possession of it for a period of time and the actions of the possessor are continuous, hostile, notorious, open, and exclusive to the actual owner. The requirements of knowledge and inaction of the owner are similar to abandonment, but adverse possession essentially requires less effort by the owner and more effort by the new possessor to change ownership. Adverse possession has a utilitarian basis, encouraging the development of land if the owner is not using it by rewarding the possessor who improves the land with ownership of that land.

50. *See* Neil Maddox, *'Abandonment' and the Acquisition of Property Rights in Separated Human Biomaterials*, 16 MED. L. INT'L 229, 246 (2016).

51. April Moreno Arellano et al., *Privacy Policy and Technology in Biomedical Data Science*, 1 ANN. REV. OF BIOMEDICAL DATA SCI. 115, 116 (2018); Takako Takai-Igarashi et al., *Security Controls in an Integrated Biobank to Protect Privacy in Data Sharing: Rationale and Study Design*, 17 BMC MED. INFORMATICS & DECISION MAKING 1, 2 (2017).

52. *See* Lawrence O. Gostin & James G. Hodge, Jr., *Personal Privacy and Common Goods: A Framework for Balancing Under the National Health Information Privacy Rule*, 86 MINN. L. REV. 1439, 1472 (2002).

53. *See* Clayton, *supra* note 21, at 3, 16 (listing non-healthcare applications of genetic information); Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 462–63 (2010) (discussing protections against discrimination based on genetic information).

54. Peter D. Jacobson, *Medical Records and HIPAA: Is it Too Late to Protect Privacy*, 86 MINN. L. REV. 1497, 1501–03 (2001) (examining rationales for disclosure of protected health information).

The right to privacy is a broad term with origins in constitutional law.[55] Privacy has been applied to areas outside health, such as the press[56] and search and seizure,[57] and was recognized as a fundamental right by the Supreme Court in health areas, including contraception[58] and abortion.[59] An important distinction is that these health cases concerned an individual's right to make a decision on a healthcare procedure.[60] Privacy has a different meaning when applied to health data,[61] described in legal scholarship as a right to control[62] or limit access[63] to health data. In this way, the right to privacy parallels the property right to exclude.[64]

While privacy may protect a parallel interest to property, privacy differs from property in how the person and the body are conceptualized.[65] Under property law, a person's body is a separate object that the person can exclude others from, but under privacy law, the body is a part of the person, and the person's right to exclude others from their body is a protection of personal identity.[66] The most robust support for health data compensation may come from adopting both of these approaches simultaneously: the health data constitute an object separate from the person (so that it can be commercialized), but that object remains a representation of the person's identity (so that the person has a claim for compensation).

2. Informed Consent

Informed consent is another doctrine that would not apply to all cases where a person's health data was used by another party to generate

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55. Griswold v. Connecticut, 381 U.S. 479, 485–86 (1965) (recognizing a constitutional "right to privacy" derived from the penumbra of the Bill of Rights).

56. *See, e.g.*, Branzburg v. Hayes, 408 U.S. 665, 693–98 (1972) (discussing "reporter's privilege" in the context of individual privacy rights).

57. *See, e.g.*, Katz v. United States, 389 U.S. 347, 350–51 (1967) (describing privacy protections afforded by the Fourth Amendment).

58. Eisenstadt v. Baird, 405 U.S. 438, 452–53 (1972) ("To say that contraceptives . . . are to be forbidden . . . conflicts with fundamental human rights.); *Griswold*, 381 U.S. 479, 485–86 (1965).

59. Roe v. Wade, 410 U.S. 113, 153 (1973) ("The right of privacy . . . is broad enough to encompass [abortion]."); *but see* Dobbs v. Jackson Women's Health Org., 597 U.S. 215, 292 (2022) ("We therefore hold that the Constitution does not confer a right to abortion.").

60. *See* Radhika Rao, *Property, Privacy, and the Human Body*, 80 B.U. L. REV. 359, 388 n.107 (2000) (exploring privacy law protections for decisions on contraception and abortion, as well as for other healthcare procedures, including refusal of medical treatment and assisted suicide).

61. *See* Jacobson, *supra* note 54, at 1499.

62. *Id.*

63. *See id.*

64. *See* Rao, *supra* note 60, at 364.

65. *Id.*

66. *Id.*

earnings, but if the elements of informed consent are met,[67] the doctrine would provide a remedy for compensation. Federal regulations require informed consent for human subjects in research.[68] Arguments against informed consent characterize it as an obstacle to socially valuable research.[69] Informed consent was not obtained in *Moore* or *Greenberg*, yet the issue was not decided in either court, possibly due to this policy rationale.[70]

For health data, the privacy protection of informed consent has been eroded because the scope of data usage by "Big Data"[71] can make it difficult for subjects at the time consent is obtained to comprehend what their data will be used for in the future.

C. *Intellectual Property*

Intellectual property is given a separate subsection from property because intellectual property has specialized conventions for protecting rights in intangible things such as ideas, inventions, and artistic expression. Health data is similarly intangible, and so the specialized conventions of intellectual property law could be suitable for health data compensation.

1. Infringement and Remedies

Infringement occurs when one party's intellectual property has been used by another, violating the right to exclude others from the use of one's intellectual property.[72] Determining whether the intellectual property has been "used" generally requires a test comparing the intellectual property to the alleged infringing use, and although these tests vary across

67. Elizabeth Bromley et al., *From "Informed" to "Engaged" Consent: Risks and Obligations in Consent for Participation in a Health Data Repository*, 48 J. OF L., MED. & ETHICS 172, 172 (2020) (stating that informed consent requires that the choice to provide consent is made voluntarily and with sufficient information to comprehend the choice).

68. 45 C.F.R. § 46.116(a)(1) (2025).

69. Angela Ballantyne & G Owen Schaefer, *Consent and the Ethical Duty to Participate in Health Data Research*, J. MED. ETHICS 392, 392 (2018).

