

Poked, Prodded, and Privacy: Parents, Children, and Pediatric Genetic Testing

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ABSTRACT: “Knowledge is power,” so the saying goes. But does that always prove true? What if knowledge comes without the power or resources to act? What if knowledge is unwanted and uninvited?

Significant advancements in genetics and genomics have thrust these and other difficult questions into the professional and public discourse. These developments include “pediatric predisposition genetic testing” (“PPGT”), a term used in this Article to describe genetic testing performed on a minor with parental consent to either determine with certainty or predict the risk that the minor will develop an adult-onset disease.

PPGT pits parental rights against children’s rights in unique and unprecedented ways. American law and tradition have long recognized the rights of parents to consent to myriad types of healthcare services for their children, presuming that parents act in their children’s best interests. But PPGT raises questions about that presumption. Problematically, PPGT may impose unwanted information on nonconsenting children—information those children must live with for the rest of their lives. Too often, children become pawns in larger sociopolitical battles fought primarily between parents and the state, with the children’s rights and interests cast aside. With PPGT, where science has outpaced law and policy, children’s rights face subordination yet again.

To mitigate harm and protect children’s rights in this “age of genetics,” this Article argues for the development of a novel theoretical framework: a “right to future privacy.” In doing so, it eschews the existing jurisprudence’s myopic focus on parental rights and parent-state conflicts and proposes a framework that accounts for children’s privacy and autonomy amid fast-developing, and

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often under-regulated, technologies like PPGT. At a time when privacy rights are threatened by myriad sources, this Article reaffirms and reinvigorates the value of children's lifelong genetic and personal privacy.

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INTRODUCTION

In May 2013, in an uncharacteristically public and personal *New York Times* opinion piece, international celebrity Angelina Jolie revealed she had undergone a preventative double mastectomy.¹ She made this dramatic decision after learning she carried a deleterious mutation in the *BRCA1* gene, which her doctors estimated put her at an eighty-seven percent risk of breast cancer and a fifty percent risk of ovarian cancer.² Jolie encouraged women “to

1. Angelina Jolie, *My Medical Choice*, N.Y. TIMES (May 14, 2013), <https://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html> (on file with the *Iowa Law Review*).

2. *Id.* The *BRCA1* and *BRCA2* genes produce proteins that help repair damaged DNA. A woman's risk of developing breast or ovarian cancer during her life “is markedly increased if she inherits a harmful variant” of either gene. *BRCA Gene Mutations: Cancer Risk and Genetic Testing*,

seek out the information and medical experts who can help you through this aspect of your life, and [help you] make your own informed choices.”³ Women and their healthcare providers heeded Jolie’s call: In the weeks and months following her article, significantly more women were referred for, qualified for, and received genetic testing.⁴

Interest in and use of genetic testing was not new when Jolie’s story went public, but her personal experience fostered newfound interest in genetic testing for *BRCA1* and *BRCA2* mutations.⁵ More broadly, it reinvigorated debates about making decisions like Jolie’s based on the results of genetic testing.⁶ Jolie’s story exemplifies the phrase “knowledge is power.”⁷ She explained: “[T]oday it is possible to find out through a blood test whether you are highly susceptible to breast and ovarian cancer, and then take action. . . . I feel empowered that I made a strong choice”⁸

But is knowledge always power? What if knowledge comes without the power to act? What if, instead, the knowledge may be “toxic” because it is

NAT’L CANCER INST. (Nov. 19, 2020), <https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet> [<https://perma.cc/99PH-T5VP>].

3. Jolie, *supra* note 1.

4. Sunita Desai & Anupam B. Jena, *Do Celebrity Endorsements Matter? Observational Study of BRCA Gene Testing and Mastectomy Rates After Angelina Jolie’s New York Times Editorial*, BRIT. MED. J., Nov. 2016, at 1, 4; D. Gareth R. Evans et al., *The Angelina Jolie Effect: How High Celebrity Profile Can Have a Major Impact on Provision of Cancer Related Services*, BREAST CANCER RSCH., Sept. 2014, at 1, 3–5. Jolie was neither the first nor the last celebrity to spark an uptick in health care utilization. Recently, sellers of full-body MRI scans “saw an ‘abnormal’ increase in sign-ups” after Kim Kardashian posted on Instagram about her full-body MRI scan. Mohana Ravindranath & Lizzy Lawrence, *Kim Kardashian Sparks Debate on the Benefits of Full-Body MRI Scans*, STAT (Aug. 11, 2023), <https://www.statnews.com/2023/08/11/kim-kardashian-full-body-mri-scans> [<https://perma.cc/2QLQ-6B5K>].

5. See sources cited *supra* note 4.

6. Predisposition genetic testing identifies gene variants/mutations that suggest a person may be at risk or susceptible to developing a disease associated with the gene(s). See Catherine M. Bove, Sara T. Fry & Deborah J. MacDonald, *Presymptomatic and Predisposition Genetic Testing: Ethical and Social Considerations*, 13 SEMINARS ONCOLOGY NURSING 135, 136 (1997) (defining predisposition testing). Jolie’s testing for the *BRCA1* mutation represents one example. Predisposition genetic testing does not mean the person is guaranteed to develop the disease. Diagnostic testing, in contrast, determines with certainty whether a disease currently exists or whether the disease will develop later in a person’s life, such as Huntington’s disease. See SIMON TRIPP & MARTIN GRUEBER, *THE ECONOMIC IMPACT AND FUNCTIONAL APPLICATIONS OF HUMAN GENETICS AND GENOMICS* 34 (2021), <https://www.ashg.org/wp-content/uploads/2021/05/ASHG-TEconomy-Impact-Report-Final.pdf> [<https://perma.cc/T32U-T4HV>]; *Medical Genetics: How Genetic Testing Is Used*, STANFORD MED. CHILD.’S HEALTH, <https://www.stanfordchildrens.org/en/topic/default?id=medical-genetics-how-genetic-testing-is-used-90-P02160> [<https://perma.cc/55S9-REW7>]; *Genetic Testing*, AM. MED. ASS’N, <https://www.ama-assn.org/delivering-care/precision-medicine/genetic-testing> [<https://perma.cc/KE7K-6G2N>].

7. This phrase is generally attributed to Francis Bacon’s “Meditationes Sacrae,” in which he wrote “Nam et ipsa scientia potestas est” (“Knowledge is power”). JOHN BARTLETT, *BARTLETT’S FAMILIAR QUOTATIONS: A COLLECTION OF PASSAGES, PHRASES, AND PROVERBS TRACED TO THEIR SOURCES IN ANCIENT AND MODERN LITERATURE* 164 (Geoffrey O’Brien ed., 18th ed. 2012).

8. Jolie, *supra* note 1 (emphasis added).

either not definitive, not actionable, or both?⁹ Jolie, a wealthy celebrity of international fame, had ample resources to access world-class experts and care. Many, if not most, lack her good fortune. Moreover, while some individuals may desire this information, others do not. Furthermore, what if the knowledge is *uninvited*, thrust upon a person without their desire or consent? Jolie made an autonomous decision to obtain and act upon her genetic information based on her family history and personal risk. Yet for others, ignorance may be bliss.¹⁰ In an era where information of all kinds and from all sources is at our fingertips, we too easily presume the benefits of having access to volumes of information and fail to pause and consider potential drawbacks. “Available” does not necessarily translate to “valuable.”

Over the past three decades, significant advancements and increasing public interest in genetics and genomics¹¹ thrust these and other thorny questions into the minds of many in our society—scientists working in labs, policymakers and legislators, healthcare providers and patients in clinics, and individuals in their homes ordering direct-to-consumer (“DTC”) genetic tests from companies like 23andMe.¹²

The growth of genetic testing owes much to the completion of the Human Genome Project in 2003. The Project was an international effort started in 1990 that ultimately generated the first sequence of the human genome.¹³ Human genome sequencing has facilitated tremendous innovation

9. See Bruce Grierson, *To Know or Not to Know*, PSYCH. TODAY (Dec. 20, 2020), <https://www.psychologytoday.com/us/articles/201105/know-or-not-know> [<https://perma.cc/6EVF-JLBP>]; see also Robert Wachbroit, *Disowning Knowledge: Issues in Genetic Testing*, in PHILOSOPHICAL DIMENSIONS OF PUBLIC POLICY 239, 241 (Verna V. Gehring & William A. Galston eds., 2002) (discussing how some knowledge in genetic testing can lead to social and psychological harm).

10. See Claudia Wallis, *Angelina Jolie's Mastectomy Was the Right Decision for Her, but Not for Everyone*, NEW REPUBLIC (May 12, 2013), <https://newrepublic.com/article/113218/angelina-jolies-mastectomy-right-decision-her-not-all> [<https://perma.cc/Q76S-ULAY>]; Johan Bester, Maya Sabatello, Clara D.M. van Karnebeek & John D. Lantos, *Please Test My Child for a Cancer Gene, but Don't Tell Her*, PEDIATRICS, Apr. 2018, at 1, 1 (“Some people seem to prefer living with uncertainty over getting test results that may be perceived as depressing.”); Jane Wilson, *To Know or Not to Know? Genetic Ignorance, Autonomy, and Paternalism*, 19 BIOETHICS 492, 493 (2005) (“[N]ot everyone considers medical information regarding themselves to be something that they wish to possess. Indeed, some may hold that there are times when *ignorance* is preferable to knowing.”).

11. According to the National Human Genome Research Institute, “[g]enetics refers to the study of genes and the way that certain traits or conditions are passed down from one generation to another,” whereas “[g]enomics describes the study of all of a person’s genes (the genome).” *Genetics vs. Genomics Fact Sheet*, NAT’L HUM. GENOME RSCH. INST. (Sept. 7, 2018), <https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics> [<https://perma.cc/G77C-UF2A>].

12. See 23ANDME, <https://www.23andme.com> [<https://perma.cc/NCP5-KMG6>] (offering a variety of different at-home tests relating to ancestry, health, and traits).

13. *Fact Sheet: Human Genome Project*, NAT’L HUM. GENOME RSCH. INST. (Aug. 24, 2022), <https://www.genome.gov/about-genomics/educational-resources/fact-sheets/human-genome-project> [<https://perma.cc/CY4U-NYRX>]. At the time of the Project’s completion in 2003, scientists had sequenced about ninety-two percent of the total human genome. *Id.* The remaining eight percent was completed in early 2022. *Id.*; *First Complete Sequence of a Human Genome*, NAT’L INSTS.

in health care, including the development of genetic tests to diagnose disease (“diagnostic testing”) or to determine the risk or susceptibility of future disease (“predisposition testing”).¹⁴

Despite concerns, society has not transformed into a dystopian Gattaca-like state.¹⁵ But the march continues toward a day when genetic testing becomes part of mainstream medicine—a patient’s yearly physical will no longer just involve standard blood tests for blood cell counts, electrolytes, and cholesterol levels, but also a variety of genetic testing options or even whole genome sequencing.¹⁶ The possibilities seem endless. Nevertheless, the promises of genetic medicine raise a myriad of legal, ethical, and sociopolitical questions and controversies: privacy, informed consent, discrimination, eugenics, accessibility, affordability, and health disparities, to name just a few.¹⁷ Pediatric genetic testing raises particularly thorny questions, including when these tests should be used; who can access the results; how the data may be collected, retained, and shared; and whether the tested individual wants—and consents—to undergo the test and receive or disclose the results.

The challenging questions raised by emerging medical technologies affect all members of society, but the burdens often magnify for vulnerable populations. History provides many examples of vulnerable populations being

OF HEALTH (Apr. 12, 2022), <https://www.nih.gov/news-events/nih-research-matters/first-complete-sequence-human-genome> [<https://perma.cc/LZ2N-CF65>].

14. See *supra* note 6 (defining predisposition and diagnostic testing); see also Dena S. Davis, *Genetic Dilemmas and the Child’s Right to an Open Future*, 28 RUTGERS L.J. 549, 550 (1997) (noting the “almost infinite number of choices, decisions and interventions theoretically available as a result of the [Human Genome Project]”).

15. *Gattaca* is a 1997 dystopian science fiction film that depicts a future society where children are conceived through eugenics-like genetic selection to ensure they have the best genetic traits. GATTACA (Columbia Pictures Industries, Inc. 1997).

16. See Swaroop Aradhya & Robert L. Nussbaum, *Genetics in Mainstream Medicine: Finally Within Grasp to Influence Healthcare Globally*, 6 MOLECULAR GENETICS & GENOMIC MED. 473, 474–75 (2018). Moreover, although using genome editing “to create tall, beautiful, highly intelligent, and athletic ‘designer babies’”—as envisioned in *Gattaca*—is “simply beyond what is technologically feasible at this point in time—and perhaps ever,” parents may still select some traits, such as sex and the absence of certain genetic diseases. PAUL ENRIQUEZ, *REWRITING NATURE: THE FUTURE OF GENOME EDITING AND HOW TO BRIDGE THE GAP BETWEEN LAW AND SCIENCE* 276 (2021). Future possibilities remain unknown.

17. See *Policy Issues in Genomics*, NAT’L HUM. GENOME RSCH. INST. (Jan. 6, 2022), <https://www.genome.gov/about-genomics/policy-issues> [<https://perma.cc/P883-Z3YD>]; see also *United States v. Kriese*, 720 F.3d 1137, 1147 (9th Cir. 2013) (“[W]e are dealing with a rapidly changing world in which risks of undue intrusions on privacy are also changing.”); Allison M. Whelan & Michele Goodwin, *Will the Past Be Prologue? Race, Equality, and Human Genetics*, 102 B.U. L. REV. ONLINE 37, 37–38 (2022) (discussing important questions regarding genome editing regulation, accessibility, and affordability).

abused and exploited “in the name of science.”¹⁸ Minors¹⁹ represent one such vulnerable population that has been subject to mistreatment throughout history in the areas of science, medicine, and beyond.²⁰ The mistreatment of vulnerable populations may even be reinforced by law, which has long been used as a tool to establish patterns of discrimination based on race, sex, disability, sexual orientation, gender identity, age, and other identities.²¹

This Article focuses specifically on potential harms to children associated with emerging medical technologies, but the general issues gliding under the surface are not of recent vintage. On the contrary, there exists a long and sometimes continuing history of the law permitting or even condoning

18. See generally HARRIET A. WASHINGTON, *MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT* (2006) (revealing a long history of Black Americans being exploited as unwilling and unwitting experimental subjects in medical research); Alicia Ouellette, *People with Disabilities in Human Subjects Research: A History of Exploitation, a Problem of Exclusion*, in *THE OXFORD HANDBOOK OF RESEARCH ETHICS* (Ana S. Iltis & Douglas MacKay eds., 2020) (illustrating a long history of people with disabilities being mistreated as human research subjects); see also Allison M. Whelan, *Unequal Representation: Women in Clinical Research*, 106 CORNELL L. REV. ONLINE 87, 87 (2021) (discussing the “long history of paternalism and lack of respect for women’s autonomy that has resulted in the exclusion of women from research”).

19. This Article uses the term “minor” or “child” to refer to an individual under the relevant age of majority, which is generally set by state law. Most states set eighteen as the age of majority. See Jon M. Garon, *To Be Seen but Not Heard: How the Internet’s Negative Impact on Minors’ Constitutional Right to Privacy, Speech, and Autonomy Creates a Need for Empathy-by-Design*, 73 MERCER L. REV. 463, 465 n.5 (2022); *Getting Ready for When Your Teen Reaches the Age of Majority: A Parent’s Guide*, CTR. FOR PARENT INFO. & RES. (May 2023), <https://www.parentcenterhub.org/age-of-majority-parent-guide> [<https://perma.cc/PQG8-T4ST>]. But see *infra* note 30 (listing examples of common exceptions found in various state laws that allow minors under the general age of majority to consent to certain medical services without parental involvement).

20. See WASHINGTON, *supra* note 18, at 271–96 (describing research on young African Americans); Douglas S. Diekema, *Conducting Ethical Research in Pediatrics: A Brief Historical Overview and Review of Pediatric Regulations*, 149 J. PEDIATRICS S3, S3–S4 (Supp. 2006). Vulnerability increases further for children in the foster care system. See, e.g., WASHINGTON, *supra* note 18, at 294, 333–37 (describing a study involving HIV-positive children in foster care who “were given high doses of experimental, risky antiretroviral drugs without their parents’ knowledge or permission”); Jascha Hoffman, *New York City Foster Home Accused of Unethical AIDS Drug Trials*, 11 NATURE MED. 5, 5 (2005).

21. For example, according to Professor Eric Segall of the Georgia State University College of Law:

Ever since the court stopped Congress from ending slavery in the territories in 1857, our nation’s highest “court” has been a reactionary force in American politics much more often than not, preserving out-of-date ideas and white male Christian supremacy. It is well past the time the people and the elected branches see this supreme veto council for what it is and isn’t. It is not a court of law but a tool of oppression.

Benjamin Morse, *The Supreme Court’s Entire Term Was an Exercise in Reactionary Rollback of Basic Rights*, JACOBIN (July 6, 2022), <https://jacobin.com/2022/07/supreme-court-roe-conservatives-rights> [<https://perma.cc/VA4A-G7KD>].

practices harmful to children: child labor,²² child neglect and abuse,²³ child marriage,²⁴ and much more. It therefore remains appropriate and necessary to revisit an area where American law and tradition have tolerated harms and imposed barriers to justice for a vulnerable and often voiceless population.²⁵

To mitigate the intentional or unintentional exploitation of children and to ensure that their rights are protected, we must proceed with caution when emerging medical technologies are used with and upon children. This includes “pediatric predisposition genetic testing” (“PPGT”), a term used in this Article to describe genetic testing done on a minor, consented to by their parent(s), for the purpose of (1) determining whether the minor has any genetic mutations that will result in an adult-onset disease that lacks a known cure or method of prevention, such as Huntington’s disease or amyotrophic lateral sclerosis (“ALS”); or (2) assessing the risk, but not guarantee, that the

22. See, e.g., Edwin Rios, *Arkansas Leads Charge to Weaken Child Labor Protections*, GUARDIAN (Mar. 8, 2023, 12:22 PM), <https://www.theguardian.com/us-news/2023/mar/08/arkansas-bill-child-labor-protections> [<https://perma.cc/B2NP-3P4S>]. See generally Michael Schuman, *History of Child Labor in the United States—Part 1: Little Children Working*, U.S. BUREAU OF LAB. STAT. (Jan. 2017), <https://www.bls.gov/opub/mlr/2017/article/history-of-child-labor-in-the-united-states-part-1.htm> [<https://perma.cc/5Q96-8SDH>] (examining the history of child labor in various industries from the Industrial Revolution through the early twentieth century).

23. Even today, the laws in some states provide immunity to parents from child neglect or abuse charges if the parents’ actions stem from religious or spiritual beliefs. See, e.g., 325 ILL. COMP. STAT. ANN. § 5/3 (West Supp. 2023) (“A child shall not be considered neglected or abused for the sole reason that such child’s parent or other person responsible for his or her welfare depends upon spiritual means through prayer alone for the treatment or cure of disease or remedial care as provided under Section 4 of this Act.”). See generally Rita Swan, *Faith-Based Medical Neglect: For Providers and Policymakers*, 13 J. CHILD & ADOLESCENT TRAUMA 343 (2020) (arguing for the repeal of religious exemptions from child health and safety laws); Aleksandra Sandstrom, *Most States Allow Religious Exemptions from Child Abuse and Neglect Laws*, PEW RSCH. CTR. (Aug. 12, 2016), <https://www.pewresearch.org/fact-tank/2016/08/12/most-states-allow-religious-exemptions-from-child-abuse-and-neglect-laws> [<https://perma.cc/VGU6-4UCZ>] (identifying and examining states with religious exemptions in civil child abuse statutes).

24. See generally NICHOLAS L. SYRETT, *AMERICAN CHILD BRIDE: A HISTORY OF MINORS AND MARRIAGE IN THE UNITED STATES* (2016) (describing how the marriage of children has been relatively common throughout the history of the United States); HEATHER HEIMAN & JEANNE SMOOT, TAHIRIH JUST. CTR., *FORCED MARRIAGE IN IMMIGRANT COMMUNITIES IN THE UNITED STATES: 2011 NATIONAL SURVEY RESULTS* (Layli Miller-Muro ed., 2011), <https://www.tahirih.org/wp-content/uploads/2015/03/REPORT-Tahirih-Survey-on-Forced-Marriage-in-Immigrant-Communities-in-the-United-States.pdf> [<https://perma.cc/2EANYC3B>] (identifying and analyzing problem of forced marriages in U.S. immigrant communities); Fraidy Reiss, *America’s Child-Marriage Problem*, N.Y. TIMES (Oct. 13, 2015), <https://www.nytimes.com/2015/10/14/opinion/americas-child-marriage-problem.html> (on file with the *Iowa Law Review*) (illustrating that many states allow minors to legally marry, usually with parental consent).

25. As one example, the United States remains the only country that has signed but not ratified the Convention on the Rights of the Child (“CRC”). *Status of Treaties: Chapter IV Human Rights: 11. Convention on the Rights of the Child*, UNITED NATIONS TREATY COLLECTION, https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-11&chapter=4&clang=en [<https://perma.cc/5MYC-PVXD>].

minor will develop an adult-onset disease, including those with known curative treatment options such as various types of cancer.

This Article uses the term PPGT to refer to genetic testing performed on children *after* birth for the two specific purposes just listed. It therefore represents a technology distinct from preimplantation genetic testing or diagnosis (“PGT” or “PGD”), which is performed in conjunction with various artificial reproductive technologies (“ARTs”) such as in vitro fertilization (“IVF”) prior to implantation or performed on an embryo or fetus in utero.²⁶ The Supreme Court’s decision in *Dobbs v. Jackson Women’s Health Organization*, which overturned the constitutional right to abortion established in *Roe v. Wade* and *Planned Parenthood of Southeastern Pennsylvania v. Casey*,²⁷ has stimulated the next battles: greater policing of pre- and postconception decisions and fetal personhood laws, which confer the legal rights of persons to a fetus.²⁸ Attempting to ban or restrict the use of PGD and PGT for specific purposes is not something for which this Article advocates. Regulating the decision to use PGD or PGT would require policing the motives behind a person’s most intimate decisions about conception and would only add strength to recent regressive trends in matters relating to reproduction, sexual intimacy, and family.²⁹

Refocusing on PPGT, minors, especially preadolescents, represent a particularly vulnerable population because they are considered by law to be incapable of providing their own consent and thus may remain voiceless in decision-making.³⁰ Instead, parents³¹ possess the authority to consent to

26. See *Pre-Implantation Genetic Diagnosis*, UNIV. OF CAL. S.F. HEALTH, <https://www.ucsfhealth.org/treatments/pre-implantation-genetic-diagnosis> [<https://perma.cc/TQT2-XFBG>]; *Prenatal Genetic Screening Tests*, AM. COLL. OF OBSTETRICIANS & GYNECOLOGISTS (Oct. 2020), <https://www.wacog.org/womens-health/faqs/prenatal-genetic-screening-tests> [<https://perma.cc/SD8R-Q6XU>].

27. *Dobbs v. Jackson Women’s Health Org.*, 142 S. Ct. 2228, 2242 (2022).

28. See Mary Ziegler, *The Next Step in the Anti-Abortion Playbook Is Becoming Clear*, N.Y. TIMES (Aug. 31, 2022), <https://www.nytimes.com/2022/08/31/opinion/abortion-fetal-personhood.html> (on file with the *Iowa Law Review*).

29. See *infra* notes 37–38, 360 and accompanying text.

30. See 45 C.F.R. § 46.402(a) (2022) (defining children, for purposes of medical research, as “persons who have not attained the legal age for consent to treatments or procedures involved in . . . research”). Many states, however, allow adolescents over a specific age to consent to certain healthcare services, such as drug and alcohol treatment, reproductive health services, treatment for sexually transmitted infections, outpatient mental health services, emergency services, and other general healthcare services including certain vaccines. See Robert S. Olick, Y. Tony Yang & Jana Shaw, *Adolescent Consent to COVID-19 Vaccination: The Need for Law Reform*, 137 PUB. HEALTH REPS. 163, 164–65 (2022). See generally Lisa Klee Mihaly, Naomi A. Schapiro & Abigail English, *From Human Papillomavirus to COVID-19: Adolescent Autonomy and Minor Consent for Vaccines*, 36 J. PEDIATRIC HEALTH CARE 607 (2022) (recommending increased access to vaccines for adolescents); *State Laws that Enable a Minor to Provide Informed Consent to Receive HIV and STD Services*, DIV. OF HIV PREVENTION, NAT’L CTR. FOR HIV, VIRAL HEPATITIS, STD, & TB PREVENTION, CTRS. FOR DISEASE CONTROL & PREVENTION (Oct. 25, 2022), <https://www.cdc.gov/hiv/policies/law/states/minors.html> [<https://perma.cc/gALK-RQ2F>] (identifying state laws that allow minors to give informed consent for receiving vaccines).

31. For brevity, this Article uses the term “parents” to include parents and other legal guardians.

medical care and services for their children, sometimes even over the child's own objections.³² Parents also act as the primary recipients of information about their children's health. These practices are deeply entrenched in American law, society, and jurisprudence.³³ Yet despite general acceptance and understanding of the parental rights jurisprudence, guidance as to how those rights apply—or *should* apply—to decisions involving minors and emerging medical technologies remain underdeveloped, unsatisfactory, ad hoc, or unworkable.

Scholars in medicine and bioethics have long engaged in debates about genetic testing, such as the proper method for returning incidental findings discovered during the course of research.³⁴ This Article, while informed by the bioethics literature, grounds itself more squarely in law and jurisprudence. Further, it focuses specifically on the use of PPGT in the clinical, rather than research, context. With that focus, this Article first queries whether the long-recognized constitutional rights of parents to direct the care, custody, and control of their children clearly encompass the right to consent to PPGT. It then questions whether that jurisprudence informs workable pathways forward that adequately protect the rights of all parties involved, particularly those of children.³⁵ After concluding that the jurisprudence fails to adequately protect children's rights, due in large part to a myopic focus on parental rights and parent-state conflicts, this Article proposes a novel conceptual framework—the right to future privacy—to protect and reinvigorate children's privacy and autonomy in ways that account for emerging technologies like PPGT. Moreover, it aims to properly allocate rights and

32. See, e.g., ARK. CODE ANN. § 20-16-508 (2018) (providing that, for treatment of sexually transmitted diseases, “[t]he information may be given to . . . the spouse, parent, or guardian *without the consent and over the express objection of the minor*”) (emphasis added); MD. CODE ANN., HEALTH-GEN. § 20-102(f) (West Supp. 2022) (similar); 1988–89 La. Op. Att’y Gen. 40 (1988), 1988 WL 428422 (noting “[a] minor . . . has no right to refuse medical treatment when that treatment is consented to by his parents and proposed by a licensed physician”).

