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.