70. In *Moore*, the patient voluntarily allowed doctors to take biomaterials because he was misled to believe that it was part of his treatment and not solely for the purpose of research and commercialization. In *Greenberg*, the biomaterials were voluntarily provided for research but without the knowledge that the research would lead to commercialization. *See Moore*, 793 P.2d 479 at 126; *Greenberg*, 264 F. Supp. 2d at 1067–68.

71. A. Michael Froomkin, *Big Data: Destroyer of Informed Consent*, 21 YALE J. L. & TECH. 27, 27 (2019).

72. *See* 35 U.S.C. § 271 (2025).

patents,[73] design patents,[74] copyrights,[75] and trademarks,[76] each test shares a common goal of determining how similar the protected intellectual property is to the alleged infringing use. Elements of these tests could be adapted to compare a person's "raw information" to the health data at issue in an analysis of health data compensation.

Available remedies for infringement are injunctive relief and compensation.[77] In many cases, both types of relief are provided: injunctive relief to stop the other party from using the intellectual property, and compensation for the earnings the other party obtained by using the intellectual property.

If health data is considered intellectual property, then the mechanisms of infringement and remedies would support health data compensation.

2. Subject Matter

Health data would not be subject matter worthy of intellectual property protections, based on the Supreme Court's decision against classifying genetic information as patentable subject matter in *Association of Molecular Pathology v. Myriad Genetics*.[78] The policy

73. Warner-Lambert Co. v. Teva Pharms. USA, Inc., 418 F.3d 1326, 1340 (Fed. Cir. 2005) (stating that, as a question of fact, "the court must compare the accused product or process to the properly construed claims" and that "[i]nfringement may be found only where the accused product or process contains each limitation of the claim, either literally or under the doctrine of equivalents.").

74. Carl J. Hall, *A Patently Offensive Test: Proposing Changes to the Test for Design Patent Infringement*, 53 VAL. U. L. REV. 297, 302 n.26 (2018) (citing L.A. Gear, Inc. v. Thom McAn Shoe Co., 988 F.2d 1117, 1124 (Fed. Cir. 1993) (stating that the plaintiff has the burden to prove "by a preponderance of the evidence that the design protected by the design patent and the accused design are substantially similar.")).

75. Mark A. Lemley, *Our Bizarre System for Proving Copyright Infringement*, 57 J. COPYRIGHT SOC'Y 719 (2010) (citing Sid & Marty Krofft Television Prods., Inc. v. McDonald's Corp., 562 F.2d 1157, 1164 (9th Cir. 1977) (stating that the plaintiff must prove "substantial similarity not only of the general ideas but of the expressions of those ideas as well" between the plaintiff's work and the alleged infringing work)).

76. Barton Beebe, *An Empirical Study of the Multifactor Tests for Trademark Infringement*, 94 CALIF. L. REV. 1581, 1582 (2006) (stating that "each circuit requires that the district court conduct a multifactor analysis of the likelihood of consumer confusion according to the factors set out by that circuit").

77. Eric R. Claeys, *The Conceptual Relation Between IP Rights and Infringement Remedies*, 22 GEO. MASON L. REV. 825, 826–29 (2015).

78. *See* Ass'n for Molecular Pathology v. Myriad Genetics, 569 U.S. 576 (2013). In *Myriad*, the biotech company Myriad Genetics attempted patent testing for two genes that indicated a heightened risk for breast cancer. The Supreme Court ruled that the subject matter was unpatentable because human genes were natural phenomena and therefore a patent would be invalid under 35 U.S.C. § 101. The *Myriad* decision would appear to prevent any external parties from asserting control over a person's genetic information and, therefore, support an argument for health data compensation. But the *Myriad* decision also prevents that person from having rights with respect to their own genetic information.

rationale of the *Myriad* decision was to ensure that nobody could be excluded from performing potentially lifesaving tests to determine breast cancer risk.[79] Following this line of reasoning, the *Myriad* decision could be interpreted to mean that nobody can have an intellectual property interest in genetic information because restricting access to this data would be detrimental to the public good.

However, patent law is an intellectual property doctrine that not only encourages but also requires public disclosure of information.[80] The patent holder is rewarded for sharing their information to the public with the grant of the right to exclude others from marketing an invention[81] for a period—usually twenty years—after which the right to exclude expires.[82] In this way, a patent's right to exclude serves as compensation for the data shared by the patent holder with the public, and therefore, patent law could help support health data compensation, although health data compensation would be monetary rather than a right to exclude.

An intellectual property protection that could include genetic information as subject matter is trade secret law, which the *Myriad* decision led some biotechnology companies (including Myriad Genetics) to turn to for products created using genetic information.[83] However, trade secret law protects against public disclosure,[84] which, if applied to health data, would harm the public good.

This seems like a good place to review the difference in magnitude between the data discussed in this section and the data used in precision medicine. The medical data in the *Myriad* case were genes, small portions of genetic information that occur in a range of individuals, whereas precision medicine data includes genomes, which are entire sets of genetic information unique to each individual. When discussing compensation for health data, the conclusions in this section regarding protections of genetic information do not directly apply to protections of health data for precision medicine, due to differences in quantity and uniqueness of the data.

Also of note: why did the *Myriad* court evaluate genetic information as intellectual property? Intellectual property protects products of human

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79. *See* Ajay Dara & Pratap Devarapalli, *The Impact of Gene Patent Decision and the Changing IP Strategies of Myriad Genetics*, EUR. INTELL. PROP. REV., Aug. 2023, at 9. (explaining that while other gene patents were granted by the Supreme Court, Myriad Genetics' anticompetitive practices along with the prevalence and mortality of breast cancer swayed the court to rule differently in *Myriad*).

80. Jeanne C. Fromer, *Machines as the New Oompa-Loompas: Trade Secrecy, the Cloud, Machine Learning, and Automation*, 94 N.Y.U. L. REV. 706, 713 (2019).

81. Sarah Leah Schwartz, *Owning the Code of Life: Human Gene Patents in America* (2015) (S.M. Thesis, Massachusetts Institute of Technology) (on file with DSpace@MIT).

82. 35 U.S.C. § 154(a)(2) (2025).