33. See *infra* Part II.

34. See generally Gail P. Jarvik et al., *Return of Genomic Results to Research Participants: The Floor, the Ceiling, and the Choices in Between*, AM. J. HUM. GENETICS 818 (2014) (arguing that clinical researchers should be prepared to report incidental findings); Brian Van Ness, *Genomic Research and Incidental Findings*, 36 J.L., MED. & ETHICS 292 (2008) (noting the legal and ethical problems that accompany incidental findings); Susan M. Wolf, *Return of Individual Research Results and Incidental Findings: Facing the Challenges of Translational Science*, ANN. REV. GENOMICS & HUM. GENETICS 557 (2013) (addressing the debate on whether to return incidental findings to genetic research participants); Susan M. Wolf et al., *Managing Incidental Findings and Research Results in Genomic Research Involving Biobanks and Archived Data Sets*, GENETICS IN MED. 361 (2012) (making recommendations regarding the return of incidental findings in a biobank research system).

35. Primary results in the clinical setting are those related to the indication for the test or sequencing. See Robert C. Green et al., *ACMG Recommendations for Reporting of Incidental Findings in Clinical Exome and Genome Sequencing*, 15 GENETICS IN MED. 565, 565–66 (2013). Incidental findings “are results that are not related to the indication for [the test or] sequencing but that may . . . be of medical value or utility to the [healthcare provider] and the patient.” *Id.* at 565.

responsibilities to the child, the parents, and the state in an area where technology has outpaced the law.

Myriad important and pressing questions lurk under the surface of the specific questions posed by this Article, all of which warrant additional consideration in future work. For example, how does the law address—or fail to address and keep pace with—new and emerging technologies more generally?³⁶ Even more broadly, what is the proper method for determining the roles of parents, children, and the state with respect to all decisions made about a child?

Too often, children become pawns in political and culture wars fought between parents and the state. On the one hand, there has been a recent resurgence of the parental rights movement, largely among conservative circles.³⁷ Yet on the other, there has also been a troubling trend of states policing decisions—parental and otherwise—that were historically left to the private sphere.³⁸ The controversies are often depicted as pitting parents against the state. Yet in reality, children bear the brunt of the short- and long-term harms. By failing to focus on the child, American law and jurisprudence have neglected to address the “parent-state-child rights triad” in ways that

36. Future work may explore some of these questions, but it is beyond the scope of this Article to address the myriad issues raised by emerging technologies. This Article instead lays some important groundwork, the first part of a larger project that may explore other related concerns.

37. Recent events and trends illuminate this issue. *See, e.g.*, Catherine Caruso, *The Parental Rights Movement Is History Repeating Itself*, DAME (Mar. 9, 2022), <https://www.damemagazine.com/2022/03/09/the-parental-rights-movement-is-history-repeating-itself> [<https://perma.cc/W6GB-PLYE>] (noting the “recent resurgence” of “the conservative push for parents’ rights in education”). *See generally* FREEDOM FOR ALL AMs., FREEDOM FOR ALL AMERICANS FINAL REPORT (2023), <https://freedomforallamericans.org/legislative-tracker/medical-care-bans> [<https://perma.cc/TU2H-ZLXD>] (compiling legislation prohibiting gender-affirming medical care for adolescents).

38. *See, e.g.*, Lara Freidenfelds, *When the Constitution Was Drafted, Abortion Was a Choice Left to Women*, WASH. POST (May 23, 2022, 6:00 AM), <https://www.washingtonpost.com/outlook/2022/05/23/when-constitution-was-drafted-abortion-was-choice-left-women> (on file with the *Iowa Law Review*) (explaining how “abortion was something women were supposed to take care of, away from the public sphere”); Peter Hayes, *Alabama Claims Primacy over Parents on Treating Transgender Kids*, BL (June 28, 2022, 12:24 PM), <https://news.bloomberglaw.com/litigation/alabama-claims-primacy-over-parents-on-treating-transgender-kids> (on file with the *Iowa Law Review*) (reporting Alabama’s claim that it could “regulate or prohibit . . . interventions for children, even if an adult wants the drugs for his child”); *AMA to States: Stop Interfering in Health Care of Transgender Children*, AM. MED. ASS’N (Apr. 26, 2021), <https://www.ama-assn.org/press-center/press-releases/ama-states-stop-interfering-health-care-transgender-children> [<https://perma.cc/N4MY-gHKT>] (reporting the AMA’s criticism of prohibitions of necessary gender transition-related care for minor patients as “a dangerous intrusion into the practice of medicine”). Interestingly, the conservative-led movements to restrict access to abortion and to prohibit parents from obtaining gender-affirming care for their children are in many ways in tension with the conservative-led parental rights movement, which is grounded largely in notions about the privacy of the family. *See* Julia Bowes, *Overturing Roe Could Threaten Rights Conservatives Hold Dear*, WASH. POST (June 24, 2022, 11:26 AM), <https://www.washingtonpost.com/outlook/2022/06/24/overturing-roe-could-threaten-rights-conservatives-hold-dear> (on file with the *Iowa Law Review*).

adequately protect the current and future rights of the child.³⁹ Relatedly, the “best interests” standard,⁴⁰ used often by courts, the medical profession, and others when making determinations about children, often fails to achieve its child-centered goals. This standard, which purports to center on *children’s* rights and interests, is nevertheless often interpreted in ways that prioritize *parental* rights and interests.⁴¹

These failures make clear the need to consider how to incorporate and recognize the rights of children as individual beings, even when those rights conflict with the rights of their parents.⁴² Historic and ongoing practices that render children voiceless and powerless make this an issue in urgent need of attention. Indeed, the recent resurgence of the parental rights movement often proves antithetical to recognizing children’s autonomy or even protecting their best interests. As articulated by Jaclyn Friedman:

[T]he last thing [the parental rights movement] want[s] is for young people to have actual power . . . [They] want[] to “conserve” a power structure that relies on oppressed kids growing compliantly into oppressed adults and never once complaining. Teaching kids about their own power will upset their entire plan, which is why they are all in on certain parents’ “rights,” *but never the rights of young people*.⁴³

When it comes to children’s genetic future and future privacy, they must not be silenced.

Despite a plethora of medical and bioethical scholarship and debate on PPGT and related issues, the law and legal discourse have not kept pace with

39. The term “parent-state-child rights triad” is used to describe the different and sometimes incompatible rights at issue in conflicts involving parental rights, state interests, and children’s rights.

40. See Loretta M. Kopelman, *Children and Bioethics: Uses and Abuses of the Best-Interests Standard*, 22 J. MED. & PHIL. 213, 213 (1997) (“[The best interests standard] is intended to guide moral, social, and legal decisions for children, as well as other incompetent persons.”); CHILD.’S BUREAU, U.S. DEP’T HEALTH & HUM. SERVS. & CHILD WELFARE INFO. GATEWAY, DETERMINING THE BEST INTERESTS OF THE CHILD 2 (2020), https://www.childwelfare.gov/pubpdfs/best_interest.pdf [<https://perma.cc/R3U4-46PJ>] [hereinafter DETERMINING THE BEST INTERESTS] (describing the “best interests of the child” as “refer[ring] to the deliberation that courts undertake when deciding what type of services, actions, and orders will best serve a child as well as who is best suited to take care of a child”).

41. Janet L. Dolgin, *Why Has the Best-Interest Standard Survived?: The Historic and Social Context*, CHILD.’S LEGAL RTS. J., 1996, at 1, 2 (“The standard, presumed to determine and protect the interests of children, more often seems to encourage courts to focus on and to protect the interests of disputing adults.”).

42. See, e.g., Caruso, *supra* note 37 (noting potential harms of certain parental rights legislation); Jaclyn Friedman, *Why the Parental Rights Movement Is Making a Comeback*, REWIRE NEWS GRP. (Apr. 11, 2022, 8:59 AM), <https://rewirenewsgroup.com/2022/04/11/why-the-parental-rights-movement-is-making-a-comeback> [<https://perma.cc/7V4G-HLJL>] (highlighting how various parental rights policies harm children); Jane Gray & Jaime Jara, *The “Parental Rights” Movement Is Harming Our Children*, SALON (Apr. 5, 2022, 5:22 AM), <https://www.salon.com/2022/04/05/th-e-parental-rights-movement-is-harming-our-children> [<https://perma.cc/ZGN7-3R7N>] (describing potential harms of “parental rights” legislation).

43. Friedman, *supra* note 42 (emphasis added).

new developments in genetic technologies, creating gaps and vulnerabilities. This Article revisits the parental rights jurisprudence to reconceptualize the issues and analyses as they relate to PPGT.⁴⁴ Current law and Supreme Court jurisprudence have not adequately considered the implications of emerging medical technologies for the rights of parents and children. In an era when children are too often used as pawns in heated sociopolitical battles, keeping their rights at the fore must be paramount. To that end, this Article introduces and begins to conceptualize a novel framework—a right to future privacy—to better concretize and protect children’s rights in this space.

Importantly, rather than focusing on situations where rights and authorities over children are transferred from parents to the state (e.g., in child abuse and neglect cases, state prohibitions on parents consenting to gender-affirming care for their children, or state mandates for certain childhood vaccinations), this Article evaluates whether the rights of children—as individuals with rights and interests separate from their parents—may at times require withholding decision-making authority from any actor to instead preserve it for the child in the future.⁴⁵ This Article does so through the lens of a right to future privacy. Addressing tensions between parents and the state remains crucial,⁴⁶ but balancing the rights of parents with the rights of children represents an equally important issue that too easily gets overlooked in sociopolitical battles between parents and the state.⁴⁷

This Article engages with these issues in three parts. Part I provides a descriptive account, exploring health care for minors generally and then PPGT specifically, unpacking whether and how PPGT raises different considerations from other types of pediatric health care for which parents routinely provide consent. Part II then canvasses the jurisprudential

44. This Article focuses primarily on U.S. Supreme Court jurisprudence addressing the rights of parents, children, and the state. Although supplemented by decisions from lower federal courts and state courts, see, for example, *infra* Section II.D, it is beyond the scope of this Article to address every approach taken by the myriad federal and state courts.

45. This Article views “interests” and “rights” as two separate concepts, borrowing from philosopher Joseph Raz’s interest theory of rights. See *infra* notes 208–10 and accompanying text; Aleardo Zanghellini, *Raz on Rights: Human Rights, Fundamental Rights, and Balancing*, 30 *RATIO JURIS* 25, 26 (2017); see also J. Raz, *On the Nature of Rights*, 93 *MIND* 194, 195–96 (1984) (defining “rights”).

46. Cf. Allison M. Whelan, Note, *That’s My Baby: Why the State’s Interest in Promoting Public Health Does Not Justify Residual Newborn Blood Spot Research Without Parental Consent*, 98 *MINN. L. REV.* 419, 421 (2013) (arguing that the state’s interest in promoting public health does not override parental rights to consent to children’s participation in research).

47. The lack of case law involving direct conflicts between parents and children (or the failure of courts to pay attention to potential conflicts) may be due, in part, to the fact that such direct conflicts arise infrequently and do not rise to the same level as the conflicts between parents and the state. Alternatively, the conflicts may not reach the courts in the first place because children are less likely to have the knowledge and resources to institute legal action when direct parent-child conflicts arise. This last point—that children often lack the ability to contest their parent’s choices—provides strong justification for giving attention to this issue to ensure children’s rights and interests are protected. See *infra* note 309 and accompanying text.

foundations of parental rights generally and in the context of healthcare decision-making specifically. Part III turns to normative considerations, arguing that decisions about PPGT should be postponed until the minor attains the capacity to consent. To ground this conclusion, this Article establishes a new framework—“the right to future privacy”—and lays important foundations for future development and framing of that right.

I. HEALTH CARE AND GENETIC TESTING FOR MINORS

The trends are clear: Patients increasingly seek and utilize healthcare services derived from new and emerging biotechnologies. Assisted reproductive technology, genetic testing and genome sequencing, and personalized medicine like gene therapy provide just a few examples. Yet with novelty comes uncertainty, which heightens the need for patients to be adequately informed to ensure they can make thoughtful, voluntary, and autonomous decisions about the risks and benefits of utilizing emerging biotechnologies.

Parents typically provide the necessary consent for their children’s medical care, a practice with deep roots in common law.⁴⁸ Buttressing this tradition is a longstanding recognition by the U.S. Supreme Court that parents have a constitutional right to direct the care, custody, and control of their children.⁴⁹ Yet these rights are not absolute, and exceptions exist. In 1975, for example, an Indiana court held that the common law attributes of the parent-child relationship did not permit a mother to ask for and consent to the sterilization of her fifteen-year-old son, who had a slightly below average IQ, because her desire was to prevent him from having children rather than to save his life or prevent harm.⁵⁰ Today, many state laws provide exceptions to the general requirement of parental consent for medical care.⁵¹

Indeed, law and society have both increasingly emphasized that parental decision-making should be guided by the best interests of the child.⁵² Decisions that are not clearly in a child’s best interest can—and should—be challenged. Courts have now also recognized that children do, in fact, have

48. See *Bonner v. Moran*, 126 F.2d 121, 122 (D.C. Cir. 1941) (“[T]he general rule is that the consent of the parent is necessary for an operation on a child.”); *Zoski v. Gaines*, 260 N.W. 99, 102 (Mich. 1935) (“Except in the very extreme cases, a surgeon has no legal right to operate upon a child without the consent of its parents or guardian.”).

49. See *infra* Part II.

50. *A.L. v. G.R.H.*, 325 N.E.2d 501, 502 (Ind. Ct. App. 1975).

51. See *supra* note 30 (listing common situations in which minors may consent to medical services without involvement of a parent).

52. Cf., e.g., Douglas S. Diekema, *Revisiting the Best Interest Standard: Uses and Misuses*, 22 J. CLINICAL ETHICS 128, 128 (2011) (describing best interest standards and factors considered in determining the best interests of the child); Dolgin, *supra* note 41, at 2 (noting the “vitality of the best-interest standard” despite “criticisms of the standard”); DETERMINING THE BEST INTERESTS, *supra* note 40, at 1 (indicating that several state statutes describe best interest factors).

their own cognizable constitutional rights in a variety of circumstances, separate and apart from those of their parents or another third party.⁵³

This longstanding tradition and the general societal and legal acceptance of that tradition raise questions about whether and why decisions about PPGT might deserve a unique approach. Section I.A sets the scene by describing three scenarios that arise in the medical care of children, both historically and as a result of emerging biotechnologies. Section I.B then considers unique considerations and concerns that arise in the third scenario—PPGT.

A. *MEDICAL DECISION-MAKING FOR MINORS: FROM ROUTINE
TO CONTROVERSIAL*

This Section describes three scenarios that may arise in medical decision-making for minors and how the rights of parents may play out in those scenarios. No decision about the medical care of minors—discussed below or otherwise—is black and white.⁵⁴ On the contrary, thorny, unanticipated, and novel questions often emerge. By unpacking situations in which medical decisions must be made for children and highlighting potential differences between these scenarios, this Section aims to inform the discussion about whether PPGT raises unique concerns that require reconceptualizing current legal frameworks.

1. Scenario One: Treatment of a Sick Child⁵⁵

For the first scenario, consider a three-year-old child diagnosed with cancer. With treatment—such as chemotherapy, surgery, or radiation—more than eighty percent of children diagnosed with cancer are cured.⁵⁶ Left untreated, however, the cancer can spread to other areas of the body. Few would disagree that this child’s parent can—or even must—consent to potentially life-saving surgery and other necessary care to treat the child’s

53. See, e.g., *In re Gault*, 387 U.S. 1, 13 (1967) (“[N]either the Fourteenth Amendment nor the Bill of Rights is for adults alone.”); *J.D.B. v. North Carolina*, 564 U.S. 261, 271–77 (2011) (addressing minors’ constitutional rights when questioned by the police); *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52, 74 (1976) (“Constitutional rights do not mature and come into being magically only when one attains the state-defined age of majority. Minors, as well as adults, are protected by the Constitution and possess constitutional rights.”); *Tinker v. Des Moines Indep. Cmty. Sch. Dist.*, 393 U.S. 503, 506 (1969) (asserting that students do not “shed their constitutional rights to freedom of speech or expression at the schoolhouse gate”).

54. The scenarios are also not intended to be exhaustive, as there are many situations in which a parent may consent to a medical procedure for their child.

55. Scenario One would also include decisions relating to the prevention of a known risk, such as routine and recommended childhood vaccinations. See *Child and Adolescent Immunization Schedule by Age*, CTRS. FOR DISEASE CONTROL & PREVENTION (Apr. 27, 2023), <https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html> [<https://perma.cc/U8DZ-GU4W>] (listing recommended vaccines for individuals ages eighteen and under).

56. See *Pediatric Chemotherapy*, YALE MED., <https://www.yalemedicine.org/conditions/pediatric-chemotherapy> [<https://perma.cc/85FH-TA9M>].

cancer. Given the child's young age, this will be done without the child's consent or even assent.

Controversies involving Scenario One most often arise when parents refuse to treat or decide to use alternative or unproven treatments for religious or other reasons.⁵⁷ When a recommended or standard treatment is expected to be successful, or when failure to treat increases the risk of serious harm or death, state intervention may result.⁵⁸ Indeed, the doctrine of *parens patriae* recognizes that a state may act as a "surrogate parent" when necessary to protect the health and well-being of children.⁵⁹

The case of thirteen-year-old Daniel Hauser exemplifies a Scenario One controversy. Daniel's story made international news in 2009 when his mother refused to consent to chemotherapy to treat Daniel's Hodgkin's lymphoma. The decision was based on her belief in natural healing, and Daniel himself did not want chemotherapy even though it was proving to be successful.⁶⁰ At the time, the survival rate for people under age twenty treated for Hodgkin's

57. See *infra* notes 58–63 and accompanying text; Lindsey Bever, *Baby Dies After Parents Refused Medical Help for "Religious Reasons,"* NDTV WORLD (Aug. 9, 2018, 9:10 AM), <https://www.ndtv.com/world-news/michigan-baby-dies-after-parents-refused-medical-help-for-religious-reason-s-1897535> [<https://perma.cc/5VB8-2DAY>]; Michael Rubinkam, *2-Year-Old Girl Dies After Faith-Healing Parents Refuse Medical Treatment: Officials,* NBC PHILA. (Feb. 2, 2017, 7:52 AM), <https://www.nbcphiladelphia.com/news/national-international/ella-foster-faith-healing-death/29977> [<https://perma.cc/B2Q7-JV6C>]; Jason Wilson, *Letting Them Die: Parents Refuse Medical Help for Children in the Name of Christ,* GUARDIAN (Apr. 13, 2016, 10:30 AM), <https://www.theguardian.com/us-news/2016/apr/13/followers-of-christ-idaho-religious-sect-child-mortality-refusing-medical-help> [<https://perma.cc/DXW3-LD5H>] (describing cases where parents have refused medical treatment for their children based on their religious, spiritual, or moral beliefs).

58. See Douglas S. Diekema, *Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention,* 25 THEORETICAL MED. & BIOETHICS 243, 255 (2004) ("[State intervention is] most clear for cases that involve medical treatments that are proven to be efficacious, pose little medical risk, and offer significant benefit by preventing the harm of death."); Alexa Renee, *When Can the Government Override a Parent's Medical Decision in the U.S.?*, ABC 10 (July 25, 2017, 1:04 PM), <https://www.abc10.com/article/news/local/when-can-the-government-override-a-parents-medical-decision-in-the-us/103-459250777> [<https://perma.cc/49EW-GXSR>]; see also *Zucht v. King*, 260 U.S. 174, 175, 177 (1922) (upholding a Texas ordinance requiring that children be vaccinated to attend school); *Phillips v. City of New York*, 775 F.3d 538, 540 (2d Cir. 2015) (rejecting argument that New York's mandatory vaccine requirement for schools violates substantive due process and other provisions of the U.S. Constitution).

59. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) ("Acting to guard the general interest in youth's well being, the state as *parens patriae* may restrict the parent's control . . ."); see also *Jehovah's Witnesses v. King Cnty. Hosp.*, 278 F. Supp. 488, 491, 507–08 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598, 598 (1968) (mandating a blood transfusion for a minor, a Jehovah's Witness, over the parents' objections when it was medically necessary to protect the minor's life).

60. See Amy Forliti, *Daniel Hauser Done with Chemotherapy*, MPR NEWS (Sept. 4, 2009, 3:14 PM), <https://www.mprnews.org/story/2009/09/04/daniel-hauser-done-with-chemo> [<https://perma.cc/XG6A-TYH6>] ("Danny was dead set against [chemotherapy] from the first day . . ." (quoting Dan Zwakman, spokesman for the Hauser family)); Ben Jones & Carolyn Pesce, *Medicine, Religion Collide in Chemo Refusal*, USA TODAY (May 21, 2009), https://usatoday30.usatoday.com/news/nation/2009-05-21-forced-chemo-thursday_N.htm [<https://perma.cc/U77M-3PLA>].

lymphoma was ninety-one percent, whereas those untreated often died.⁶¹ After a court ordered Daniel's treatment, Daniel and his mother fled their home in Minnesota.⁶² The pair ultimately returned to Minnesota, where Daniel completed chemotherapy.⁶³

In scenarios like Daniel's or the first hypothetical, where the disease or condition has the potential to cause death or significant morbidity and a known treatment exists, the best interest standard looms large: Parents have the authority to make decisions about the care of their child until such decisions harm the child's best interests. In these scenarios, given the anticipated benefits of treatment and the risks of nontreatment, standard treatment generally represents the course of action deemed in the child's best interest.⁶⁴

In the absence of standard, generally successful treatment options, the calculus changes because the benefits of treatment may no longer outweigh the risks.⁶⁵ Where treatments do not exist, are unproven, unlikely to be successful, or the risks of forgoing treatment are low, the state is less inclined to intervene.⁶⁶ The child's age may also influence the state's involvement as well as the outcome of any judicial decisions on the matter. For example, when an adolescent agrees with their parent's decision and appears sufficiently mature and capable of consent, courts may let that decision stand.⁶⁷

An important factor influencing outcomes in Scenario One is that the decision typically cannot be postponed until the child "possess[es] adequate capacity, cognitive ability, and judgment to engage effectively in the informed consent or refusal process for proposed goals of care."⁶⁸ Instead,

61. Jones & Pesce, *supra* note 60.

62. *Id.*

63. Forliti, *supra* note 60.

64. See Lee Black, *Limiting Parents' Rights in Medical Decision Making*, 8 AM. MED. ASS'N J. ETHICS 676, 676 (2006) ("[I]f the proposed medical treatment has a good chance of success and the predicted outcome without treatment is death, courts are more likely to intervene and overrule parental decisions . . .").

65. See Kathryn L. Weise, Alexander L. Okun, Brian S. Carter & Cindy W. Christian, *Guidance on Forgoing Life-Sustaining Medical Treatment*, PEDIATRICS, Sept. 2017, at 1, 2. ("Applying the best interests standard leads to favoring interventions that are likely to provide greater benefit than burden for the child and discouraging the initiation or continuation of interventions that are likely to lead to greater burden than benefit.")

66. Black, *supra* note 64, at 676 ("[I]f the proposed medical treatment does not have a high likelihood of success or the predicted outcome is not death, courts frequently uphold the decision of parents. Generally, it is only when the child's life is at risk that the weighing of interests favors the child and the government authority that is asserting the child's rights.")

67. See, e.g., *In re E.G.*, 549 N.E.2d 322, 327-28 (Ill. 1989) (allowing a minor, with the support of her mother and upon a court determination that she possessed the requisite degree of maturity, to refuse life-sustaining medical treatment); Art L. Caplan, *Challenging Teenagers' Right to Refuse Treatment*, 9 AM. MED. ASS'N J. ETHICS 56, 56-57 (2007) (describing the story of sixteen-year-old Abraham Cherrix who, along with his parents, wanted to pursue an alternative and unproven treatment for his cancer, which the courts ultimately allowed).

68. Weise et al., *supra* note 65, at 3 (quoting Aviva L. Katz & Sally A. Webb, Comm. on Bioethics, *Informed Consent in Decision-Making in Pediatric Practice*, PEDIATRICS, Aug. 2016, at 1, 5).

Scenario One involves situations where decisions must be made in the short-term (e.g., treatment for an *existing* cancer) to avoid potentially fatal or life-altering consequences.

Further complications and controversies arise in Scenario One when parental decisions, such as to forego standard treatment, are grounded in religious beliefs. As discussed further in Part II, the U.S. Supreme Court has long upheld the rights of parents to make decisions for their children based on religion, particularly in the realm of education.⁶⁹ Lower federal and state courts have extended these rights to medical decisions,⁷⁰ and some states have codified them into law.⁷¹ Yet at the same time, the Court has made clear in persuasive dictum that “[t]he right to practice religion freely does not include liberty to expose the community or the child to communicable disease or the latter to ill health or death.”⁷² These and other cases demonstrate that little is black and white when it comes to medical decision-making for minors.

2. Scenario Two: Medical Intervention to Save Another

A second, less frequent, but more controversial scenario, arises when parents consent to medical interventions and services for their child, but the intent is not to treat or prevent disease in that child. Instead, the goal is to save the life of *another*, such as through bone marrow donation to a sibling. In some cases, the child may have been created for this purpose by using ART and PGT.⁷³

69. See, e.g., *Wisconsin v. Yoder*, 406 U.S. 205, 234–36 (1972); *Pierce v. Soc’y of Sisters*, 268 U.S. 510, 534–36 (1925); *Meyer v. Nebraska*, 262 U.S. 390, 403 (1923); see also *infra* Section II.A (discussing *Meyer*, *Pierce*, *Yoder*, and other parental rights jurisprudence).

70. See, e.g., *Bendiburg v. Dempsey*, 909 F.2d 463, 470 (11th Cir. 1990) (“[N]either the state nor private actors, concerned for the medical needs of a child, can willfully disregard the right of parents to generally make decisions concerning the treatment to be given to their children.”); *Nassau Cnty. Dep’t of Soc. Servs. ex rel. A.Y. v. R.B.*, 870 N.Y.S.2d 874, 879 (N.Y. Fam. Ct. 2008) (holding that a mother’s opposition to vaccinations for her children was genuine, sincere, and rooted in religious belief); *In re Appeal in Cochise Cnty. Juv. Action No. 5666-J*, 650 P.2d 459, 465 (Ariz. 1982) (en banc) (“If there is a direct collision of a child’s right to good health and a parent’s religious beliefs, the parent’s rights must give way.”).

71. See, e.g., 325 ILL. COMP. STAT. ANN. § 5/3 (West Supp. 2023) (“A child shall not be considered neglected or abused for the sole reason that such child’s parent or other person responsible for his or her welfare depends upon spiritual means through prayer alone for the treatment or cure of disease or remedial care as provided under Section 4 of this Act.”); see also Aleksandra Sandstrom, *Most States Allow Religious Exemptions from Child Abuse and Neglect Laws*, PEW RSCH. CTR. (Aug. 12, 2016), <https://www.pewresearch.org/fact-tank/2016/08/12/most-states-allow-religious-exemptions-from-child-abuse-and-neglect-laws> [https://perma.cc/6DXJ-53LY] (showing that some states have codified the protections into law).

