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GENEALOGY SITES AND ADOPTIONS—CONNECTING FAMILIES OR RUINING THEM?

*Taylor Bialek**

JANE’S STORY**

Jane knew from a young age that she was adopted. She had a great relationship with her adoptive parents and considered them her family. However, her whole life, Jane struggled with curiosity about her birth parents. As she grew older, she feared that if she did not at least try to find them now, she would never have the opportunity.

Jane's adoption was a closed one—she had no information about her biological parents. For her 30th birthday, Jane's husband bought her a genealogy kit—to discover the answers she clearly was desperate for. *Who were her biological parents? Did she look like them? Why did they give her up? Was she really even Italian?*

* Issue Editor, *Touro Law Review*; J.D. Candidate 2023, Touro University Jacob D. Fuchsberg Law Center; Washington University in St. Louis, Bachelor of Arts in Anthropology: Global Health and the Environment, 2018. I would like to thank my faculty advisor, Professor Rena Sepowitz and the Editorial Board of the *Touro Law Review* for the guidance and time dedicated to helping me complete this Article. I would also like to thank the doctors and staff at NYU Langone Long Island in the Department of Pediatrics for the experiences and opportunities with which they provided me that inspired my passion for this topic. I would also like to express my gratitude to the Intellectual Property & Technology attorneys at Wilson Elser Moskowitz Edelman & Dicker LLP for fostering my interest in Intellectual Property which contributed to the development of this publication. Lastly, I would like to thank my parents, brothers, family, and friends for their endless encouragement and support.

** While based on several real-life stories of adoptees using genealogy sites to find their biological parents, Jane’s Story is a fictional example used only for the purposes of this Article.

She submitted her sample and waited anxiously for the results. Eight weeks later, the results were in. Jane was, in fact, Italian—but only 25%. Her test, instead, revealed that she was mostly Ashkenazi Jewish. What it did not reveal, at first, was the identity of her biological family.

Devastated in her failed attempt, Jane didn't bother looking through the rest of her report. It wasn't until her adoptive father passed that she reopened those results. She was grieving and desperate to connect with family.

When she finally read through the rest of her results, Jane discovered that her report revealed she had a brother. She was so excited. She sent him a message eager to connect.

Two weeks went by—no response. Then a month went by and still, Jane heard nothing from her brother. Around the three-month mark, long after she had given up hope for a reunion, he responded. "Please do not contact me again." She was devastated.

Jane did not consider that, because it was a closed adoption, her birth parents may never have wanted to be found. She did not stop to think about the implications of reaching out.

Years later, a woman called Jane and left a message: "This sounds crazy, but I think you're my sister. My brother just told me about you and what happened. Please call me."

Jane returned her call almost immediately and they talked for hours. She learned that her brother had seen her message and asked his parents about it; they were furious and did not want to talk about it. Seeing how upset they were, he let it go. When his sister found out, she persisted—she, too, wanted answers.

It turns out, Jane's adoption was closed because her biological parents conceived her while they were still in high school and could not afford to keep the baby; they wanted her to have a full and happy life and they knew that they were not going to be able to provide one for her. They were ashamed and did not want to be found. They never told their kids about it. It was a long-kept family secret until their son, Jane's brother, registered his DNA on the genealogy site. They, themselves, never signed up in fear that this secret would be exposed. But despite their efforts, they were still found.

I. INTRODUCTION

Genetic testing, sequencing, and analysis have become increasingly commercialized, as for-profit entities now offer consumers affordable and accessible ways to inquire about their health, ethnicity, and heritage. This significant rise in patronage of genealogy sites enabled companies, such as Ancestry and 23andMe,¹ to create commercialized genetic databases—extensive archives of an individual's most private and sensitive information.² The number of customers registering their genetic information on these sites directly correlates with the success of the companies' service in matching individuals with their relatives.³

¹ Ancestry and 23andMe are two of the leading companies providing genetic analysis directly to consumers. This Article focuses specifically on these two companies to demonstrate the lack of consideration of specific individual privacy rights with respect to such genetic testing to emphasize the need for policy reform and regulation.

² Although Ancestry and 23andMe offer slightly different services, both offer services that present privacy concerns, especially in regard to closed adoptions. The main difference between them is that 23andMe provides various health-testing capabilities, while Ancestry is focused more on genealogy and family matching. See Allison Torres Burtka, *AncestryDNA or 23andMe? How to Choose the Best DNA Kit*, INSIDER (Sept. 27, 2022), <https://www.insider.com/guides/health/ancestrydna-vs-23andme>.

³ See generally 23andMe Customer Care, *What Can 23andMe Do For Me If I Am Adopted?*, 23ANDME.COM, <https://customercare.23andme.com/hc/en-us/articles/202908010-What-Can-23andMe-Do-for-Me-if-I-Am-Adopted-#relatives> (last visited Oct. 9, 2021) (explaining how DNA Relatives, a featured service offered by 23andMe, compares a user's DNA to "other 23andMe users that are participating in

Recent technological advancements encourage these companies to offer additional services and features tailored to the specific curiosities of their consumers. Ancestry was founded in 1983 as an ancestry search company, and in 2002, later entered the DNA testing business.⁴ 23andMe was founded in 2006, to offer genetic testing and interpretation to individuals.⁵ Only one year later, 23andMe became the first company to offer autosomal DNA testing for ancestry.⁶ In 2012, Ancestry then developed AncestryDNA—a feature that provides its users with information about their ethnicity through an autosomal DNA test.⁷ Autosomal DNA tests match an individual’s DNA with the DNA of people who have common ancestry; this allows individuals to discover their ethnic origins as well as DNA relatives.⁸ These genetic databases create a type of “social network with a genetic twist,”⁹ connecting users not only across the country, but around the world.¹⁰

Despite the clear benefits to using technology to connect biological relatives, this practice poses significant privacy concerns.¹¹ For

DNA Relatives and predicts a relationship based on the amount of DNA [they] share”).

⁴ See Bryn Baffer, *Closed Adoption: An Illusory Promise to Birth Parents and the Changing Landscape of Sealed Adoption Records*, 28 CATH. U. J.L. & TECH. 147, 147 (2020) (citing *Our Story*, ANCESTRY, <https://www.ancestry.com/corporate/about-ancestry/our-story> (last visited Apr. 22, 2020)).

⁵ See Thomas Goetz, *23andMe Will Decode Your DNA for \$1,000. Welcome to the Age of Genomics*, WIRED (Nov. 18, 2007), <https://www.wired.com/2007/11/ff-genomics/?currentPage=all>.

⁶ See Int’l Soc. Genetic Genealogy Wiki, *Autosomal SNP Comparison Chart*, ISOGG WIKI, https://isogg.org/wiki/Autosomal_SNP_comparison_chart (last visited Dec. 19, 2022).

⁷ See Baffer, *supra* note 4 (internal citations omitted).

⁸ See *id.* (internal citations omitted).

⁹ Anna Hecht, *Unlock Your Family History with 25% Off 23andMe DNA Kits*, CNN (June 19, 2019), <https://www.cnn.com/2018/06/19/cnn-underscored/23andme-deal-dna-kits-sale-shop>.

¹⁰ See Ancestry Team, *AncestryDNA Expands to New Markets Globally*, ANCESTRYCORPORATE: BLOG (Oct. 18, 2022), <https://www.ancestry.com/corporate/blog/ancestrydna-expands-new-markets-globally> (“AncestryDNA is the largest global consumer DNA network with more than 22 million people with ancestry from nearly every country in the world. With more than 1,500 distinct regions and nearly 1 trillion DNA matches, there’s endless opportunities to find family connections and better understand the different regions that make up your estimate.”).

¹¹ See, e.g., Eric Spitznagel, *My Ancestry Test Revealed a Genetic Bombshell*, N.Y. POST (Aug. 11, 2018), <https://nypost.com/2018/08/11/ancestry-tests-are-revealing-shocking-family-secrets/> (“DNA results don’t just reveal unexpected dads. Roberta Estes, a genetic genealogist who helps people translate their DNA results, says she’s

example, by using genealogy sites to find biological relatives online, adoptees bypass adoption laws enacted specifically to protect the privacy of birth families.¹² Not everyone wants to be found.¹³ Sites like Ancestry and 23andMe allow nearly anyone to trace their own genealogy and track down members of their biological family, even if those relatives do not use those sites.¹⁴

A majority of states currently do not allow adoptees to access their Original Birth Certificate (“OBC”) or adoption records.¹⁵ Through sites like Ancestry and 23andMe, adoptees can find their respective birth families, and in doing so ignore these laws and the privacy interests of the parties they were enacted to protect.

Millions of Americans have been affected by adoption.¹⁶ As such, it is critical that there are adequate laws to protect the interests of all parties involved in adoptions, and that these laws are enforced. When it comes to genealogy sites in particular, these laws are key to

consulted dozens of people who’ve discovered so-called ‘secret siblings,’ proof of their father’s (and sometimes mother’s) infidelities.”); Elle Hunt, *Your Father’s Note Your Father*, THE GUARDIAN (Sept. 18, 2018), <https://www.theguardian.com/life-andstyle/2018/sep/18/your-fathers-not-your-father-when-dna-tests-reveal-more-than-you-bargained-for> (noting that DNA tests are “increasingly . . . bringing light to infidelities, adoptions, cover-ups and lies that have been concealed for decades”). Of the many privacy issues impacted by the ease of finding biological relatives online, this Article focuses primarily on those problems that genealogy sites pose to adoptions.

¹² See S.I. Rosenbaum, *The Twilight of Closed Adoptions*, BOS. GLOBE (Aug. 4, 2018), <https://www.bostonglobe.com/ideas/2018/08/04/the-twilight-closed-adoptions/1Iu4c5da4W5qNblPn5IEml/story.html>.

¹³ See, e.g., Sarah Zhang, *When a DNA Test Shatters Your Identity*, THE ATLANTIC (July 17, 2018), <https://www.theatlantic.com/science/archive/2018/07/dna-test-misattributed-paternity/562928/>.

¹⁴ See, e.g., Wesley Muller, *Anti-Abortion Group Opposes Giving Adopted People Access to Birth Certificates*, LA. ILLUMINATOR (Mar. 15, 2022), <https://lailluminator.com/2022/03/15/pro-life-group-opposes-giving-adopted-people-access-to-birth-certificates/>; Brian Resnick, *How Your Third Cousin’s Ancestry DNA Test Could Jeopardize Your Privacy*, VOX (Oct. 15, 2015), <https://www.vox.com/science-and-health/2018/10/12/17957268/science-ancestry-dna-privacy>.

¹⁵ See *State Adoption Laws*, AM. ADOPTION CONG., <https://americanadoptioncongress.org/state.php> (last visited Dec. 18, 2022). See also *infra* notes 180-94 (discussing Restricted Access states).

¹⁶ Kellie Pantekoek, *Adoption Statistics and Legal Trends*, FINDLAW (Dec. 13, 2022), <https://www.findlaw.com/family/adoption/adoption-statistics-and-legal-trends.html> (“[O]ne in 25 U.S. families with children have a child who is adopted, and almost 100 million Americans have adopted individuals in their immediate family.”).

securing the privacy of individuals who have legally elected not to be found.

This Article exposes gaps in legislation that permit genealogy sites—such as Ancestry and 23andMe—to reveal information traditionally kept confidential, such as information generally found within sealed adoption records. It further proposes solutions to bridge these legislative gaps, which would develop a compromise between an adoptee’s wish to discover his or her roots and the birth parents’ privacy concerns. Section II provides an overview of genetic sequencing, leading up to the commercialization of genetic databases. Section III offers insight into the operation of genealogy sites. Section IV outlines adoption record legislation and introduces the continued controversy between adoptees’ pleas to access their adoption records and birth parents’ fight to protect their privacy. Section V discusses the failures of current legislation aimed at protecting personal information and various other barriers that impede the protection of personal information, which leave personal data collected by commercial entities unregulated and user data exposed. Section VI proposes solutions to the existing legislative failures that address adoptees’ requests without undermining the privacy interests of birth parents.