83. Dara & Devarapalli, *supra* note 79, at 16.

84. Fromer, *supra* note 800, at 713.

intellect that are commercially valuable.[85] The genes in *Myriad* were discovered and isolated by humans and thus were claimed to be the product of human intellect.[86] The arguments concerning the genes in the *Myriad* case illustrate how "raw information" requires the input of human ingenuity and effort to create useful health data. But, based on the *Myriad* court's reasoning, no intellectual property protection could be afforded because the "raw information" fell into the subject matter category of natural phenomena, and in this case, not enough ingenuity and effort was applied to make something substantially different from the natural phenomenon. Intellectual property protections, encumbered by a need to distinguish between what occurs naturally and what is created, would frequently encounter gray areas (as in *Myriad*) if used in support of health data compensation.

3. Fair Use

Fair use doctrine is a defense in copyright infringement similar to the public utility arguments supporting open access to health data.[87] Fair use doctrine has been used in defense of generative artificial intelligence algorithms trained using copyrighted data.[88] This relationship between algorithm and data is very close to that between precision medicine algorithms and health data. Therefore, the factors of fair use doctrine are worth considering when proposing a legal doctrine for health data compensation.

D. *Ethics and the Law*

1. Custodianship

Custodianship is an ethical model, not a legal doctrine. In the context of human biomaterials, custodianship places the burden on research entities to "recognize their ethical obligations and serve the best interests

85. *Intellectual Property*, BLACK'S LAW DICTIONARY (11th ed. 2019); *see* Weeden, *supra* note 25, at 643–44 (stating intellectual property protections could be suitable for genetic information because genetic information is intangible and has both fungible and non-fungible qualities).

86. *Myriad*, 569 U.S. at 580 (holding that naturally occurring DNA segments are products of nature and therefore not patentable, distinguishing them from complementary DNA (cDNA), which is patent eligible because it is synthetically created and not naturally occurring).

87. 17 U.S.C. § 107 (2025). Under fair use, how copyrighted material is used by a party can provide relief when that party has used copyrighted material without obtaining a license from the copyright holder. The factors for determining fair use are: (1) the purpose of the use; (2) the nature of the copyrighted work; (3) the proportion of the copyrighted work that was used; and (4) the effect of the use on the value of the copyrighted work.

88. Peter Henderson et al., *Foundation Models and Fair Use*, 24 J. OF MACH. LEARNING RSCH. 1, 5 (2023).

of biomedical research."[89] This means that, unlike legal doctrines, no legal action is required by the donor of the biomaterials to enforce their rights. The donor's interests are maintained by the researchers' adherence to the model of custodianship, one that "clarifies control of biospecimens and minimizes conflicts between concerned stakeholders."[90]

2. Profit Sharing

One proposal for biomaterials compensation places the burden on investigators who collect biospecimens to extend an offer to share in profits.[91] The proposed profit-sharing model would be based on the relative value of the contributions of the subjects and the investigators.[92] This model is supported by the American Medical Association Code of Ethics, which states that physicians should obtain permission to commercialize a patient's donated biomaterials and share any profits with the patient.[93]

3. Equity

Equity is both a legal doctrine and an ethical model. Equity can be a legal doctrine used to resolve conflicts when other areas of law are rigid and the facts do not conform.[94] Equity is also an ethical model that can lead to results contrary to those produced by the law.[95] Equity further provides the historical foundation for many legal doctrines and rules of civil procedure.[96]

In short, equity is pervasive and amorphous. For purposes of health data compensation, equity can be viewed as a formalized representation of the "gut feeling" described in the Introduction, providing the foundation for a proposed doctrine to support health data compensation.

4. Unjust Enrichment

Unfortunately for this analysis, the *Moore* court did not address the merits of Moore's unjust enrichment claim,[97] but unjust enrichment was

89. Rihab Yassin et al., *Custodianship as an Ethical Framework for Biospecimen-Based Research*, 19(4) CANCER EPIDEMIOLOGY, BIOMARKERS & PREVENTION 1012, 1013 (2010).

90. *Id.* at 1012.

91. David S. Wendler, *The Claims of Biospecimen Donors to Credit and Compensation*, 36 TRENDS IN GENETICS 630, 632 (2020).

92. *Id.* at. 631–32.

93. American Medical Association, *AMA Code of Ethics Opinion 7.3.9: Commerical Use of Human Biological Materials*, https://code-medical-ethics.ama-assn.org/ethics-opinions/commercial-use-human-biological-materials [https://perma.cc/WZ8T-MZNW] (last visited Sept. 4, 2025).

94. Henry E. Smith, *Equity as Meta-Law*, 130 YALE L.J. 1050, 1060 (2020).

95. *Id.* at 1050.

96. *Id.* at 1072.

97. Anderlik & Rothstein, *supra* note 6, at 452.

discussed as support for compensation in the dissenting opinion on Moore's conversion claim.[98] The dissent framed its unjust enrichment argument as a policy consideration combining equity and ethics.[99]

Unjust enrichment is a doctrine based on principles of equity and restitution[100] that may be applied to support remedies in contract and tort cases when a defendant is enriched as a result of a breach of contract or duty.[101] Unjust enrichment can support compensation in cases where contract, tort, or property theories do not,[102] giving the doctrine a gap-filling purpose similar to equity.[103] The flexible nature of unjust enrichment makes the doctrine difficult to define clearly,[104] but one concrete application is illustrated in the *Greenberg* case.[105]

The plaintiffs in *Greenberg* provided biomaterial samples from deceased relatives to a doctor motivated by a desire to help isolate the gene responsible for, and develop a screening test for, the disease that claimed their relatives' lives.[106] The doctor did just that, but then patented the gene and the testing method,[107] allowing himself to become enriched.[108] The court did not dismiss a claim for unjust enrichment because the plaintiffs "invest[ed] time and significant resources" in providing the biomaterial samples.[109] However, the court did not rule on the merits of the claim because the case was settled out of court.[110]

In a set of recent high-profile cases[111] in which unjust enrichment was similarly claimed to support compensation for human biomaterials, two

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98. *Moore*, 793 P.2d at 517.