72. *Prince v. Massachusetts*, 321 U.S. 158, 166–67 (1944); see also, e.g., *In re McCauley*, 565 N.E.2d 411, 413 (Mass. 1991) (holding that a parent’s interest in the religious upbringing of their children “[does] not warrant the view that parents have an absolute right to refuse medical treatment for their children on religious grounds”).

73. PGT, also referred to as PGD is often used to reduce the risk of passing on inherited conditions but may also be used to ensure a future child is a match for a family member needing

Over the past few decades, the concept of “savior siblings” emerged in the scholarly and lay discourse, with the 2009 movie adaptation of Jodi Picoult’s book, *My Sister’s Keeper*, helping to ignite debate.⁷⁴ Picoult’s novel centers on Anna, a child conceived using PGT so that she would be a bone marrow match for her older sister Kate, who suffered from acute promyelocytic leukemia.⁷⁵ Picoult’s thought-provoking novel offers more than just fictional intrigue; it has basis in reality. Adam Nash, the world’s first known savior sibling was born on August 29, 2000.⁷⁶ His older sister, Molly, suffered from an inherited condition called Fanconi anemia.⁷⁷ Individuals with Fanconi anemia cannot produce sufficient blood cells and often die early in childhood or, if they survive, have a high incidence of certain types of cancer.⁷⁸ Without treatment, Molly was unlikely to see her tenth birthday.⁷⁹ At the time of Adam’s birth, transferring stem cells from a sibling’s umbilical cord represented the best treatment option because it reduced the risk of rejection by the recipient.⁸⁰ Adam’s conception using PGT had two goals: to ensure that he (1) would not suffer from Fanconi anemia and (2) could be a donor for his sister.⁸¹

In addition to savior siblings conceived with the intent of saving an older sibling, children conceived prior to a sibling’s diagnosis may also undergo testing or other procedures to aid the treatment of an ailing sibling. For example, a child may undergo blood tests to determine whether they are a bone marrow match or an appropriate living kidney donor.⁸²

bone marrow. See *Pre-Implantation Genetic Diagnosis*, UNIV. OF CAL. S.F. HEALTH, <https://www.ucsfhealth.org/treatments/pre-implantation-genetic-diagnosis> [<https://perma.cc/RB6L-LT8A>]. This Article uses the term “PGT” rather than “PGD” because, in the context of savior siblings, the purpose of the prenatal testing is not necessarily to diagnose a condition, but rather to test and confirm whether the savior sibling is a donor match.

74. See generally JODI PICOULT, *MY SISTER’S KEEPER* (2004); *MY SISTER’S KEEPER* (New Line Cinema 2009).

75. See generally PICOULT, *supra* note 74.

76. See Donna M. Gitter, *Am I My Brother’s Keeper? The Use of Preimplantation Genetic Diagnosis to Create a Donor of Transplantable Stem Cells for an Older Sibling Suffering from a Genetic Disorder*, 13 GEO. MASON L. REV. 975, 975–76 (2006).

77. *Id.* at 977; Amy T. Y. Lai, *To Be or Not to Be My Sister’s Keeper?: A Revised Legal Framework Safeguarding Savior Siblings’ Welfare*, 32 J. LEGAL MED. 261, 261–62 (2011).

78. Zachary E. Shapiro, *Savior Siblings in the United States: Ethical Conundrums, Legal and Regulatory Void*, 24 WASH. & LEE J.C.R. & SOC. JUST. 419, 420 (2018).

79. See Gitter, *supra* note 76, at 977.

80. *Id.*

81. See Shapiro, *supra* note 78, at 421. According to Adam’s parents, he was not conceived solely to save Molly. See *id.* at 420–21. The Nashes originally wanted more than one child, which was in doubt because both parents carried the gene for Fanconi anemia. *Id.* PGT therefore allowed them to have additional children without the disorder as well as give birth to Adam, who would be a donor match for Molly. *Id.* at 421.

82. Although rare for minors to act as living solid organ donors, examples exist. See Catherine Kim, *Children as Live Kidney Donors for Siblings*, 5 AM. MED. ASS’N J. ETHICS 319, 320 (2003) (citing two court cases allowing minor siblings to act as living kidney donors); Lainie

Significant debate continues about the creation of savior siblings and the rights of parents to consent to nontherapeutic medical procedures for one child to benefit another. Although revisiting these debates in detail is beyond the scope of this Article,⁸³ Scenario Two clearly raises different questions than Scenario One. In considering the best interests of the child under Scenario One, the primary if not sole focus remains on the child receiving a medical intervention that is deemed necessary to protect the child's life or well-being. In Scenario Two, new variables emerge: the best interest of a well child and a sick child. On the one hand, the benefits to the sick child may be significant and even lifesaving. Viewed in isolation, the parents would be well within their authority to consent to the treatment of their sick child. Yet on the other hand, the benefits to the well child (the savior sibling) are relatively minimal while the risks, depending on the procedure, may be significant. Even where the physical risks remain low, such as blood tests and bone marrow donation,⁸⁴ forced or nonconsensual medical interventions impact the well child's rights to bodily integrity, dignity, and autonomy.⁸⁵ Opponents of the practice "suggest that no matter how the parents choose to love and care for [the savior sibling], it still does not ameliorate the harm caused by the fact that this child may be aware that they were born for the purpose of saving their sibling."⁸⁶

Friedman Ross, J. Richard Thistlethwaite, Jr. & the Comm. on Bioethics, *Minors as Living Solid-Organ Donors*, 122 PEDIATRICS 454, 454-55 (2008) (discussing history and examples of minors acting as living solid-organ donors). In *Strunk v. Strunk*, the court authorized the removal of a kidney from a twenty-seven-year-old, who had been deemed incompetent, to his brother. *Strunk v. Strunk*, 445 S.W.2d 145, 145-46, 149 (Ky. 1969). This case did not involve a minor, but it is analogous because it involved an individual who had been deemed incompetent to consent and thus had a legal status similar to a minor. *Id.* at 146.

83. For more fulsome engagement in the debate about savior siblings, see generally MICHELLE TAYLOR-SANDS, SAVIOUR SIBLINGS: A RELATIONAL APPROACH TO THE WELFARE OF THE CHILD IN SELECTIVE REPRODUCTION (2013); Gitter, *supra* note 76; Lai, *supra* note 77; S. Sheldon & S. Wilkinson, *Should Selecting Saviour Siblings Be Banned?*, 30 J. MED. ETHICS 533 (2004).

84. See AM. CANCER SOC'Y, STEM CELL OR BONE MARROW TRANSPLANT 22 (Aug. 4, 2020), <https://www.cancer.org/content/dam/CRC/PDF/Public/128.00.pdf> [<https://perma.cc/X43D-3VHE>] ("There aren't many risks for donors and serious complications are rare.")

85. Cf. Lynn E. Lebit, *Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgment Doctrine*, 7 J.L. & HEALTH 107, 108 (1992) ("In many cases, courts have incorrectly applied the doctrine of 'substituted judgment' to violate the bodily integrity of a minor . . . to bring about a result which on its face seems beneficial to all involved. What courts have failed to do, however, is protect the best interests of these incompetent persons and to recognize their right to be protected, especially when they cannot consent, from non-therapeutic bodily invasions."); Mary Koll, *Growth, Interrupted: Nontherapeutic Growth Attenuation, Parental Medical Decision Making, and the Profoundly Developmentally Disabled Child's Right to Bodily Integrity*, 2010 U. ILL. L. REV. 225, 228 (arguing that nontherapeutic, growth-attenuating interventions on disabled children "severely and irreversibly violat[e] the child's right to bodily integrity").

86. Shapiro, *supra* note 78, at 423; see also Allane Madanamoothoo, *Saviour-Sibling and the Psychological, Ethical and Judicial Issues that It Creates: Should English and French Legislators Close the Pandora's Box?*, 18 EUR. J. HEALTH L. 293, 301 (2011) ("The psychological consequences for the saviour child should also be highlighted. Indeed, they may feel of having been conceived for the

Consensus has not yet been reached about the ethics and legality of savior siblings, and no formal regulations exist in the United States to govern the use or creation of savior siblings.⁸⁷ That said, some courts and commentators suggest that savior siblings are justified by the benefit to the sick child, the relatively minimal physical risk to the well child, and the potential psychological and emotional benefits to the well child.⁸⁸ For example, in *Hart v. Brown*, a case decided decades before the concept of “savior siblings” emerged, the court held that parents had the right to consent to the transplantation of a kidney from their seven-year-old daughter to her identical twin, who was likely to die without the transplant.⁸⁹ In reaching this conclusion, the court discussed at length the potential risks to the prospective recipient if a transplant was not performed.⁹⁰ The court also highlighted the relatively minimal physical risks to the donor sibling as well as testimony of a psychiatrist who attested to the donor’s “strong identification with her twin sister” and how, if successful, the transplant “would be of immense benefit to the donor,” who “would be better off in a family that was happy than in a

sole purpose of caring for their elder brother or sister. . . . [T]he child is not expected for himself, but others have decided for him without his knowledge and through an action which might compromise his body.”).

87. See Shapiro, *supra* note 78, at 422–23. Attempting to “ban” savior siblings would be highly problematic, if not impossible, and something that the author cautions against. First, would savior siblings be banned only if the sole reason the parents want to have another child is to save an existing child? What if, like the Nashes, the couple intended to have additional children anyway? Regulating a couple’s decision to create a savior sibling would require policing the motives behind a couple’s most intimate decisions about conception. As discussed previously, that should cause significant pause in light of the Supreme Court’s recent decision to overturn *Roe* and *Casey*. See *Dobbs v. Jackson Women’s Health Org.*, 142 S. Ct. 2228, 2242 (2022). *Dobbs*, and state actions following that case, highlight regressive trends in matters relating to reproduction and sexual intimacy. The long-term potential consequences, some of which remain unknown, highlight a need for caution when thinking about the role of law and policy in intimate personal and family decisions. See *supra* notes 26–28 and accompanying text; *infra* note 360 and accompanying text.

88. See *infra* notes 89–91 and accompanying text; see also *Strunk v. Strunk*, 445 S.W.2d 145, 146, 149 (Ky. 1969) (finding that the parent’s consent to kidney removal from their incompetent adult son and donation to his brother was in his best interests because losing his brother would have been emotionally and psychologically damaging); Kim, *supra* note 82, at 320 (discussing cases and the reliance on psychological benefits); Ross et al., *supra* note 82, at 455 (discussing some potential psychological and emotional benefits for a living donor); Sheldon & Wilkinson, *supra* note 83, at 535–37 (refuting the argument that savior siblings will suffer physically and/or emotionally). As noted by Zachary Shapiro, “there is currently little direct evidence to back up claims that being a savior sibling is damaging to the welfare, psychological or emotional health of the savior sibling.” Shapiro, *supra* note 78, at 435. That said, Shapiro notes one possible reason for this lack of evidence is the relative novelty of savior siblings and thus lack of long-term investigation. *Id.*

89. *Hart v. Brown*, 289 A.2d 386, 386–87, 391 (Conn. Super. Ct. 1972).

90. *Id.* at 388–89.

family that was distressed and in that it would be a very great loss to the donor if the donee were to die from her illness.”⁹¹

Limited data exist about the frequency with which savior siblings are conceived and about their short- and long-term physical and socioemotional outcomes. Thus far, the evidence is mixed. For his part, Adam Nash has no regrets or feelings of ill-will toward his parents or sibling. On the contrary, he “like[s] being able to help” his sister, which he feels has given him “a very heavy purpose.”⁹² Other data, however, show that donor siblings experience more anxiety and lower self-esteem, as well as anger toward their parents during and following the process.⁹³ More research is needed before any legal or regulatory decisions are made about the use of donor siblings.

Although they represent distinct situations, a few commonalities between Scenarios One and Two emerge. First, decisions must be informed, in part, by the parents’ authority to make decisions regarding the care and treatment of an ill child. Second, and importantly, the decision cannot be postponed until the savior sibling reaches an age at which they have the capacity to consent and make their own autonomous decisions. That said, as discussed in Scenario Three below, savior siblings—at least those created with the use of ART and PGT—represent another area where emerging technologies have outpaced law and policy and may not fit comfortably within traditional legal frameworks.

3. Scenario Three: Pediatric Predisposition Genetic Testing

Scenario Three illuminates the main focus of this Article and involves parental consent to PPGT for adult-onset diseases that (1) have no known cure or reliable method of prevention;⁹⁴ and/or (2) merely show susceptibility

91. *Id.* at 389; *see also* Shapiro, *supra* note 78, at 436 (arguing that a savior sibling may “feel pride and contentment in the knowledge that he or she is responsible for saving the life of a sibling”).

92. *17 Years Later, Nash Family Opens Up About Controversial Decision to Save Dying Daughter*, DENVER7 (Nov. 14, 2017, 3:49 PM), <https://www.denver7.com/news/local-news/17-years-later-nash-family-opens-up-about-controversial-decision-to-save-dying-daughter> [<https://perma.cc/2JLC-PDC8>] (quoting Adam Nash); *see also* Shapiro, *supra* note 78, at 436 & n.110 (citing “anecdotal interview data report[ing] high level[s] of satisfaction for the savior sibling”).

93. *See* Wendy Packman, Kimberly Gong, Kelly VanZutphen, Tani Shaffer & Mary Crittenden, *Psychosocial Adjustment of Adolescent Siblings of Hematopoietic Stem Cell Transplant Patients*, 21 J. PEDIATRIC ONCOLOGY NURSING 233, 240–41 (2004); *see also* Lori S. Wiener, Emilie Steffen-Smith, Terry Fry & Alan Wayne, *Hematopoietic Stem Cell Donation in Children: A Review of the Sibling Donor Experience*, 25 J. PSYCHOSOCIAL ONCOLOGY 45, 49–50 (2007) (reviewing the literature and finding a range of psychological distress responses in donor siblings); Andrea D. Winther Klippenstein, Caroline C. Piotrowski, Janice Winkler & Christina H. West, *Growth in the Face of Overwhelming Pressure: A Narrative Review of Sibling Donor Experiences in Pediatric Hematopoietic Stem Cell Transplant*, 27 J. CHILD HEALTH CARE 60, 67–69 (2021) (describing four themes of the donor sibling literature: fear and anxiety related to testing, pressure to donate, guilt and blame when the ill child died, and emotional and physical isolation following donation).

94. To clarify further: the first group of adult-onset diseases is distinguishable from the second group because diseases in the first group have no known cure or reliable method of prevention. This could include conditions such as Huntington’s disease, for which genetic testing

to a disease and are generally performed on an otherwise asymptomatic child.⁹⁵ As science evolves, the number and type of tests within each category will change.

The first category would include tests that show whether a disease is guaranteed to develop as well as tests that show mere susceptibility/risk of developing a disease, but in either case the disease being tested for has no known cure or method of prevention, such as Huntington's disease⁹⁶ or ALS.⁹⁷ Huntington's disease is a rare, inherited disease that causes progressive

can show definitively whether a person will develop the disease, but the disease lacks a known cure or method of prevention. This could also include diseases for which tests can only show susceptibility to a disease that lacks a known cure or method of prevention, such as ALS. In contrast, the diseases in the second group, such as various types of cancer, may be curable, but the genetic testing only shows a person's susceptibility to the disease rather than indicating definitively that the disease will develop. Testing for *BRCA1* and *BRCA2* mutation represents an example of this latter group.

95. Many diseases have a genetic component, but most are not like Huntington's disease, which is caused by a variant/mutation in a single gene. Instead, most diseases are the result of a complex mix of factors including genetics, lifestyle, and myriad environmental factors, meaning that genetic testing can show susceptibility but cannot definitively say the particular disease will develop. *What Are Complex or Multifactorial Disorders?*, MEDLINEPLUS, NAT'L LIBR. OF MED. (May 14, 2021), <https://medlineplus.gov/genetics/understanding/mutationsanddisorders/complexdisorders> [<https://perma.cc/6FQH-C398>]. Given the numerous factors that influence disease development, a person with sufficient resources may be able to reduce their nongenetic risks of disease, such as through diet, exercise, and routine preventative care. Yet historic and ongoing racism, discrimination, and other structural barriers often mean that members of historically marginalized and vulnerable populations—who may already be at higher risk for disease—cannot avail themselves of these preventive measures, increasing their risks of myriad diseases and poor health outcomes. See, e.g., MELANIE CARVER, HANNAH JAFFEE, SANAZ EFTEKHARI & MO MAYRIDES, ASTHMA & ALLERGY FOUND. OF AM., 2020 ASTHMA DISPARITIES IN AMERICA: A ROADMAP TO REDUCING BURDEN ON RACIAL AND ETHNIC MINORITIES 11, 14 (2020), <https://www.aafa.org/wp-content/uploads/2022/08/asthma-disparities-in-america-burden-on-racial-ethnic-minorities.pdf> [<https://perma.cc/97ZS-HSB3>] (explaining how the burden of asthma in the United States falls disproportionately on communities of color); Ruqaiyah Yearby, Brietta Clark & José F. Figueroa, *Structural Racism in Historical and Modern US Health Care Policy*, 41 HEALTH AFFS. 187, 188–92 (2022) (providing an account of structural racism in healthcare policy and its consequences); David R. Williams, Opinion, *Stress Was Already Killing Black Americans. Covid-19 Is Making It Worse.*, WASH. POST (May 13, 2020), <https://www.washingtonpost.com/opinions/2020/05/13/stress-was-already-killing-black-americans-covid-19-is-making-it-worse/> (on file with the *Iowa Law Review*) (describing the “pandemic of stress” faced by Black Americans and how COVID-19 combined with this pandemic of stress and made “everything that’s already bad about a hundred times worse”).

96. Huntington's disease results from a single abnormal gene. Scientists have isolated the Huntington's disease gene, so genetic testing can be used to confirm whether or not a person carries the abnormal gene, and thus whether they will develop the disease. Mayo Clinic Staff, *Huntington's Disease, Symptoms & Causes*, MAYO CLINIC (May 17, 2022), <https://www.mayoclinic.org/diseases-conditions/huntingtons-disease/symptoms-causes/syc-20356117> [<https://perma.cc/S9TV-F6SG>].

97. The FDA has approved three medicines to treat the symptoms and slow the course of the disease, but there is no cure. See Mayo Clinic Staff, *Amyotrophic Lateral Sclerosis (ALS), Diagnosis & Treatment*, MAYO CLINIC (Apr. 25, 2023), <https://www.mayoclinic.org/diseases-conditions/amyotrophic-lateral-sclerosis/diagnosis-treatment/drc-20354027> [<https://perma.cc/UP8F-NPV4>].

breakdown of nerve cells in the brain.⁹⁸ Huntington's is an autosomal dominant condition caused by an inherited mutation in a single gene, meaning a person needs to inherit only one copy of the mutated gene to develop the disease.⁹⁹ People with the mutation will typically develop Huntington's symptoms in their thirties and forties, although those with "juvenile Huntington's" can experience symptoms earlier in life.¹⁰⁰ The symptoms of Huntington's are progressive and ultimately devastating. They include movement disorders (e.g., involuntary jerking, muscle rigidity, difficulty with speech or swallowing), cognitive disorders (e.g., difficulty organizing or focusing on tasks, lack of impulse control, difficulty in learning new information), and psychiatric disorders (e.g., depression, obsessive-compulsive disorder, mania, bipolar disorder).¹⁰¹ "[C]ompleted suicide has been reported to be as high as [thirteen percent] in [those with] Huntington's . . . reflecting a seven- to [twelve]-fold increase from the rate in the general population."¹⁰² Genetic testing reveals whether a person will develop Huntington's, but it cannot indicate when symptoms will first appear or the severity of symptoms the person will experience.¹⁰³ Huntington's disease cannot be prevented¹⁰⁴ and there are no known cures or treatments to alter the course of the disease, although medications may lessen some symptoms.¹⁰⁵

ALS, another progressive nervous system disease that affects nerve cells in the brain and spinal cord, causing loss of muscle control, cannot be predicted definitively with genetic testing and "genetics alone do not cause [ALS]".¹⁰⁶ However, "a large number of genetic mutations have been associated with" ALS that may increase a person's risk of developing the

98. Mayo Clinic Staff, *Huntington's Disease, Symptoms & Causes*, *supra* note 96.

99. *Id.*

100. *Id.*

101. *Id.*

102. Jane S. Paulsen, Karin Ferneyhough Hoth, Carissa Nehl & Laura Stierman, *Critical Periods of Suicide Risk in Huntington's Disease*, 162 AM. J. PSYCHIATRY 725, 725 (2005).

103. Mayo Clinic Staff, *Huntington's Disease, Diagnosis & Treatment*, MAYO CLINIC (May 17, 2022), <https://www.mayoclinic.org/diseases-conditions/huntingtons-disease/diagnosis-treatment/drc-20356122> [<https://perma.cc/ANX5-KDYW>].

104. Mayo Clinic Staff, *Huntington's Disease, Symptoms & Causes*, *supra* note 96. To clarify, there is no method of prevention once an individual is born. *See id.* However, a person who carries the Huntington's gene can prevent Huntington's in a future offspring by using donor eggs or sperm or by using in vitro fertilization and PGD so that only embryos that test negative for the Huntington gene are implanted in the uterus. *Id.*

105. *Id.*

106. *ALS and Genetics*, ALS NEWS TODAY (Nov. 30, 2021), <https://alsnewstoday.com/als-and-genetics> [<https://perma.cc/6S33-GZVG>].

disease.¹⁰⁷ Yet, similar to Huntington's, ALS cannot be cured or prevented, although medicines can slow the course of the disease and ease symptoms.¹⁰⁸

The second category would include tests such as those utilized by Angelina Jolie, which can determine whether a person has certain genetic mutations that make them more susceptible to developing a disease later in life, such as certain types of cancer.¹⁰⁹ These diseases may have known therapeutic or even curative treatments, but unlike tests for Huntington's, genetic testing cannot determine with certainty whether a person will develop the disease.¹¹⁰ Historically, these tests have been performed on asymptomatic individuals with a family history of the specific disease, as was the case with Jolie. With the advent of direct-to-consumer and consumer-directed¹¹¹ genetic testing, far more individuals are using these tests, including individuals with no known risk factors for particular diseases.¹¹²

As genetic testing capabilities emerged during the late twentieth and early twenty-first centuries, the medical and bioethical communities largely agreed that children should not be tested for adult-onset disorders that lacked any existing cure or treatments.¹¹³ Today, although generally still discouraged, "[t]he emerging position is one of greater flexibility," with decisions made on a case-by-case basis.¹¹⁴ The extent to which PPGT occurs in the clinical setting

107. *Id.*; see also Hanae Armitage, *Discovery of Hundreds of Genes Potentially Associated with ALS May Steer Scientists Toward Treatments*, STANFORD MED. (Jan. 18, 2022), <https://med.stanford.edu/news/all-news/2022/01/genes-amyotrophic-lateral-sclerosis.html> [<https://perma.cc/5TUM-TEGU>] (detailing the discovery of "almost 700 genes potentially associated with ALS").

108. See Mayo Clinic Staff, *Amyotrophic Lateral Sclerosis (ALS), Diagnosis & Treatment*, *supra* note 97.

109. See sources cited *supra* note 6 (defining predisposition genetic testing and diagnostic genetic testing).

110. See, e.g., Mayo Clinic Staff, *Genetic Testing*, MAYO CLINIC (Apr. 14, 2020), <https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827> [<https://perma.cc/3BS7-VFY4>] ("[I]n some situations, a negative result doesn't guarantee that you won't have a certain disorder.").

111. Direct-to-consumer genetic testing does not involve a healthcare provider. Scott M. Weissman, Brianne Kirkpatrick & Erica Ramos, *At-Home Genetic Testing in Pediatrics*, 31 CURRENT OP. PEDIATRICS 723, 724 (2019). "Consumer-directed clinical testing . . . enables the []consumer to request a clinical test online," which will be ordered by a healthcare provider and performed in a certified laboratory. *Id.*

112. See, e.g., *Health + Ancestry Service, Frequently Asked Questions*, 23 AND ME, <https://www.23andme.com/dna-health-ancestry> [<https://perma.cc/99MK-GKHM>] (stating that the company's tests and "reports can tell you how your DNA can impact your chances of developing certain conditions").

113. Jeffrey R. Botkin, *Ethical Issues in Pediatric Genetic Testing and Screening for Current Opinion in Pediatrics*, 28 CURRENT OP. PEDIATRICS 700, 702 (2016); see also Bonnie Steinbock, *Prenatal Testing for Adult-Onset Conditions: Cui Bono?*, 15 REPROD. MED. ONLINE 38, 38 (2007) (noting the general consensus).

114. Botkin, *supra* note 113, at 702; see also Dawn C. Allain, *Testing Children for Adult-Onset Disorders*, in ETHICAL DILEMMAS IN GENETICS AND GENETIC COUNSELING 96, 98 (Janice L. Berliner ed., 2015) ("[W]ith the onset of new genetic technology the position of deferring testing until the minor has attained adulthood is being considered again . . ."); Angela Fenwick, Mirjam Plantinga, Sandi Dheensa & Anneke Lucassen, *Predictive Genetic Testing of Children for Adult-Onset Conditions: Negotiating Requests with Parents*, 26 J. GENETIC COUNSELING 244, 244-45 (2017) ("Although professional consensus not to test in childhood for later-onset conditions has been

is unknown and perhaps unknowable, but as availability and affordability improves, requests from parents will likely increase.¹¹⁵ Moreover, easily accessible and relatively affordable at-home testing options raise the specter of parents testing their children at home without the benefit of consultation with a pediatrician and/or genetic counselor.¹¹⁶ Misunderstanding these results can have long-term consequences.¹¹⁷ As positions on this issue and professional guidance continue to evolve, further discussion and debate—grounded squarely in the rights and interests of the child—remain necessary.

Given that parents make—and often *must* make—medical decisions for their children in a variety of different situations, what, if anything, distinguishes decisions about PPGT from others, such as those described in Scenarios One and Two? Despite some similarities, a number of differences deserve recognition.

B. SCENARIO THREE: THE DISTINCTIONS

A key difference among the Scenarios is that in Scenario Three neither the child nor a sibling is currently sick and in need of immediate treatment, nor is there a well child receiving standard medical care to maintain their current well-being (e.g., annual physicals) or to prevent known risk of a disease (e.g., a recommended childhood vaccine). Proponents of PPGT might suggest that it aligns with rationales for preventive care, as PPGT could provide the opportunity to take steps to reduce the risk of an adult onset disease, such as through lifestyle changes (diet and exercise) or more frequent health screenings.¹¹⁸ For diseases that cannot be prevented, proponents of testing claim that early knowledge of the impending onset of the disease provides individuals more time to prepare and plan, allowing them to make life plans, learn coping skills, and develop systems of support and caregiving.¹¹⁹ Nevertheless, these alleged benefits must be weighed against unique harms that can arise in Scenario Three.

consistent, there has been a noticeable change in emphasis as genetic technology has encompassed genomic testing.”); Jeremy R. Garrett et al., *Rethinking the “Open Future” Argument Against Predictive Genetic Testing of Children*, 21 GENETICS MED. 2190, 2190 (2019) (stating that prior professional recommendations and consensus “are now being questioned”).