II. GENETIC SEQUENCING

A. History and Overview of Genetic Sequencing

Human interest in genetics and heredity can be traced back centuries—long before modern science.¹⁷ Today, genetics is defined as

[T]he scientific study of genes and heredity—of how certain qualities or traits are passed from parents to offspring as a result of changes in DNA sequence. A gene is a segment of DNA that contains instructions for

¹⁷ See A.M. Winchester, *Genetics*, BRITANNICA (Sept. 10, 2022), <https://www.britannica.com/science/genetics> (“Curiosity must first have been based on human family resemblances, such as similarity in body structure, voice, gait, and gestures. Such notions were instrumental in the establishment of family and royal dynasties. Early nomadic tribes were interested in the qualities of the animals that they herded and domesticated and, undoubtedly, bred selectively. The first human settlements that practiced farming appear to have selected crop plants with favorable [sic] qualities. Ancient tomb paintings show racehorse breeding pedigrees containing clear depictions of the inheritance of several distinct physical traits in the horses.”).

building one or more molecules that help the body work.¹⁸

Deoxyribonucleic acid (“DNA”) is the molecule that carries the genetic code—the genetic information—for all living organisms.¹⁹

DNA was first identified in the 1860s by Swiss chemist Johann Friedrich Miescher.²⁰ However, genetics, as a scientific discipline, is largely credited to Gregor Mendel—the “father of modern genetics.”²¹ Despite his lack of knowledge of the physical or chemical nature of genes, Mendel, based on his observations, believed that traits were inherited as distinct units;²² these units laid the foundation for our current understanding of heredity.²³

The twentieth century saw major advancements in technology, which encouraged the human understanding of genetics.²⁴ In 1953, due in large part to the work of British scientist Rosalind Franklin, whose research provided insight into DNA’s helical structure,²⁵ American biologist, James Watson, and English physicist, Francis Crick, discovered the three-dimensional double-helix structure of DNA.²⁶ This landmark discovery led to modern molecular biology, which focuses on understanding gene-control over chemical processes within cells.²⁷

It was not until English biochemist Fred Sanger’s breakthrough in 1977, however, that DNA could finally be sequenced.²⁸ “Sanger

¹⁸ See *Genetics*, NAT’L INST. GEN. MED. SCIS., <https://nigms.nih.gov/education/factsheets/Pages/genetics.aspx#:~:text=Genetics%20is%20the%20scientific%20study,that%20help%20the%20body%20work> (last visited Oct. 3, 2022).

¹⁹ See Nat’l Hum. Genome Rsch. Inst., *Deoxyribonucleic Acid (DNA)*, GENOME.GOV (Oct. 3, 2022), <https://www.genome.gov/genetics-glossary/Deoxyribonucleic-Acid>.

²⁰ See *The Discovery of DNA*, YOURGENOME.ORG, <https://www.yourgenome.org/stories/the-discovery-of-dna/> (last visited Oct. 3, 2022).

²¹ Winchester, *supra* note 17; see also *Gregor Mendel*, BIOGRAPHY.COM, <https://www.biography.com/scientist/gregor-mendel> (last visited Oct. 3, 2022).

²² Winchester, *supra* note 17.

²³ *Id.*

²⁴ Asude Alpman Durmaz et al., *Evolution of Genetic Techniques: Past, Present, and Beyond*, 2015 BIOMED RSCH. INT’L 1, 2 (2015).

²⁵ Winchester, *supra* note 17.

²⁶ James M. Heather & Benjamin Chain, *The Sequence of Sequencers: The History of Sequencing DNA*, 107 GENOMICS 1 (2016).

²⁷ See *The Discovery of the Double Helix, 1951-1953*, NAT’L LIBR. MED., <https://profiles.nlm.nih.gov/spotlight/sc/feature/doublehelix> (last visited Oct. 3, 2022).

²⁸ See Heather & Chain, *supra* note 26 (discussing Sanger’s chain-termination technique).

sequencing”—a dideoxy chain-termination method for sequencing DNA—quickly became the most commonly used technology to sequence DNA,²⁹ and until the early twenty-first century, was the dominating technique in the field of genetics research.³⁰

1. *The Human Genome Project*

Shortly after Sanger’s breakthrough in 1977, the U.S. Department of Energy (DOE) and the International Commission for Protection against Environmental Mutagens and Carcinogens (ICPEMC) co-sponsored the Alta Summit in December of 1984, which called attention to the rise in prominence of recombinant DNA technologies.³¹ Soon thereafter, in March of 1986, the DOE Office of Health and Environmental Research held a Genome Sequencing Workshop to evaluate the viability and practicability of a Human Genome Project.³² In October of 1988, the National Institutes of Health (NIH), along with the DOE, signed a memorandum of understanding³³ to “coordinate research and technical activities related to the human genome.”³⁴

Finally launched in October of 1990, and completed in April of 2003, the Human Genome Project accomplished what is considered “one of the greatest scientific feats in history”³⁵—its signature accomplishment: generating the first sequence of the human genome.³⁶ The

²⁹ *Id.*

³⁰ Linda Koch et al., *Sequencing Moves to the Twenty-First Century*, NATURE (Feb. 10, 2021), <https://www.nature.com/articles/d42859-020-00100-w>.

³¹ See *Human Genome Project Timeline*, NAT’L HUM. GENOME RSCH. INST., <https://www.genome.gov/human-genome-project/timeline> (last visited Oct. 3, 2022). The DOE co-sponsored the Alta Summit (1984) along with the International Commission for Protection against Environmental Mutagens and Carcinogens (ICPEMC). *Id.*

³² *Id.*

³³ Dep’t of Energy & Nat’l Insts. Health, Memorandum of Understanding Between the United States Department of Energy and the National Institutes of Health to Coordinate Research and Technical Activities Related to the Human Genome (Oct. 7, 1988), https://www.genome.gov/Pages/About/Understanding_Our_Genetic_Inheritance_1st_5years_HGP.pdf.

³⁴ See *Human Genome Project Timeline*, *supra* note 31. At the same time, Otis R. Bowen (Secretary of Health and Human Services (HHS)), created the Office for Human Genome Research within the NIH Office of the Director [James Wyngaarden]. *Id.*

³⁵ *Id.*

³⁶ *Id.*

Human Genome Project has significantly impacted modern society.³⁷ For over three decades, this Project has tasked biologists with considering the social implications of their research.³⁸ Despite this challenge, the Human Genome Project dedicated only five percent of its budget to considerations of any social, ethical, or legal aspects of acquiring and understanding the human genome sequence.³⁹

In 1992, the Human Genome Organisation (HUGO) was founded to “provide scientific leadership on approaches to intellectual property [as well as] on ethical, legal and social issues.”⁴⁰ The initial concerns included ensuring participant autonomy as well as participant privacy and confidentiality.⁴¹

2. *The Bermuda Principles*

In 1996, the same scientific leaders who advanced the Human Genome Project developed the Bermuda Principles, which were formally implemented in 1998.⁴² The Principles were created to coordinate “the rapid, electronic sharing of data for the joint benefits of science and society.”⁴³ The Principles were largely aspirational and often

³⁷ Leroy Hood & Lee Rowen, *The Human Genome Project: Big Science Transformations Biology and Medicine*, 5 *GENOME MED.* 79 (2003).

³⁸ *Id.*

³⁹ *Id.*

⁴⁰ Bartha Maria Knoppers et al., *The Human Genome Organisation: Towards Next-Generation Ethics*, 5 *GENOME MED.* 38 (2013).

⁴¹ *Id.* (noting that the initial concerns of HUGO’s Ethics Committee and its Intellectual Property Committee were “to ensure participant autonomy through informed consent, respect for participant privacy and confidentiality in light of the sensitive nature of genetic information, and an equitable distribution of the burdens and benefits of genetic research”). See also Kathryn Maxon Jones et al., *The Bermuda Triangle: The Pragmatics, Policies, and Principles for Data Sharing in the History of the Human Genome Project*, 51 *J. HIST. BIOLOGY* 693, 702 (2018) (“When the HGP’s scientists turned from mapping to sequencing the human genome in 1996, quality control and project coordination remained central issues.”).

⁴² See Duke Univ. Librs., *The Bermuda Principles*, *DUKESPACE*, <https://dukespace.lib.duke.edu/dspace/handle/10161/7407> (last visited Jan. 5, 2023). See also Caroline Barranco, *The Human Genome Project*, *NATURE* (Feb. 10, 2021), <https://www.nature.com/articles/d42859-020-00101-9>. The Principles expressly provided for the (i) automatic release of sequence assemblies greater than one kilobyte, preferably within twenty-four hours, (ii) immediate publication of finished annotated sequences; and (iii) making the entire sequence freely available to the public domain for both research and development to maximize its benefits to society. See *id.*

⁴³ See Duke Univ. Librs., *supra* note 42.

not interpreted literally; their flexibility was easily applied to science policies because they could readily be adapted to local scientific and political contexts, and could ultimately be developed for other rhetorical purposes.⁴⁴ The Human Genome Project used the Bermuda Principles to challenge attempts to patent or commercialize human genome sequences, further hindering additional research efforts.⁴⁵

In 2003, a group of select professionals working in genomics expressed their support for the scientific community's unrestricted access to genome-sequencing data before formal publication.⁴⁶ Known as the Fort Lauderdale Agreement, this declaration established the collective responsibility of funding agencies, resource producers, and users to develop and sustain communal genomic data.⁴⁷ Later implemented as policy by the NIH, as well as other funding agencies, these Principles continue to mandate rapid data-sharing in grant requirements.⁴⁸ The Human Genome Project has amassed an estimated \$800 billion in revenue and created significant changes through this publicly funded project.⁴⁹

The Human Genome Project provided the first view into the entire human genome and marked the beginning of an era of high-throughput digital biology, resulting in rapid technological and computational developments and team-oriented research, which continue to influence the clinical and life sciences.⁵⁰ Part of this continuing influence over modern science is the ongoing debate over privacy considerations.

III. GENEALOGY SITES

Before the commercialization of genealogy sites, people traced their heritage using traditional documentation,⁵¹ and relied largely on

⁴⁴ See *id.* (noting that “[a]fter 2003[,] and the declared completion of the HGF, this flexibility also fostered the extension of the Principles to further ‘community resource projects’ in biology.”).

⁴⁵ Barranco, *supra* note 42.

⁴⁶ *Id.*

⁴⁷ *Id.*

⁴⁸ *Id.*

⁴⁹ *Id.*

⁵⁰ *Id.*

⁵¹ Traditional documentation consists of sources such as civil vital records (births, marriages, and deaths), church records, census, immigration records, military records, obituaries, and wills, as well as some secondary sources (such as biographies,

information provided by their relatives. Genealogy sites go beyond what can be learned from relatives or such traditional documentation.⁵² Sites such as Ancestry and 23andMe use both traditional methods as well as information obtained from genetic testing (examining DNA) to help individuals trace their heritage.⁵³ There are multiple methods of genetic testing that are used in genealogy, all of which rely on the analysis of a user's DNA.⁵⁴ While most genetic testing is conducted through healthcare providers (clinical genetic testing),⁵⁵ ancestry

genealogies, and local histories). *Genealogy*, FAMILYSEARCH, <https://www.familysearch.org/en/wiki/Genealogy#:~:text=Original%20sources%20include%20civil%20vital,local%20histories%20sometimes%20mention%20ancestors.> (last visited Jan. 3, 2023).

⁵² Nat'l Libr. Med., *What is Genetic Ancestry Testing*, MEDLINEPLUS, <https://medlineplus.gov/genetics/understanding/dtcgenetictesting/ancestrytesting/> (last visited Oct. 4, 2022).