99. *Id.*

100. Abigail C. Lepsch, *Greenberg v. Miami Children's Hospital Research Institute*, 3 GROVE CITY CJL PUB. POL'Y 145, 146 (2012).

101. Debra L. Greenfield, *Greenberg v. Miami Children's Hospital: Unjust Enrichment and the Patenting of Human Genetic Material*, 15 ANNALS HEALTH L. 213, 215 (2006).

102. *Id.*

103. *See* Smith, *supra* note 94.

104. *See* Lepsch, *supra* note 100, at 152–53.

105. *See* Greenberg, 264 F. Supp. 2d at 1072. In *Greenberg*, the court applied the elements of unjust enrichment from precedent in Florida case law: "(1) the plaintiff conferred a benefit on the defendant, who had knowledge of the benefit; (2) the defendant voluntarily accepted and retained the benefit; and (3) under the circumstances it would be inequitable for the defendant to retain the benefit without paying for it."

106. *Id.* at 1067.

107. *See Myriad*, 569 U.S. at 596; *see also supra* text accompanying note 78. Isolated genes responsible for diseases and associated testing methods for those genes are no longer valid subject matter after *Myriad*, so if the facts of *Greenberg* were to reoccur today, the doctor's patent application would be rejected, and the doctor would likely have never been enriched.

108. *See Greenberg*, 264 F. Supp. 2d at 1072–73.

109. *Id.* at 1073.

110. *See* Lepsch, *supra* note 100, at 148.

111. Civil Compl. & Request for Jury Trial, Estate of Lacks v. Thermo Fisher Sci., Inc., No. 1:21-cv-02524-DLB (D. Md. Oct. 4, 2021); ("Lacks I"); Civil Compl. & Request for Jury Trial, Estate of Lacks v. Viatris Inc., No. 1:24-cv-02267-DLB (D. Md. Aug. 5, 2024) ("Lacks II").

defendants so far have settled out of court. The suits were brought by the family of Henrietta Lacks against biotechnology and pharmaceutical companies.[112] Cervical cancer cells taken from Lacks in 1952 were used to create the notorious "HeLa" cell line, which has yielded over sixty tons of cells, numerous crucial scientific breakthroughs, and billions in earnings for private companies.[113] Unlike *Greenberg*, where the inequity basis for unjust enrichment arose from the plaintiffs' expended time and effort,[114] in *Lacks I* and *Lacks II*, the unjust enrichment claim was based on the disparity between the value of Lacks's cells (monumental societal benefit and private enrichment) and zero compensation for Lacks's family (prior to the two settlements), coupled with racial injustice surrounding the taking of Lacks's cells.[115]

Although for different reasons than in *Moore* and *Greenberg*, the unjust enrichment claim in *Lacks I* was also never decided in court.[116] Therefore, we are left without any clear doctrine for unjust enrichment in the context of human biomaterials compensation, outside the claim elements listed, but not ruled on, in *Greenberg*.

E. *The Winner: Quasi-Property*

The issue of health data compensation does not slot neatly into property, privacy, intellectual property, or ethics doctrines. Quasi-property is selected primarily because the core issue here is equity, and the doctrine of quasi-property was invented to solve an equity issue.[117] Quasi-property is selected over unjust enrichment because unjust enrichment would limit health data compensation to cases where the user of health data benefited at the detriment of the person whose health data was taken.

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112. Meredith Wadman, *What Does the Historic Settlement Won by Henrietta Lacks's Family Mean for Others?*, SCI. INSIDER (Aug. 7, 2023, at 11:45 AM), https://www.science.org/content/article/what-does-historic-settlement-won-henrietta-lacks-s-family-mean-others [https://perma.cc/W97Y-2R6T]; Jenna Greene, *Novartis Quietly Settles Henrietta Lacks Suit as Family's Legal Push Gains Steam*, REUTERS (Feb. 23, 2026), https://www.reuters.com/legal/litigation/novartis-quietly-settles-henrietta-lacks-suit-familys-legal-push-gains-steam-2026-02-24/ [https://perma.cc/8B3C-GC9D].

113. Robert Klitzman, *Henrietta Lacks' Family's Lawsuits: Ethical Questions and Solutions*, 40 TRENDS IN BIOTECH. 769, 769 (2022).

114. *See* Greenfield, *supra* note 101, at 228.

115. *See* Wadman, *supra* note 112 (noting that the extents of the disparity and racial injustice in Lacks' case are well documented).

116. *Id.*; *but see* Greene, *supra* note 112 (stating that *Lacks II* is pending against other defendants, separate suits are pending against different defendants, and additional litigation is likely forthcoming against other biotechnology and pharmaceutical companies, leaving open the possibility that a judge may rule on an unjust enrichment claim for this set of facts in the near future).

117. *See* Balganesh, *supra* note 27, at 1895.

The following table details the elements of the proposed quasi-property doctrine.

Table 2: Elements of Proposed Quasi-Property Doctrine

Element	Basis	Purpose
Δ uses π's health data	Quasi-property	Specific class, limits quasi-property right
Δ's use of π's health data generates earnings for Δ	Equity	Triggering event, limits quasi-property right
Substantial similarity between Δ's use and π's health data	Intellectual property	Defines "use" for specific class and triggering event elements
Dollar amount threshold for Δ's earnings	Quasi-property	Triggering event, limits quasi-property right
π's health data is substantial, unique, or useful	Quasi-property, intellectual property	Triggering event, limits quasi-property right
π does not receive equitable compensation from Δ	Quasi-property, profit-sharing, equity	Cause of action
Monetary relief for π	Equity	Remedy

The proposed quasi-property doctrine is classified as a subcategory of quasi-property, incorporating elements from other areas of law and ethics. A quasi-property right to health data compensation is a very limited right. The person holding the right has no control over the use of the data (meaning injunction is not an available remedy) but would be compensated if that use were especially commercially valuable. If an entity finds a use for the person's health data with high social utility but no commercial value, the person would not be compensated. This remains the same whether the entity is a private individual or organization, or a public agency or institution.