115. Fenwick et al., *supra* note 114, at 245.

116. See Weissman et al., *supra* note 111, at 724; see also Kandamurugu Manickam et al., *Exome and Genome Sequencing for Pediatric Patients with Congenital Anomalies or Intellectual Disability: An Evidence-Based Clinical Guideline of the American College of Medical Genetics and Genomics (ACMG)*, 23 GENETICS MED. 2029, 2034 (2021) (providing recommendations for genetic counseling).

117. See Weissman et al., *supra* note 111, at 725; Salma Abdalla, *At-Home Genetic Testing Leads to Misinterpretations of Results*, BOS. UNIV. SCH. PUB. HEALTH (Feb. 20, 2018), <https://www.bu.edu/sph/news/articles/2018/at-home-genetic-testing-leads-to-misinterpretations-of-results> [<https://perma.cc/LY23-SJXX>].

118. See Anne-Marie Laberge & Wylie Burke, Commentary, *Testing Minors for Breast Cancer*, 9 AM. MED. ASS’N J. ETHICS 6, 7 (2007) (describing possible benefits of predisposition testing).

119. See Sandi Wiggins et al., *The Psychological Consequences of Predictive Testing for Huntington’s Disease*, 327 NEW. ENG. J. MED. 1401, 1404 (1992) (“[P]redictive testing for Huntington’s disease

The rights implicated and potential harms that may arise when decisions about PPGT are left to parents can be summarized succinctly. Three primary harms include: (1) subjecting the child to excessive testing and invasive procedures; (2) creating parental overconfidence and inaction when test results are negative;¹²⁰ and (3) imposing socioemotional burdens on children who receive positive results, who may be treated differently by parents and society as a result. Four primary rights at stake include: (1) the right against compelled disclosure of private information to others or to oneself (i.e., the right not to know); (2) the right against unreasonable search and seizure of one's body and one's personal information; (3) the right against intrusion upon seclusion; and (4) the right to autonomy and bodily privacy. The first three rights relate to "information privacy," which includes "the right of individuals to control information about themselves."¹²¹ The last right draws upon the concept of "decisional privacy," which constitutes "the right of individuals to make certain kinds of fundamental choices with respect to their personal and reproductive autonomy, and has its locus in the constitutional jurisprudence of *Roe v. Wade* and *Griswold v. Connecticut*."¹²² Taken together, these four rights support and coalesce into what this Article refers to as a "right to future privacy," which is described further in Part III.¹²³

From a physical perspective, PPGT is minimally invasive and low risk, typically involving a blood test or cheek swab.¹²⁴ Nevertheless, the child's physical health can be affected if certain actions are taken based on the results, which may have positive or negative consequences. As noted, a parent might incorporate various lifestyle changes to reduce the child's risk of diseases like cancer. Yet there is no guarantee that preventative actions will ultimately influence whether the disease develops, and people may lack the resources to engage in the preventative measures most likely to be effective.¹²⁵

may maintain or even improve the psychological well-being of many people at risk. . . . Knowing the result of the predictive test, even if it indicates an increased risk, reduces uncertainty and provides an opportunity for appropriate planning."); Janet K. Williams et al., *Personal Factors Associated with Reported Benefits of Huntington Disease Family History or Genetic Testing*, 14 GENETIC TESTING & MOLECULAR BIOMARKERS 629, 631–33 (2010) (reporting various perceived benefits of testing for Huntington's); *Genetic Testing & Family Planning*, HUNTINGTON'S DISEASE SOC'Y OF AM., <https://hdsa.org/what-is-hd/history-and-genetics-of-huntingtons-disease/genetic-testing-family-planning> [<https://perma.cc/ER8J-9S7J>] (noting that some "want an end to uncertainty so that they can make informed choices about the future").

120. "Negative" results refer to results that show no increased risk of future disease, whereas "positive" results are those that show an increased risk or presence of a genetic condition that will develop in the future.

121. Neil M. Richards, *The Information Privacy Law Project*, 94 GEO. L.J. 1087, 1089 (2006); see also *infra* notes 298–302 and accompanying text (further discussing information and decisional privacy).

122. Richards, *supra* note 121, at 1089 (citations omitted).

123. See *infra* Part III.

124. Mayo Clinic Staff, *Genetic Testing*, *supra* note 110.

125. If PPGT were to become routine, individuals may undergo testing and receive results they cannot act on due to insufficient resources and other structural constraints. Cf. *supra* note

Moreover, PPGT is not required to induce such general preventative behaviors. On the contrary, these types of lifestyle modifications should be undertaken regardless of the results of a genetic test.¹²⁶

On the negative side, test results that suggest an increased risk for disease may cause parents to seek more radical interventions or excessive testing, which come with financial, physical, and emotional costs.¹²⁷ In many cases, the best methods of prevention—if they exist—will be unavailable or inadvisable during childhood. For example, consider a mother who learns that her child has the *BRCA1* or *BRCA2* mutation and is told that her child has the same increased risk of cancer as Jolie.¹²⁸ It is unlikely that any healthcare provider would recommend or agree to perform a prophylactic double mastectomy or oophorectomy¹²⁹ on the child.¹³⁰ At the other end of

95 (noting that discrimination and various structural barriers may impose insurmountable barriers to a person's ability to engage in certain preventative measures).

126. In many ways, the argument for making those changes is even stronger if there is *no* genetic predisposition, as that means disease development will largely be influenced by lifestyle and environmental factors. This is the well-known “nature versus nurture” debate. See, e.g., Hasan Korkaya & Max S. Wicha, *Cancer Stem Cells: Nature Versus Nurture*, 12 NATURE CELL BIOLOGY 419, 419 (2010).

127. For example, some parents may seek out certain imaging tests to try to discover any early physical changes or presence of disease. These might include things like X-rays, CT scans, or other radiological imaging. Such imaging tests are noninvasive and relatively low risk, but overexposure to radiation may increase the risk of certain cancers. See Martha S. Linet et al., *Cancer Risks Associated with External Radiation from Diagnostic Imaging Procedures*, 62 CA: CANCER J. FOR CLINICIANS 75, 75 (2012); *Do X-Rays and Gamma Rays Cause Cancer?*, AM. CANCER SOC'Y (Nov. 10, 2022), <https://www.cancer.org/healthy/cancer-causes/radiation-exposure/x-rays-gamma-rays/do-xrays-and-gamma-rays-cause-cancer.html> [<https://perma.cc/G5X5-4YFC>]; see also Jeffrey R. Botkin et al., *Outcomes of Interest in Evidence-Based Evaluations of Genetic Tests*, 12 GENETICS MED. 228, 230 (2010) (noting risks of “needless additional testing” and “inappropriate therapy”); Weissman et al., *supra* note 111, at 725 (indicating that potential risks of at-home and consumer-directed testing include “changes to health screening, diet or medications that are inappropriate or not medically indicated”); Ravindranath & Lawrence, *supra* note 4 (“[R]adiologists have been sounding the alarm on the dangers of overtesting for decades While MRIs can pick up legitimately threatening conditions, they also pick up abnormalities that are completely benign. Patients then spend time and money seeking more invasive tests, panicking about something that never would have harmed them in the first place.”).

128. See *supra* notes 1–2 and accompanying text.

129. “An oophorectomy . . . is a surgical procedure to remove one or both of [a person's] ovaries.” Mayo Clinic Staff, *Oophorectomy (Ovary Removal Surgery)*, ABOUT, MAYO CLINIC (Feb. 11, 2022), <https://www.mayoclinic.org/tests-procedures/oophorectomy/about/pac-20385030> [<https://perma.cc/VH5P-NFN9>].

130. See Laberge & Burke, *supra* note 118, at 7 (“[N]o interventions would be recommended [for eight- and ten-year-olds] . . . even if either tested positive [for a *BRCA1* mutation].”); F. M. Hodges, J. S. Svoboda & R. S. Van Howe, *Prophylactic Interventions on Children: Balancing Human Rights with Public Health*, 28 J. MED. ETHICS 10, 11–12 (2002) (arguing against the use of prophylactic mastectomies on infants and children who have not attained the age of majority or competence to consent); see also Ying L. Liu et al., *Risk-Reducing Bilateral Salpingo-Oophorectomy for Ovarian Cancer: A Review and Clinical Guide for Hereditary Predisposition Genes*, 18 JCO ONCOLOGY PRAC. 201, 202, 204 (2021) (noting that a prophylactic oophorectomy is

the spectrum, where testing finds no increased risk (i.e., a “negative” result), false reassurance and overconfidence in the negative result could have the opposite effect, leading parents (and the child during adulthood) to decline care and various risk-reducing, potentially life-saving interventions, screenings, and other measures.¹³¹ Importantly, genetic predispositions, or lack thereof, are not guarantees. Yet, they are too often treated as such, which risks serious consequences.

Perhaps of greater concern are the possible psychological, social, dignitary, and privacy-related consequences for the child. Broader and more affordable access to genetic testing increases the risk that PPGT will be used without taking adequate pause to consider the consequences of having this information. The results of PPGT may reveal information that directly or indirectly alters the course of a person’s life.¹³² Notably, once learned, the information cannot be unlearned. The parents, and importantly the child—who did not have a say in whether to seek out this information—must live with that knowledge for the rest of their lives. Unfortunately, the burdens of this knowledge are immeasurable, and may include various social and emotional struggles.

Information from PPGT can be both a blessing and a curse. Studies correlate deleterious genetic testing results with poor body image and self-esteem, as well as feelings of unworthiness and/or shame.¹³³ Other possible harms include social stigmatization and damage to familial relationships.¹³⁴ As one genetic counselor explains:

The underlying premise is that if a parent knows that his or her child is at risk for a genetic disease, how the parent treats the child and his or her expectations/hopes for the child’s future will change. The concern is that parents will potentially change how they support their children, specifically by withdrawing or limiting resources—

recommended for ages thirty-five through forty for *BRCA1* mutation carriers, and ages forty through forty-five for *BRCA2* mutation carriers).

131. See Botkin et al., *supra* note 127, at 231; Comm. on Genetics, *Consumer Testing for Disease Risk*, AM. COLL. OBSTETRICIANS & GYNECOLOGISTS e4 (Jan. 2021), <https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2021/01/consumer-testing-for-disease-risk.pdf> [<https://perma.cc/F5X3-E6T7>].

132. *Dr. Drew* (HLN television broadcast Oct. 8, 2012) (transcript available at *Transcripts*, CNN, <http://edition.cnn.com/TRANSCRIPTS/1210/08/ddhln.01.html> [<https://perma.cc/C67-FX3T>]) (“As much as I think that having knowledge is great, it also alter[s] . . . your path in life.” (quoting Wendy Brokaw, who tested positive for a *BRCA1* gene mutation)).

133. See Allain, *supra* note 114, at 101–02 (citing studies); Laberge & Burke, *supra* note 118, at 7 (citing studies).

134. See Allain, *supra* note 114, at 102 (citing studies); Laberge & Burke, *supra* note 118, at 7 (noting potential effects on sibling relationships).

emotionally, financially, and physically—from a child who is at risk for developing a disease.¹³⁵

The relative novelty and infrequent use of PPGT means there is a dearth of evidence-based literature on the psychological and social impacts of PPGT. With time, data may support or refute the existence of long-term harms.¹³⁶ Empirical work must continue to ensure law and policy reflect reality rather than assumptions.

Yet regardless of what future data show, other important and perhaps paramount considerations will remain. First is a related yet less tangible potential harm: the minor's present and future autonomy and right to self-determination.¹³⁷ Autonomy concerns are well represented in ethics literature. In short, PPGT disregards children's future decision-making capacity¹³⁸ and forces information upon them that they may not want to know, neither now nor in the future. Philosopher Joel Feinberg's concept of the "right to an open future" informs these arguments.¹³⁹ Feinberg developed the concept of "rights-in-trust," which he describes as follows:

When sophisticated autonomy rights are attributed to children who are clearly not yet capable of exercising them, [rights-in-trust] refer to rights that are to be *saved* for the child until he is an adult, but which can be violated "in advance," so to speak, before the child is even in a position to exercise them. . . . His right while he is still a child is to have these future options kept open until he is a fully formed, self-determining adult capable of deciding among them.¹⁴⁰

Opponents of PPGT thus assert that delaying decisions about PPGT ensures that the child retains the ability to make their own determinations in the future about the risks and benefits associated with genetic testing.¹⁴¹ Importantly, this includes the right to *not know at all*. Indeed, a principal harm of PPGT is that once the results are learned, they cannot be unlearned—

135. Allain, *supra* note 114, at 102; *see also* Laberge & Burke, *supra* note 118, at 7 ("Knowledge of an adverse test result could change the parents' expectations of the child's future in a negative way. In response to an adverse test result, parents might think of the child as 'sick and damaged' or might perceive her as vulnerable and become overly protective of her." (citations omitted)).

136. Garrett et al., *supra* note 114, at 2190 ("[A]ccumulating evidence" suggests these harms may be "less common and less impactful than originally feared").

137. *Id.* at 2191 ("[U]nlike the concern about immediate psychosocial harms, the violation of a moral right [like autonomy] is a value claim that cannot be refuted by empirical evidence.").

138. Allain, *supra* note 114, at 103.

139. JOEL FEINBERG, FREEDOM AND FULFILLMENT: PHILOSOPHICAL ESSAYS 76–97 (1992); *see also* Garrett et al., *supra* note 114, at 2190–91 (noting the origins of the phrase).

140. FEINBERG, *supra* note 139, at 76–77.

141. *See, e.g.*, Alan Fryer, *Inappropriate Genetic Testing of Children*, 83 ARCHIVES DISEASE CHILDHOOD 283, 283 (2000) (citing a survey of pediatric health care professionals); Cara Mand, Lynn Gillam, Martin B Delatycki & Rony E Duncan, *Predictive Genetic Testing in Minors for Late-Onset Conditions: A Chronological and Analytical Review of the Ethical Arguments*, 38 J. MED. ETHICS 519, 520 (2012) (citing failure to respect a child's future autonomy as a reason against testing minors).

Pandora's box cannot be closed. These types of autonomy-based concerns and the right to an open future ground the historical consensus against the use of PPGT, but that consensus may be changing.¹⁴² Even while many Americans want to know their genetic predispositions, others do not.¹⁴³ In a space as important and personal as genetics, law and policy must avoid ascribing the views of the majority to all members of society.

The autonomy harms relate closely to another issue that infiltrates genetic testing: privacy. Privacy concerns often arise from fears about genetic discrimination. Some concerns have been assuaged by the passage of laws such as the Genetic Information Nondiscrimination Act of 2008 ("GINA"), a federal law that prohibits discrimination on the basis of genetic information with respect to health insurance and employment.¹⁴⁴ Additional protections against genetic discrimination can be found in (1) the Health Insurance Portability and Accountability Act ("HIPAA"), which limits the release of a patient's health information (including genetic information) and prohibits the use of health information by insurers to determine health insurance benefits and premiums;¹⁴⁵ (2) the Patient Protection and Affordable Care Act ("ACA"), which prohibits health insurers from discriminating against patients because of "preexisting condition[s]" and limits criteria upon which premiums

142. Garrett et al., *supra* note 114, at 2190–91; *see supra* note 114 and accompanying text.

143. *See, e.g., Genetic Testing: Ancestry Interest, but Privacy Concerns*, ASSOCIATED PRESS-NORC CTR. FOR PUB. AFFS. RSCH. 4 (July 2018), https://www.norc.org/content/dam/norc-org/pdfs/Genetic%20Testing_%20Ancestry%20Interest,%20But%20Privacy%20Concerns%20_%20NORC.pdf [<https://perma.cc/ASS3-3CHF>] (reporting that thirty-nine percent of respondents would not want to know if they carried a gene associated with an incurable disease); UNIV. OF MICH., NATIONAL POLL ON HEALTHY AGING: OLDER ADULTS' VIEWS ON GENETIC TESTING 2 (2018), https://deepblue.lib.umich.edu/bitstream/handle/2027.42/145710/NPHA_Genetic-Testing-Report_092518-FINAL.pdf?sequence=1&isAllowed=y [<https://perma.cc/XAT6-C3MQ>] (finding that forty percent of respondents would not be interested in genetic testing to estimate risk of future disease); Karen E. Anderson et al., *The Choice Not to Undergo Genetic Testing for Huntington Disease: Results from the PHAROS Study*, 96 CLINICAL GENETICS 28, 28 (2019) (reporting current estimates that only twelve to seventeen percent of adults at risk for Huntington's disease pursue genetic testing); *National Poll Shows Public Divided on Genetic Testing to Predict Risk*, UNIV. OF UTAH HEALTH (Feb. 4, 2014), <https://healthcare.utah.edu/press-releases/2014/02/national-poll-shows-public-divided-genetic-testing-predict-risk> [<https://perma.cc/JLD7-4AK3>] (finding that thirty-four percent of respondents would not seek genetic testing of a hereditary cancer, even if cost were not an issue).

144. *See* Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881. Specifically, GINA (1) prohibits health insurers from using genetic information to determine a person's eligibility for insurance or to make decisions about coverage, underwriting, or premiums; and (2) prohibits employers from using genetic information in employment decisions such as hiring, firing, promotions, pay, and job assignments. *Id.*

145. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 100 Stat. 1936.

may be based;¹⁴⁶ and (3) “[a] patchwork of state laws” that vary in scope and applicability and may provide protections beyond those found in federal laws.¹⁴⁷

All of these protections, however, have important limitations¹⁴⁸:

- GINA’s protections do not apply to long-term care insurance, life insurance, or disability insurance.¹⁴⁹
- GINA’s employment protections do not extend to the U.S. military, thus allowing the military to use genetic information in employment decisions.¹⁵⁰
- “GINA does not apply to employers with fewer than [fifteen] employees,”¹⁵¹ an important gap given that approximately twenty million Americans work for employers with fewer than twenty employees.¹⁵²
- Many Republican politicians continue to call for the repeal of the ACA, which would eliminate the current protections for those with preexisting conditions.¹⁵³

As for HIPAA, many believe it “protects a lot more health information than it actually does.”¹⁵⁴ For example, HIPAA “contains exceptions that could allow prosecutors to compel businesses to relinquish information relevant to . . . [various] kinds of legal action.”¹⁵⁵ And importantly, HIPAA “applies to the results of genetic tests administered by . . . health-care provider[s], but it

146. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119, 154 (2010) (codified at 42 U.S.C. § 360gg-3(a)) (“A group health plan and a health insurance issuer offering group or individual health insurance coverage may not impose any preexisting condition exclusion with respect to such plan or coverage.”).

147. See *Genetic Discrimination*, NAT’L HUM. GENOME RSCH. INST. (Jan. 6, 2022), <https://www.genome.gov/about-genomics/policy-issues/Genetic-Discrimination> [<https://perma.cc/B3Z2-D2QU>].

148. See generally *id.* (“GINA sets a floor of minimum protection against genetic discrimination and does not preempt state laws with stricter protections.”).

149. Some state laws extend protections to these forms of insurance. *Id.*

150. Relatedly, “eligibility for [the U.S. Military’s] TRICARE insurance [program] is contingent upon employment by the military, and so genetic test results [necessarily impact] one’s ability to access TRICARE insurance.” *Id.*

151. *Id.*

152. OFF. OF ADVOC., U.S. SMALL BUS. ADMIN., 2020 SMALL BUSINESS PROFILE 1 (2020), <https://advocacy.sba.gov/wp-content/uploads/2020/06/2020-Small-Business-Economic-Profile-States-Territories.pdf> [<https://perma.cc/87QN-NYZ3>].

153. See Steve Benen, *Why It Matters When Republican Senate Hopefuls Endorse ACA Repeal*, MSNBC: MADDOWBLOG (Apr. 6, 2022, 11:53 AM), <https://www.msnbc.com/rachel-maddow-show/maddowblog/matters-republican-senate-hopefuls-endorse-aca-repeal-rcna23247> [<https://perma.cc/JRP5-WNPC>].

154. Eric Boodman, Tara Bannow, Bob Herman & Casey Ross, *HIPAA Won’t Protect You If Prosecutors Want Your Reproductive Health Records*, STAT (June 24, 2022), <https://www.statnews.com/2022/06/24/hipaa-wont-protect-you-if-prosecutors-want-your-reproductive-health-records> [<https://perma.cc/NQ5X-LSSL>] (quoting University of Michigan bioethics professor Kayte Spector-Bagdady).

155. *Id.*

doesn't apply to DTC genetic testing companies."¹⁵⁶ In fact, "no federal law directly addresses consumer privacy issues resulting from DTC genetic testing."¹⁵⁷ Furthermore, databases holding genetic information, such as electronic health records and those of DTC testing companies, are vulnerable and have experienced data breaches.¹⁵⁸

156. Consumer Reps., *The Privacy Risks of At-Home DNA Tests*, WASH. POST (Sept. 14, 2020, 9:00 AM), https://www.washingtonpost.com/health/dna-tests-privacy-risks/2020/09/11/6a783a34-d73b-11ea-9c3b-dfc394c03988_story.html (on file with the *Iowa Law Review*). DTC testing companies all have policies against data sharing, but they are not immune from law enforcement requests. See, e.g., *Data Sharing*, 23ANDME (Dec. 14, 2022), <https://www.23andme.com/legal/privacy/#data-sharing> [<https://perma.cc/EGQ5-HVFE>] (providing that 23andMe will provide consumers' information to law enforcement or regulatory agencies when "required by law to comply with a valid court order, subpoena, or search warrant" for genetic or personal information, as those terms are defined by the company); *Nebula Genomics—Privacy Policy 2023*, NEBULA GENOMICS (Mar. 12, 2023), <https://nebulagenomics.zendesk.com/hc/en-us/articles/14126324560660-Nebula-Genomics-Privacy-Policy-2023> [<https://perma.cc/ND76-W7ZV>] ("[U]nder certain circumstances your . . . Genetic Data may be subject to processing pursuant to laws, regulations or judicial or governmental orders, warrants or subpoenas."). In 2019, a Florida court approved a warrant that allowed state law enforcement officials to access and search the full database of GEDmatch's one million users. Kashmir Hill & Heather Murphy, *Your DNA Profile Is Private? A Florida Judge Just Said Otherwise*, N.Y. TIMES (Nov. 5, 2019, 2:14 PM), <https://www.nytimes.com/2019/11/05/business/dna-database-search-warrant.html> (on file with the *Iowa Law Review*). And in 2018, "California police used GEDmatch to identify a man they believe [to be] the Golden State Killer, Joseph James DeAngelo." *Id.* Since then, "investigators have . . . used genetic genealogy to identify suspects and victims in more than [seventy] cases." *Id.* GEDmatch does not itself offer genetic testing services, but rather it is a DNA comparison and analysis website. *About GEDmatch, Genealogy Research Reimagined and Expanded*, GEDMATCH (2023), <https://www.gedmatch.com/about-us> [<https://perma.cc/AKU3-PGLF>]. People can upload their DNA data from companies like 23andMe and then "GEDmatch processes the file, adds it to a genealogical database, and provides applications for matching and further analysis." *Id.*

157. Consumer Reps., *supra* note 156.

158. *Id.*; see Eric Rosenbaum, *5 Biggest Risks of Sharing Your DNA with Consumer Genetic-Testing Companies*, CNBC DISRUPTOR 50 (June 16, 2018, 2:18 PM), <https://www.cnbc.com/2018/06/16/5-biggest-risks-of-sharing-dna-with-consumer-genetic-testing-companies.html> [<https://perma.cc/CZ4J-DZL4>]. Relatedly, use of DTC tests often results in more than just sharing genetic information. According to Consumer Reports' Digital Lab, which evaluated five DTC genetic testing companies:

[T]hese apps potentially collect more data than could be needed to deliver their core service. We also found through our privacy-policy analysis that when consumers opt into "research," many are providing third-party access not only to their DNA but also to other types of data the company has about you, which can include information about your relatives and family history. And we learned through both testing and privacy-policy review that all of these companies share non-DNA data that could potentially be used to target ads and develop data profiles on consumers, with few obvious tools to help users protect their privacy.

Catherine Roberts, *The Privacy Problems of Direct-to-Consumer Genetic Testing*, CONSUMER REPS. (Jan. 14, 2022), <https://www.consumerreports.org/dna-test-kits/privacy-and-direct-to-consumer-genetic-testing-dna-test-kits-a1187212155> [<https://perma.cc/XW4X-4P8F>]; see also Samuel Becher & Andelka M. Phillips, *DNA Testing Is Not "Just Saliva"*, REGUL. REV. (Jan. 9, 2023), <https://www.theregreview.org/2023/01/09/becher-phillips-dna-testing-is-not-just-saliva> [<https://perma.cc/PK64-2J7X>] (describing some of the various risks and limitations of DTC genetic testing).

Privacy concerns are not unique to genetic testing. We live in a digital society and our personal data are everywhere, as are threats to the privacy of that data.¹⁵⁹ Widespread improvements are needed to safeguard our personal information. Protections for genetic privacy and prohibitions of genetic discrimination remain particularly underdeveloped and inconsistent, leaving important gaps that render our most intimate data vulnerable to misuse.¹⁶⁰ Wide swaths of this intimate data are merely clicks away, housed in electronic health records, digital databases, mobile apps, and more. As Professor Danielle Citron presciently warns, “[o]ur fertility, dating, and health apps, digital assistants, and cellphones track our every move, doctor visit, health condition, prescription, and search; the details of our intimate lives are sold to advertisers, marketers, and data brokers. Law enforcers can purchase or subpoena [that] data.”¹⁶¹ Without additional protections, “[e]veryone’s life opportunities are on the line.”¹⁶²

Privacy concerns compound for minors because decisions to collect, store, and share their genetic information are generally made by their parents. In many cases, particularly for young children, the minor—the person to whom that information truly belongs—is left out of the discussion and decision.

The legal protections discussed above also do not address a primary privacy concern raised by PPGT: a child’s right to privacy from their parents. Whereas adults may have the power and ability to limit their parents’ access to their genetic information—at least to some degree—that is not true for minors. For minors, the parents represent the primary recipients of PPGT results. Thus, the minor’s most personal information is outside of their control from the start:

Testing a minor for a genetic disorder violates his or her confidentiality because the test result will be shared with the parents without the child’s consent. The child also has no control over with

159. Cameron F. Kerry, *Why Protecting Privacy Is a Losing Game Today—And How to Change the Game*, BROOKINGS INST. (July 12, 2018), <https://www.brookings.edu/research/why-protecting-privacy-is-a-losing-game-today-and-how-to-change-the-game> [<https://perma.cc/V39U-3AJZ>] (“More and more data about each of us is being generated faster and faster from more and more devices, and we can’t keep up. It’s a losing game both for individuals and for our legal system.”).