⁵³ *Id.* "Examination of DNA variations can provide clues about where a person's ancestors might have come from and about relationships between families. Certain patterns of genetic variation are often shared among people of particular backgrounds. The more closely related two individuals, families, or populations are, the more patterns of variation they typically share." *Id.*

⁵⁴ *Id.* (discussing the three most-commonly used types of genetic ancestry testing: (1) Y chromosome testing; (2) Mitochondrial DNA testing; and (3) Single nucleotide polymorphism testing). "Because the Y chromosome is passed on in the same pattern as are family [surnames] in many cultures, Y chromosome testing is often used to investigate questions such as whether two families with the same surname are related." *Id.* Mitochondrial DNA testing identifies genetic variations in mitochondrial DNA and can be useful in genealogy as it "preserves information about female ancestors that may be lost from the historical record because of the way surnames are often passed down." *Id.*

⁵⁵ Nat'l Libr. Med., *What is Direct-to-Consumer Genetic Testing?*, MEDLINEPLUS, <https://medlineplus.gov/genetics/understanding/dtcgenetictesting/directtoconsumer/> (last visited Jan. 4, 2023) ("Healthcare providers determine which test is needed, order the test from a laboratory, collect the DNA sample, send the DNA sample to the lab for testing and interpretation, and share the results with the patient. Often, a health insurance company covers part or all of the cost of testing."). There are several reasons to seek genetic testing from health care providers, such as to determine if a genetic condition runs throughout a family, to evaluate the likelihood of conceiving a child with a genetic condition, or to understand the likelihood of developing certain cancers and to create a possible prevention or treatment plan. *See* Off. Sci. (OS), Off. of Genomics & Precision Pub. Health, *Genetic Testing*, CDC.GOV, https://www.cdc.gov/genomics/gtesting/genetic_testing.htm (last visited Jan. 4, 2023). These motivations, as well as others, also exist among many genealogy site users. *See, e.g.*, Megan Molteni, *Ancestry Branches Out Into Genetic Health Screening*, WIRED (Oct. 15, 2019), <https://www.wired.com/story/ancestry-branches-out-into-genetic-health-screening/>; Barry Starr, *You Can Transform Your Genetic Ancestry Data Into Health Info, But Your Results May Vary*, KQED (June 30, 2014),

testing is most commonly done through direct-to-consumer genetic testing ("DTC genetic testing").⁵⁶ DTC genetic testing differs from clinical genetic testing in many ways, one of which is that it does not typically involve a healthcare provider or health insurance company in the process.⁵⁷

Although Ancestry and 23andMe are two of the largest private genealogy companies in the world, there are a few key differences in their services. The main difference is their focus on ancestry reports.⁵⁸

[Ancestry's] emphasis is mostly on helping you build a detailed family tree. To do this, it pulls from billions of historical records, which you can access as part of a subscription service. While 23andMe recently started offering a family tree builder . . . it does not have a robust database to pull from. On the other hand, **23andMe gives you much more in-depth information on other ancestry details**, including your ethnic origins, your ancestors' migrations over time, your Neanderthal heritage, and your maternal and paternal haplogroups.⁵⁹

Despite their differences, both companies provide services that match users to a list of potential relatives as well as an estimate of how closely they are related.⁶⁰

<https://www.kqed.org/science/18728/you-can-transform-your-genetic-ancestry-data-into-health-info-but-your-results-may-vary>.

⁵⁶ See Nat'l Libr. Med., *supra* note 55.

⁵⁷ *Id.*

⁵⁸ Moss Stern, *23andMe vs AncestryDNA Review 2022: Detailed Comparison*, DNAWEEKLY: BLOG, <https://www.dnaweekly.com/blog/andme-vs-ancestrydna/> (last visited Dec. 12, 2022).

⁵⁹ *Id.* (emphasis added) (noting that Ancestry's database is comprised of genetic information collected from fifteen million people, whereas 23andMe has only tested five million).

⁶⁰ See *id.* (suggesting that the main difference is that Ancestry allows users to link their family trees to their matches to grow their family trees).

A. User Agreements⁶¹

1. *Ancestry's Terms and Conditions*⁶²

Pursuant to its Terms and Conditions (“Terms”), Ancestry defines “Users” as “everyone who uses the Services, whether an unregistered guest, free registered guest, paid subscriber, or a purchaser or activator of a DNA kit.”⁶³ If Ancestry was the genealogy site that Jane and her biological brother used, while Jane, Jane’s husband, and Jane’s biological brother would be Users under Ancestry’s definition, Jane’s birth parents and biological sister would not.

In agreeing to Ancestry’s Terms, Users further agree that they will comply with Ancestry’s policies, as well as with *all* applicable laws.⁶⁴ Additionally, in exchange for using Ancestry’s services, Users acknowledge the potential discovery of unexpected results:

When using our Services, you may discover unexpected facts about yourself or your family in public records, Ancestry Content, DNA results, or another User’s

⁶¹ This Article focuses on the laws applicable to U.S. customers, and thus, unless otherwise noted, will only discuss the sections of these agreements and the provisions therein that are aimed at U.S. customers.

⁶² See *Terms and Conditions*, ANCESTRY.COM (Aug. 15, 2022), <https://www.ancestry.com/c/legal/termsandconditions> [hereinafter “Ancestry Terms”]. Note that within the Terms and Conditions, Ancestry includes provisions for dispute resolution (including, but not limited to arbitration), that will be discussed separately in this Article.

⁶³ *Id.* at § 1.2 (“Eligibility to Use the Services”).

⁶⁴ *Id.* at § 1.3 (“Use of the Services”). The Terms provide that:

In exchange for your access to the services, you agree that you will: Comply with Ancestry’s Community Rules, Cookie Policy, Copyright Policy, and Renewal and Cancellation Terms; To comply with all applicable laws; To be responsible for all use and activity of the Services associated with your account or log-in information; To contact us if you suspect your account has been used without your authorization or you believe your username and password have been stolen; Not to resell the Services or resell, reproduce, or publish any content or information found on the Services, except as explicitly described in these Terms; Not to circumvent, disable or otherwise interfere with security-related features of the services; and Not to access or collect data in bulk or using automated means, or attempt to access data without permission. This includes, but is not limited to, any bots, crawlers, spiders, data-miners, or scrapers.

Id.

content. You acknowledge that such discoveries may have a strong emotional impact on you and others with whom you share these discoveries. You expressly agree to assume all risks associated with your use of the Services, and that Ancestry shall not be liable for any social, emotional, or legal consequences of such discoveries.⁶⁵

Thus, individuals like Jane’s biological parents, who would *not* be considered Users under Ancestry’s Terms, can still be significantly impacted by the discoveries of others.

With respect to DNA Services, Ancestry has a special provision under which Users also agree that Ancestry “may directly or through other companies who help [Ancestry] provide the DNA Services . . . [c]ompare your DNA results with other DNA Data in the Ancestry database to provide the Services, including matching you to others in [Ancestry’s] database with whom you share DNA (you are in control as to whether or not to see and be seen by your DNA matches)[.]”⁶⁶ Again, despite not being Ancestry Users, Jane’s biological parents and biological sister would still be connected through the DNA shared by Jane and her biological brother.

Ancestry services allow Users to contribute content, “including but not limited to family trees, photos, audio/video recordings, stories, record annotations, comments, messages, and feedback provided to Ancestry about the Services (Your Content).”⁶⁷ Ancestry’s Terms state that User Content which contains Personal Information is treated in accordance with its Privacy Statement.⁶⁸

⁶⁵ *Id.* at § 1.1 (“Unexpected Results”). This language was updated in 2022, the prior version of Ancestry’s Terms (Aug. 3, 2021) provided: “[w]hen using our Services, you may discover unexpected facts about yourself, or your family (e.g. you may discover an unknown genetic sibling or parent, surprising facts about your ethnicity, unanticipated genetic test results, or unexpected information in public records). Once discoveries are made, we can’t undo them.” *Terms and Conditions*, ANCESTRY.COM (Aug. 3, 2021), <https://www.ancestry.com/cs/legal/termsandconditions> (last visited Aug. 25, 2021).

⁶⁶ See Ancestry Terms, *supra* note 62, at § 1.4 (“Additional Terms Applicable to Use of DNA Services”).

⁶⁷ *Id.* at § 3 (internal quotations omitted).

⁶⁸ *Id.*

2. *23andMe's Terms of Service*⁶⁹

Whereas Ancestry expressly defines who is considered a User pursuant to its Terms,⁷⁰ 23andMe does not.⁷¹ Despite believing that everyone should have access to, understand, and benefit from their genome, 23andMe limits its services to individuals who are (1) at least eighteen years old; (2) able to form a binding contract with 23andMe; (3) not barred from receiving its services under the laws of the jurisdiction in which the Services are being used; and (4) not an insurance company or an employer.⁷²

23andMe not only restricts *who* can use its services, but it further limits *how* these services can be used.⁷³ 23andMe's Terms of Service explicitly prohibits the use of its services for investigative forensic genealogy purposes.⁷⁴ Specifically with respect to samples provided to 23andMe, its Terms of Service states that “[a]ny sample you provide to 23andMe is either your own, or the sample of a minor for whom you are a parent or legal guardian, or the sample of a person for whom you are a legally authorized representative.”⁷⁵ In situations such as Jane's, Jane and her biological brother provided only their own samples, yet the genetic information within their samples was able to connect more than just the two of them.

Geographically, 23andMe is licensed in the State of California as a clinical laboratory.⁷⁶ Because 23andMe is not licensed universally by all state, federal, or international authorities for genetic testing, its services are not offered in certain jurisdictions because it does not have the required licenses.⁷⁷

⁶⁹ *Terms of Service*, 23ANDME.COM (June 8, 2022), <https://www.23andme.com/legal/terms-of-service/> [hereinafter “23andMe Terms”].

⁷⁰ See Ancestry Terms, *supra* note 62, at § 1.2 (“Eligibility to Use the Services”).

⁷¹ See 23andMe Terms, *supra* note 69, at § 1 (“Who Can Use the Services”).

⁷² *Id.*

⁷³ See *id.*

⁷⁴ *Id.* Forensic genealogy describes “the use of SNP-based relative matching combined with family tree research to produce investigative leads in criminal investigations and missing persons cases.” Daniel Kling et al., *Investigative Genetic Genealogy: Current Methods, Knowledge and Practice*, 52 GENETICS 1, 2 (2021).

⁷⁵ See 23andMe Terms, *supra* note 69, at § 1 (includes additional restriction prohibiting samples from bone marrow or stem cell recipients).

⁷⁶ *Id.* (stating further that “not all jurisdictions require [23andMe's] Services to be subject to license”).

⁷⁷ *Id.*

As a parallel to Ancestry's Terms' acknowledgment of "unexpected results,"⁷⁸ 23andMe's Terms of Service include an entire section dedicated to the risks and considerations regarding its services.⁷⁹ 23andMe recognizes that not all discoveries made through the use of its services will be welcome or positive.⁸⁰ Its Terms of Service encourage consultations with physicians and genetic counselors before providing a sample for testing as there is the potential for users to make troubling discoveries that are beyond their control.⁸¹ Genetic testing for clinical purposes does not raise the same privacy concerns as do genealogy sites. In addition to the protections afforded under federal statutes such as HIPAA and GINA, genetic testing for the purpose of discovering genetic disorders or predispositions does not rely on the identities of biological parents. Whether Jane, or any user, were to provide 23andMe with a sample for clinical purposes, it still has the potential to expose her biological relatives' identities through her biological brother's use of 23andMe's services.

B. Privacy Policies

1. Ancestry's Privacy Statement⁸²

Ancestry's Privacy Statement outlines its practices for collecting, storing, and processing User's Personal Information.⁸³ Ancestry defines Personal Information as "any information that can identify you directly or indirectly . . . such as your name, email or address, or information that could reasonably be linked back to you, including your

⁷⁸ See Ancestry Terms, *supra* note 62, at § 1.1.

⁷⁹ See 23andMe Terms, *supra* note 69, at § 1.

⁸⁰ *Id.*

⁸¹ *Id.* (providing that if you use 23andMe's services, you may "discover things about yourself that trouble you and that you may not have the ability to control or change (e.g., your father is not genetically your father, surprising facts related to your ancestry, or someone with your genotype may have a higher than average chance of developing a specific condition or disease)").

⁸² *Your Privacy*, ANCESTRY.COM (Aug. 15, 2022), <https://www.ancestry.com/c/legal/privacystatement> [hereinafter "Ancestry Privacy"]. For purposes of this Article, privacy concerns will be limited to personal and genetic information (and will not include payment or financial information, browsing history and related information, etc.), unless otherwise explicitly stated.

⁸³ *Id.* at § 1. Ancestry excludes information about deceased persons from Personal Information as referenced to and protected under its Privacy Statement. *Id.*

Genetic Information.”⁸⁴ Ancestry collects Personal Information not just from its Users, but also from public records, historical records, and third parties.⁸⁵ Again, as included in its Terms, Ancestry’s Privacy Statement suggests that Users “may discover unexpected facts about [themselves] or [their] family when using [Ancestry’s] services. Once discoveries are made, [Ancestry] can’t undo them.”⁸⁶

i. Personal Information Collected from Ancestry Users

While not all Ancestry Users have Ancestry accounts, the Personal Information collected through account creation is limited to a User’s name, email address, and password.⁸⁷ In creating a User Profile, however, Ancestry collects information provided by its users (such as a profile image, an account username, the User’s name, biography, age, location, and linked account usernames) as well as information about the User from her family tree.⁸⁸ A User’s profile information is visible to other Users.⁸⁹

With respect to Genetic Information, Ancestry extracts a User’s DNA from a saliva sample and converts it into biometric data that it processes to provide Users with ethnicity estimates and

⁸⁴ *Id.* Ancestry further defines “Genetic Information” as User’s “machine-readable biometric data” and any information derived from it such as ethnicity estimates, communities, traits, and genetic relative matches. *Id.* at § 3.

⁸⁵ *Id.* at § 16.3 (“Categories of Sources of Personal Information”). With respect to third parties, certain Ancestry features support third-party sign-in services from social media sites, as well as Google and Apple that may provide Ancestry with Personal Information such as name, email address and profile information. *See id.*, at § 3. Ancestry’s Privacy Statement further states that

If you interact with social media through the Services, for example “Share,” “Post,” “Tweet,” “Pin,” or “Follow US” links to sites such as Facebook, Twitter, Pinterest, Instagram, and YouTube, Ancestry will collect these interactions and whatever account information these services make available to us dependent on your privacy settings with that third party.