A quasi-property right to health data compensation is enforceable only against a specific class and triggered by a certain event. The specific class is any entity that uses a person's health data. The triggering event is that the entity's use of the person's health data generates earnings for the entity.

The specific class and triggering event are limited by other elements of the proposed quasi-property doctrine. The word "use" is limited by a

test of similarity borrowed from the tests for design patent and copyright infringement: the plaintiff must prove that the health data "use" that generates earnings for the entity is substantially similar to the person's "raw information" health data. The triggering event is limited by the requirement that the commercial value of the health data use must exceed a dollar amount threshold. The triggering event is further narrowed with a requirement similar to that in patent law, where an invention must be novel and useful.[118] For the quasi-property right, the triggering event definition includes that the health data must be substantial, unique, or useful.

The limitations of the quasi-property right are intended to overcome the policy objection that health data compensation would stifle socially valuable research. Another policy aim of limiting the right is to avoid encouraging people to make their health data available as a business venture. However, if a person's health data is taken through the course of care delivery, and the health data generates earnings for someone else, that person can receive equitable relief.

The cause of action is that the person has not received equitable compensation from the entity that benefits from the use of the health data. This means that there could still be a cause of action in a scenario where a profit-sharing agreement is already in place, but the agreement does not provide equitable compensation to the plaintiff.

If the elements of the proposed quasi-property doctrine are not met, a person may still be able to receive health data compensation through other means, such as an unjust enrichment suit or a profit-sharing agreement.

The next section evaluates the proposed quasi-property doctrine through application to a hypothetical.

II. COULD THERE BE HEALTH DATA COMPENSATION?

A proposed doctrine for health data compensation is not feasible if there is no real-world situation in which it applies. Therefore, in proposing the quasi-property doctrine, it is important to hypothesize a set of facts and apply the quasi-property doctrine to evaluate its feasibility. Here, the hypothetical is a health data analogue to the human biomaterials cases discussed previously, achieved through the technology of precision medicine. The proposed quasi-property doctrine is applied to the hypothetical to support the conclusion that health data compensation is justified in this case.

The following table shows the assumptions made in constructing the hypothetical.

118. *See Myriad*, 569 U.S. at 576–77.

Table 3: Assumptions for Hypothetical

Assumption	Purpose
The precision medicine algorithm is a commercial product that generates earnings, possibly by making discoveries or diagnoses.	Necessary condition for compensation to be an equitable remedy.
The precision medicine algorithm is a supervised machine learning model with only one person's health data used as labeled output data in training.	Hypothetical use of health data analogous to the uses of human biomaterials in *Moore*, *Greenberg*, *Lacks I,* and *Lacks II*, in that one person's health data is crucial to the success of the commercial product.
The person can be identified as the individual from whom the data was taken.	Proof that the person is the correct party to assert the quasi-property right to compensation.

A. *Constructing the Hypothetical*

1. What the Hypothetical Precision Medicine Algorithm Does

The hypothetical algorithm must be able to generate earnings. It could do so in ways similar to *Greenberg* and *Myriad*, where genes that caused diseases were discovered and isolated, patented, and then used to market diagnostic tests based on detection of those genes. The precision medicine algorithm could be an empirical tool shaped by the person's health data to discover and isolate new genes or compounds that correlate to certain conditions. The precision medicine algorithm could also be a diagnostic tool that would base its decisions (at least in part) on the person's health data and would be able to predict likelihood of a condition based on correlations between the "omics" of the person whose data were used to make the tool and the "omics" from patients that the tool receives as input.

2. How the Hypothetical Precision Medicine Algorithm Works

The person's health data must be crucial to the success of the hypothetical precision medicine algorithm. One way to build an algorithm that depends heavily on one person's health data, similar to how the commercial products in *Moore*, *Greenberg*, *Lacks I*, and *Lacks II* each relied on one person's biomaterials, is through machine learning.

Precision medicine can rely on technologies other than artificial intelligence.[119] But, because precision medicine requires analysis of vast amounts of complex data from varying sources, machine learning (a subset of artificial intelligence) offers several advantages over the statistical methods that have been traditionally used.[120]

Machine learning is a branch of artificial intelligence that involves computer algorithms that can get better at a given task with experience.[121] Just like artificial intelligence is not actual intelligence,[122] machine learning is not actually learning, but rather an algorithmic method of finding patterns in data and adjusting parameters to improve performance.[123]

From a legal perspective, it can be helpful to view machine learning as a multistep process consisting of two main workflows: "playing with the data" and "the running model."[124] The "playing with the data" workflow concerns the input that is used to select and train the appropriate machine learning model. In this workflow, the training data that is collected as the input is not "raw information" (a person's health data, as it originates, would likely not be useful like training data without the application of human ingenuity and effort, steps that would take place before the first workflow). The "running model" workflow results in the output of the machine learning model,[125] where the model makes decisions informed by what it learned from the data in the first workflow. Therefore, the training data is not simply used by the machine learning

119. *See* Peck, *supra* note 16.

120. *See* MacEachern & Forkert, *supra* note 20, at 11–12 (listing such advantages as: (1) most machine learning algorithms do not make strict assumptions about data distribution, allowing these algorithms to handle combinations of data sets and variables without extensive data preprocessing; (2) many machine learning algorithms use regularization, which offers an advantage when analyzing noisy data and large variances within the data; (3) machine learning algorithms can be trained on small datasets; and (4) machine learning algorithms can identify multifaceted, nonlinear patterns in the training data).

121. Harry Surden, *Machine Learning and Law*, 89 WASH. L. REV. 87, 89 (2014) [hereinafter *Machine Learning and Law*].

122. Harry Surden, *Artificial Intelligence and Law: An Overview*, 35 GA. ST. U. L. REV. 1305, 1309 (2019) [hereinafter *Artificial Intelligence and Law*] (claiming that artificial intelligence does not resemble or match human thinking but uses computational methods to achieve results that would require cognition if performed by humans).

123. *Machine Learning and Law*, *supra* note 121, at 89.