160. Samantha Cook, *Genes Talk: The Current State of DNA Privacy Law*, JURIS MAG. (May 5, 2019), <https://sites.law.duq.edu/juris/2019/05/05/genes-talk-the-current-state-of-dna-privacy-law> [<https://perma.cc/4P2D-7YCV>] (“Although the law is incrementally addressing genetic discrimination, there is yet to be a cohesive piece of legislation to address all facets of genetic privacy protections.”); Kerry, *supra* note 159 (referring to a “checkerboard” of existing laws that aim to protect various types of data, including genetic information, and arguing for “a more comprehensive and ambitious approach” to privacy protections).

161. Danielle Keats Citron, *The End of Roe Means We Need a New Civil Right to Privacy*, SLATE (June 27, 2022, 11:36 AM), <https://slate.com/technology/2022/06/end-roe-civil-right-intimate-privacy-data.html> [<https://perma.cc/SHE8-VHJR>].

162. *Id.*

whom the parents share the genetic test results. Disclosure of these results by a healthcare provider to the parents, or by the parents with other individuals, without express consent of the minor violates the minor's autonomous right to privacy.¹⁶³

Moreover, minors lack adequate power to prevent the disclosure of their genetic information and also lack any avenue for recourse when it occurs. As Dr. Ellen Wright Clayton explains:

Unemancipated minors have virtually no access to the courts to enjoin parental behavior and so have little independent legal basis to obtain an injunction to stop genetic or genomic testing for which their parents have given permission. They are not even able individually to seek damages from their parents after the fact, as parents are generally immune from liability for actions that are deemed to be within their latitude to discipline or control, a concept that courts have interpreted very broadly to protect parents¹⁶⁴

Some may challenge the idea that a minor has a right to privacy from their parents. Parents, by necessity, already have access to hosts of "confidential" information about their children, including health information.¹⁶⁵ And as Part II explains further, the law and jurisprudence generally support such access.

This Article does not contest that parents should, and often must, know intimate information about their children. Indeed, such information is often necessary to ensure the child's safety and well-being.¹⁶⁶ Yet important distinctions must be acknowledged when considering PPGT, which are explored further below. In brief: There is no longstanding tradition of parents having access to information about a child's genetic predisposition to future disease, nor is there any pressing need for them to have such access. Historically, this type of information would be learned only after the child reached adulthood and could make their own decisions, including whether to share that information with their parents. Indeed, federal laws like HIPAA, in conjunction with myriad state laws, protect that privacy for adults.¹⁶⁷ But prior to adulthood, a child's right to privacy from their parents remains

163. Allain, *supra* note 114, at 104.

164. Ellen Wright Clayton, *How Much Control Do Children and Adolescents Have over Genomic Testing, Parental Access to Their Results, and Parental Communication of Those Results to Others?*, 43 J.L., MED. & ETHICS 538, 540 (2015). Exceptions exist, however, such as if the parent has acted negligently. *See id.* at 544 n.28.

165. As noted previously, some state laws allow minors to consent to certain healthcare services without their parents' knowledge or consent. *See supra* note 30.

166. *See infra* notes 355-57 and accompanying text (describing situations where a parent may be justified in intruding on their child's privacy).

167. *See* Michelle Andrews, *States Offer Privacy Protections to Young Adults on Their Parents' Health Plan*, KFF HEALTH NEWS (June 28, 2016), <https://khn.org/news/states-offer-privacy-protections-to-young-adults-on-their-parents-health-plan> [<https://perma.cc/22EZ-7SZ6>].

limited.¹⁶⁸ The advent of PPGT continues to expand the breadth of information available to parents, potentially violating a child's right to future privacy of their medical information, as well as their right not to know this information in the first place. In an era of "sharenting," there is reason for pause and more robust consideration of whether and when parents may access certain information about their children.¹⁶⁹

Traditional frameworks governing parental consent and child privacy were not developed with emerging technologies in mind, resulting in important gaps that must be addressed. Part II now turns to explore the jurisprudence governing parental rights, which was developed long before the possibility of genetic testing.

II. PARENTAL RIGHTS: THEN AND NOW

According to U.S. Supreme Court Justice Sandra Day O'Connor, "the interest of parents in the care, custody, and control of their children . . . is perhaps the oldest of the fundamental liberty interests recognized by this Court."¹⁷⁰ Over the past century, the Supreme Court has consistently held that parents have a constitutional right to make decisions about their children's care and upbringing. Yet as this Part shows, the jurisprudence does not adequately inform whether these rights include the right to consent to PPGT and thrust that information upon a nonconsenting child. Nor does it resolve direct conflicts between children and parents.¹⁷¹

We no longer live in an era where parents only make decisions for their children that *must* be made during childhood (e.g., decisions about primary education, consent to surgery or treatment for existing conditions, consent to childhood vaccinations). With PPGT, parents can now also make decisions and access information that historically was left to the control of the child

168. See Clayton, *supra* note 164, at 541 ("[A]s a general rule, minors have little ability to prevent their parents from obtaining their medical records [including genetic information] unless their parents have agreed to honor their child's confidentiality."). There are a number of situations in which minors may consent to medical services without involvement of a parent, and keep that information confidential, but there are no exceptions addressing genetic information explicitly. See *id.*; *supra* note 30 and accompanying text.

169. The term "sharenting" refers to the use of social media by parents to share content and information about their children. See L. Lin Ong et al., *Sharenting in an Evolving Digital World: Increasing Online Connection and Consumer Vulnerability*, 56 J. CONSUMER AFFS. 1106, 1007 (2022); Nila Bala, *Why Are You Publicly Sharing Your Child's DNA Information?*, N.Y. TIMES (Jan. 2, 2020), <https://www.nytimes.com/2020/01/02/opinion/dna-test-privacy-children.html> (on file with the *Iowa Law Review*).

170. *Troxel v. Granville*, 530 U.S. 57, 65 (2000).

171. As this Part shows, the Court's position remains unclear on the proper outcome when present or future rights of the child conflict directly with the rights of the parents. However, it must be acknowledged that in many parental rights cases, the Court either was not confronted with the issue directly or no such conflict existed because the child and parents did not disagree with each other. When the desires of parents and children align, courts are, understandably, unlikely to consider the potential conflict.

upon reaching adulthood. Longstanding jurisprudence and traditional legal and policy frameworks do not necessarily translate well to address emerging technologies. Indeed, more often than not, the law fails to keep pace with medical and other technological advancements. The uncertainty that transpires sets the stage for legal, political, and ethical battles, which too often results in harms, particularly to vulnerable populations.

To explore these potential gaps, this Part considers the jurisprudential history of parental rights. Section II.A first unpacks early twentieth century Supreme Court jurisprudence and Section II.B then considers parental rights in the specific context of medical decision-making.

A. PARENTAL RIGHTS: GENERAL FOUNDATIONS

In 1923, Arthur F. Mullen, arguing for the plaintiffs in *Meyer v. Nebraska*,¹⁷² told the U.S. Supreme Court that a state law prohibiting the teaching of modern foreign languages in public and private schools “would ‘change the history of the entire human race’” by allowing the state to “take the child from the parent and prescribe the mental bill of fare which that child shall follow in its education.”¹⁷³ Seven Justices, in apparent agreement with Mullen, struck down the Nebraska law.¹⁷⁴ Justice McReynolds’s brief opinion for the Court remains the foundational case for parental rights, establishing that the liberties protected by the Fourteenth Amendment of the U.S. Constitution include the right to “bring up children.”¹⁷⁵ Many subsequent cases reaffirm and expound upon the breadth of parental authority over the care, custody, and control of their children.¹⁷⁶

172. See generally *Meyer v. Nebraska*, 262 U.S. 390 (1923).

173. Jeffrey Shulman, *Meyer, Pierce, and the History of the Entire Human Race: Barbarism, Social Progress, and (the Fall and Rise of) Parental Rights*, 43 HASTINGS CONST. L.Q. 337, 338 (2016) (quoting Transcript of Oral Argument at 8, *Meyer v. Nebraska*, 262 U.S. 390 (1923) (No. 325)).

174. *Meyer*, 262 U.S. at 403. *Meyer* must be understood, at least in part, as “a creature of its judicial time,” coming to the Court amidst concerns about communism, which “taught that the abolition of the family was the fruit of history’s steady and upward march to an antipatriarchal and propertyless new world order.” Shulman, *supra* note 173, at 339; see also Stephen Provasnik, *Judicial Activism and the Origins of Parental Choice: The Court’s Role in the Institutionalization of Compulsory Education in the United States, 1891–1925*, 46 HIST. EDUC. Q. 311, 346–47 n.120 (2006) (noting that the case was “enacted out of fear of socialism and communism taking hold”). Many Americans, including Supreme Court Justices, were thus eager to prevent state intrusion into the home and family life.

175. *Meyer*, 262 U.S. at 399.

176. See, e.g., *Troxel v. Granville*, 530 U.S. 57, 75 (2000) (holding that a Washington law allowing any person to petition for a court-ordered right to see a child over a custodial parent’s objection, even if visitation is in the child’s best interest, interferes with the parent’s fundamental right to direct the care, custody, and control of their children); *Wisconsin v. Yoder*, 406 U.S. 205, 207–08, 234–35 (1972) (holding that Wisconsin’s compulsory education law violated an Amish father’s right to remove his fourteen- and fifteen-year-old children from school to complete their education in Amish ways at home); *Pierce v. Soc’y of Sisters*, 268 U.S. 510, 530, 534–35 (1925) (striking down an Oregon statute requiring children to attend public schools, reasoning it interfered with parent’s right to select private or parochial schools); Cynthia Starnes, *Swords in*

A common theme emerges in the early parental rights jurisprudence: The Court tends to ignore or disregard the child's point of view or the child's right as an *individual* separate from their parents, even as the Court claims to apply the best interests of the child standard.¹⁷⁷ Instead, the Court concentrates primarily on an overarching conflict between the parents and the state, spilling little ink on whether the laws at issue implicate the rights of children.¹⁷⁸ Indeed, where support in the jurisprudence exists for the arguments in this Article, which emphasize the child's rights, it is found in the dissenting opinions.

Pierce v. Society of Sisters followed two years after *Meyer* and continues this early jurisprudential theme.¹⁷⁹ In *Pierce*, plaintiffs challenged an Oregon law that required children to attend public schools.¹⁸⁰ A unanimous Court struck down the law.¹⁸¹ But again, the Court did not consider whether the law promoted or infringed upon the rights of the children. On the contrary, the Court suggests that children do not direct or influence their own destinies.¹⁸² That right belonged to the parents, "who nurture [their children] and direct [their] destin[ies]."¹⁸³

In an illuminating revisionist history of *Meyer* and *Pierce*, Professor Barbara Woodhouse explains that although we tend to think of the rights to establish a home and bring up children "as the good personal liberty gold of substantive due process,"¹⁸⁴ a "dark side" emerges upon closer examination: The establishment of "a dangerous form of liberty, the right to control another human being."¹⁸⁵ Professor Woodhouse explains: "Stamped on the reverse side of the coinage of family privacy and parental rights are the child's

the Hands of Babes: Rethinking Custody Interviews After Troxel, 2003 WIS. L. REV. 115, 117 (referring to "*Troxel's* reaffirmation of the significance and breadth of parental rights").

177. See Emily Buss, *What Does Frieda Yoder Believe?*, 2 U. PA. J. CONST. L. 53, 60 n.28 (1999) (listing cases where children failed to secure separate constitutional protection when their rights were at odds with their parents).

178. In *Meyer*, parental rights were pitted against the state's interest in preventing the allegedly "baneful effects of permitting foreigners, who had taken residence in [the United States], to rear and educate their children in the language of their native land," which would be "inimical to our own safety." *Meyer*, 262 U.S. at 397–98. The only mention of potential harm to children is found in the Court's statement that "[m]ere knowledge of the German language cannot reasonably be regarded as harmful." *Id.* at 400. Interestingly, however, over twenty years later in *Prince v. Massachusetts*, the Court described *Meyer* as protecting "*children's* rights to receive teaching in languages other than the nation's common tongue . . . against . . . state[] encroachment." *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (emphasis added).

179. *Pierce*, 268 U.S. at 534–35 (1925).

180. *Id.* at 530–31.

181. *Id.* at 534–36.

182. See *id.* at 535.

183. *Id.* (emphasis added).

184. Barbara Bennett Woodhouse, "*Who Owns the Child?*": *Meyer and Pierce and the Child as Property*, 33 WM. & MARY L. REV. 995, 997 (1992).

185. *Id.* at 1000–01.

voicelessness, objectification, and isolation from the community.”¹⁸⁶ In short, the rights of children remain secondary to their parents, if acknowledged at all. These cases thus “serve as a reminder that substantive due process can be a conservative as well as a liberating force Especially in family law, which deals with collective organisms, liberty is a difficult concept: one individual’s liberty can spell another’s suppression or defeat.”¹⁸⁷ That warning has salience for PPGT, which risks prioritizing the parent’s immediate rights over the child’s right to future privacy.

The general lack of consideration given to children in the early jurisprudence slowly gave way to greater concern for child welfare and the recognition of children as free individuals who are “merely entrusted to the parent for nurture.”¹⁸⁸ To align with this evolution, courts began addressing the welfare and interests of children more directly. In 1944, in an early limitation on parental authority, the Supreme Court upheld a child labor law grounded in concern for child welfare.¹⁸⁹ This case, *Prince v. Massachusetts*, clarified that parental rights are broad but not absolute, and may be subject to state intervention “to protect the welfare of children.”¹⁹⁰ The Court concluded that the law did not infringe plaintiff’s freedom of religion or parental rights, noting the state’s interest in protecting children from certain harms.¹⁹¹ For example, the Court referenced “the crippling effects of child employment . . . and the possible harms arising from other activities subject to all the diverse influences of the street.”¹⁹² The Court described the law as “appropriately designed to reach such evils,” even if it went “against the parent’s claim to control of the child.”¹⁹³ From this case comes the crucial principal that “[p]arents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children *before they have reached the age of full and legal discretion when they can make that choice for themselves.*”¹⁹⁴

Yet even while *Prince* began to establish important boundaries on the rights of parents, those boundaries largely represent the point where *parental* rights end and the *state’s* right to intervene begins. That is, *Prince* did not

186. *Id.* at 1001.

187. *Id.* at 1110.

188. *Id.* at 1040 (describing how “Lockean theories of individual liberty” influenced views of the child); *see also id.* at 1040–41 (describing how child welfare grew into a recognized social science during the twentieth century); John E.B. Myers, *A Short History of Child Protection in America*, 42 *FAM. L.Q.* 449, 454–56 (2008) (providing an overview of child protections since 1962).

189. *Prince v. Massachusetts*, 321 U.S. 158, 159, 170–71 (1944). At issue was a Massachusetts child labor law that, among other things, prohibited minors from selling literature or other goods in a public place. *Id.* at 159–61.

190. *Id.* at 165.

191. *Id.* at 168–70.

192. *Id.* at 168.

193. *Id.* at 169.

194. *Id.* at 170 (emphasis added).

consider the interests of the child *as represented by the child* or describe children as having rights of their own, separate from their parents or the state. This shines through only in dissenting opinions. In his dissent, Justice Murphy placed greater emphasis on the child's freedom of religion and the importance of the child's own voice.¹⁹⁵ He described the law at issue as an attempt "to prohibit a child from exercising *her* constitutional right to practice her religion on the public streets."¹⁹⁶ Citing the child's testimony "that she was motivated by her love of the Lord," Justice Murphy argued that the child engaged in the labor at issue (handing out religious pamphlets on a public street) based on "her *own* desire."¹⁹⁷ According to Justice Murphy, the child's rights and desire—not just those of the parents or state—must be considered.

Any critique of the Court's failure to consider children's voices in these early cases must acknowledge possible reasons for the omission. For example, the parents and child may have agreed with each other, thereby making the parents adequate representatives of their child's desires. But the Court may have also overlooked or ignored the potential for conflict by automatically assuming that parents have the child's best interests in mind.¹⁹⁸ Take *Wisconsin v. Yoder* as an example.¹⁹⁹ Striking down another compulsory education law, the Court continued its myopic focus on the rights of the parents versus the state.²⁰⁰ The Court proclaimed that its holding "in no degree depends on the assertion of the religious interest of the child as contrasted with that of the parents."²⁰¹

The dissent again provides a reminder about the *child's* rights and interests. In dissent, Justice Douglas argued that children have their own constitutionally protectable interests, which must be considered separate and apart from those of their parents.²⁰² Justice Douglas states:

If the parents in this case are allowed a religious exemption, the inevitable effect is to impose the parents' notions of religious duty

195. See *id.* at 171–76 (Murphy, J., dissenting).

196. *Id.* at 171 (emphasis added).

197. *Id.* at 172 (emphasis added).

198. See *Troxel v. Granville*, 530 U.S. 57, 68 (2000) ("[T]here is a presumption that fit parents act in the best interests of their children."); *Parham v. J.R.*, 442 U.S. 584, 604 (1979) (noting "the traditional presumption that the parents act in the best interests of their child").

199. *Wisconsin v. Yoder*, 406 U.S. 205, 232 (1972) ("The State's argument proceeds without reliance on any actual conflict between the wishes of parents and children."); see also *id.* at 237 (Stewart, J., concurring) ("[T]here is no suggestion whatever in the record that the religious beliefs of the children here concerned differ in any way from those of their parents.").

200. The law at issue required children to attend school until the age of sixteen. *Id.* at 207 (majority opinion).

201. *Id.* at 230. The Court also noted that the law penalized parents but not the child, so the Court declined to consider any rights of the children. *Id.* at 230–31; see also FEINBERG, *supra* note 139, at 84 (describing Chief Justice Burger's opinion for the Court, stating that he "shows very little sensitivity . . . to the interests of the Amish child in choosing his own vocation in life").

202. *Yoder*, 406 U.S. at 241–43 (Douglas, J., dissenting).

upon their children. Where the child is mature enough to express potentially conflicting desires, it would be an invasion of the child's rights to permit such an imposition without canvassing his views.²⁰³

Professor Emily Buss describes this dissent "as a beacon for those calling for the recognition of children's rights independent of the rights of their parents."²⁰⁴

The early parental rights jurisprudence also reflects how societal and cultural views influence judicial thinking. By the early twentieth century, although many no longer viewed children solely "as paternal property subject to paternal whim," "obstinate counter-trends" remained: "Patriarchal ideals and structures that treated the child as property of the parent continued to exist side-by-side with Lockean theories of individual liberty, in which the child was essentially free, merely entrusted to the parent for nurture."²⁰⁵ It thus comes as little surprise that some courts failed to meaningfully consider the rights and desires of children.

Indeed, despite increasing attention to child welfare and the "best interests of the child" throughout the latter part of the twentieth century, courts continued to interpret those interests as represented by the parents or the state, rather than the child. In that way, children's rights "belonged" either to their parents or the state; the recognition and protection of their rights depended largely on others.²⁰⁶ Judicial language reflects this, framing the issues as involving children's "interests" rather than "rights."²⁰⁷ Although often conflated, *rights* and *interests* represent distinct concepts.²⁰⁸ According to Joseph Raz's theory of rights, *interests* inform and are ground for *rights*.²⁰⁹ Essentially, *rights* are stronger than *interests* and exist when an aspect of a person's well-being (i.e., an interest) is of sufficient importance to ground

203. *Id.* at 242. Justice Douglas would have returned the case to the lower courts to provide the children an opportunity to testify and be heard. *Id.* at 245-46.

204. Buss, *supra* note 177, at 53 & n.4 (collecting sources).

205. Woodhouse, *supra* note 184, at 1039-40; *see also supra* note 174 (noting that fears of communism may have influenced the Court's decision in *Meyer*).

206. *See* Woodhouse, *supra* note 184, at 1048; *see also In re Clark*, 185 N.E.2d 128, 132 (Ohio Ct. Com. Pl. 1962) ("The child is a citizen of the State. While he 'belongs' to his parents, he belongs also to his State."); *Heaton v. Jackson*, 171 N.E. 364, 365 (Ohio Ct. App. 1930) (referring to children as "belong[ing]" to their parents); *In re Riff*, 205 F. 406, 407-08 (E.D. Ark. 1913) (asserting that the services of children "belong to the parents"); Woodhouse, *supra* note 184, at 1054 (describing early accounts of children's rights as "reflect[ing] a sense of the child not as private property of his parent, *nor of himself*, but as belonging to the community, the collective family" (emphasis added)).

207. Woodhouse, *supra* note 184, at 1057; *cf. In re Clausen*, 502 N.W.2d 649, 665 (Mich. 1993) (recognizing that children "have a due process liberty interest in their family life," but stating that "those interests are not independent of the . . . parents").

208. *See* Raz, *supra* note 45, at 207-10; *see also* Zanghellini, *supra* note 45, at 26 (explaining Raz's distinction between interests and rights).

209. Zanghellini, *supra* note 45, at 26. Raz's interest theory of rights, like other philosophical definitions of that term, "attempt to capture the way the term is used in legal, political and moral writing and discourse." Raz, *supra* note 45, at 195 (footnote omitted).

duties in others.²¹⁰ Scholars have long debated whether and to what extent children can be “rights-holders.”²¹¹

By denying children their own voice, identity, and distinct rights, a child’s purpose is reduced to being a mere “conduit” for the interests and rights of their parents.²¹² This proves problematic in cases where the rights and interests of children and parents may conflict. Existing jurisprudence provides far less guidance on how to approach such situations, explaining that “[i]ndeed, in most of the cases in which bold declarations about children’s rights are made, children’s interests and views are indistinguishable from those of their parents.”²¹³ And although the Supreme Court has concluded that the child’s interest may prevail in the face of a parent-child conflict,²¹⁴ many court decisions reach the opposite conclusion, finding that the child has no protectable interest or a lesser liberty interest than their parent.²¹⁵ In the context of PPGT—where the parent’s authority to consent to health care and the parent’s interest in knowing genetic information about their child conflict with the child’s rights to future privacy and right to decide *not* to know—existing jurisprudential frameworks are unsatisfactory and ill-equipped to adequately protect the rights of minors.

Although much of the parental rights jurisprudence gives inadequate attention to the potential for parent-child conflicts, the Supreme Court has hinted at the need for a unique approach when such conflicts occur. Take *Elk*

210. Raz, *supra* note 45, at 195–96; Zanghellini, *supra* note 45, at 26.

211. See generally DAVID WILLIAM ARCHARD, STANFORD ENCYC. OF PHIL., *Children’s Rights* (2023), <https://plato.stanford.edu/entries/rights-children> [<https://perma.cc/K6GE-VXWH>] (summarizing arguments for and against children as “rights-holders”). The United Nations’s Convention on the Rights of the Child explicitly recognizes children as rights holders. See General Comment No. 7: Implementing Child Rights in Early Childhood, Comm. on the Rts. of the Child on Its Fortieth Session, U.N. Doc. CRC/C/GC/7/Rev.1 (2005), https://www.unicef-irc.org/portfolios/general_comments/GC7.Rev.1_en.doc.html [<https://perma.cc/SU5F-7JHP>].

212. Woodhouse, *supra* note 184, at 1114.

213. Buss, *supra* note 177, at 59.

214. See *Elk Grove Unified Sch. Dist. v. Newdow*, 542 U.S. 1, 16–17 (2004). Another area in which courts may defer to children’s preferences, even when they directly contradict parental preferences, is in custody determinations. See, e.g., Samantha Williams & Lior Haas, *Child Custody, Visitation & Termination of Parental Rights*, 15 GEO. J. GENDER & L. 365, 372–75 (2014) (providing factors codified in state laws that are deemed relevant for determining the child’s best interest, including the child’s preference); Elizabeth S. Scott, N. Dickon Reppucci & Mark Aber, *Children’s Preference in Adjudicated Custody Decisions*, 22 GA. L. REV. 1035, 1035 (1988); DETERMINING THE BEST INTERESTS, *supra* note 40, at 4.

215. See, e.g., *Michael H. v. Gerald D.*, 491 U.S. 110, 130–31 (1989) (concluding that the child had no liberty interest in maintaining filial relationship with her biological father where that interest conflicts with her legal father’s constitutionally protected parental interest); *In re Kirchner*, 649 N.E.2d 324, 339 (Ill. 1995) (concluding that the child had no protected liberty interest in maintaining a relationship with foster parents where such a relationship would interfere with the biological father’s exercise of his parental rights); see also *Troxel v. Granville*, 530 U.S. 57, 89 (2000) (Stevens, J., dissenting) (suggesting that any liberty interest of a child in maintaining contact with a particular individual should not “be treated . . . as on a par with that child’s parents’ contrary interests”).

Grove Unified School District v. Newdow as an example. In that case, the Court refused to consider a father's challenge to the phrase "under God" in the Pledge of Allegiance, which his daughter recited at school.²¹⁶ The father sued on behalf of his daughter as "next friend."²¹⁷ Writing for the majority, Justice Stevens stated:

This case concerns not merely Newdow's interest in inculcating his child with his views on religion, but also the rights of the child's mother as a parent generally and under the Superior Court orders specifically. *And most important, it implicates the interests of a young child[.] . . . In marked contrast to our case law on *ius tertii*, the interests of this parent and this child are not parallel and, indeed, are potentially in conflict.*²¹⁸

Here, Newdow's daughter did not object to the Pledge, and the Court indicated that it was "mindful . . . that 'children themselves have constitutionally protectible interests.'"²¹⁹ Further, the Court recognized that "the future of the student, not the future of the parents" was at stake.²²⁰ The same is true for PPGT.

Newdow represents the Court's acknowledgement that minors have their own constitutional rights.²²¹ Prior to *Newdow*, in 1967, the Supreme Court declared that "neither the Fourteenth Amendment nor the Bill of Rights is for adults alone."²²² Both the traditional parental rights jurisprudence and increasing judicial and statutory protection for children's rights influence medical decision-making for minors, to which this Article now turns.

B. MEDICAL DECISION-MAKING FOR MINORS

American law and society presume that parents act in the best interests of their children.²²³ This presumption has long applied to medical decision-making, with parents' authority to grant or withhold consent for their child's medical care recognized at common law.²²⁴ Today, that authority may be

216. *Newdow*, 542 U.S. at 8, 17–18. Relevant to the Court's decision was that Newdow had joint physical custody of his daughter, but not the power to make ultimate decisions when he disagreed with the child's mother. *Id.* at 14. The power to make ultimate decisions had been awarded by a California court to his ex-partner. *Id.*

217. *Id.* at 8.

218. *Id.* at 15 (emphasis added) (citation omitted).

219. *Id.* at 15 n.7 (emphasis added) (quoting *Wisconsin v. Yoder*, 406 U.S. 205, 243 (1972) (Douglas, J., dissenting)).

220. *Id.* at 15–16 n.7 (emphasis added) (quoting *Yoder*, 406 U.S. at 245).

221. Of course, Justice Douglas had previously made this pronouncement explicit in his *Yoder* dissent. *Yoder*, 406 U.S. at 243 (Douglas, J., dissenting).

222. *In re Gault*, 387 U.S. 1, 13 (1967); see also sources cited *supra* note 53.