Id. at § 4. The interactions between these third parties and Ancestry features are governed by the privacy policy of the applicable third-party entity. *Id.*

⁸⁶ *See generally* Ancestry Privacy, *supra* note 82.

⁸⁷ *Id.* at §§ 2, 3. Again, account creation is not required to be considered a “User” under Ancestry’s Terms. *See* Ancestry Terms, *supra* note 62, at § 1.2.

⁸⁸ *See* Ancestry Privacy, *supra* note 82, at § 3.

⁸⁹ *Id.* (Ancestry suggests limiting this information and that Users use a username different from her real name to protect their privacy).

information pertaining to their “degree of relatedness to other users in [Ancestry’s] DNA database.”⁹⁰ Interestingly, Ancestry Users’ saliva and extracted DNA are *not* considered Personal Information as protected under the Privacy Statement.⁹¹

More concerning than Ancestry’s exclusion of its Users’ saliva and DNA from what it protects as “Personal Information” under its Privacy Statement is that HIPAA does not apply to or protect any User data.⁹² While discussed later in further detail, the lack of HIPAA protection over information and data collected by Ancestry is a clear example of the lack of regulation over such information and data, as well as the need for distinct protections.

ii. Non-User Information and Data

Ancestry not only collects and uses information from its own Users, but from Non-Users as well.⁹³ Ancestry allows its Users to research their family history and collaborate with other Users, enabling shared research to promote extensive discoveries about their ancestors.⁹⁴ Ancestry notes that there are two sources of information about non-Ancestry users on its site.⁹⁵

The first source of information about non-Ancestry users is information uploaded by users to their family trees.⁹⁶ The second source of information about non-Ancestry users includes third-party records that may relate to living people (both users and non-users), such as records from archives or maintained by local authorities (i.e., birth, marriage, or death records, records of military service, or census details).⁹⁷ In fact, Ancestry promotes that the majority of the records on its services are those of deceased individuals, which it claims

⁹⁰ *Id.*

⁹¹ *Id.*

⁹² *Id.* (noting that “Ancestry is not a covered entity under the Health Insurance Portability and Accountability Act . . . and as a result no data provided by [User(s)] is subject to or protected by HIPAA”).

⁹³ *How Do We Process Non-User Data*, ANCESTRY.COM, <https://www.ancestry.com/c/legal/nonuser> (last visited Dec. 10, 2022). As seen through the example in Jane’s Story, information was collected about Jane’s biological parents and biological sister, despite being non-users.

⁹⁴ *Id.*

⁹⁵ *Id.*

⁹⁶ *Id.* (such information can include “photos, names, dates of birth, significant events, stories, and other content”).

⁹⁷ *Id.*

“minimizes privacy concerns and the relevance of data protection legislation.”⁹⁸

Despite acknowledging its maintenance of records containing non-user data, Ancestry claims that none of this non-user data is DNA data.⁹⁹ Ancestry’s DNA-matching services compare a user’s DNA against the DNA of other users in its database and generates a list of Ancestry users that share a DNA connection.¹⁰⁰

DNA-matching is problematic; it is the primary source of the unexpected revelations that are made through such sites.¹⁰¹

DNA Matches may reveal unexpected connections, including genetic relationships that contradict existing familial relationships that might appear in a family tree (e.g., **in cases of adoption or donor conception where sperm, egg or embryo donation was used**). **Sometimes this reveals the parentage of a user which is different from what the user may have previously understood about their parentage.**¹⁰²

Take Jane, for example—while Jane always knew she was adopted, she did not know about her biological siblings. Using DNA matching, she discovered that she not only had a biological brother, who was also an Ancestry user, but through this match, she discovered that she had a biological sister as well. Though Jane knew she had biological parents, Ancestry’s DNA-matching feature helped her find them through her biological brother’s information despite her biological parents not being Ancestry users themselves. Jane’s story is only one example of how DNA Matches may reveal unexpected connections. DNA-matching features on genealogy sites such as Ancestry can also reveal

⁹⁸ *Id.*

⁹⁹ *Id.* (“Ancestry does not have non-Ancestry user’s DNA in our AncestryDNA database. You must be an Ancestry user and have taken an AncestryDNA test for Ancestry to have DNA data about you.”).

¹⁰⁰ *Id.* (noting that these DNA matches are provided only if a user “expressly chooses to view (and be viewed) by their DNA matches”).

¹⁰¹ *Id.*

¹⁰² *Id.* (emphasis added) (suggesting that “[i]f users are concerned about the implications of DNA Matches, they can elect not to view or be viewed by DNA Matches in DNA Settings”).

adoption status in general; not everyone who is adopted is aware that they are adopted.¹⁰³

2. *23andMe's Privacy Statement*¹⁰⁴

As compared with Ancestry, 23andMe uses “Personal Information” more generally to refer to different data categories that personally identify users.¹⁰⁵ Personal Information can be either individual-level information—described as “information about a single individual, such as their genotypes, diseases or other traits or characteristics”—or de-identified information—“information that has been stripped of identifying data such that an individual cannot reasonably be identified.”¹⁰⁶

23andme collects six categories of information: (1) Registration Information; (2) Genetic Information; (3) Sample Information; (4) Self-Reported Information; (5) User Content; and (6) Web-Behavior Information.¹⁰⁷ It gathers this information from three sources—users, service providers, and other third parties.¹⁰⁸

With respect to protecting the data and information it collects, 23andMe’s Privacy Statement lays out who it does and does not share user information with.¹⁰⁹ 23andMe allows its users to direct the sharing of Personal Information with “friends, family members, doctors or other healthcare professionals, and/or any other individuals or entities who may or may not be using [23andMe’s] Services, including through third party services such as social networks and third-party apps that connect to [23andMe’s] Services.”¹¹⁰ By permitting this type of sharing with third parties, it further allows the collection and distribution of information without the individual’s knowledge or consent. In the case of Jane, Jane’s biological brother shared Jane’s information with

¹⁰³ This is true for individuals conceived via egg, sperm, and embryo donation as well. For purposes of this Article, however, the focus remains on the privacy concerns, considerations, and implications specifically with respect to adoptions.

¹⁰⁴ *Privacy Statement, 23ANDME.COM* (June 8, 2022), <https://www.23andme.com/legal/privacy/full-version/> [hereinafter “23andMe Privacy”].

¹⁰⁵ *Id.*

¹⁰⁶ *Id.*

¹⁰⁷ *Id.*

¹⁰⁸ *Id.*

¹⁰⁹ *Id.*

¹¹⁰ *Id.* (providing further that if users share their Personal Information with a third party, that third party may use that information differently than 23andMe).

his sister, a non-user. Additionally, users can opt-in or opt-out of certain sharing features, including DNA Relatives or My Connections.¹¹¹ Users that opt-out of these sharing features choose not to share their information with genetic relatives or other users, while users who participate in this type of sharing opt to share their information to discover genetic relatives or make connections.¹¹² Ultimately, while opting out of such sharing features may make it more difficult to be found, it does not prevent it altogether. Jane's story demonstrates that even non-users can be found (Jane's biological sister and biological parents). Had Jane's biological brother opted out of the sharing features, there is nothing to say that Jane would not have found her biological family through matching with a second or third cousin.

23andMe's Privacy Statement indicates that user privacy and data protection are tailored to each user.¹¹³ In addition to choosing whether to opt-in to certain sharing features, 23andMe also allows its users to control (1) whether their sample is stored, (2) if they want to view their health reports, (3) communication preferences, and (4) research participation.¹¹⁴

IV. CLOSED ADOPTIONS

Regardless of recent trends, American domestic adoptions, throughout history, have been completely confidential.¹¹⁵ In completely confidential adoptions (more commonly known as "closed adoptions"), there is no contact between the birth parents and the

¹¹¹ *Id.*

¹¹² *Id.*

¹¹³ *See id.* ("It's your data, and we make it easy to make decisions and certain choices about it.")

¹¹⁴ *Id.* All four of the control options implicate privacy concerns not only in matters relating to adoption, but in general.

¹¹⁵ *See, e.g., US Adoption Statistics*, ADOPTION NETWORK, <https://adoptionnetwork.com/adoption-myths-facts/domestic-us-statistics/> (last visited Oct. 3, 2022) (citing CHRISTINE ADAMEC & WILLIAM L. PIERCE, *THE ENCYCLOPEDIA OF ADOPTION* (2d ed., 2000)) ("Today almost 60-70% of domestic adoptions are now open adoptions, which means there is a degree of openness and disclosure of information between adoptive and birth parents regarding the adopted child."); Erica Kramer, *Open vs. Closed Adoptions: A Post Adoption Mental Health Perspective*, BOS. POST ADOPTION RES. (Oct. 23, 2019), <https://bpar.org/open-vs-closed-adoptions-a-post-adoption-mental-health-perspective/> (noting that as of 2012, it is estimated that only about five percent of domestic adoptions were closed adoptions). *See also* Baffer, *supra* note 4, at 151 (internal citations omitted).

adoptive parents, and no identifying information is exchanged.¹¹⁶ In closed adoptions, court records are typically sealed as well.¹¹⁷ This further supports the overall goal of closed adoptions, which is to promote confidentiality and protect parties' privacy interests.¹¹⁸ Although closed adoptions are becoming less common,¹¹⁹ the intent remains the same—to maintain confidentiality and privacy of the involved parties. Nevertheless, genealogy sites such as Ancestry and 23andMe interfere with this intent through the DNA matching of individuals that exposes this confidential information. Consider again Jane's story—her biological parents chose to place her up for adoption and opted for the adoption to be closed; they did not want to be contacted. When Jane's biological brother registered his information on a genealogy site, Jane was still able to find her biological parents (and biological sister) through him.

A. Adoption Records

It was not too long ago that our society encouraged adopted children to be raised as if they were born into the adopted family, without information about their family.¹²⁰ This perspective led to state legislation limiting the access and information available to adoptees.¹²¹

In 1917, when the first state sealed adoptions records law was passed, privacy of the parties involved was already a point of concern.¹²² As the first state to pass such a law, Minnesota focused

¹¹⁶ *Id.* (internal citations omitted).

¹¹⁷ *See id.*

¹¹⁸ *See, e.g.,* Callie Smothers, *Closed Adoption Definition*, ADOPTION.COM (Dec. 9, 2019), <https://adoption.com/closed-adoption-definition/> (“An original goal of closed adoption for birth mothers was that they would get the chance to remain anonymous and, therefore, could continue life after placement without negative social stigmas associated with unwed pregnancies.”).

¹¹⁹ *See, e.g.,* *Open vs. Closed Adoption: What is the Difference?*, AM. ADOPTIONS, <https://www.americanadoptions.com/adopt/open-closed-semi-adoption#:~:text=Today%2C%20the%20vast%20majority%20of,of%20modern%20adoption%20are%20closed.> (last visited Jan. 9, 2023) (“Today, the vast majority of adoptions are considered open. In fact, according to open vs. closed adoption statistics, it's estimated that only 5% of modern adoptions are closed.”); Kramer, *supra* note 115.

¹²⁰ *See* Baffer, *supra* note 4, at 151.

¹²¹ *Id.*

¹²² *Id.* at 151-52 (noting that Minnesota passed the first sealed adoption records law in 1917); *see also id.* at 151 (citing Rotem Peretz, *At a Glance: Adoptees' Right to Know—The Decades-Long Battle for Unsealing Adoption Records*, EREPOSITORY AT

primarily “on the privacy of the parties involved and keeping the covered information from society at large, not necessarily from parties to adoption.”¹²³ By the 1940s, most states had enacted laws that required adoption records to be sealed;¹²⁴ and by the 1950s, nearly all states had enacted similar legislation.¹²⁵

In consideration of the biological family’s privacy, additional legal protections were given to original birth certificates.¹²⁶

Original birth certificates can be key documents in an adult adoptees’ search for birth families because they contain facts such as a birth parent’s name and address and the name of the hospital where the child was born. Once adoptions are finalized, however, original birth certificates are sealed, making them inaccessible to the public.¹²⁷

After an adoption is finalized, the birth certificate is amended to include the adoptive parents as the parents of the child.¹²⁸ By the 1960s, most states had laws that included an adoptee’s original birth certificate as part of adoption records that were sealed as a matter of law.¹²⁹

The Open Records Movement (sometimes referred to as the “Adoptees Rights Movement”) began in the 1970s, when adoptees began seeking legal access to their original birth records.¹³⁰ This movement, started in large part by the Adoptees’ Liberty Movement Association, was aimed at lobbying for legislative reform that legally

SETON HALL: LAW SCH. STUDENT SCHOLARSHIP (May 1, 2013) at 4, https://scholarship.shu.edu/cgi/viewcontent.cgi?article=1284&context=student_scholarship.