124. David Lehr & Paul Ohm, *Playing with the Data: What Legal Scholars Should Learn About Machine Learning*, 51 U.C. DAVIS L. REV. 653, 655 (2017) (claiming that legal scholarship is too focused on the outputs of the second workflow while neglecting the issues surrounding the first workflow. In the first workflow, a problem is defined, training data is collected, and then the training data is "played with" through data cleaning, summary statistics review, data partitioning, model selection, and model training. The second workflow is the model making real-world predictions, normally after being integrated with a larger software system).

125. *See id.* at 716.

model in the first workflow and then discarded; the training data becomes part of the model and can influence any output the model produces.

There is a growing volume of legal scholarship[126] and litigation[127] surrounding copyright infringement by artificial intelligence arising from instances where copyrighted works are used in the first workflow to train machine learning models. The hypothetical begins to take form, considering that similar conflicts could arise when a person's health data (protected by the proposed quasi-property doctrine) is repurposed by machine learning in an analogous way to these instances where machine learning has repurposed a person's intellectual creation (protected by copyright law).

A variety of machine learning models show promise for applications in precision medicine. Machine learning models can be broadly categorized as reinforcement, unsupervised, or supervised.[128] Reinforcement models require direct feedback from humans in the loop, and as such are not widely used in precision medicine.[129] Unsupervised models rely on unlabeled data and find patterns within that data that can help identify smaller datasets for further analysis with different methods.[130] Unsupervised methods can be classified as association algorithms, which search for trends in data, or clustering algorithms, which search for common characteristics and sorts data accordingly.[131] Precision medicine applications for unsupervised models include the classification of brain tumor types to find new subclasses based on test

126. Jessica Gillotte, *Copyright Infringement in AI-Generated Artworks*, 53 U.C. DAVIS L. REV. 2655 (2020); Andres Guadamuz, *Do Androids Dream of Electric Copyright? Comparative Analysis of Originality in Artificial Intelligence Generated Works*, INTELL. PROP. Q. (2017); Victor M. Palace, *What if Artificial Intelligence Wrote This: Artificial Intelligence and Copyright Law*, 71 FLA. L. REV. 217 (2019); Jane C. Ginsburg & Luke A. Budiardjo, *Authors and Machines*, 34 BERKELEY TECH. L.J. 343 (2019); Annemarie Bridy, *Coding Creativity: Copyright and the Artificially Intelligent Author*, STAN. TECH. L. REV. 5 (2012); Ana Ramalho, *Will Robots Rule the (Artistic) World? A Proposed Model for the Legal Status of Creations by Artificial Intelligence Systems*, J. OF INTERNET L. (2017).

127. Compl., *Alter v. OpenAI, Inc.*, No. 1:23-cv-10211 (S.D.N.Y. filed Nov. 28, 2023); Compl., *Authors Guild v. OpenAI, Inc.*, No. 1:23-cv-08292 (S.D.N.Y. filed Sept. 19, 2023); Compl., *Doe v. GitHub, Inc.*, No. 4:22-cv-06823-JST (N.D. Cal. filed Nov. 10, 2022); Compl., *N.Y. Times Co. v. Microsoft Corp.*, No. 1:23-cv-11195 (S.D.N.Y. filed Dec. 27, 2023).

128. *See* MacEachern & Forkert, *supra* note 20, at 418; *see* Hannah L. Nicholls et al., *Reaching the End-Game for GWAS: Machine Learning Approaches for the Prioritization of Complex Disease Loci*, 11 FRONTIERS IN GENETICS 350, 352 (2020).

129. *See* MacEachern & Forkert, *supra* note 20, at 418.

130. *Id.*; *see* Nicholls et al., *supra* note 128, at 2.

131. Guido Zampieri et al., *Machine and Deep Learning Meet Genome-Scale Metabolic Modeling*, 15(7) PLOS COMPUTATIONAL BIOLOGY ee1007084 (July 11, 2019), https://doi.org/10.1371/journal.pcbi.1007084 [https://perma.cc/S4Z2-RFC5].

cases[132] and identification of type 2 diabetes subgroups based on electronic medical records.[133]

Supervised models are distinct in that, during the "playing with the data" workflow, supervised models receive labeled output variables.[134] A labeled output variable represents a true value the model should predict based on the input data.[135] The model is selected and then "learns" based on its ability to consistently produce the labeled output variables from the input data.[136]

Because supervised models receive labeled data as training data, in addition to finding patterns, supervised models can also infer labels to those patterns without the need to apply other methods.[137] The ability of supervised models to handle multidimensional data makes them very practical for precision medicine applications involving multiple omics datasets.[138]

Supervised methods can be categorized as either classification, the goal of which is to predict sample classes, or regression, which aims to predict numerical results.[139] Supervised models include support vector machines, random forests, and deep neural networks,[140] some of which can accomplish both classification and regression tasks.[141] Precision medicine applications for supervised models include cancer survival analysis that can identify multi-omics contributing factors[142] and genome-wide association that can predict disease.[143]

While machine learning models are promising in their ability to handle complex datasets, machine learning models have inherent traits that may limit their applications in precision medicine.[144] Also, there are

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132. Derek Wong & Stephen Yip, *Machine Learning Classifies Cancer*, 555 NATURE 446, 447 (2018).

133. Li Li et al., *Identification of Type 2 Diabetes Subgroups Through Topological Analysis of Patient Similarity*, 7 SCI. TRANSLATIONAL MED. 311ra174 (Oct. 28, 2015) https://www.science.org/doi/10.1126/scitranslmed.aaa9364 [https://perma.cc/D3WK-H5SE].

134. *See* Lehr & Ohm, *supra* note 124, at 673.

135. *Id.*

136. *See id.* at 696; *see* Nicholls et al., *supra* note 128.

137. *See* MacEachern & Forkert, *supra* note 20; s*ee* a*lso* Nicholls et al., *supra* note 128.

138. Lianhe Zhao et al., *DeepOmix: A Scalable and Interpretable Multi-Omics Deep Learning Framework and Application in Cancer Survival Analysis*, 19 COMPUT. & STRUCTURAL BIOTECH. J. 2719 (2021).

139. *See* Zampieri et al., *supra* note 131.