223. See sources cited *supra* note 198 (noting the presumption).

224. See *supra* note 48 and accompanying text.

codified in state law,²²⁵ and lower courts often rely on the Supreme Court's broader parental rights jurisprudence to support this right.²²⁶

There is limited Supreme Court jurisprudence squarely addressing the medical decision-making rights of minors. And what does exist involves fairly unique situations such as abortion and commitment to mental hospitals.²²⁷ Moreover, because the foundational jurisprudence discussed in Section II.A generally did not consider the potential for conflicts between parents and children, transposing the principles espoused by cases like *Meyer*, *Pierce*, and *Yoder* proves difficult. The Court's considerations in select cases, viewed alongside increasing judicial and societal attention to children's rights as individuals, are nevertheless informative when scrutinizing parental consent to PPGT.

1. *Parham v. J.R.*

In *Parham v. J.R.*, minors challenged a Georgia law that allowed parents and guardians to request their child's admission to a state mental hospital, alleging that Georgia's procedures violated the Due Process Clause of the Fourteenth Amendment.²²⁸ The Court upheld the law, but also held "that the risk of error inherent in the parental decision to have a child institutionalized for mental health care is sufficiently great that some kind of inquiry should be made by a 'neutral factfinder' to determine whether the statutory requirements for admission are satisfied."²²⁹ This decision thus importantly acknowledges that parents are not infallible; even the most well-meaning and responsible parents can make mistakes.

Nevertheless, the Court makes clear that when parent-child conflicts occur, parents do not necessarily lose their decision-making authority: "Simply because the decision of a parent is not agreeable to a child . . . does not automatically transfer the power to make that decision from the parents to some agency or officer of the state."²³⁰ And even while the decision

225. See, e.g., DEL. CODE ANN. tit. 13, § 707(b) (2023) (providing that, subject to some exceptions, parents may consent to healthcare services for minors). Even when no statutory provision explicitly requires parental consent, the expectation is suggested by numerous state laws providing exceptions to that rule for certain types of medical services. See *supra* note 30.

226. See, e.g., *Brandt v. Rutledge*, 551 F. Supp. 3d 882, 892 (E.D. Ark. 2021) (finding that parents "have a fundamental right to seek medical care for their children and, in conjunction with their adolescent child's consent and their doctor's recommendation, make a judgment that medical care is necessary"). For further discussion of *Brandt*, see *infra* notes 263–71 and accompanying text.

227. See *infra* Sections II.B.1–2.

228. *Parham v. J.R.*, 442 U.S. 584, 587–91 (1979).

229. *Id.* at 606.

230. *Id.* at 603. One reading of the Court's language is that it viewed children's choices as irrelevant if those views are contrary to their parents' choices:

We cannot assume that the result in *Meyer v. Nebraska* and *Pierce v. Society of Sisters* would have been different if the children there had announced a preference to learn

recognizes that minors have protectable due process rights,²³¹ the Court suggests those rights are not wholly separate from their parents. Instead, a child's interest in not being committed "is inextricably linked with the parents' interest in and obligation for the welfare and health of the child."²³² Thus, the private interest at stake in *Parham* was "a combination of the child's and parents' concerns."²³³

Relatedly, the Court followed its common practice of focusing on whether decisions should be made by the parent or transferred to the state, giving little attention to the voice of the child or whether the child should play a role in the decision-making process.²³⁴ According to the Court, most children, even adolescents, lack the "maturity, experience, and capacity for judgment required for making life's difficult decisions."²³⁵ Thus, the power to decide lies primarily with the parents,²³⁶ who must be able to make decisions (relatively) free from intrusion or review by the state or the courts.²³⁷

The Court did, however, hint at a limited role for the child, stating that the "inquiry must . . . [o]f course . . . include an interview with the child."²³⁸ Yet the purpose of that interview is unclear—is it to probe the child's wishes as to whether they want to be, or believe they should be, committed to the hospital? Or is it merely to gather more information about the child's current mental health? If the former, the Court at least cursorily recognized the importance of the child's voice. If the latter, then the child's views about their commitment remained ignored, as commonly seen throughout Supreme Court jurisprudence. In sum, although *Parham* acknowledged that minors

only English or a preference to go to a public, rather than a church, school. The fact that a child may balk at hospitalization or complain about a parental refusal to provide cosmetic surgery does not diminish the parents' authority to decide what is best for the child.

Id. at 603–04 (citations omitted).

231. *Id.* at 600 ("It is not disputed that a child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment and that the state's involvement in the commitment decision constitutes state action under the Fourteenth Amendment.")

232. *Id.*

233. *Id.* (emphasis added).

234. Under the facts of *Parham*, however, most would agree that the minors in this case, who were six and seven years of age at the time of their treatment, would not be of sufficient maturity to make the decision on their own. That said, many scholars and medical practitioners believe that even at young ages, children should be involved in discussions and decisions about their medical care, such as through "assent." See, e.g., Maria De Lourdes Levy et al., *Informed Consent/Assent in Children. Statement of the Ethics Working Group of the Confederation of European Specialists in Paediatrics (CESP)*, 162 EUR. J. PEDIATRICS 629, 629 (2003) (arguing that all children have the right to receive information in a way they can understand).

235. *Parham*, 442 U.S. at 602.

236. See *id.*

237. See *id.* at 603 ("Simply because the decision of a parent is not agreeable to a child or because it involves risks does not automatically transfer the power to make that decision from the parents to some agency or officer of the state.")

238. *Id.* at 606–07.

have protectable due process rights and recognized, at least implicitly, that parents are not infallible when making decisions, the case largely reaffirmed the traditional model of the parent-child relationship undergirding *Meyer*, *Pierce*, and *Yoder*.

2. *Bellotti v. Baird*

During the same term as *Parham*, the Court issued another seminal decision involving healthcare decisions and minors: *Bellotti v. Baird*.²³⁹ *Bellotti* involved a challenge to a Massachusetts law requiring pregnant minors seeking abortions to obtain either the consent of their parents or judicial approval following parental notification.²⁴⁰ At the time of the decision in 1979, abortion remained a constitutionally protected right,²⁴¹ including for minors.²⁴² In keeping with *In re Gault*, the Court noted that “[a] child, merely on account of his minority, is not beyond the protection of the Constitution,” and held that the Massachusetts law unconstitutionally burdened the right of pregnant minors to obtain an abortion.²⁴³ As a result of this decision, states typically include a judicial bypass procedure, which allows minors to obtain court approval for abortions without parental consent or notification.²⁴⁴

Bellotti established more assertively that parents do not have an unfettered right to dictate decisions for their children, particularly when the minor’s constitutional rights are at stake. Yet at the same time, *Bellotti* failed to recognize that minors may be capable of making autonomous decisions *on their own*. On the one hand, *Bellotti* liberated adolescents from parental involvement in decisions about abortion. On the other, it required the state—through a judicial bypass procedure—to approve their choices. In short, the

239. See generally *Bellotti v. Baird*, 443 U.S. 622 (1979).

240. *Id.* at 625–26.

241. The Supreme Court’s decision in *Dobbs v. Jackson Women’s Health Organization*, 142 S. Ct. 2228, 2284 (2022), which overruled *Roe v. Wade*, 410 U.S. 113, 164–65 (1973) and *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833, 878–79 (1992), means that abortion is no longer a right protected by the Constitution. See *infra* notes 246–50 and accompanying text.

242. *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52, 72–75 (1976) (invalidating a state law requiring written consent of a parent or guardian for a minor seeking an abortion in the first twelve weeks of pregnancy, holding that the state cannot lawfully authorize an absolute parental veto over a minor’s decision to terminate her pregnancy).

243. *Bellotti*, 443 U.S. at 633. Specifically, the Court cited two problematic aspects of the law:

First, it permit[ted] judicial authorization for an abortion to be withheld from a minor who is found by the superior court to be mature and fully competent to make this decision independently. Second, it require[d] parental consultation or notification in every instance, without affording the pregnant minor an opportunity to receive an independent judicial determination that she is mature enough to consent or that an abortion would be in her best interests.

Id. at 651.

244. *Parental Involvement in Minors’ Abortions*, GUTTMACHER INST. (Sept. 1, 2023), <https://www.guttmacher.org/state-policy/explore/parental-involvement-minors-abortions> [https://perma.cc/68WW-227M].

state stepped into the role of the parent. Moreover, the Court makes clear that although minors generally deserve the same constitutional protections as adults, “the State is entitled to adjust its legal system to account for children’s vulnerability and their needs for ‘concern, . . . sympathy, and . . . paternal attention.’”²⁴⁵

The Supreme Court’s decision in *Dobbs v. Jackson Women’s Health Organization*,²⁴⁶ which overturned the constitutional right to abortion established in *Roe v. Wade*²⁴⁷ and reaffirmed by *Planned Parenthood v. Casey*,²⁴⁸ raises questions about relying on *Bellotti*²⁴⁹ to inform the scope of a minor’s right to control certain decisions about their health and, more broadly, their futures. Even while *Dobbs* did not overrule *Bellotti* explicitly, because abortion is no longer considered a constitutional right, minors’ rights to access abortion—in states where the procedure remains legal—without involving their parents hangs in the balance.²⁵⁰ That said, while the holding specific to abortion may no longer stand, the case still represents the Court’s recognition that where a parent’s authority encroaches on a child’s constitutional rights, the parent’s authority may be reined in or supplanted by state authority. The Court’s reasoning in *Bellotti*, taken together with *Parham*,²⁵¹ helps inform how to conceptualize the rights at stake with PPGT. Before turning to those considerations in Part III, a brief discussion of jurisprudence not specific to minors and decisions from state and lower federal courts warrant comment.

C. THE RIGHT TO REFUSE MEDICAL TREATMENT

In *Cruzan v. Missouri Department of Health*, the U.S. Supreme Court proclaimed that “competent [individuals have] a constitutionally protected

245. *Bellotti*, 443 U.S. at 635 (omissions in original) (quoting *McKeiver v. Pennsylvania*, 403 U.S. 528, 550 (1971)).

246. *Dobbs*, 142 S. Ct. at 2284.

247. *Roe v. Wade*, 410 U.S. 113, 164–65 (1973), *overruled by Dobbs*, 142 S. Ct. at 2228.

248. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 878–79 (1992).

249. *Bellotti*, 443 U.S. at 624.

250. Some state courts have indicated that their judicial bypass procedures remain valid despite changes in abortion laws generally. The Texas Supreme Court, for example, upheld the state’s judicial bypass procedure. See Janet Miranda, *Texas High Court Keeps Judicial Bypass Abortion Rule for Minors*, BL (Sept. 6, 2022, 5:21 PM), <https://news.bloomberglaw.com/litigation/texas-high-court-keeps-judicial-bypass-abortion-rule-for-minors> (on file with the *Iowa Law Review*). That said, Texas law currently bans abortion at all stages of pregnancy, except in cases of medical emergencies. See TEX. HEALTH & SAFETY CODE ANN. § 170.002 (2022); Megan Burbank, *Long Uncertain, Young People’s Access to Abortion Is More Complicated than Ever*, NAT’L PUB. RADIO (Aug. 13, 2022, 7:00 AM), <https://www.npr.org/sections/health-shots/2022/08/13/1116775457/a-bortion-access-roe-vs-wade-dobbs-opinion> [<https://perma.cc/92HT-BJPV>] (“[I]f abortion is gone in [the] state, there’s no path for [a minor to obtain an abortion] . . . just like adults who live in a state like Texas, where all the clinics have closed, youth are completely cut off from abortion.” (quoting Rosann Mariappuram, executive director of Jane’s Due Process)).

251. *Bellotti* involved the minor’s constitutional right to an abortion, and *Parham* involved the minor’s substantial liberty interest in not being confined unnecessarily for medical treatment. *Bellotti*, 443 U.S. at 639–40; *Parham v. J.R.*, 442 U.S. 584, 600 (1979).

liberty interest in refusing unwanted medical treatment.”²⁵² *Cruzan* did not involve the typical parent-state-child triad because the “child” was not a minor but rather an adult woman rendered incompetent after a car accident left her in a persistent vegetative state.²⁵³ Six years after the accident, “Nancy Cruzan had virtually no chance of regaining her mental faculties” so her parents requested the withdrawal of life-sustaining treatment.²⁵⁴ “The Supreme Court of Missouri held that . . . there was no clear and convincing evidence of Nancy’s desire to have life-sustaining treatment withdrawn under [the] circumstances,” and thus reversed the lower court’s order that directed state employees to carry out the parents’ request.²⁵⁵

The U.S. Supreme Court affirmed, holding that a state does not violate the U.S. Constitution by requiring clear and convincing evidence of the incompetent person’s wishes.²⁵⁶ According to the Court, requiring such evidence is appropriate because “there is no automatic assurance that the view of close family members will necessarily be the same as the patient’s would have been had she been confronted with the prospect of her situation while competent.”²⁵⁷

Despite key factual differences, the Court’s decision and statements in *Cruzan* help inform some of the primary considerations undergirding PPGT. Specifically: It is not the desires of the surrogate (i.e., the parents) that matter, but rather the desires of the incompetent person expressed as if they were competent. In *Cruzan*, that determination required looking backward, such as to oral statements made prior to Nancy’s car accident.²⁵⁸ PPGT requires looking forward and acknowledging that a minor’s desire to know, or not know, certain genetic information will form and change over time. The minor’s ultimate desires when confronted with the prospect of PPGT at the age of consent “will [not] necessarily be the same as” the desires of their parents.²⁵⁹ As a result, minors should have the right, like they had before PPGT emerged, to make their own decisions about this type of information during adulthood. *Cruzan* makes clear that the wishes of a once-competent person take precedent in determinations about the withdrawal of life-sustaining medical care. So too should the wishes of a currently incompetent but future competent minor about PPGT, a nonurgent decision that can and should be postponed until the minor attains competence.

252. *Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261, 278 (1990). In contrast, the Court has held that there is no constitutional right to assisted suicide. *Washington v. Glucksberg*, 521 U.S. 702, 705–06 (1997); *Vacco v. Quill*, 521 U.S. 793, 797 (1997).

253. *Cruzan*, 497 U.S. at 266, 266–67 n.1.

254. *Id.* at 267.

255. *Id.* at 265.

256. *Id.* at 265, 280, 284.

257. *Id.* at 286.

258. *Id.* at 285.

259. *Id.* at 286.

D. EMERGING STATE AND LOWER COURT DECISIONS

State and lower federal courts have had greater occasion to consider the triad of parent-state-child rights in healthcare decisions for minors, and many state laws allow adolescents over a certain age to consent to certain types of healthcare services without parental involvement or a requirement to use a judicial bypass procedure.²⁶⁰ None of these laws address PPGT directly, and publicly available sources suggest that no court has considered the issues of PPGT addressed by this Article.

Like the U.S. Supreme Court, state and lower federal courts have frequently considered minors' rights to access abortion.²⁶¹ A new line of nonabortion cases working their way through the courts may inform a new era in healthcare decision-making for minors. Specifically, many courts are now tasked with considering state laws that protect or restrict access to gender-affirming healthcare services.²⁶² All of these cases involve the parent-state-child triad, and initial orders from various courts emphasize different parts of that triad.

On one end of the spectrum are cases where parents and healthcare providers sue the state over laws that ban or restrict minors' access to gender-affirming healthcare services. Many of these cases are ongoing. Thus far, court decisions have relied on a complex mixture of considerations, including an emphasis on the parental rights established by the Supreme Court's jurisprudence discussed above. The theme discussed in Part I again emerges, with courts often focused on conflicts between the parents and state rather than parent and child or state and child.²⁶³ Nevertheless, initial court

260. See *supra* note 30. The Supreme Court has addressed the exceptions for abortion, see *supra* Section II.B.2, but has not addressed any other laws that allow minors to access healthcare services without parental involvement.

261. See *supra* note 244 and accompanying text.

262. "Gender-affirmative health care . . . include[s] . . . social, psychological, behavioural or medical (including hormonal treatment or surgery) interventions designed to support and affirm an individual's gender identity." *Gender Incongruence and Transgender Health in the ICD*, WORLD HEALTH ORG. (2023), <https://www.who.int/standards/classifications/frequently-asked-question/s/gender-incongruence-and-transgender-health-in-the-icd> [<https://perma.cc/CX4R-REL6>].

263. See, e.g., *Brandt v. Rutledge*, No. 21-cv-00450, 2023 WL 4073727, at *36 (E.D. Ark. June 20, 2023), *appeal filed sub nom.* *Brandt v. Griffin*, No. 23-2681 (8th Cir. July 21, 2023) (permanently enjoining state law prohibiting gender transition services for minors and stating that parents "have a fundamental right to seek medical care for their children"); *Eknes-Tucker v. Marshall*, 603 F. Supp. 3d 1131, 1138 (M.D. Ala. 2022) (similar), *vacated sub nom.* *Eknes-Tucker v. Governor of Ala.*, No. 22-11707, 2023 WL 5344981 (11th Cir. Aug. 21, 2023). In an ongoing case in Texas, the family of a transgender teenager sued Governor Abbott and the Texas Department of Family and Protective Services over a directive from Governor Abbott, which stated that gender transition services for minors should be considered and investigated as a form of child abuse. See *Court Cases*, *Doe v. Abbott*, ACLU (Sept. 22, 2023), <https://www.aclu.org/cases/doe-v-abbott> [<https://perma.cc/SWP4-SX2L>]. The parents allege that the directive "infringes on the rights of parents to direct the custody and care of their children, including by providing them with needed medical care." Plaintiffs' Original Petition & Application for Temp. Restraining Ord., Temp. Injunction, Permanent Injunction, & Request for Declaratory Relief at

decisions may suggest greater acknowledgement and consideration of a minor's rights and desires in the decision-making process.

Brandt v. Rutledge provides one recent example. In *Brandt*, transgender minors and their healthcare providers filed suit against Arkansas state officials alleging that "Act 626" violated the Equal Protection Clause, the Due Process Clause, and the First Amendment.²⁶⁴ Act 626 prohibited healthcare providers from providing or referring any individual under the age of eighteen for "gender transition procedures."²⁶⁵ In June 2023, a federal district court permanently enjoined the state from enforcing Act 626.²⁶⁶ The court found in favor of the plaintiffs on all their claims, including that the law violated the equal protection rights of the minors.²⁶⁷ And even when the court focused on the due process rights of the parents—reiterating the presumption that parents act in the best interests of their children and that parents "have a fundamental right to seek medical care for their children"²⁶⁸—the court did not ignore the minors' rights. On the contrary, the court stated that the parent's fundamental right to seek medical care for their child is "*in conjunction with their adolescent child's consent.*"²⁶⁹ As to equal protection, the court acknowledged the minors' right to equal protection under the law, concluding that the law discriminated on the basis of the minors' sex and, also, that "transgender people constitute at least a quasi-suspect class."²⁷⁰ That said, because the parents' interests aligned with those of their children, the court focused primarily on the conflict between the parents and the state.²⁷¹

A few publicly available cases involve actual conflicts between the parent and child. Yet even here, because these cases often involve a degree of *state* intervention in parental decision-making, available court documents continue to focus on the parent-state conflict rather than parent-child conflict.²⁷² In *T.F. v. Kettle Moraine School District*, an unresolved and ongoing

31, Doe v. Abbott, No. D-1-gn-22-000977, 2022 WL 831383 (Tex. Dist. Ct. Mar. 11, 2022), 2022 WL 617257 [hereinafter Plaintiffs' Original Petition]; see also *id.* at 33–34 (additional allegations concerning parental rights). The Texas Third Court of Appeals upheld the district court's temporary injunction blocking the directive and the Texas Supreme Court affirmed the decision, though it narrowed the scope of the injunction. See *Court Cases*, Doe v. Abbott, *supra*.

264. *Brandt*, 2023 WL 4073727, at *1.

265. *Id.*

266. *Id.* at *38.

267. *Id.* at *35–38.

268. *Id.* at *36.

269. *Id.* (emphasis added).

270. *Id.* at *31 (alteration in original) (quoting Grimm v. Gloucester Cnty. Sch. Bd., 972 F.3d 586, 607 (4th Cir. 2020)).

271. At the time of this writing, the state had filed an appeal with the Court of Appeals for the Eighth Circuit. Notice of Appeal at 1, *Brandt v. Griffin*, No. 21-cv-00450 (E.D. Ark. July 20, 2023).

272. According to one conservative commentator, the "plan" of transgender rights advocates is to "use the government to force parents to affirm a false sex for their child, agree to hormone blockers, and accept a transition to their son or daughter's preferred gender. If parents refuse? Removal of the child from the family, due to alleged medical neglect." Margot Cleveland, *LGBT*

case as of this writing, parents of children currently or previously enrolled in the Kettle Moraine School District sued, alleging that the “District . . . violated [their] parental rights by adopting a policy to allow, facilitate, and affirm a minor student’s request to transition to a different gender identity at school without parental consent and even over the parents’ objection.”²⁷³ A Wisconsin Circuit Court judge denied the district’s motion to dismiss.²⁷⁴ In doing so, the court discussed only the potential rights of the parents, giving no mention to the rights of the minor children.²⁷⁵

Brandt, Kettle Moraine, and numerous other cases involving the rights of transgender youth continue to work their way through the courts. Ultimately, the issue may reach the Supreme Court, in light of a circuit split that has emerged. As litigation proceeds, these cases may prove enlightening in broader considerations about the roles of the parent, state, and child in healthcare decision-making for minors.²⁷⁶

American law and jurisprudence make the strength and breadth of parental rights clear. Yet the lack of case law addressing the unique concerns

Activists Teaching Judges to Yank Kids from Parents Who Won’t Transgender Them, FEDERALIST (Feb. 12, 2019), <https://thefederalist.com/2019/02/12/lgbt-activists-teaching-judges-yank-kids-parents-wont-transgender> [<https://perma.cc/35BD-NDNR>].

273. T.F. v. Kettle Moraine Sch. Dist., No. 2021-cv-1650, slip op. at 1 (Wis. Cir. Ct. June 1, 2022); see also Complaint at 12–13, B. & T.F. v. Kettle Moraine Sch. Dist., No. 21-cv-30701 (Wis. Cir. Ct. Nov. 17, 2021) (alleging that the policy “violates parents’ constitutional rights by taking a major, controversial, psychologically impactful, and potentially life-altering decision out of parents’ hands and puts it into the hands of school employees, who have no relevant expertise in these issues, and/or children who lack the ‘maturity, experience, and capacity for judgment required for making life’s difficult decisions’” (quoting Parham v. J.R., 442 U.S. 584, 602 (1979))).

274. *Kettle Moraine*, slip op. at 3–4.

275. *Id.*

276. As of November 5, 2023, the parents of three transgender children from Tennessee have filed a petition for certiorari with the Supreme Court, asking the Court to overturn a federal appeals court decision that allowed a state law banning gender affirming care for minors to take effect. Anita Wadhvani, *Families of Tennessee Transgender Children Petition U.S. Supreme Court to Overturn Ruling on Care*, TENN. LOOKOUT (Nov. 1, 2023, 5:40 PM), <https://tennesseelookout.com/briefs/families-of-tennessee-transgender-children-petition-u-s-supreme-court-to-overturn-ruling-on-care> [<https://perma.cc/9Y28-ADFQ>]. An important thing to note about some of these cases, however, is that they rely on state constitutional claims and are thus less relevant to the considerations of this Article, which focuses primarily on federal law and jurisprudence. See, e.g., Plaintiffs’ Original Petition, *supra* note 263, at 32–34 (raising claims under the Texas Constitution); Complaint, *supra* note 273, at 10–13 (raising claims under the Wisconsin Constitution). Nevertheless, state constitutions provide an important alternative or supplementary method of promoting and protecting individual rights when federal law and jurisprudence fail. See, e.g., King v. State, 535 S.E.2d 492, 494 (Ga. 2000) (“Th[e] right of privacy guaranteed by the Georgia Constitution is far more extensive than that protected by the Constitution of the United States.”); Jon Shirek, *Georgia’s Pending Abortion Restrictions Could End Up Before the State Supreme Court*, 11 ALIVE (June 28, 2022, 6:04 AM), <https://www.11alive.com/article/news/politics/georgias-abortion-restrictions-state-supreme-court/85-beg09ddc-b2f6-4061-b289-813bfc5053c8> [<https://perma.cc/D28S-V7PP>] (“Georgia’s state constitutional tradition has a much more robust right to privacy than the federal constitution.” (quoting Fred Smith, Professor, Emory Univ. Sch. of L.)).

of PPGT, particularly direct and indirect parent-child conflicts, raises concern that the traditional jurisprudence cannot provide a workable framework for PPGT. The next Part thus considers possible pathways forward.

III. THE RIGHT TO FUTURE PRIVACY

As discussed in Part II, existing Supreme Court jurisprudence does not provide a clear answer as to whether minors have—or should have—control over PPGT and how that right should be exercised and protected. These rights include the rights to control whether they receive testing, whether and how they act on the results, and with whom the results are shared. Scenarios One²⁷⁷ and Two,²⁷⁸ along with a long line of cases establishing and reaffirming broad parental authorities,²⁷⁹ suggest that courts would lean toward granting parents the right to consent to PPGT for their children. The lack of case law or a statutory framework addressing PPGT results in gaps and vulnerabilities, creating the potential for significant harms.²⁸⁰ The issue deserves attention now, before PPGT becomes part of routine medical care.

Section I.B catalogued some of the relevant rights at issue and harms that may arise when children lack control over whether they receive PPGT, how PPGT results are acted upon, and with whom the results are shared. These rights and harms justify a privacy-based intervention. Part III takes up that call by developing a novel concept: a “right to future privacy.” Section III.A begins by providing a framework for what a right to future privacy might look like and how that right may be grounded in existing law and jurisprudence. Section III.B then addresses additional and ancillary issues that require further consideration as the right develops. This Article lays the conceptual groundwork and represents just the start of the discussion. Future work must dig deeper into the nuances of privacy law to properly frame the right to future privacy and how such a right affects PPGT and other decisions.²⁸¹

277. See *supra* Section I.A.1.

278. See *supra* Section I.A.2.

279. See *supra* Part I.

280. See *supra* notes 120–23 and accompanying text (cataloguing the rights and harms when children cannot control decisions about PPGT). There are many reasons why litigation involving parent-child conflicts over PPGT is likely to be rare. First, there may be no conflict at all (i.e., the parents and child may agree). Second, the minor may not fully understand the testing and its implications—or even know it is being performed. Finally, where conflict does occur, the minor has few if any viable avenues to seek recourse if they believe the tests should not be or have been performed. See Clayton, *supra* note 164, at 540 (noting limitations on a minor’s ability to prevent parents from obtaining medical services or seek recourse for doing so). Therefore, preventing PPGT from occurring before the child can provide their own consent mitigates the harms that transpire from a minor’s lack of recourse.

281. The purpose of this Article is to expose important gaps and conceptualize a pathway forward to fill those gaps. It does not endeavor to unpack all the relevant privacy jurisprudence or arguments for and against establishing a right to future privacy. That must be done in future work now that the gaps have been exposed.