¹²³ See Baffer, *supra* note 4, at 151-52 (citing Peretz, *supra* note 122, at 5).

¹²⁴ *Id.* at 152 (citing Peretz, *supra* note 122, at 4).

¹²⁵ *Id.*

¹²⁶ See, e.g., Nina Williams-Mbengue, *Adult Adoptee Access to Original Birth Certificates*, NAT’L CONF. STATE LEGISLATURES (NCSL) (May 15, 2019), <https://www.ncsl.org/research/human-services/adult-adoptee-access-to-original-birth-certificates.aspx>.

¹²⁷ *Id.*

¹²⁸ *Id.* (noting further that if, upon adoption, the child is given a new name, the amended birth certificate will reflect the child’s new name).

¹²⁹ See Baffer, *supra* note 4, at 152 (citing Jenni Bergal, *With Push From Adoptees, States Open Access to Birth Records*, PEW CHARITABLE TRUSTS (Aug. 12, 2016), <https://www.pewtrusts.org/en/research-and-analysis/blogs/state-line/2016/08/12/with-push-from-adoptees-states-open-access-to-birth-records>).

¹³⁰ Emily Ingall, *A Presumption in Favor of Openness: Unsealing Adoption Records*, 26 CARDOZO J. EQUAL RTS. & SOC. JUST. 305, 307 (2020) (internal citations omitted).

permitted adoptees' access to their adoption records and original birth certificates.¹³¹ Subsequently, several states passed legislation permitting adult adoptees access to their adoption records.¹³²

1. *Adoption Laws*

Adoptions and family planning are issues that fall within family law.¹³³ Jurisdiction over family law issues has historically been reserved to the states.¹³⁴ Current laws, however, fail to regulate whether adoptees have a right to secure birth information from genealogy sites.

Because adoption is a state issue, no uniform standard exists for courts to apply to adoption cases. With respect to adoption records in particular, there is significant disparity across the country as to how much information is sealed versus released.¹³⁵ A majority of states still have laws in place that keep adoption records sealed.¹³⁶ Adoption record laws are classified into five categories based on their strictness: (1) unrestricted access; (2) access with restrictions; (3) partial access; (4) partial access with restrictions; and (5) sealed (also referred to as “restricted”).¹³⁷

¹³¹ *Id.*

¹³² *See, e.g., Adoption*, BRITANNICA, <https://www.britannica.com/topic/adoption-kinship#ref793732> (last visited Jan. 8, 2023).

¹³³ *See, e.g., Baffer, supra* note 4, at 153 (internal citations omitted).

¹³⁴ Linda D. Elrod, *The Federalization of Family Law*, ABA (July 1, 2009) http://www.americanbar.org/publications/human_rights_magazine_home/human_rights_vol36_2009/summer2009/the_federalization_of_family_law. *See also* *In re Burrus*, 136 U.S. 586, 593-94 (1890) (“The whole subject of the domestic relations of husband and wife, parent and child, belongs to the laws of the States and not to the laws of the United States.”).

¹³⁵ *See Baffer, supra* note 4, at 154. The American Adoption Congress (AAC) last updated its legislative policy statement in 2018:

It is the formal policy of the [AAC] to support state-by-state legislative efforts to restore unrestricted access to original birth certificates (OBC) for all adult adoptees. This is also known as “clean” adoption reform, which is in accordance with widely accepted best practices in adoption. As an umbrella organization, the AAC will also support efforts to gain access to all adoption agency and court records if panned within legislation or government actions.

State Adoption Laws, supra note 15.

¹³⁶ *See id.* (includes information on adoption laws by state, including the District of Columbia).

¹³⁷ *Id.*

i. Unrestricted Access to Adoption Records

In states allowing unrestricted access to adoption records, adult adoptees are entitled to their original birth certificates without any discriminatory restrictions or conditions, other than regular procedures for obtaining a state vital record.¹³⁸ Within the United States, twelve states currently provide adult adoptees with unrestricted access to their adoption records.¹³⁹ This number is trending upward, as Massachusetts was the most recent state to legislate for adult adoptees' access to their own original birth certificates in November of 2022,¹⁴⁰ and Vermont will join this category on July 1, 2023.¹⁴¹

The designation “unrestricted access,” however, can be misleading, as not all states within this category provide this level of access to *all* adoption records.¹⁴² For example, even though New York is considered an Unrestricted Access state, this level of access applies

¹³⁸ See Baffer, *supra* note 4, at 154.

¹³⁹ See, e.g., *The United States of OBC*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/united-states-obc/> (last visited Dec. 21, 2022) (“As of November 3, 2022, adult adopted people born in twelve states . . . have the right to request and obtain a copy of their own original birth certificates.”); *State Adoption Laws*, *supra* note 15. The twelve Unrestricted Access states include: Alabama, Alaska, Colorado, Connecticut, Kansas, Louisiana, Maine, Massachusetts, New Hampshire, New York, Oregon, and Rhode Island. *Id.* It is important to note that Hawaii also falls partially within this category regarding adoptions within the state. *Id.*

¹⁴⁰ *Id.* (“On August 5, 2022, Massachusetts became the 13th state to announce a policy of unrestricted access to original birth certificates for all adult adoptees. The new law went into effect on November 3, 2022.”). The provision of the newly enacted Massachusetts law that went into effect on November 3, 2022, provides “[r]estoration of unrestricted access to original birth certificates (OBC) for all adult adoptees born between 7/17/74 and 1/1/08 (MA adoptees born outside that period already enjoyed, since 2007, original birth certificate access upon reaching adulthood).” *Id.*

¹⁴¹ See *The United States of OBC*, *supra* note 139; H.B. 629, 2021-2022 Reg. Sess. (Vt. 2022), available at <https://legislature.vermont.gov/bill/status/2022/H.629>. See also, e.g., Gregory D. Luce, *Vermont’s Equal Rights Law: A FAQ*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/vermonts-equal-rights-law-faq/> (July 12, 2022); Agency of Hum. Servs., Dep’t Child. & Fams., *Vermont’s New Adoption Law*, STATE OF VERMONT: BLOG (Nov. 29, 2022), <https://dcf.vermont.gov/dcf-blog/vermonts-new-adoption-law>. Vermont is currently a “partial access with restrictions” state. See *State Adoption Laws*, *supra* note 15.

¹⁴² See, e.g., Gregory D. Luce, *New York*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/new-york/> (Nov. 24, 2022), (recognizing New York as a state that, while classified as an Unrestricted state, still imposes very restrictive policies with respect to certain information such as identifying information).

to OBC (pre-adoption birth certificates), and *not* to other adoption records which contain identifying information.¹⁴³ In New York, identifying information can still only be released by court order, or in the case of mutual consent, through the state's adoption registry.¹⁴⁴

ii. Access With Restrictions

There are currently fourteen states that fall within this category, which provide adult adoptees access to their adoption records with limitations.¹⁴⁵ The limitations and the severity of them varies from state-to-state, and do not always necessarily provide equal rights to adoptees.¹⁴⁶

a. Age-Based Restrictions

All fourteen states that fall within the Access with Restrictions category require the party requesting the information to have reached a certain age of legal adulthood.¹⁴⁷ In seven of these states, legal

¹⁴³ *See id.*

¹⁴⁴ *Id.*

¹⁴⁵ *See id.*; Baffer, *supra* note 4, at 155 (internal citations omitted). States that fall within this category include Arkansas, Delaware, Idaho, Illinois, Indiana, Iowa, Missouri, New Jersey, Ohio, Pennsylvania, Tennessee, Utah, Washington, and Wisconsin. *See State Adoption Laws, supra* note 15. While Tennessee still technically falls within this category, its policies tend towards those of an Unrestricted Access state. *See* Gregory D. Luce, *Tennessee, ADOPTEE RTS. L. CTR. PLLC*, <https://adopteerightslaw.com/tennessee/> (Nov. 27, 2022) (“While nearly all Tennessee-born adopted people have a right at age 21 to obtain their ‘adoption records’—which will include the original birth certificate—there are limited exceptions. Documents will be withheld ‘if such records indicate that, with respect to the adopted person, the biological parent was the victim of rape or incest.’ In such cases the written consent of the birth parent is required for release.”).

¹⁴⁶ *See generally, State Adoption Laws, supra* note 15. As an example of unequal access, in Wisconsin, an adult adoptee will receive identifying information if at least one birth parent has filed an affidavit with the Department of Children and Families providing consent to the release of such information. Gregory D. Luce, *Wisconsin, ADOPTEE RTS. L. CTR. PLLC*, <https://adopteerightslaw.com/wisconsin/> (Nov. 22, 2022) (including that in Wisconsin, the legal age of adulthood is eighteen years old). If no such affidavit is included in the file, and an adult adoptee requests access to the information, the state will search for the known birth parent to affirmatively request consent or refusal to release the information to the adult adoptee. *Id.*

¹⁴⁷ *See State Adoption Laws, supra* note 15; *see also The United States of OBC, supra* note 139. Some states permit individuals other than the adoptee to request access to an adoptee's adoption records. *See, e.g., id.* For example, in Arkansas, upon the

adulthood begins at age eighteen,¹⁴⁸ while six states elevate the age of legal adulthood to twenty-one years of age.¹⁴⁹

Pennsylvania places additional restrictions on who can access adoption records.¹⁵⁰ In Pennsylvania, adoptees seeking unrestricted access to their OBCs must be at least eighteen years of age, *and* either (a) be a high school graduate, (b) possess a GED, or (c) be legally withdrawn from school.¹⁵¹

Also consider that adult adoptees not only have unequal access to their adoption records depending on what state they are from, but also that their access to these records is unequal to those who are not adopted. For example, in Arkansas, adoptees must be twenty-one years old to request access to their OBCs, while non-adopted people only have to reach the age of eighteen.¹⁵²

b. Date-Based Restrictions

Some states that allow for restricted access to adoption records and OBCs restrict access based on the date of adoption.¹⁵³ Five states have date-based restrictions;¹⁵⁴ of these states, Idaho has most recently

death of an adoptee, requests for access to the adoptee's OBC may be made by the adoptee's surviving spouse or by a legal guardian of the adoptee's children. Gregory D. Luce, *Arkansas*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/arkansas/> (Nov. 20, 2022).

¹⁴⁸ See *State Adoption Laws*, *supra* note 15. The legal age of adulthood, with respect to requests for access to adoption records and OBC, is eighteen in the following states: Idaho, Missouri, New Jersey, Pennsylvania, Utah, Washington, and Wisconsin. *Id.*

¹⁴⁹ *Id.* The legal age of adulthood, with respect to requests for access to adoption records and OBC, is twenty-one in the following states: Arkansas, Delaware, Illinois, Indiana, Iowa, and Tennessee. *Id.* Note that in Ohio, the age of the adoptee requesting these records further depends on an additional date-based restriction. See *id.*

¹⁵⁰ See *id.*; see also Gregory D. Luce, *Pennsylvania*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/pennsylvania/> (Dec. 9, 2022).

¹⁵¹ See *State Adoption Laws*, *supra* note 15; see also Original Birth Record Act of 2016, Pub. L. No. 993-127 (Pa. 2016), <https://www.legis.state.pa.us/cfdocs/legis/LI/uconsCheck.cfm?txtType=HTM&yr=2016&sessInd=0&smthLwInd=0&act=0127>.

¹⁵² See Gregory D. Luce, *Getting an Arkansas Original Birth Certificate*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/arkansas-obc-law-faq/> (Aug. 1, 2018).

¹⁵³ See generally *State Adoption Laws*, *supra* note 15.

¹⁵⁴ *Id.* States that have date-based restrictions on access to adoption records include Idaho, Illinois, Iowa, Ohio, and Tennessee. *Id.* The state of Washington has used “two different methods to deny adult adoptees access to their [OBCs]. For adoptions

modified its legislation with respect to date-based restrictions on access to adoption laws.¹⁵⁵ Idaho's current law applies *only* to people adopted on or after July 1, 2022, and who are at least eighteen years of age.¹⁵⁶ This law, therefore, will have little significance until 2040.¹⁵⁷ Until then, the vast majority of Idaho-born adoptees are subject to limitations that mirror those of a Restricted state; for Idaho-born adoptees whose adoptions were finalized before the new law's effective date, OBC access remains by court order.¹⁵⁸ As such, while technically classified as an Access with Restrictions state, Idaho laws largely reflect the principles associated with a Restricted state.