140. *See* MacEachern & Forkert, *supra* note 20, at 418.

141. *See* Zampieri, et al., *supra* note 131, at 3.

142. *See* Zhao et al., *supra* note 138, at 2719–20.

143. Daniel Sik Wai Ho et al., *Machine Learning SNP Based Prediction for Precision Medicine*, 10 FRONT. GENETICS 267 (Mar. 27, 2019); *see also* Nicholls et al., *supra* note 128, at 6.

144. Jack Wilkinson et al., *Time to Reality Check the Promises of Machine Learning-Powered Precision Medicine*, 2 THE LANCET DIGIT. HEALTH 677, 677–79 (2020) (listing

concerns with the stated effectiveness of machine learning models in precision medicine, based on how some studies report results.[145]

Regardless of the model or the application, a precision medicine machine learning model can learn from health data. The decisions or predictions a precision medicine machine learning model yields later can be lucrative to the owner or licensee of the model. Those lucrative outputs, and the model itself, are directly shaped by the health data. For some models, such as supervised models trained with labeled data, health data could have an exceptionally high influence on both the model's creation and its outputs. The hypothetical now becomes clearer.

The hypothetical precision medicine algorithm is a supervised machine learning model. An output variable used to train the supervised model could be unique to one person, in which case that person's health data plays a critical role in every output of the model and the formation of the model itself. There is also evidence that the model, in some circumstances, could produce an output that is essentially a regurgitated copy of part of the training data.[146]

One crucial assumption for this hypothetical is that the training data for the precision medicine algorithm are linked to individuals. A concern with this assumption is that it might not be technically feasible due to characteristics including the size and complexity of the information. For a person to assert a claim on their genetic information, they would likely need other identifying information linked to the genetic information to recognize that it is, in fact, theirs. Technologies that can link genetic

limitations of machine learning applications in precision medicine as: (1) models are evaluated under conditions that are not relevant to routine clinical practice, emphasizing predictive performance over clinical utility; (2) models perform badly or require retraining when presented with data from different environments than the training data; (3) models are designed to make predictions or classifications, but not for causal explanation and causal effect estimation; and (4) models that are accurate over a large data set are not necessarily accurate on an individual level, and the goal of precision medicine is to provide tailored treatments to individuals).

145. *See* Darren Plant & Anne Barton, *Machine Learning in Precision Medicine: Lessons to Learn*, 17 NAT. REV. RHEUMATOLOGY. 5 (2021).

146. Nicholas Carlini et al., *Extracting Training Data from Diffusion Models*, 32 USENIX SEC. SYMP. 5253, 5256 (2023) (detailing an instance when the output of a generative artificial intelligence model, an image of a portrait, was just a copy of a portrait used as training data when providing the model with the name of person in the portrait as a prompt).

information to other identifying information include matrices,[147] blockchain,[148] and cloud encryption.[149]

In this hypothetical, three parties are responsible for guiding the person's health data from "raw information" to the hypothetical precision medicine algorithm. A hospital collects the "raw information" from the person. The hospital performs basic data processing to get health data from the "raw information," and then sells the health data to the data science firm. The data science firm further processes and manipulates the health data into useful data before it sells the useful data to the software firm. The software firm uses the useful data as labeled output data to train a supervised machine learning model for a precision medicine application that generates earnings for the software firm.

In the following subsection, the actions of these three parties will be examined through the lens of the proposed quasi-property doctrine to determine whether the person whose health data is collected has a right to compensation.

B. *Application of the Quasi-Property Doctrine*

The mechanism for compensation is a lawsuit for violation of the quasi-property right to compensation. The plaintiff is the person from whom the health data is collected. There are multiple potential defendants, who could be any people or entities that benefit from the commercial value of the plaintiff's health data. The potential defendants in this hypothetical are the three parties identified in the previous subsection: (1) the hospital, which collected the plaintiff's "raw information" and performed initial data processing; (2) the data science firm, which purchased access to the health data from the hospital and further processed the health data to create useful data; and (3) the software firm, which purchased the useful data from the data science firm and then used the useful data to create the precision medicine machine learning algorithm. Under the proposed quasi-property doctrine, the plaintiff would be able to receive compensation if the limitations of the doctrine are met.

The plaintiff would have to show that the plaintiff is the source of the health data that was "used" by the defendant. This burden on the plaintiff

147. J. Patrick Woolley et al., *Responsible Sharing of Biomedical Data and Biospecimens Via the "Automatable Discovery and Access Matrix" (ADA-M)*, 3 NPJ GENOM. MED. 17 (July 23, 2018).

148. *See* S.A. Ahmed & R. Hrzic, *Blockchain and Homomorphic Encryption for Genomic and Health Data Sharing: An Ethical Perspective*, 33 ETHICS, MED. & PUB. HEALTH 101127 (May 29, 2025).

149. *See, e.g.*, Dmitry Grishin & George M. Church, *Blockchain-Enabled Genomic Data Sharing and Analysis Platform*, HARV. MED. SCH. (Feb. 7, 2018), https://arep.med.harvard.edu/pdf/Grishin_Church_v4.52_2018.pdf [https://perma.cc/HD5P-4XHF].

would limit the quasi-property right and serve to disincentivize litigation of quasi-property infringement in cases with a lower likelihood of success for the plaintiff. The plaintiff could prove that each defendant "used" the plaintiff's health data through a substantial similarity test based on the preponderance of the evidence, including: (1) a side-by-side comparison of the person's health "raw information" to the health data products that generated earnings for each defendant; (2) records of transactions between defendants that can be traced back to the entity that collected the "raw information" from the plaintiff; or (3) a showing that a health data product that generated earnings for a defendant is labeled with or contains information identifying the plaintiff. Here, there are records of transactions that can be traced from the software firm back to the data science firm and ultimately back to the hospital, which is the entity that collected the "raw information" from the plaintiff. Additionally, as part of the analysis, the hospital's health data, the data science firm's useful data, and the software firm's precision medicine machine learning algorithm would each be compared to the plaintiff's raw information to evaluate similarity. The hospital's health data and the software firm's useful data would be considered similar to the plaintiff's "raw information" because these products are processed forms of the plaintiff's "raw information." The software firm's precision medicine machine learning algorithm would be considered similar to the plaintiff's "raw information" because the algorithm is trained using a dataset consisting only of processed forms of the plaintiff's "raw information" as labeled output data. Furthermore, there would have to be identifying information in the hospital's health data, the software firm's useful data, and the software firm's precision medicine algorithm—otherwise the plaintiff would not be aware that a quasi-property health data compensation claim could be made against each defendant.