A. *THE RIGHT TO FUTURE PRIVACY: LAYING THE GROUNDWORK*

Despite the jurisprudential gaps, a key point emerges: “[N]either the Fourteenth Amendment nor the Bill of Rights is for adults alone.”²⁸² Important principles flow from this assertion. First, *children have rights*. And second, if we conclude, normatively, that minors should have the right to control decisions about PPGT, grounding that right in existing law or jurisprudence will help make the right concrete. Cases discussed in Part II support these takeaways: *Parham* acknowledged that minors have a substantial liberty interest protected by the Fourteenth Amendment in not being confined unnecessarily for medical treatment;²⁸³ *Bellotti* grounded the minor’s right to an abortion without parental involvement in the (now-defunct) constitutional right to an abortion;²⁸⁴ and *Brandt* recognized that transgender minors have a right to equal protection under the Fourteenth Amendment.²⁸⁵

Grounding the normative arguments in law and legal jurisprudence reinforces a key premise of this Article: Minors—not parents—should possess the primary right to control (1) whether they receive PPGT,²⁸⁶ (2) whether and how they act on the results, and (3) whether they share the results and with whom. Because many minors may lack the requisite competence to make these decisions at the time when PPGT is contemplated by their parents, this normative premise requires that decisions about PPGT be postponed until a minor attains the competence to consent, a determination informed by law, medicine, and ethics.²⁸⁷

Given the deeply entrenched rights of parents to consent to healthcare services for their children and to know intimate details about their children, we must consider whether and how the law and jurisprudence can support the normative positions of this Article. Specifically, how should we frame the rights at stake with PPGT?

Privacy rights provide a reasonable starting point. Specifically, this Article introduces and begins to conceptualize a “right to future privacy.” From the outset, it is not the ambition of this Article to fully develop and determine the precise contours of a right to future privacy. Rather, it begins this important work by giving the right a name and providing a framework from which to build. Future work may engage in a deeper analysis of how to best ground the right to future privacy in a way that supports the normative conclusions of the Article.

282. *In re Gault*, 387 U.S. 1, 13 (1967); see also sources cited *supra* note 53.

283. See *supra* notes 228–29 and accompanying text.

284. See *supra* notes 239–51 and accompanying text.

285. See *supra* note 267 and accompanying text.

286. See text accompanying *supra* note 26 (defining the types of tests involved in PPGT).

287. See text accompanying *infra* notes 363–64 (acknowledging that the issues addressed by this Article require further consideration of capacity, consent, assent, and how to determine when an individual achieves the requisite capacity to make various types of decisions).

The right to future privacy springs from Feinberg's broader "right to an open future."²⁸⁸ It represents a right to be "held in trust," saved for the child until the child is capable of fully exercising and appreciating their right to privacy and what that means with respect to their genetic information.²⁸⁹ As Feinberg explains, protecting rights in trust may require "interfering with parents *so as to postpone the making of serious and final commitments* until the child grows to maturity and is legally capable of making them himself."²⁹⁰ Feinberg's statement encapsulates what must happen in the context of PPGT: Protecting children's right to future privacy requires shielding certain genetic information from being disclosed to others, including parents, as well as to the children themselves. This is important because once learned, the information cannot be unlearned.

Historically, prior to the advent of genetic testing, the type of information learned from PPGT was unknowable to parents; thus a minor's future privacy was ensured. Once a child reached adulthood, information about their health was theirs alone to learn and share, and it received at least some protection from disclosure to various third parties, including parents.²⁹¹ PPGT eviscerates

288. See FEINBERG, *supra* note 139, at 76; *supra* note 140 and accompanying text. Feinberg does not discuss the right to future privacy explicitly nor does he address parental authority over medical decision-making.

289. See FEINBERG, *supra* note 139, at 76–77. Joseph Millum describes Feinberg's right to an open future as

protect[ing] the child against having important life choices determined by others before she has the ability to make them for herself. The content of the right to an open future therefore includes restrictions on what parents (and others) are allowed to do to children, and, on some interpretations, tells us with what parents (and others) ought to provide children.

Joseph Millum, *The Foundation of the Child's Right to an Open Future*, 45 J. SOC. PHIL. 522, 522 (2014). Feinberg contrasts rights in trust to "dependency rights," which "derive from the child's dependence upon others for the basic instrumental goods of life—food, shelter, protection." FEINBERG, *supra* note 139, at 76. Dependency rights are those that *must* be exercised by others during childhood.

290. FEINBERG, *supra* note 139, at 80 (emphasis added).

291. HIPAA, for example, generally requires a patient to identify the individuals to whom their personal health information may be disclosed. See *Does the HIPAA Privacy Rule Permit a Doctor to Discuss a Patient's Health Status, Treatment, or Payment Arrangements with the Patient's Family and Friends?*, U.S. DEP'T HEALTH & HUM. SERVS. (Dec. 28, 2022), <https://www.hhs.gov/hipaa/for-professionals/faq/488/does-hipaa-permit-a-doctor-to-discuss-a-patients-health-status-with-the-patients-family-and-friends/index.html> [<https://perma.cc/6UT6-ZNVZ>] (describing how healthcare providers can generally share information about a patient's health status to "a spouse, family members, friends, or other persons *identified by [the] patient*" (emphasis added)). Nevertheless, there are important gaps and exceptions to the protections provided by HIPAA. See, e.g., 45 C.F.R. § 164.510(a)(3)(i)(B) (2022) (allowing disclosure of "some or all" of a person's protected health information in emergency circumstances when the disclosure is "[i]n the [child]'s best interest as determined by the covered health care provider, in the exercise of professional judgment"); *Family Members and Friends*, U.S. DEP'T HEALTH & HUM. SERVS. (Dec. 23, 2022), <https://www.hhs.gov/hipaa/for-individuals/family-members-friends/index.html> [<https://perma.cc/H7JC-ZKMP>] (listing some exceptions to HIPAA's Privacy Rule, including sharing information with

this control and protection, allowing parents to intrude into their children's future adult lives and intimate information well before they reach adulthood.²⁹² Medical innovation, while important and often beneficial, should not require individuals to forfeit important rights.

Professor Jamal Greene refers to the right to privacy as “polysemous.”²⁹³ Indeed, privacy can be nebulous and comprised of many threads, including “the right to prevent dissemination of one’s name, creative works, or photographic image; to be free from eavesdropping or physical search by government agents; to associate with others without unjustified intrusion or exposure by the state; or to exercise reproductive or sexual freedom.”²⁹⁴ Despite imprecise boundaries and the fact that the U.S. Constitution does not mention a right to privacy explicitly, a line of decisions spanning well over a century “has recognized that a right of personal privacy, or a guarantee of certain areas or zones of privacy, does exist under the Constitution.”²⁹⁵ This right may be rooted in the First, Fourth, Fifth, or Ninth Amendments; the penumbras of the Bill of Rights; or in the liberty protected by the Fourteenth Amendment.²⁹⁶ The right to prevent the collection, retention, or disclosure of one’s genetic information—perhaps the most intimate form of information that exists²⁹⁷—could be encompassed within one or more of these grounds.

Parental consent to PPGT and access to the results affect a child’s right to future privacy in various ways, implicating both “information privacy” and “decisional privacy.” As described by Professor Neil Richards, “information privacy” represents “the right of individuals to control information about themselves.”²⁹⁸ Information privacy draws heavily from tort law, state and federal privacy protections, and various constitutional protections, such as

individuals involved in a person’s health care or payment for health care). In many ways “HIPAA is a health care portability law with a side of privacy protection, not a health privacy law.” DANIELLE KEATS CITRON, *THE FIGHT FOR PRIVACY: PROTECTING DIGNITY, IDENTITY, AND LOVE IN THE DIGITAL AGE* 97 (2022).

292. The privacy concerns emerging from PPGT and other new technologies are not novel. In 1890, two American lawyers—Samuel Warren and future U.S. Supreme Court Justice Louis Brandeis—expressed concerns about how emerging technologies were being used to invade individual privacy. See Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 195 (1890); see also CITRON, *supra* note 291, at xiv (“The details of our intimate lives are a valuable commodity in the age of ‘informational capitalism[.]’ . . .”).

293. Jamal Greene, *The So-Called Right to Privacy*, 43 U.C. DAVIS L. REV. 715, 720 (2010).

294. *Id.*

295. *Roe v. Wade*, 410 U.S. 113, 152 (1973), *overruled by* *Dobbs v. Jackson Women’s Health Org.*, 142 S. Ct. 2228 (2022).

296. *Roe*, 410 U.S. at 152 (citing supportive cases).

297. HUM. GENETICS COMM’N, *NOTHING TO HIDE, NOTHING TO FEAR?* 45 (2009), <https://www.statewatch.org/media/documents/news/2009/nov/uk-dna-human-genetics-commission.pdf> [<https://perma.cc/7MZ9-CYGV>] (quoting JUSTICE, a law reform organization, which referred to information contained within DNA samples as “the most intimate medical data an individual may possess”).

298. Richards, *supra* note 121, at 1089.

those guaranteed by the Fourth Amendment.²⁹⁹ “Decisional privacy” constitutes “the right of individuals to make certain kinds of fundamental choices with respect to their personal and reproductive autonomy, and has its locus in the constitutional jurisprudence of *Roe v. Wade* and *Griswold v. Connecticut*.”³⁰⁰ Both represent important fields of study, and although scholars have traditionally viewed these two types of privacy as distinct,³⁰¹ more recently some scholars suggest they are less distinct than implied by the traditional view.³⁰²

As described in Section I.B, PPGT risks various harms and rights violations.³⁰³ The right to future privacy conceptualized in this Article emerges as a novel way to prevent those harms and protect those rights. To reiterate, the right to future privacy draws upon at least four existing doctrines: (1) the right against compelled disclosure of private information to others and to oneself (i.e., the right not to know); (2) the right against unreasonable search and seizure, both of one’s body and of one’s personal information; (3) the right against intrusion upon seclusion; and (4) the right to autonomy and bodily privacy. Each of these doctrines is explored further below.

First, the U.S. Constitution includes various protections against compelled disclosure of private information.³⁰⁴ Justice Marshall proclaimed that “[a]n invasion into the home is . . . the worst kind of invasion of privacy.”³⁰⁵ Invasion into one’s body and genetic makeup would seem of equal, if not greater, magnitude. Despite a clear need to protect compelled and unwanted disclosure of personal information to any source, the privacy rights that flow from the Constitution protect most strongly against *government* intrusion.

299. *Id.*

300. *Id.* (footnotes omitted). Given the source of decisional privacy, recent Supreme Court jurisprudence, including *Dobbs*, suggests that decisional privacy may be at risk, as least for certain types of decisions. Nevertheless, it remains important and relevant to parental consent to PPGT, which eliminates a minor’s right to make certain choices and decisions with respect to their genetic information, which arguably lies at the heart of personal autonomy.

301. *Id.* (“[I]nformation privacy scholars have tended to base their work either expressly or implicitly upon a binary distinction between ‘decisional privacy’ and ‘information privacy.’”).

302. *See generally id.* (suggesting that informational privacy and decisional privacy are largely analytically indistinct).

303. *See supra* notes 120–23 and accompanying text.

304. *See* Larry J. Pittman, *The Elusive Constitutional Right to Informational Privacy*, 19 NEV. L.J. 135, 138 (2018) (analyzing federal court jurisprudence and arguing that the Fourth Amendment supports a constitutional right to informational privacy); *see also* Whalen v. Roe, 429 U.S. 589, 599–600 (1977) (referring to “the individual interest in avoiding disclosure of personal matters”); *In re* Search Warrant (Sealed), 810 F.2d 67, 71 (3d Cir. 1987) (“It is indeed clear beyond peradventure that ‘the Constitution embodies a promise that a certain private sphere of individual liberty will be kept largely beyond the reach of government.’” (quoting Thornburgh v. Am. Coll. of Obstetricians & Gynecologists, 476 U.S. 747, 772 (1986))).

305. *New York v. Harris*, 495 U.S. 14, 27 (1990) (Marshall, J., dissenting).

This reflects the “state action” requirement, under which only the government, but not private persons, can violate an individual’s constitutional rights.³⁰⁶

Yet there are situations in which a private actor may be considered a state actor, such as “when there is a sufficiently close nexus between the state and the challenged action of the regulated entity so that the action of the latter may be fairly treated as that of the state itself,”³⁰⁷ or “where the state so closely encourages a party’s activity that the private actor is said to be ‘cloaked with the authority of the state.’”³⁰⁸ Might the roles of parents and the state in ensuring child welfare be sufficiently close to render parental consent to PPGT a form of state action, at least to some degree? That is, by consistently recognizing and strengthening parental rights through case law or statute, the law effectively condones wide swaths of parental decisions, including those about the testing and disclosure of a minor’s genetic information.

Here, it is worth reiterating that minors generally lack adequate power to prevent the disclosure of their genetic information and also lack any avenue for recourse when it occurs.³⁰⁹ This gap leaves minors vulnerable to the decisions of others, no matter the consequences.³¹⁰ Furthermore, despite the longstanding recognition that parents possess the authority to make medical decisions for their children and to access their children’s medical information, that tradition does not justify PPGT. Unlike other medical decisions authorized by parents, PPGT and the information that results are neither necessary to a child’s current well-being nor relevant to a parent’s constitutional right to direct the care, custody, and control of their children.³¹¹ As discussed, the ability to meaningfully act on information

306. As Professor John Fee describes:

The United States Constitution enables and restrains government power. Its provisions do not directly control the conduct of private individuals and organizations, no matter how harmful their conduct may be. Accordingly, the state action doctrine holds that a claim based on the Constitution must be dismissed if the alleged injury is not the result of government wrongdoing.

John Fee, *The Formal State Action Doctrine and Free Speech Analysis*, 83 N.C. L. REV. 569, 575 (2005) (footnote omitted). An exception is the Thirteenth Amendment, which prohibits slavery and involuntary servitude, which applies to both government and private actors. *Id.* at 575 n.16 (citing U.S. CONST. amend. XIII).

307. *Wolotsky v. Huhn*, 960 F.2d 1331, 1335 (6th Cir. 1992).

308. Julie K. Brown, Note, *Less Is More: Decluttering the State Action Doctrine*, 73 MO. L. REV. 561, 567 (2008) (quoting Gregory D. Malaska, Note, *American Manufacturers Mutual Insurance Company v. Sullivan: “Meta-Analysis” as a Tool to Navigate Through the Supreme Court’s “State Action” Maze*, 24 WORKER’S COMP. L. REV. 343, 354 (2002), *reprinted in* 17 J. CONTEMP. HEALTH L. & POL’Y 619, 630 (2001)); *see also* Brown, *supra* at 564–68 (describing various tests used by courts to determine whether a private person’s actions should be considered acts of the government).

309. *See* Clayton, *supra* note 164, at 540–41.

310. *Id.* at 540. Exceptions exist, however, such as if the parent has acted negligently. *See id.* at 544 n.28.

311. *Troxel v. Granville*, 530 U.S. 57, 65 (2000) (noting parents’ liberty interest “in the care, custody, and control of their children”).

learned through PPGT during childhood remains limited.³¹² Often, the information will serve little present purpose beyond satisfying parental curiosity or seeking reassurance, two justifications that cannot outweigh the significant harms that could transpire.³¹³ The minimal benefits do not outweigh the harms to child's future autonomy and right to an open future. PPGT impairs these rights by removing the child's intimate genetic information from their control, thrusting information upon them that they may not want to know—neither now nor in the future—and potentially leading to the disclosure of the information to others. These consequences are irreversible and will follow the child for the rest of their life.

The second privacy right implicated by PPGT flows from the first and originates from the Constitution: protection against unreasonable search and seizure. As noted above, unless subject to an exception to the state action doctrine, the initial testing would implicate the Fourth Amendment only if compelled by the government.³¹⁴ That is not the case considered by this Article. Instead, it involved the parent, not the state, doing the initial “search” of their child's genetic information. Yet the Fourth Amendment's protections remain relevant because once a parent consents to PPGT, it may be possible for other third parties, including the government, to access or compel access to the results.³¹⁵

That risk should not be dismissed as far-fetched or merely hypothetical. Law enforcement agencies have used information from databases with genetic information to investigate crimes³¹⁶ and state healthcare institutions have performed nonconsensual diagnostic tests to obtain evidence of a patient's criminal conduct for law enforcement purposes.³¹⁷ Further, exceptions to

312. See *supra* notes 128–31 and accompanying text.

313. See *supra* notes 127–34 and accompanying text.

314. See *supra* notes 304–06 and accompanying text.

315. See, e.g., sources cited *supra* note 156 (describing cases where the government has sought access to the databases of at-home genetic testing companies).

316. *Id.*

317. Supreme Court decisions on nonconsensual diagnostic testing in the context of criminal investigations vary based on the circumstances. For example, in 2001, the Court held that a state hospital violated the Fourth Amendment right against unreasonable search and seizure when it performed nonconsensual drug tests on obstetrical patients who tested positive for cocaine. See *Ferguson v. City of Charleston*, 532 U.S. 67, 73, 85–86 (2001). But then in 2019, the Court ruled that police may, without a warrant, order blood drawn from an unconscious person suspected of driving under the influence of alcohol. *Mitchell v. Wisconsin*, 139 S. Ct. 2525, 2538–39 (2019). Relatedly, newborn blood samples, which contain genetic information and are almost always collected at birth, have allegedly been sent to the U.S. military to create a “national mitochondrial DNA database.” Mary Ann Roser, *Suit Possible over Baby DNA Sent to Military Lab for National Database*, AUSTIN AM.-STATESMAN (Sept. 27, 2018, 3:33 AM), <https://www.statesman.com/story/news/2012/09/20/suit-possible-over-baby-dna-sent-to-military-lab-for-national-database/9815469007> [<https://perma.cc/F4HH-FAQK>]. Newborn blood tests screen for a variety of conditions, including those that may be life-threatening if not diagnosed and treated shortly after birth. State law varies, but newborn blood spots may be retained indefinitely unless a parent or guardian directs their destruction. See, e.g., *Newborn Screening Program Information, Blood Spots and Test Results*:

HIPAA's protections allow disclosure of personal health information for law enforcement purposes, both with and without a warrant, and do not require the individual to be informed that their information was obtained.³¹⁸ Here, the child's genetic information is being obtained and retained without their consent and without a valid reason for doing so.³¹⁹ The information, often housed in electronic health records and elsewhere, perhaps indefinitely, remains vulnerable to search.³²⁰ The vulnerability exists regardless of whether the PPGT is performed for medical purposes by a healthcare provider or by the parents through the use of an at-home genetic test.

The first and second threads of privacy, which require satisfying the state action doctrine, require broad interpretations unlikely to garner sufficient judicial, political, or scholarly support. Nevertheless, these threads should be further explored as the right to future privacy is developed.

A third privacy right originates from tort law: intrusion upon a person's seclusion, solitude, or private affairs.³²¹ The intrusion must be more than mundane; it must "be offensive or objectionable to a reasonable man" and must target something that is "entitled to be[] private."³²² As explained by Professor William Prosser: A person "has no right to be alone" in a public place, "and it is no invasion of his privacy to do no more than follow him about."³²³ Yet "prying" into a person's genetic makeup and genetic future should without doubt fall within the realm of information that is "entitled" to privacy and that a reasonable person would find offensive or objectionable if disclosed without consent.³²⁴

A final and important privacy right of possible relevance is the right to privacy of one's body, sometimes described as a right to bodily integrity.³²⁵ As

Retention Practices, MINN. DEP'T OF HEALTH (Aug. 27, 2023), <https://www.health.state.mn.us/people/newbornscreening/program/retention.html> [<https://perma.cc/4GCA-2VGP>]; see also Whelan, *supra* note 46, at 428–29 (describing newborn blood spot retention and use).

318. See, e.g., 45 C.F.R. § 164.512(f)(1)–(2) (2022).

319. See *supra* notes 311–13 and accompanying text.

320. HHS CYBERSECURITY PROGRAM, OFF. OF INFO. SEC., U.S. DEP'T OF HEALTH & HUM. SERVS., ELECTRONIC MEDICAL RECORDS IN HEALTH CARE 12 (2022), <https://www.hhs.gov/sites/default/files/2022-02-17-1300-emr-in-healthcare-tpwhite.pdf> [<https://perma.cc/QH93-KUW7>] (reporting that more than forty million patient records were compromised in 2021).

321. See William L. Prosser, *Privacy*, 48 CALIF. L. REV. 383, 389 (1960); CITRON, *supra* note 291, at 102.

322. Prosser, *supra* note 321, at 390–91.

323. *Id.* at 391.

324. See *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 577 (3d Cir. 1980) ("There can be no question that an employee's medical records, which may contain intimate facts of a personal nature, are well within the ambit of materials entitled to privacy protection. Information about one's body and state of health is matter which the individual is ordinarily entitled to retain within the 'private enclave where he may lead a private life.'") (footnote omitted) (quoting *United States v. Grunewald*, 233 F.2d 556, 581–82 (2d Cir. 1956) (Frank, J., dissenting)).

325. See, e.g., *Vacco v. Quill*, 521 U.S. 793, 807 (1997) (referring to "well-established, traditional rights to bodily integrity"); *Washington v. Glucksberg*, 521 U.S. 702, 727 (1997) ("[M]any of the rights and liberties protected by the Due Process Clause sound in personal

Justice Stevens proclaimed: “The sanctity, and *individual privacy*, of the human body is obviously fundamental to liberty.”³²⁶

It is helpful to discuss the right to privacy of one’s body alongside a related and broader privacy right, which exists within what courts have called “zones of privacy.”³²⁷ The most commonly discussed “zones” include matters relating to marriage, procreation, contraception, family relationships, and child rearing and education.³²⁸ Courts have also recognized that certain information, such as medical information, can fall within a zone of privacy.³²⁹ The first three strands of privacy discussed above remain relevant here, because within these zones, individuals should have “a concomitant right to prevent unlimited disclosure of information,”³³⁰ as well as an expectation of

autonomy”); *Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261, 269 (1990); *Winston v. Lee*, 470 U.S. 753, 761–62 (1985); *Washington v. Harper*, 494 U.S. 210, 237 (1990) (Stevens, J., concurring in part and dissenting in part) (“Every violation of a person’s bodily integrity is an invasion of his or her liberty.”). There may be additional threads to explore in future work.

326. *Cruzan*, 497 U.S. at 342 (Stevens, J., dissenting) (emphasis added). Justice Stevens explains:

[J]ust as the constitutional protection for the “physical curtilage of the home . . . is surely . . . a result of solicitude to protect the privacies of the life within,” so too the constitutional protection for the human body is surely inseparable from concern for the mind and spirit that dwell therein.

Id. at 342–43 (omissions in original) (citation omitted) (quoting *Poe v. Ullman*, 367 U.S. 497, 551 (1961) (Harlan, J., dissenting)); *see also* *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891) (“No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”).

327. *Griswold v. Connecticut*, 381 U.S. 479, 484–85 (1965).

328. *Roe v. Wade*, 410 U.S. 113, 152–53 (1973) (citing some of the zones of privacy), *overruled by* *Dobbs v. Jackson Women’s Health Org.*, 142 S. Ct. 2228 (2022).

329. *Hancock v. County of Rensselaer*, 882 F.3d 58, 65 (2d Cir. 2018) (“The Fourteenth Amendment’s due process clause . . . protects individuals in this circuit from arbitrary intrusions into their medical records.”); *Norman-Bloodsaw v. Lawrence Berkeley Lab’y*, 135 F.3d 1260, 1269 (9th Cir. 1998) (“The constitutionally protected privacy interest in avoiding disclosure of personal matters clearly encompasses medical information and its confidentiality.”); *Doe v. City of New York*, 15 F.3d 264, 267 (2d Cir. 1994) (discussing the right to privacy and confidentiality of one’s medical records); *Westinghouse Elec. Corp.*, 638 F.2d at 577 (“Information about one’s body and state of health is matter which the individual is ordinarily entitled to retain within the ‘private enclave where he may lead a private life.’”) (footnote omitted) (quoting *Grunewald*, 233 F.2d at 581–82 (Frank, J., dissenting)); *Haw. Psychiatric Soc’y v. Ariyoshi*, 481 F. Supp. 1028, 1043 (D. Haw. 1979) (indicating that personal information, such as that contained in a psychiatrist’s patient files, is encompassed in the right to privacy); *In re Lifschutz*, 467 P.2d 557, 567 (Cal. 1970) (“[W]e believe that the confidentiality of the psychotherapeutic session falls within one such zone [of privacy].”); *cf.* *Nat’l Treasury Emps. Union v. U.S. Dep’t of Treasury*, 25 F.3d 237, 243 (5th Cir. 1994) (referring to a “zone of personal information”).

330. *Indus. Found. of the S. v. Tex. Indus. Accident Bd.*, 540 S.W.2d 668, 679 (Tex. 1976); *see also* *Whalen v. Roe*, 429 U.S. 589, 599 (1977) (referring to “the individual interest in avoiding disclosure of personal matters”); *Nixon v. Adm’r of Gen. Servs.*, 433 U.S. 425, 457 (1977) (same); *Westinghouse Elec. Corp.*, 638 F.2d at 577 (holding that a person’s medical information “falls within one of the zones of privacy entitled to protection”); *King v. Paxton*, 576 S.W.3d 881, 900 (Tex. Ct. App. 2019) (“The right of ‘disclosural privacy’ is the ‘right to control information’ within

privacy against unreasonable search and seizure or intrusion into their private matters.³³¹

As the Supreme Court described in *Griswold v. Connecticut*, these zones of privacy can be derived from multiple sources, including: (1) in various “penumbras” of specific guarantees of the Bill of Rights,³³² (2) in the First Amendment right of association, (3) in the Third Amendment’s prohibition against quartering soldiers, (4) in the Fourth Amendment’s prohibition against unreasonable searches and seizures, (5) in the Fifth Amendment’s protection against self-incrimination, (6) in the Ninth amendment,³³³ and (7) flowing from the Fourteenth Amendment’s guarantee of personal liberty.³³⁴ In *Griswold*, the Court explained the right, its constitutional groundings, and how the right to privacy is a “legitimate” right, despite “many controversies over these penumbral rights of ‘privacy and repose.’”³³⁵

PPGT implicates these strands of privacy in important ways. It violates the minor’s right to bodily privacy by intruding into their bodies through the test itself (e.g., the blood draw) as well as through the collection, discovery, and disclosure of their genetic futures. As stated by one district court, even if genetic information is not disclosed, “there is an invasion of privacy in the information having been gathered, and harm in the information simply existing.”³³⁶ Indeed, as consistently reiterated by this Article: Once the information from PPGT is known, it cannot be unknown, thereby violating an individual’s right not to know. For many, the knowledge may be a blessing, but for others, it is a curse.³³⁷

‘zones of privacy’ that the United States Supreme Court has deemed ‘fundamental’ or ‘inherent in the concept of ordered liberty.’” (quoting *Indus. Found. of the S.*, 540 S.W.2d at 679–80)).

331. A right to protect information within these “zones” is not unlimited. See *Westinghouse Elec. Corp.*, 638 F.2d at 577–78 (classifying medical records as “within the ambit of materials entitled to privacy protection” while also noting that even material subject to protection can be required to be disclosed upon a showing of proper governmental interest); cf. *Nat’l Treasury Emps. Union*, 25 F.3d at 243 (noting that plaintiffs must have “a reasonable expectation of privacy” to be protected (emphasis added)).