*c. Mutual Consent Registries &
"Search and Consent"
Procedures*

In addition to age- and date-based restrictions, some states provide access to adoption records and OBCs based on mutual consent registries. Mutual consent registries can be used to facilitate contact and consent-based sharing of identifying information between adopted people, siblings, and birth parents.¹⁵⁹ These registries, or any method of reunion that requires consent from all parties to release or provide access to identifying information, are seemingly the most ethical compromise; they explicitly provide for contact in cases of mutual consent.

finalized after October 1, 1983, birth parents were allowed to file affidavits of non-disclosure until July 28, 2013. A limited number of these affidavits may still be on file." Gregory D. Luce, *Washington*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/washington/> (Nov. 22, 2022).

¹⁵⁵ See *State Adoption Laws*, *supra* note 15. Idaho's current law went into effect on July 1, 2022. *Id.* See also S.B. 1320, 66th Leg., 2d Reg. Sess. 2022 (Idaho 2022), available at <https://legislature.idaho.gov/wp-content/uploads/sessioninfo/2022/legislation/S1320.pdf>.

¹⁵⁶ Gregory D. Luce, *Idaho's Discriminatory Law: A FAQ*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/idahos-new-discriminatory-law-a-faq/> (Nov. 18, 2022).

¹⁵⁷ This is because children born and adopted after July 1, 2022, will not reach the age of eighteen until at least 2040.

¹⁵⁸ See *State Adoption Laws*, *supra* note 15.

¹⁵⁹ See, e.g., U.S. Dep't of Health & Hum. Servs., Admin. for Child. & Fams., Children's Bureau, *Access to Adoption Records*, CHILD WELFARE INFO. GATEWAY (2020), <https://www.childwelfare.gov/pubpdfs/infoaccessap.pdf>; Gregory D. Luce, *Iowa*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/iowa/> (Nov. 20, 2022).

Genealogy sites such as Ancestry and 23andMe on the other hand require no such mutual consent.¹⁶⁰

Within the Access with Restrictions category, eight states have established and used mutual consent registries to connect parties to adoption.¹⁶¹ For example, New Jersey’s Department of Children and Families operates its own state-run adoption registry, where “adult adopted people, adoptive parents of minor adoptees, and birthparents may register to determine if there is another match with another registered person.”¹⁶² New Jersey’s registry is limited to requests to search only *for* birth parents; birth parents may not request these search services.¹⁶³ This means that adoptees are the only parties to adoptions that have the ability to request search services, and not the adoptive parents or the biological parents. For instance, Jane would be able to request search services, but her biological parents would not be able to. Her request for these services would violate their privacy as they opted not to be contacted and wished to remain anonymous.

Search and Consent procedures function differently from mutual consent registries but can be used for the same purpose. Search and Consent laws “authorize public or private agencies to assist adult adoptees in locating biological parents to ascertain whether they are willing to disclose their identities or actually meet with their

¹⁶⁰ Although genealogy sites may allow users to opt-out of certain sharing features, non-users are not afforded the same options and therefore can be connected or exposed regardless of their desire to remain anonymous.

¹⁶¹ See generally *The United States of OBC*, *supra* note 139. These states include Idaho, Illinois, Indiana, Iowa, Missouri, New Jersey, Pennsylvania, and Utah. *Id.* While the state of Washington does not have a mutual consent registry, it does have a confidential intermediary system which is overseen by state courts. See Luce, *Washington*, *supra* note 154 (“State courts in Washington oversee a confidential intermediary program that allows for the court appointment of a confidential intermediary, who can then review confidential court and other records in order to search for and potentially find birthparents, adoptees, and other relatives.”). In addition to its own, state-run adoption registry, Illinois also has a confidential intermediary system, similar to that of Washington. See Gregory D. Luce, *Illinois*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/illinois/> (Nov. 23, 2022). Moreover, these eight Access with Restrictions states are not the only states that have mutual consent registries, but for the purposes of this Article, they are the only ones discussed in this section.

¹⁶² See Gregory D. Luce, *New Jersey*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/new-jersey/> (Nov. 20, 2022).

¹⁶³ *Id.*

adoptee.”¹⁶⁴ Just as with mutual consent registries, Search and Consent procedures also require both parties to consent for the release of information.¹⁶⁵

d. Contact Preference Forms

Some states provide for contact preference forms which are documents that indicate a birth parent’s preference regarding contact with the adoptee.¹⁶⁶ While these preferences vary from state-to-state, they generally offer birth parents the option of preference for contact or to opt out of such preference.¹⁶⁷ These forms typically do not, however, function as a tool that vetoes disclosure, but in some states may allow birth parents to request redactions to any identifying information in the adoptee’s OBC.¹⁶⁸

e. Disclosure and Contact Vetoes

Birth parents can affirmatively and expressly deny adoptees access to their adoption records through disclosure and contact vetoes,¹⁶⁹ which function similarly to contact preference forms. Several states expressly provide for such vetoes and thus limit access based on the legal validity and enforcement of such vetoes.¹⁷⁰

In certain states, such as Missouri, current law allows the release of a copy of the OBC to an adult adoptee, subject to significant

¹⁶⁴ Jason Kuhns, *The Sealed Adoption Records Controversy: Breaking Down the Walls of Secrecy*, 24 GOLDEN GATE U. L. REV. 259, 265 (1994).

¹⁶⁵ *Id.* at 265-66 (“Where the biological parents refuse consent, these states will not release identifying information unless the adoptee can establish “good cause.”).

¹⁶⁶ See generally *The United States of OBC*, *supra* note 139.

¹⁶⁷ See, e.g., *id.*; *State Adoption Laws*, *supra* note 15.

¹⁶⁸ See, e.g., *The United States of OBC*, *supra* note 139.

¹⁶⁹ Bastard Nation, *State Adoption Disclosure Laws at a Glance*, BASTARDS.ORG, <http://bastards.org/state-adoption-disclosure-laws-at-a-glance/> (last visited Dec. 27, 2022). A disclosure veto is a “document filed by one party to register a refusal to the release of any identifying information,” whereas a contact veto is a “document filed by one party to register a refusal to be contacted by the searching party. Sometimes [a contact veto] extends to *all* lineal relatives and descendants.” *Id.* (emphasis added). Recent legislation tends to conflate contact vetoes with disclosure vetoes, encompassing the prohibition of releasing identifying information. *Id.*

¹⁷⁰ See *The United States of OBC*, *supra* note 139. The Access with Restrictions states that expressly provide for disclosure vetoes include Delaware, Indiana, Missouri, Ohio, and Washington. *Id.*

restrictions, such as the birth parent's power to veto the adoptee's access.¹⁷¹

Missouri-born adoptees who are 18 years of age or older may apply for non-certified copy of their [OBC]. A birthparent, however, may restrict the release of the OBC by filing a corrupt contact preference form that says "I prefer not to be contacted." Depending on whether one or two parents are listed on the [OBC], the OBC is either withheld entirely from the adoptee or identifying information is redacted.¹⁷²

Additionally, in Missouri, birth parents can also request the record, but the adoptee has the same veto-power.¹⁷³

Some of these states additionally expressly provide for what is known as a "Zombie Veto."¹⁷⁴ A Zombie Veto extends the protections provided by the traditional disclosure vetoes beyond death.¹⁷⁵ Extending protections beyond death emphasizes that death does not imply consent and raises further concern about privacy considerations post-mortem.

f. Court Order

Although Access with Restrictions states are classified differently from restricted states, some states within this category, like restricted states, still require a court order for access to adoption records that contain identifying information.¹⁷⁶

¹⁷¹ Gregory D. Luce, *Missouri*, ADOPTEE RTS. L. CTR. PLLC, <https://adopteerightslaw.com/missouri/> (Nov. 23, 2022).

¹⁷² *Id.* (noting further that "identifying information on the OBC is also redacted if a parent requests contact through an intermediary").

¹⁷³ *Id.* ("In addition, birthparents may also request the record, though the adopted person may also veto disclosure through a corrupt contact preference form.").

¹⁷⁴ *See generally The United States of OBC*, *supra* note 139. Of the Access with Restrictions states, Indiana, Missouri, and Ohio all expressly provide for Zombie vetoes. *Id.*

¹⁷⁵ *Id.* (stating that jurisdictions which have Zombie Vetoes are "[s]tates where 1) a disclosure veto continues beyond the death of a birth parent or 2) where any required consent is deemed unavailable even after the birth parent dies").

¹⁷⁶ *See id.* Of the Access with Restrictions states, Arkansas, Delaware, Idaho, Missouri, New Jersey, Utah, Washington, and Wisconsin still require court orders for access to adoption records. *Id.* Illinois law is ambiguous with respect to the need for a court order. *See Luce, Illinois*, *supra* note 161.

Despite being classified as Access with Restrictions states, these states have statutes that reflect the need for additional protection for documents with identifying information. Despite the trend of states permitting adoptees at least restricted access to their adoption records, these restrictions can be so severe, as in the case of the need for a court order, that the law appears to still be in favor of sealing such records and protecting such information.

iii. Partial Access to Adoption Records

The American Adoption Congress separates states that allow partial access to adoption records from states that provide for partial access to such records with restrictions.¹⁷⁷ Arizona is currently the only state that provides for partial access to adoption records *without* restrictions.¹⁷⁸

a. *Partial Access With Restrictions*

Similar to Arizona, eight other states provide adult adoptees with partial access to their adoption records; these eight other states, however, limit this access based on the adult adoptee's birth year, as well as if they can overcome other restrictions.¹⁷⁹ This category, in reality, is no different from the Access with Restrictions category. This classification appears to include states that restrict access limited primarily to date-based restrictions, as discussed above. Like those states classified under Access with Restrictions, the states within this category may include additional restrictions to access in addition to date-based restrictions, which are governed by the date of birth or date of adoption of the adult adoptee.

iv. Sealed Adoption Records

¹⁷⁷ See *State Adoption Laws*, *supra* note 15.

¹⁷⁸ *Id.*

¹⁷⁹ *Id.* The states that fall within this category include Maryland, Michigan, Minnesota, Montana, Nebraska, Oklahoma, South Carolina, and Vermont. *Id.*; see also Baffer, *supra* note 4, at 156. As already mentioned, come July 2023, Vermont, which is currently a Partial Access with Restrictions state will become an Unrestricted state due to recently passed legislation. *The United States of OBC*, *supra* note 139; H.B. 629, 2021-2022 Reg. Sess. (Vt. 2022), <https://legislature.vermont.gov/bill/status/2022/H.629>.

(“Restricted” States)

Most states maintain that adoption records stay sealed.¹⁸⁰ In terms of adoption legislation, particularly with respect to records, “restricted” means that parental permission or a court order is required for an adult adoptee to obtain a copy of the original birth certificate.¹⁸¹

While this category of OBC access still represents the majority, its lead in comparison to the other categories is very slim.¹⁸² While the classifications appear to be trending towards providing adult adoptees with more access to their adoption records, the legislation still appears to reflect the significance and necessity of privacy protections.

Despite legislating to seal adoption records, Restricted states maintain policies permitting adoptees with access to their records on a need-based case-by-case basis.¹⁸³ Restricted states have enacted statutes providing for all records to be sealed except where there are compelling reasons to grant access, such as “good cause and exceptional circumstances, the protection or promotion of the welfare of the child, the best interests of the child or the public, or psychological trauma or medical need.”¹⁸⁴

Some states that have permanently sealed adoption records have employed “good cause” standards, allowing adult adoptees access to their adoption records only if this standard is met.¹⁸⁵ The burden for proving “good cause” is on the requesting party to show that there is “a medical or psychiatric need for the sealed information, and that the information is not attainable elsewhere.”¹⁸⁶ This burden is met where medical or psychiatric needs exist and are documented, and

¹⁸⁰ See *State Adoption Laws*, *supra* note 15 (including the fifty states as well as the District of Columbia).

¹⁸¹ See *The United States of OBC*, *supra* note 139.

¹⁸² See *id.* This category includes California, District of Columbia, Florida, Georgia, Kentucky, Mississippi, Nevada, New Mexico, North Carolina, North Dakota, South Dakota, Texas, Virginia, West Virginia, and Wyoming. *Id.* Hawaii’s legislation falls partially within this category, as it seals the records of adoptees born *in* Hawaii but adopted outside of the state. *Id.*

¹⁸³ See, e.g., Ingall, *supra* note 130, at 310.

¹⁸⁴ *Id.* (citing Wayne Deloney, *Unsealing Adoption Records: The Right to Privacy Versus the Right of Adult Adoptees to Find Their Birthparents*, 7 WHITTIER J. CHILD & FAM. ADVOC. 117 (2007)) (internal quotations omitted).