Therefore, any of the three potential defendants would meet the "specific class" limitation. Although they play various roles, all of them use the plaintiff's health data to generate earnings. The plaintiff could choose to sue any or all of the three parties, free to choose a strategy like that employed by the plaintiffs in *Lacks I* and *Lacks II*, where, based on their success against a first defendant, the plaintiff could pursue claims against other defendants.

To meet the "triggering event" limitation, the defendants' use of the plaintiff's health data must have generated earnings. For each defendant, this element is met: the hospital's sale of the health data generated earnings, the data science firm's sale of the useful data generated earnings, and the software firm's precision medicine machine learning algorithm is assumed to generate earnings.

Additionally, these earnings must be in excess of a dollar amount threshold. The threshold would be calculated based on the sum of all

earnings generated by use of the plaintiff's health data. Because earnings are considered instead of profit, the cost for the data science firm of purchasing access to the health data would not subtract from the earnings generated from the sale of the processed health data; both would be counted as earnings, for the hospital and data science firm, respectively. However, the court should consider proportions of earnings when determining whether to allow a cause of action against a defendant.

For example, if the hospital received a relatively small sum for providing access to the hospital's health data in proportion to the large earnings reaped by the software firm from marketing the algorithm, then the proposed doctrine would not support a claim for compensation against the hospital unless the software firm was included as a defendant in the action.

Another element of the "triggering event" limitation is the requirement for the plaintiff's health data to be substantial, useful, or unique. "Substantial" health data means that the plaintiff's health data used to generate earnings represents a high quantity of data, which could be determined by hardware storage space (gigabytes of data) or possibly as a percentage of total health data points possible for one person (if this is quantifiable). "Unique" health data means that the plaintiff's health data used to generate earnings represent uncommon or unusual data, which could be measured as a probability or percentage of identical data present in the health data of others—for example, a large proportion of the genome is shared among most of the global population,[150] so this health data would not be "unique" to one person. "Useful" health data means any other health data with qualities that the earnings generated can be attributed to. "Useful" health data would be harder to measure, and the definition and metrics could be molded by court interpretation. The cause of action is that the plaintiff did not receive equitable compensation from one or more of the defendants.

The remedy would be monetary damages awarded to the plaintiff. The amount of monetary damages in proportion to the earnings generated by the plaintiff's health data for each defendant could be evaluated on a case-by-case basis. There is no need in the proposed quasi-property doctrine for punitive damages in cases where there is a finding of bad behavior because this can be addressed with a separate claim of unjust enrichment.

CONCLUSION

First, a problem was identified: it feels wrong when people are not compensated for health data that generates earnings for others. After analysis of various legal doctrines and ethical models, a doctrine to

150. *See* Clayton, *supra* note 21, at 2.

support health data compensation was proposed and then applied to a hypothetical.

Because the hypothetical was designed specifically to illustrate the proposed doctrine, it is unresolved how the proposed doctrine would apply to other problems. Different hypotheticals or case studies would be needed to determine the range of situations to which the proposed doctrine could apply.

One area for further investigation could be evaluating whether the doctrine could be applied to cases with multiple plaintiffs, or even a class action. Having multiple plaintiffs could weaken the support for the proposed doctrine in areas such as privacy and equity.

An area of improvement for the proposed doctrine could be a disclosure requirement. The person who is the source of the health data cannot initiate an action for health data compensation without knowledge of how their health data is used. Research is needed to determine how much information should be disclosed and to whom, as well as how the disclosure requirement would be enforced and implemented.

Another future direction for this problem is the economics of health data compensation. Further research is needed to define equitable compensation, so that appropriate profit-sharing agreements could be offered to avoid health data compensation lawsuits. Additionally, further research is required to formulate an appropriate dollar amount threshold for earnings generated. In cases with multiple defendants, investigation is needed to confirm whether the threshold should apply to the earnings of individual entities or the sum of all entities using one person's health data, and to determine whether the liability for compensation should be market share or joint and several.

Among the assumptions made in the analysis is that health data is intangible. However, if health data is stored in a tangible medium and, as such, could be considered tangible, then a property doctrine could be more appropriate than the proposed quasi-property doctrine.

Another assumption is that health data should be analyzed similarly to human biomaterials and genetic information. Alternatively, health data could be analyzed similarly to other "things" such as biometric data or name, image, and likeness. These alternative analyses may lead to finding different doctrines more appropriate for health data compensation.

Also, the proposed quasi-property doctrine was selected instead of a privacy doctrine in large part because the analysis focused on United States legal doctrines. Evaluation of the problem through the lens of another legal doctrine, such as the European Union's GDPR—a privacy doctrine which provides a private right of action and recognizes eight fundamental rights of individuals regarding their broadly defined "personal data," in contrast with the implied constitutional protections and patchwork of industry-specific regulations for data privacy in the

United States[151]—may provide insight for improvement of the proposed quasi-property doctrine or an alternative privacy doctrine for health data compensation.

Finally, the mechanism for compensation should be evaluated. One of the reasons a mechanism of filing a quasi-property infringement lawsuit is proposed is because the most successful mechanism for human biomaterials compensation has been filing suit for unjust enrichment. This mechanism is inefficient because it relies on the court system, taking time and resources to resolve a dispute. There could be a more efficient mechanism for compensation than a lawsuit—possibly a process for grievance and mediation, or an application filed for review with a public entity.

151. Michael Cairo, *Synthetic Data and GDPR Compliance: How Artificial Intelligence Might Resolve the Privacy-Utility Tradeoff*, 28 J. TECH. L. & POL'Y 71, 80 (2023).