332. See, e.g., *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 424 (Mass. 1977) (citing *Griswold*, 381 U.S. at 484, for the proposition that there is an “unwritten constitutional right of privacy found in the penumbra of specific guaranties of the Bill of Rights”).

333. See *Griswold*, 381 U.S. at 484; see also *Winston v. Lee*, 470 U.S. 753, 762 (1985) (describing the Fourth Amendment as protecting “an individual’s personal privacy and bodily integrity”).

334. See, e.g., *Carey v. Population Servs. Int’l*, 431 U.S. 678, 684 (1977). The framers of the Fourteenth Amendment described this as “personal security” which includes “a person’s legal and uninterrupted enjoyment of his life, his limbs, his body, his health, and his reputation.” CONG. GLOBE, 39th Cong., 1st Sess. 1118 (1866) (emphasis added).

335. *Griswold*, 381 U.S. at 485.

336. *Fisher ex rel. X.S.F. v. Winding Waters Clinic, PC*, No. 15-cv-01957, 2017 WL 574383, at *8 (D. Or. Feb. 13, 2017).

337. See, e.g., Denise Grady, *Haunted by a Gene*, N.Y. TIMES (Mar. 11, 2020), <https://www.nytimes.com/2020/03/10/health/huntingtons-disease-wexler.html> (on file with the *Iowa Law Review*) (reporting that Nancy Wexler found it “easier to live with [the] ambiguity” of not knowing whether she’d develop Huntington’s); Jessica L. Easton, *Self-Understanding and Identity: The*

Genetic information represents an individual's most sensitive and private information, unknowable by sight and requiring intrusive prying into one's innermost biology. PPGT therefore intrudes into one of the most intimate zones of privacy without the minor's consent. In *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, the Ninth Circuit asserted "that the *most basic* violation [of privacy] possible involves . . . the non-consensual retrieval of previously unrevealed medical information that may be unknown even to plaintiffs."³³⁸ Not only will the minor not provide their consent to PPGT, the youngest of children will not even be aware that the information is being collected, retained, and disclosed. Importantly, the disclosure of highly personal and genetic information risks "injury, embarrassment, or stigma"³³⁹ if handled inappropriately. As astutely stated by Professor Citron, "self-development . . . [is] impossible without the ability to decide who has access to our bodies . . . and intimate data."³⁴⁰

Unlike other privacy violations, which may be temporary (e.g., nonconsensual surgery or eavesdropping on private conversations), the violation caused by PPGT is everlasting—once the test is performed and the information disclosed, it cannot be unknown. Children, their parents, and others who receive the results cannot "unknow" that information. If we believe that certain information falls within a protected zone of privacy, genetic information must certainly be included in that zone. As observed by the Ninth Circuit: "One can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic make-up."³⁴¹

Troublingly, despite the importance of bodily privacy and maintaining zones of privacy, privacy is increasingly threatened and under attack by technological advancements and even recent court decisions.³⁴² Because the Constitution does not mention a "right to privacy" explicitly, courts may rely

Experience of Adolescents at Risk for Huntington's Disease 301 (Aug. 27, 2003) (Ph.D. thesis, University of British Columbia) (on file with author) ("I don't think I could live with knowing. I would get into a deep depression and never come out. That is not what I want to do with my life." (quoting a nineteen-year-old at risk of Huntington's)).

338. *Norman-Bloodsaw v. Lawrence Berkeley Lab'y*, 135 F.3d 1260, 1269 (9th Cir. 1998). In *Norman-Bloodsaw*, the plaintiffs, as part of a preplacement employment medical exam, were tested for sickle cell trait, syphilis, and sometimes pregnancy. *Id.* at 1265–66. The plaintiffs consented to the medical exams but were not aware that their blood or urine would be tested for these conditions, nor were they informed about the tests/their results for over a month or in some cases a year. *Id.*

339. *In re Crawford*, 194 F.3d 954, 960 (9th Cir. 1999) (distinguishing disclosure of a Social Security number from disclosure of HIV status, sexual orientation, or genetic makeup); *Norman-Bloodsaw*, 135 F.3d at 1269–70 (noting the sensitive and potentially stigmatizing nature of information about pregnancy, venereal diseases, and the carrying of sickle cell trait).

340. CITRON, *supra* note 291, at 113.

341. *Norman-Bloodsaw*, 135 F.3d at 1269.

342. See, e.g., *Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228, 2284 (2022). Troublingly, Justice Thomas's concurring opinion in *Dobbs* renders tenuous any and all substantive due process rights. See *id.* at 2301 (Thomas, J., concurring).

on that absence to question privacy rights and protections. *Dobbs v. Jackson Women's Health Organization* exemplifies this judicial line of thought, where the Court implied that for the Due Process Clause of the Fourteenth Amendment to guarantee a substantive right not mentioned in the Constitution, that right "must be 'deeply rooted in this Nation's history and tradition' and 'implicit in the concept of ordered liberty.'"³⁴³ In *Dobbs*, the Court engaged in what many scholars and other commentators argue was a weak, flawed, and incoherent analysis to strike down the right to abortion.³⁴⁴ Justice Thomas's concurring opinion went further and was even more explicit, stating that "the Due Process Clause does not secure any substantive rights."³⁴⁵ Such judicial assertions render tenuous any and all substantive due process rights, like the one advanced in this Article, which are not explicitly articulated in the text of the Constitution.

343. *Id.* at 2242 (quoting *Washington v. Glucksberg*, 521 U.S. 702, 721 (1997)). The Court may also make inappropriate or strained use of history to *find* or *uphold* a right, as some claim was the case in *New York State Rifle & Pistol Ass'n v. Bruen*, where the Court struck down New York's proper-cause requirement for obtaining an unrestricted license to carry a concealed firearm. *See* N.Y. State Rifle & Pistol Ass'n v. Bruen, 142 S. Ct. 2111, 2156 (2022); Saul Cornell, *Cherry-Picked History and Ideology-Driven Outcomes: Bruen's Originalist Distortions*, SCOTUSBLOG (June 27, 2022, 5:05 PM), <https://www.scotusblog.com/2022/06/cherry-picked-history-and-ideology-driven-outcomes-bruens-originalist-distortions> [<https://perma.cc/gCAK-LE4U>] ("The majority opinion in [*Bruen*] invokes the authority of history but presents a version of the past that is little more than an ideological fantasy"); Ruth Marcus, Opinion, *Conservative Judges' New Gun-Law Rulings Show 'Originalism' Beyond Parody*, WASH. POST (Oct. 10, 2022, 8:00 AM), <https://www.washingtonpost.com/opinions/2022/10/10/originalism-parody-conservative-judges-latest-gun-law-rulings> (on file with the *Iowa Law Review*) ("History matters when it's on the side [the Justices] prefer to win and is discarded when that proves inconvenient to the desired outcome.").

344. *See* Saralyn Cruickshank, *Inside the Dobbs' Decision*, HUB (July 1, 2022), <https://hub.jhu.edu/2022/07/01/joanne-rosen-insight-dobbs-decision> [<https://perma.cc/TLJ7-765H>] ("I think this is a 'pinched' reading of the protections in the Constitution . . . and of the role of history in understanding constitutional rights." (quoting Joanne Rosen, health law and policy expert, Johns Hopkins University's Bloomberg School of Public Health)); *see also* Aziz Huq, Opinion, *Alito's Case for Overturning Roe Is Weak for a Reason*, POLITICO (May 3, 2022, 1:37 PM), <https://www.politico.com/news/magazine/2022/05/03/alito-case-roe-wade-weak-law-supreme-court-00029653> [<https://perma.cc/HTQ7-CREP>] (arguing that judicial antiabortion decisions are heavily influenced by hyperpolarization of politics); Laurence H. Tribe, *Deconstructing Dobbs*, N.Y. REV. OF BOOKS (Sept. 22, 2022) (arguing that *Dobbs* ignored precedent); AHA Advocacy, *History, the Supreme Court, and Dobbs v. Jackson: Joint Statement from the AHA and the OAH*, AM. HIST. ASS'N (July 2022), [https://www.historians.org/news-and-advocacy/aha-advocacy/history-the-supreme-court-and-dobbs-v-jackson-joint-statement-from-the-aha-and-the-oah-\(july-2022\)](https://www.historians.org/news-and-advocacy/aha-advocacy/history-the-supreme-court-and-dobbs-v-jackson-joint-statement-from-the-aha-and-the-oah-(july-2022)) [<https://perma.cc/9TZ3-79GK>] (arguing that the Court disregarded history when deciding *Dobbs*).

345. *Dobbs*, 142 S. Ct. at 2301 (Thomas, J., concurring). According to Justice Thomas, "in future cases, we should reconsider all of this Court's substantive due process precedents, including *Griswold*, *Lawrence*, and *Obergefell*." *Id.* *Griswold* established the right of married couples to buy and use contraceptives, based on a right to privacy inferred from the Constitution. *Griswold v. Connecticut*, 381 U.S. 479, 485–86 (1965). *Lawrence* invalidated sodomy laws across the United States, thereby legalizing same-sex sexual activity in the United States. *Lawrence v. Texas*, 539 U.S. 558, 578 (2003). *Obergefell* ruled that the fundamental right to marry is guaranteed to same-sex couples by both the Due Process Clause and the Equal Protection Clause of the Fourteenth Amendment to the U.S. Constitution. *Obergefell v. Hodges*, 576 U.S. 644, 672 (2015).

Yet *Dobbs* and other cases that threaten privacy rights need not spell the death of privacy as we know it. In *Dobbs*, the Court primarily attacked the right to privacy that involves “the right to make and implement important personal decisions without governmental interference.”³⁴⁶ Essentially, this describes a right of personal autonomy and “decisional privacy.”³⁴⁷ Importantly, the Court distinguishes this form of privacy from “the right to shield information from disclosure,”³⁴⁸ which is essentially “information privacy.”³⁴⁹ Thus, even while the consequences of *Dobbs* and its implications for autonomy rights in the name of privacy are seismic,³⁵⁰ the case does not “spell the end of legal protection for other forms of privacy, both under the Constitution and other laws.”³⁵⁰ This distinction drawn by the Court makes clear the importance of considering carefully how we ground a right to future privacy as it is developed further.

There are strengths and weaknesses to grounding the right to future privacy in any one of the doctrines discussed above. Compared to tort law, constitutional groundings provide stronger protection for the right, mitigating the risk that a nonconstitutional privacy right will too easily yield to a parent’s constitutional right to direct the care, custody, and control of their children. At this early conceptual stage, all bases for the right to future privacy must be explored. In the end, having more than one doctrinal basis for the right will provide the best strategy for mitigating threats and attacks that might emerge against the right to future privacy.

B. ADDITIONAL CONSIDERATIONS

New and innovative legal and policy frameworks engender controversy and debate. Recognizing new rights or reinforcing existing rights requires consideration of broader consequences, both positive and negative. Each consideration listed below will require further discussion as the right to future privacy develops.

First, critics will contend that parents already have—and must have—the authority to consent to healthcare services for their children, and that this right should include PPGT. Parents’ existing authorities also require them to have access to records containing private information about their children. Furthermore, parents cannot avoid making “future-effecting [decisions] for their children every day”³⁵¹ and “[w]e cannot just leave the child’s *entire* future

346. *Dobbs*, 142 S. Ct. at 2267.

347. See Richards, *supra* note 121, at 1089 (describing decisional privacy).

348. *Dobbs*, 142 S. Ct. at 2267.

349. See Richards, *supra* note 121, at 1089 (describing information privacy).

350. Amy Gajda, *How Dobbs Threatens to Torpedo Privacy Rights in the US*, WIRED (June 29, 2022, 11:09 AM), <https://www.wired.com/story/scotus-dobbs-roe-privacy-abortion> [<https://perma.cc/Xg89-SHN5>]. Grounding the right to future privacy in one theory of privacy over another, however, does not render the other theories of privacy unimportant. On the contrary, the right of personal autonomy at issue in *Dobbs* remains of utmost importance and in need of reinforcement.

351. Garrett et al., *supra* note 114, at 2193.

open for him to decide later according to his settled adult values.”³⁵² In fact, adopting that approach would be futile and could even result in the child having no future at all, or at least not one that could be described as “open.” Take education, for example. If decisions about childhood education are not made by parents and instead postponed until the child reaches the age of consent, that delay would certainly foreclose, or at least delay significantly, a person’s ability to enter the workforce, support themselves, gain independence from their parents, etc.³⁵³

Nevertheless, important distinctions can be made. Framing the right as the right to *future* privacy helps distinguish between (1) decisions that *must* be made for children by others *during childhood*, which cannot be postponed until the child reaches adulthood (e.g., immediate medical care, decisions about primary education); and (2) decisions that are not urgent, necessary, or appropriate to make during childhood. PPGT should fall into this second group of decisions. Other decisions in this second group might include decisions about marriage, occupation, and sexual intimacy.³⁵⁴

A second and related consideration is that parents must—within reason³⁵⁵—be able to “intrude” on their child’s privacy for reasons of health

352. FEINBERG, *supra* note 139, at 94 (emphasis added).

353. See *id.* at 82 (“An education that renders a child fit for only one way of life forecloses irrevocably his other options. He may become a pious Amish farmer, but it will be difficult to the point of practical impossibility for him to become an engineer, a physician, a research scientist, a lawyer, or a business executive.”); Mianna Lotz, *Feinberg, Mills, and the Child’s Right to an Open Future*, 37 J. SOC. PHIL. 537, 549 (2006) (“[A] child’s *positive* right to an open future imposes duties on parents to provide . . . [the] conditions necessary for the development of autonomy . . .”). On the more extreme side, a parent’s failure or refusal to make certain medical decisions could result in the child’s death, preventing the child from having *any* future (e.g., refusal to consent to life-saving cancer treatments or emergency surgery).

354. This was not always true, and tragically, there remain cases of forced child marriage and child trafficking. But at the very least, American law has evolved to prohibit those practices. See, e.g., 18 U.S.C. § 1591 (2018) (prohibiting child sex trafficking); *Forced Marriage*, U.S. CITIZENSHIP & IMMIGR. SERVS. (June 3, 2022), <https://www.uscis.gov/humanitarian/forced-marriage> [https://perma.cc/K6XS-QBEV] (“In some U.S. states, forced marriage is a crime, and in all U.S. states, people who force someone to marry may be charged with violating state laws, including those against domestic violence, child abuse, rape, assault, kidnapping, threats of violence, stalking, or coercion. People who force someone to marry may also face significant immigration consequences, such as being inadmissible to or removable from the United States.”). Yet as is always the case, the law provides an imperfect solution to societal problems.

355. Even here we must acknowledge limits and exceptions—particularly for adolescents—in cases of potential abuse or for certain types of medical decisions such as reproductive health care, mental health care, and substance abuse treatment. See *supra* note 30 (noting state laws that allow minors to consent to certain types of healthcare services). Moreover, parents should endeavor to give their children increasing privacy as they age, which fosters independence and helps minors develop a self-identity. Technological advancements in nonmedical areas also raise new issues of privacy for minors that should be addressed. See Lorrie Faith Cranor, Adam L. Durity, Abigail Marsh & Blase Ur, *Parents’ and Teens’ Perspectives on Privacy in a Technology-Filled World*, SYMP. ON USABLE PRIV. & SEC. 19, 19–20 (2014) (noting the need for new approaches to adolescent privacy in a “technology-filled world”); Anna Jones, *The Parents Who Track Their Children*, BBC (Nov. 7, 2021), <https://www.bbc.com/worklife/article/20211105-the-parents>

and safety.³⁵⁶ A parent who enters and searches their child's room without consent because they believe their child is using illicit or dangerous drugs, or contemplating suicide or other self-harm, is arguably justified in that intrusion. The same would be true for parents concerned that their child may engage in violence. One need only consider the tragic school shootings where evidence has emerged of warning signs.³⁵⁷ A fine line exists between trust and privacy, particularly for adolescents. Any recognition of a minor's right to privacy must draw a proper balance.

PPGT goes beyond these necessary and justifiable privacy intrusions. The right and need of parents to know certain information about their child, even in the face of objections by the child, does not mean that parents have a right to know *everything* about their child. This includes genetic information that

who-track-their-children [https://perma.cc/D8Y2-CW5P] (discussing the growing use of child-tracking apps); Tim Lewis, *Honey, Let's Track the Kids: The Rise of Parental Surveillance*, GUARDIAN (May 1, 2022, 3:00 PM), <https://www.theguardian.com/media/2022/may/01/honey-lets-track-the-kids-phone-apps-now-allow-parents-to-track-their-children> [https://perma.cc/J83G-7FD4].

356. Relatedly, courts have held or assumed that parents have the authority to consent to searches of their children's bedrooms or belongings. *See, e.g.*, *United States v. Whitfield*, 939 F.2d 1071, 1075 (D.C. Cir. 1991) ("When a minor child's room is involved, agents might reasonably assume that the child's mother, in the performance of her parental duties, would not only be able to enter her child's bedroom but also would regularly do so."); *In re D.C.*, 115 Cal. Rptr. 3d 837, 842 (Cal. Ct. App. 2010) ("Given the legal rights and obligations of parents toward their minor children, common authority over the child's bedroom is inherent in the parental role. Carrying out their duty of supervision and control requires a parent to have the ability to monitor their child's activities whenever the parent deems it appropriate, even when the child is in a bedroom nominally regarded as private."); *Vandenberg v. Superior Ct. ex rel. People*, 87 Cal. Rptr. 876, 880 (Cal. Ct. App. 1970) ("In the exercise of his parental authority a father has full access to the room set aside for his son for purposes of fulfilling his right and duty to control his son's social behavior and to obtain obedience. Permitting an officer to search a bedroom in order to determine if his son is using or trafficking in narcotics appears to us to be a reasonable and necessary extension of a father's authority and control over his children's moral training, health and personal hygiene." (citation omitted)).

357. Colleen Long, *Secret Service Study Explores School Shooter Warning Signs*, PBS (Nov. 7, 2019, 4:34 PM), <https://www.pbs.org/newshour/nation/secret-service-study-explores-school-shooter-warning-signs> [https://perma.cc/4J59-KSN9]. Tragically, these warning signs are often overlooked, usually inadvertently. Rarely, in more egregious cases, parents may be fully aware and ignore, or even condone, behaviors that should be immediate red flags. This was the case for Ethan Crumbley, a fifteen-year-old who pleaded guilty to numerous charges, including four counts of first-degree murder, for the shooting of four students at Michigan's Oxford High School on November 30, 2021. Ray Sanchez, Samantha Beech & Nicki Brown, *Prosecutors Seek to Introduce Evidence Michigan School Shooter's Parents Created a Pathway to Violence*, CNN (Oct. 28, 2022, 5:07 PM), <https://www.cnn.com/2022/10/28/us/ethan-crumbley-parents-michigan-hearing/index.html> [https://perma.cc/L3W7-8NRV]. After a teacher reported that she saw Ethan searching ammunition on his phone, school officials tried to contact his parents the night before the shooting but received no response. Ethan's mother sent Ethan a text message, writing "LOL, I'm not mad at you. You have to learn not to get caught." Kara Alaimo, *Charging the Parents in Michigan Shooting Sends a Powerful Message*, CNN (Dec. 3, 2021, 9:29 PM), <https://www.cnn.com/2021/12/03/opinions/parents-michigan-shooting-powerful-message-alaimo/index.html> [https://perma.cc/BA9A-A4ZV]. Ethan's parents have been charged with four counts of involuntary manslaughter. *Id.*

will not be of consequence until adulthood, if ever. The adult-onset nature of the information sets it apart in important ways from other information relevant to minors during childhood. American history and jurisprudence make clear that the parent's authority to direct the care, custody, and control of their children is "deeply rooted in this Nation's history and tradition."³⁵⁸ Yet even if we agree with that method of analysis, it does not follow that parents have the right to consent to PPGT and access the results. There is simply no deep history or tradition of parents having the right to know or demand information about their *adult* children's health or genetic destinies.

To that end, boundaries on a minor's right to future privacy must be considered and delineated. Priority should be given to the right to *future* privacy, withholding from disclosure information that need not, and traditionally would not, be learned until adulthood and thus controlled by the individual to whom that information belonged. As noted, there are valid reasons for minors to possess less extensive privacy rights than adults and parents must have the authority to consent to myriad healthcare services for their children.³⁵⁹

Third, the right must be crafted carefully to prevent it from being abused by abortion opponents and those who support "fetal personhood laws." For example, proponents of fetal personhood laws could argue that fetuses, if deemed "persons" under the law, should have a right to privacy of their genetic information, which would therefore prohibit various uses of PGD and PGT.³⁶⁰

Fourth, we must be careful not to simply shift the right to decide over to the state. As described in Part II, the parental rights jurisprudence typically pits parents against the state, taking rights from the parents and giving them to the state, or vice versa.³⁶¹ The right to future privacy, in contrast, must not follow that path by giving states the right to consent to PPGT for minors. Rather, the right to future privacy aims to save the right for the *child* to exercise in the future. Too often, the state inserts itself into private decisions in ways that harm rather than help. Relatedly, states should also not get involved by enacting judicial bypass procedures like those used for abortion—which allow minors to obtain an abortion without parental notification or

358. *Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228, 2242 (2022) (quoting *Washington v. Glucksberg*, 521 U.S. 702, 721 (1997)).

359. *See supra* notes 351–53 and accompanying text. But to reiterate, minors should have some level of *current* privacy as well, an issue beyond the scope of this proposal. *See supra* note 355 (noting some instances where minors should have the right to *current* privacy).

360. Of course, in states where fetal personhood laws are enacted, most if not all abortions will be banned, including for reasons relating to fetal diagnosis. So, any such arguments about fetal personhood laws and their impact on prenatal genetic testing may be moot, given that obtaining an abortion after receiving prenatal genetic testing results would be prohibited. These and related issues raise myriad questions requiring much further consideration as the right to future privacy develops to ensure appropriate distinctions and guardrails are created so that the right is not co-opted by abortion opponents to limit the rights of pregnant persons.

361. *See supra* Part II.

consent, but only if they receive judicial authorization. Specifically, a judicial bypass procedure should not be used for either the child or the parent. The child should not have to seek judicial approval to undergo or prevent PPGT and the parents should not be able to seek a judicial order to allow them to obtain PPGT for their child. Put succinctly: The state should not be involved. Transferring decision-making authority to the state raises risks that the decisions will be weaponized or politicized, harming rather than helping minors in the process.³⁶²

Fifth, the issues addressed by this Article expose the need to further consider capacity and consent. At what point should a minor have the right to consent to PPGT? The age of consent can vary significantly by state and by issue. For example, a resident of New York cannot marry until the age of eighteen,³⁶³ but those same minors can consent to treatment for a sexually transmitted infection.³⁶⁴ If, as this Article argues, decisions about PPGT should be postponed until the child is capable of making the decision, serious consideration must be given to consent and when the right to future privacy becomes a current right the child can act upon.

Finally, the right must be firm yet nimble enough to evolve with technological and medical innovation. For example, if innovations discover how to better prevent adult-onset diseases during childhood, then we must reconsider whether parental consent for those tests should be allowed. Indeed, that is what brought us here in the first place: the failure of law and policy to keep pace with changing technology and medical innovations.

CONCLUSION

Similar to other technological and medical innovations, genetic testing has outpaced advancements in law and policy. Genetic testing capabilities have gotten ahead of workable frameworks for deciding to whom testing should be offered, whether and when to test, who can consent to testing, and to whom results should be made available. Furthermore, genetic testing has outpaced regulation of the tests themselves.³⁶⁵

362. Sophia Naide, “Parental Involvement” Mandates for Abortion Harm Young People, but Policymakers Can Fight Back, GUTTMACHER INST. (Feb. 19, 2020), <https://www.guttmacher.org/article/2020/02/parental-involvement-mandates-abortion-harm-young-people-policymakers-can-fight-back> [https://perma.cc/99W6-qJKQ] (“Even when a judicial bypass is available, research indicates that it can harm young people through logistical burdens and emotional stress. Judicial bypass can also delay a young person’s care, compromise their confidentiality, and force them to arrange transportation and time off from school in order to go to court.”).

363. N.Y. DOM. REL. LAW § 7 (Consol. Supp. 2023).

364. N.Y. PUB. HEALTH LAW § 2305 (Consol. 2022). The law does not provide a minimum age at which a minor earns this right, suggesting that it applies to a minor of any age.

365. *Regulation of Genetic Tests*, NAT’L HUM. GENOME RSCH. INST. (Feb. 2, 2022), <https://www.genome.gov/about-genomics/policy-issues/Regulation-of-Genetic-Tests> [https://perma.cc/38M5-NW46] (“[M]ost genetic tests today are not regulated, meaning that they go to market without any independent analysis to verify the claims of the seller.”); David Nash, Opinion,

The questions and potential consequences are magnified when children are involved. Existing law and jurisprudence do not clearly answer whether minors have—or should have—control over PPGT. Moreover, a long line of cases establishing and reaffirming broad parental rights raises significant doubt that a court would side with a minor’s right to control if a case were to arise involving a child-parent conflict over PPGT. There are many legal and ethical issues implicated by parental consent for PPGT, including the “right to future privacy” introduced by this Article.

Diminishing privacy brought about by technological advancements represents a common problem extending well beyond PPGT. Myriad privacy rights continue to be eroded, threatened, or maligned,³⁶⁶ yet they remain necessary and in urgent need of reaffirmance and reinvigoration. This Article proposes one avenue for doing so, giving a name to the “right to future privacy.” Our genetic makeup represents perhaps the most intimate data we possess. By laying the initial groundwork for a right to future privacy, this Article supports efforts by scholars to reimagine and reinvigorate privacy rights. Protecting privacy in an era where private information is everywhere, available at the touch of a button, requires ambitious and creative thinking. These conversations are worth having and there exists no better time than now to start. Indeed, “[t]echnological change is at the heart of much information privacy law.”³⁶⁷ The law needs updating to combat the unwarranted invasions of future privacy facilitated by PPGT. Much work remains, and this Article lays the groundwork for important legal and policy innovations in this space.

Regulatory Policy for Biomedical Technologies: Time to Reboot!, MEDPAGE TODAY (Nov. 29, 2022), <https://www.medpagetoday.com/opinion/focusonpolicy/100918> [<https://perma.cc/VZ47-T6qj>] (“Most of these genetic tests are not regulated, and there is growing concern around their marketing without any independent analysis to verify the claims of the sellers.”).

366. Cf. Greene, *supra* note 293, at 717–18 (arguing that although the rights to privacy grounded in the First and Fourth Amendments remain strong, courts have generally moved from privacy to liberty as a constitutional basis for the freedom to make fundamental life decisions).

367. Danielle Citron, *Protecting Sexual Privacy in the Information Age*, in *PRIVACY IN THE MODERN AGE: THE SEARCH FOR SOLUTIONS* 46, 46 (Marc Rotenberg, Julia Horwitz & Jeramie Scott eds., 2015).