¹⁸⁵ *Id.* (citing Deloney, *supra* note 184, at 138); Jessica Colin-Greene, *Identity and Personhood: Advocating for the Abolishment of Closed Adoption Record Laws*, 49 CONN. L. REV. 1271, 1278-79 (2017).

¹⁸⁶ Ingall, *supra* note 130, at 310-11 (citing Deloney, *supra* note 184, at 138).

when the adoptee is unable to otherwise obtain the information.¹⁸⁷ Courts have found good cause where there is (1) a severe psychological problem caused by the absence of information;¹⁸⁸ (2) a particularly significant and overwhelming psychological need to know;¹⁸⁹ (3) a need to determine an adoptee's inheritance rights;¹⁹⁰ or (4) a sense of obligation to one's ancestral religion.¹⁹¹ And, while some courts have permitted adoptees to contact their biological parents to obtain more accurate and up-to-date medical information, adoptees must still meet the high burden for good cause.¹⁹² A problem with these "good cause" policies, however, is that there is no uniformity to what a showing of "good cause" entails.¹⁹³ Without a uniform standard to determine what meets sufficient "good cause," judges lack guidance when tasked with identifying its presence.¹⁹⁴

2. Continuing Controversy

Even though most states still legislate for adoption records to remain sealed, there is a growing trend, culturally, towards open

¹⁸⁷ Kuhns, *supra* note 164, at 263.

¹⁸⁸ Colin-Greene, *supra* note 185, at 1279 (citing to *In re Assalone*, 512 A.2d 1383, 1387-88 (R.I. 1986)).

¹⁸⁹ *Id.* (citing to *In re Dodge Estate*, 413 N.W.2d 449, 454 (Mich. Ct. App. 1987)).

¹⁹⁰ *Id.* (citing to *Massey v. Parker*, 369 So. 2d 1310, 1314 (La. 1979)).

¹⁹¹ *Id.* (citing to *In re Gilbert*, 563 S.W.2d 768, 770 (Mo. 1978)).

¹⁹² *See* Kuhns, *supra* note 164, at 263-64 ("A few courts have allowed adoptees to contact their biological parents in the hope of obtaining more accurate and up-to-date medical information, but the mere desire of adoptees for data about potential susceptibility is most often found insufficient to justify releasing names of biological parents."); *In re Hayden*, 435 N.Y.S.2d 541 (1981) (holding that where an adult adoptee feared she was at risk of developing cancer as a result of biological mother's possible DES intake while pregnant is entitled to inspect her adoption records). *See also, e.g., Golan v. Louise Wise Services*, 514 N.Y.S.2d 682, 686 (1987) ("[A]s virtually any adopted person advances in age, his or her genetic history will be desirable for treatment of a variety of ailments . . . A rule which automatically gave full disclosure to any adopted person confronted with a medical problem with some genetic implications would swallow New York's strong policy against disclosure as soon as adopted people approached middle age.>").

¹⁹³ Colin-Greene, *supra* note 185, at 1279 (citing Christopher G. A. Lorient, *Good Cause is Bad News: How the Good Cause Standard for Records Access Impacts Adult Adoptees Seeking Personal Information and a Proposal Reform*, 11 U. MASS. L. REV. 100, 111-12, 114 (2016)).

¹⁹⁴ *See generally id.* at 1279.

adoptions.¹⁹⁵ As a result of the clash between cultural and legislative trends, the question whether to unseal adoption records remains a controversial one.

i. Arguments in Favor of Sealed Adoption Records

Given the prominence of privacy issues and concerns that have historically plagued our nation, the right to privacy has long been acknowledged and protected by the Constitution.¹⁹⁶ This fundamental right to privacy, encompasses both individual privacy and the right to make choices about personal matters.¹⁹⁷ Not only is there a constitutional right to privacy, but the Supreme Court has further acknowledged a constitutional *freedom* permitting personal choices regarding matters of family life and marriage.¹⁹⁸ Issues with respect to adoption, therefore, should be within the scope of the *freedom* established and protected under the Constitution. While all parties to adoption—birth parents, adoptees, and adoptive parents—cite the Constitution to further their arguments with respect to accessing or sealing these records and associated documents, the Constitution’s fundamental right to privacy has prevailed.

Birth parents in opposition to the open records movement argue that their privacy interests are constitutionally protected.¹⁹⁹ They specifically cite the Due Process Clause of the Fourteenth Amendment as providing protection against any release of identifying information as any such disclosure would violate their rights to familial privacy.²⁰⁰ These arguments have been successful in courts, emphasizing the

¹⁹⁵ See Rosenbaum, *supra* note 12 (“As recently as the 1970s, almost all American adoptions were confidential; today, only 5% are.”).

¹⁹⁶ See, e.g., *Griswold v. Connecticut*, 381 U.S. 479 (1965) (holding broadly that a right to privacy can be inferred from several amendments in the Bill of Rights, and such a right of privacy prevents states from making the use of contraception by married couples illegal).

¹⁹⁷ See Ingall, *supra* note 130, at 318 (citing *Griswold*, 381 U.S. at 485).

¹⁹⁸ *Eisenstadt v. Baird*, 405 U.S. 438, 453-54 (1972) (ruling that the right of privacy is the right of an individual, whether married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child).

¹⁹⁹ Caroline B. Fleming, *The Open-Records Debate: Balancing the Interests of Birth Parents and Adult Adoptees*, 11 WM. & MARY J. WOMEN & L. 461, 469 (2005).

²⁰⁰ See, e.g., *id.*

strength of birth parents' constitutional arguments supporting their right to privacy.

The Supreme Court established that the Equal Protection Clause supplements due process protections when states seek to limit the exercise of protected rights to particular groups.²⁰¹ The Court implemented a standard for recognizing such rights, providing that they must be “deeply rooted in this Nation’s history and tradition”²⁰² and “implicit in the concept of ordered liberty.”²⁰³ When using this standard, courts focus on the legal development of the asserted right.²⁰⁴ Given that privacy protections are so deeply rooted in our Nation’s history and tradition, as evidenced by the decades of legislation which sealed adoption records, all that remains to be considered is whether preserving the confidentiality of adoption records is implicit in the concept of ordered liberty. The Supreme Court established that the Fourteenth Amendment protected rights which are “of the very essence of a scheme of ordered liberty”²⁰⁵ and that abolishing such rights would “violate a principle of justice so rooted in the traditions and conscience of our people as to be ranked as fundamental.”²⁰⁶

²⁰¹ Kelsey Y. Santamaria, *Privacy Rights Under the Constitution: Procreation, Child Rearing, Contraception, Marriage, and Sexual Activity*, CONGR. RSCH. SERV. (CRS) (Sept. 14, 2022), <https://crsreports.congress.gov/product/pdf/LSB/LSB10820> (noting that this has resulted in the Court “striking down laws that, for example, denied the ‘fundamental’ right to marriage to interracial or same-sex couples.”).

²⁰² *Washington v. Glucksberg*, 521 U.S. 702, 703 (1997). Recently, the Court has overruled prior decisions recognizing a right that the Court had previously characterized as “fundamental” under the Constitution. See Santamaria, *supra* note 201 (noting that “In the 2022 decisions *Dobbs v. Jackson Women’s Health Organization*, the Supreme Court upheld a Mississippi law prohibiting abortion after 15 weeks on the ground that the Constitution does not protect a right to abortion. Employing the *Glucksberg* framework, *Dobbs* overruled *Roe v. Wade* and *Planned Parenthood of Southeastern Pennsylvania v. Casey*, which recognized and then reaffirmed a right to the procedure under the Due Process Clause.”). The Court’s reassessment of *Roe* and *Planned Parenthood* raises concerns over the Court’s future assessments and reassessments of rights historically considered “fundamental,” such as the right to privacy. See, e.g., *id.* The legal analysis in this Article, however, is limited to the current governing laws, and their significance and relevance to privacy concerns with respect to adoptions and genealogy sites.

²⁰³ *Glucksberg*, 521 U.S. at 721.

²⁰⁴ Paul Matouka, *The Fundamental Right to Biological Integrity*, 67 WAYNE L. REV. 57, 62 (2021).

²⁰⁵ *Palko v. Connecticut*, 302 U.S. 319, 325 (1937).

²⁰⁶ *Id.* See also Eric T. Kasper, *The Constitutional Protection of Ordered Liberty*, THE CHRONOTYPE (Dec. 28, 2021), <https://www.apg->

While the adoptive parents' privacy interests are significantly less debated, they are no less controversial. The adoptive families are often the forgotten parties to adoption when it comes to privacy concerns. However, another purpose in sealing adoption records is to protect the identity and privacy of the adoptive parents from the birth parents.²⁰⁷ Sealed adoption records help to avoid unwanted intrusions from birth parents into the lives of the adoptee and adoptive family.²⁰⁸ As American citizens, adoptive parents and members of an adoptive family are afforded the same constitutional rights and protections as birth parents and biological relatives, including the fundamental right to privacy.

Proponents of maintaining confidentiality in the interest of privacy recognize, however, that there are certain circumstances under which the law must be flexible. Legislation has evolved to consider concerns of adoptees, while continuing to protect privacy of biological parents.²⁰⁹ Despite permitting some adoptees access to their adoption records, the high burden that the adoptee needs to meet to access this information supports the argument to protect privacy interests. Because the burden is so high, it emphasizes the limited circumstances under which adoption records should be unsealed in the interest of justice.

ii. Arguments to Unseal Adoption Records

Due to the growing trend favoring transparency in the adoption process, proponents in favor of unsealing adoption records argue that this cultural trend should be reflected in the adoption record laws.

Advocates of unsealing adoption records and providing adult adoptees with access to their OBCs argue that what is in the "best interests of the child" is the underlying principle which governs adoptions.²¹⁰ This argument is based on the theory that the state's role and

wi.com/rice_lake_chronotype/free/the-constitutional-protection-of-ordered-liberty/article_fda88744-ae8c-55e9-ab31-5503899c6ae6.html.

²⁰⁷ See Deloney, *supra* note 184, at 136.

²⁰⁸ *Id.*

²⁰⁹ See *supra* notes 185-94 (discussing the "good cause" standard used by Restricted states), 159-76 (discussing state policies implemented in response to adoptees' argument to unseal adoption records under certain circumstances). See also Kuhns, *supra* note 164, at 262.

²¹⁰ See Baffer, *supra* note 4, at 159.

interest in a child's best interest ends when the child reaches the age of majority;²¹¹

At adulthood, adoptees should be able to make all the decisions related to their best interests and the state should no longer be a part of the decision-making process. In the United States, eighteen is the age of adulthood and the beginning of all "adult" decisions. At age eighteen, parents can no longer make legal decisions that are in the best interests of their children. If parents lose this right at age eighteen, the government should as well.²¹²

Proponents of this argument further assert that it is within children's best interest to know their origins.²¹³ They base this claim on a notion that adoptees own their personal information once they reach the age of legal adulthood, and that as such, states should not be able to deny them access to their own personal information.²¹⁴ This argument is flawed as it rests entirely on conflicting privacy interests. Assuming individuals can claim ownership over their personal information, ownership would apply to individuals regardless of adoption status. Taking adoptees' argument that upon reaching the legal age of adulthood, states should not be able to deny them access to their own personal information, states should likewise be allowed to permit unauthorized access to another individual's personal information. Applying this argument to Jane's story, if Jane argues that she owns her personal information and that the state cannot deny her access to her own personal information, Jane's biological parents would be able to argue that they, too, own their personal information and thus that Jane, without authorization, is not entitled to access it.

Part of the fundamental right to know argument focuses on adoptees' ability to understand their identity, which includes their medical history.²¹⁵ In consideration of this argument, laws have evolved to become flexible in the face of medical need. Adoptees who can establish medical need and a lack of other available means, methods, or resources to obtain such information can establish "good

²¹¹ *Id.*

²¹² *Id.* (internal citations omitted).

²¹³ *See, e.g., id.* at 158.

²¹⁴ *Id.*

²¹⁵ *See id.* at 158-59.

cause,” and gain access to the necessary information contained within their adoption records even in Restricted states.²¹⁶

Finally, to further support the argument to unseal adoption records, advocates argue that birth families have never been guaranteed confidentiality.²¹⁷ Despite a lack of absolute guarantee, the extensive history and support for protection and regulations over privacy indicate the importance of such protections. While there is no ability to guarantee privacy, there is clearly a necessity to protect it.

V. PROTECTION OF PERSONAL INFORMATION

Individuals often view their genetic information as private. DNA, as a unique identifier, deserves strong privacy protection, and potentially even personal ownership over genetic data.²¹⁸

²¹⁶ See *supra* notes 185-94, 209 (further discussing the “good cause” standard that certain states have implemented as a reasonable showing for the need to unseal adoption records).

²¹⁷ See Baffer, *supra* note 4, at 160 (noting that statutes never provided complete anonymity).

Courts have concluded that a promise of confidentiality can occur “only if the laws expressly state that closure is (1) absolute and (2) permanent.” Even states with “completely sealed” laws allow court orders to open previously sealed adoption records. Therefore the “absolute” requirement is not actually met because records can still be opened. Furthermore, promises made by adoption professionals do not carry the force of law, so courts need not honor these statements.

Id. (internal citations omitted).

²¹⁸ Because DTC genetic testing companies are beyond the scope of federal laws such as HIPAA and GINA, the information that they collect, store, and provide, as well as the privacy thereof, are essentially unregulated. See *infra* notes 223-36 (discussing the lack of privacy protections over data collected by commercial entities—including genealogy sites—at the federal level). Additionally, with respect to personal ownership over genetic data, current laws fail to protect property rights. See Franklin Zemel & Ariel Deray, *Why Current Laws Won't Protect Property Rights for DNA*, LAW360 (Oct. 31, 2018, 1:46 PM), <https://www.law360.com/articles/1097231/why-current-laws-won-t-protect-property-rights-for-dna> (“In most states, there is little law or regulation giving an individual a protectable property interest in his or her DNA. And even if a recognizable and protectable property interest exists in a person’s DNA, the likelihood is that when the individual sends it to a genealogy company, he or she abandons any such rights the same way it is abandoned when a consumer tosses their pumpkin spice latte cup into the trash at Starbucks.”); see also Catherine Roberts, *The Privacy Problems of Direct-to-Consumer Genetic Testing*,

Significant technological advancements have enabled the examination of DNA with more accuracy at a lower cost, thereby contributing to the rise of genome-based approaches.²¹⁹ This trend towards genome-based technologies, however, has significant privacy implications for an individual's genetic data.²²⁰ It has thus far been difficult to develop legal principles for genetic privacy due to several factors including the variety of parties and consideration of their interests, as well as advancements in genetic technology and interaction with genetic data.²²¹ Because public policy often weighs the rights of individuals to maintain the privacy of their genetic information against the rights of other individuals to access the information, the varying situations demand trade-offs between personal and societal interests.²²²

A. Health-Related Contexts

1. HIPAA

The Health Insurance Portability and Accountability Act of 1996 (“HIPAA”)²²³ was enacted to protect personal identifiable information maintained by the healthcare industry.²²⁴ It was primarily enacted as an insurance statute, to maintain uninterrupted health coverage of employees and their dependents from one employer to another.²²⁵ The enforcement of HIPAA as privacy legislation, however, was an

CONSUMER REPS. (Jan. 14, 2022), <https://www.consumerreports.org/dna-test-kits/privacy-and-direct-to-consumer-genetic-testing-dna-test-kits-a1187212155/>.

²¹⁹ See Ellen Wright Clayton et al., *The Law of Genetic Privacy: Applications, Implications, and Limitations*, 6 J.L. & BIOSCIENCES 1, 3 (2019) (noting that these contributions to “the dramatic growth in genome-based approaches” includes “exome- or -genome-based sequencing, which can provide dramatically more information than single-gene tests”).

²²⁰ *Id.* (providing that “having genomic data makes it possible to examine all the genetic variants regardless of the original reason for testing”).

²²¹ *Id.* at *4.

²²² *Id.*

²²³ See HIPAA (1996).

²²⁴ See *id.* (“An Act to amend the Internal Revenue Code of 1986 to improve portability and continuity of health insurance coverage in the group and individual markets, to combat waste, fraud, and abuse in health insurance and health care delivery, to promote the use of medical savings accounts, to improve access to long-term care services and coverage, to simplify the administration of health insurance, and for other purposes.”).

²²⁵ See Clayton et al., *supra* note 219, at *10.

afterthought.²²⁶ HIPAA, thus, gave the US Department of Health and Human Services (HHS) jurisdiction only over entities that provide healthcare or that pay for it.²²⁷ Private companies, such as those that provide DTC testing services, however, are beyond the scope of HHS's jurisdiction under HIPAA.²²⁸

Because Congress failed to enact more stringent health and genetic privacy legislation by August of 1999, HHS gained the authority to promulgate the HIPAA Privacy Rule.²²⁹ Congress ordered HHS to add the Privacy Rule under GINA.²³⁰ Under GINA, genetic information is “health information” that is awarded protection by the HIPAA Privacy Rule.²³¹

²²⁶ *See id.*

²²⁷ *Id.*

²²⁸ *Id.* (noting that HIPAA “gave HHS no jurisdiction to regulate the multitude of [other] private companies and institutions ([e.g.,] drug manufacturers, research institutions that provide no healthcare services, companies that sell fitness-tracking devices, DTC genetic testing services, and many others) that—in our current times—use and store people’s health and genetic data in ways that affect their privacy”).

²²⁹ *Id.* at *11 (noting that “[t]he Privacy Rule was never intended to be a comprehensive health privacy regulation, but it has assumed such a role by default because of Congress’s failure to enact more sweeping and rigorous health and genetic privacy laws and regulations”), *12. The HIPAA Privacy Rule

applies only to four types of HIPAA-covered entities involved in the payment chain of healthcare: (1) healthcare providers that transmit any health information in electronic form in connection with a covered transaction; (2) health plans, including a health insurer, HMO, Medicare or Medicaid program, or other entity that provides or pays the costs of medical care; (3) health clearing-houses, public or private entities, including a billing service or health information management system, that process health information into a standard format for billing purposes; and (4) business associates of these entities, including individuals or entities that perform or assist in billing, management, administration, or other functions regulated by the Privacy Rule.

Id. at *11 (internal citations omitted).

²³⁰ *Id.* (suggesting further that genetic information is protected under the Privacy Rule as health information “even if the genetic information is not clinically significant and would not be viewed as health information for other legal purposes”); *see* GINA (2008).

²³¹ *See* Clayton et al., *supra* note 219, at *12.

B. Genetic Contexts

1. GINA

GINA is the governing law with respect to the protection of genetic information,²³² which includes (i) an individual's genetic tests; (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual.²³³

GINA is limited in the scope of its application, and only provides protection against genetic discrimination in very specific instances. Simply put, GINA is a federal statute which prohibits discrimination on the basis of genetic information;²³⁴ it applies to private, state government, and local government employers with fifteen or more employees, including federal government employees (as well as applicants for federal employment).²³⁵ Due to the limited application of HIPAA's protections, the function of genetic information with respect to commercial entities—including genealogy sites—are outside the scope of this statute.²³⁶ This clear gap in the federal statute allows genealogy sites, and the personal information they collect and analyze, to fall through the cracks, leaving them largely unregulated and exposed. It is important that these gaps be filled to encourage, and possibly ensure, the proper protections over such important information.

2. State-Level Protections

Several states have proposed legislation to fill in the gaps of privacy protection where federal laws such as HIPAA and GINA are

²³² See GINA (2008).

²³³ See Clayton et al., *supra* note 219, at *13; see also 42 U.S.C. § 2000ff(A).

²³⁴ Discrimination Under GINA: Basics, Practical Law Practice Note 4-615-0265 (citing to 42 U.S.C. §§ 2000ff-200ff-11).

²³⁵ *Id.*

²³⁶ See Elec. Frontier Found., *Genetic Information Privacy*, EFF.ORG, <https://www.eff.org/issues/genetic-information-privacy> (last visited Dec. 11, 2022) (“With genetic data—or any [PHI]—it’s important to remember that HIPAA only applies to an organization if it is either a covered entity or the business associate . . . of one. Many non-covered entities collect genetic information, such as online genetic testing companies like 23andMe and genealogy websites like Ancestry.com”). See also Ancestry Privacy, *supra* note 82, at § 3.

insufficient.²³⁷ Existing legislation at the state level seeks to protect genetic data, primarily from commercial entities and third-party use.²³⁸ In 2021, nine states introduced bills dealing specifically with the protection of consumer genetic legislation;²³⁹ seven of these bills were enacted, highlighting genetic privacy bills as the type of consumer data privacy legislation with the highest passage rate.²⁴⁰

California's Genetic Information Privacy Act was one of the seven state genetic privacy bills enacted in 2021.²⁴¹ California's new law "requires genetic testing companies to notify customers of their privacy policies and obtain customers' consent before using their genetic data or sharing it with a third party."²⁴² While this law aims to protect individual privacy from unregulated commercial entities such as Ancestry and 23andMe, it only applies to and protects consumers in

²³⁷ State Net Insights, *State Lawmakers Find Success with Genetic Privacy*, LEXISNEXIS (June 17, 2022), <https://www.lexisnexis.com/community/insights/legal/capitol-journal/b/state-net/posts/state-lawmakers-find-success-with-genetic-privacy> ("Supporters of the legislation say it's needed because existing privacy laws don't cover home DNA testing. [HIPAA] only protects genetic tests ordered by doctors, not those purchased from companies like 23andMe and Ancestry. When HIPAA was enacted in 1996, home genetic tests didn't even exist. Now nearly 20 percent of Americans have used one, according to a national survey by *Consumer Reports* in 2020.").

²³⁸ See, e.g., *id.*

²³⁹ *Id.*

²⁴⁰ *Id.* (noting that "genetic privacy bills was the type of consumer data privacy legislation with the highest passage rate among the dozen categories tracked by [the National Conference of State Legislatures]").

²⁴¹ *Id.*; S.B. 41, 2021 Leg. (Cal. 2021) (An act to add Chapter 2.6 (commencing with Section 56.18) to Part 2.6 of Division 1 of the Civil Code, relating to privacy), https://custom.statenet.com/public/resources.cgi?id=ID:bill:CA2021000S41&ciq=urn:user:PA6792530&client_md=8f33c120e5ceb8f3529da2d6360ad8d4&mode=current_text. SB 41 became effective in January 2022. *Id.*

²⁴² State Net Insights, *supra* note 237. California's new law also requires companies to provide an easy way for customers to opt-out of that consent authorization; prohibits companies from using deceptive practices to lure customers into providing consent, such as by employing popups; prohibits companies from disclosing customers' data to insurers or the customers' employers; and requires companies to provide customers a simple method of closing their accounts and having their DNA data deleted from the companies' databases and their samples destroyed, which the companies must do within 30 days of receiving customer requests.

Id.

California.²⁴³ As such, even if both Jane and her biological brother—both users—were within California’s jurisdiction, regardless of where her biological parents reside, their interests remain unprotected.

The trend in consumer data privacy legislation continued in 2022.²⁴⁴ Of the thirty-five states that considered consumer data privacy bills last year,²⁴⁵ at least ten states considered legislation specifically about genetic privacy.²⁴⁶ Additionally, in 2022 alone, fourteen states considered legislation for the protection of biometric privacy,²⁴⁷ which typically includes genetic information and data as well.²⁴⁸

²⁴³ Both Arizona and Utah enacted similar laws to address customer privacy policies, customer consent for data use, and data deletion. *Id.* See also H.B. 2069, 55th Leg., 1st Reg. Sess. (Ariz. 2021); S.B. 227, 2022 Leg., Gen. Sess. (Utah 2022) (Utah Consumer Privacy Act). These states would likely have the same limited application as California’s law.

²⁴⁴ See State Net Insights, *supra* note 237 (noting that only five months into 2022, at least thirty-four states had either introduced or considered consumer data privacy bills).

²⁴⁵ Pam Greenberg, 2022 Consumer Privacy Legislation, NAT’L CONF. OF STATE LEGISLATURES (June 10, 2022), <https://www.ncsl.org/about-state-legislatures/2022-consumer-privacy-legislation>.

²⁴⁶ *Id.* Alaska, Hawaii, Kentucky, Maryland, Minnesota, New Jersey, Pennsylvania, Virginia, Vermont, and Wyoming all considered legislation directly aimed at consumer genetic privacy in 2022. *Id.* General consumer data privacy laws are also applicable to the Personal Information and data collected by genealogy sites. For purposes of this Article, a deliberate emphasis is placed on the additional intent to protect genetic data, but the overwhelming amount of legislation aimed at consumer data privacy protection should not be lost as it, too, supports the concern over the lack of federal regulation and legislation in this area.

²⁴⁷ *Id.* (providing that, in 2022, the following states considered legislation specific to biometric privacy: California, Illinois, Kentucky, Maine, Maryland, Massachusetts, Missouri, New Jersey, New York, Oklahoma, Rhode Island, South Carolina, Vermont, and West Virginia).

²⁴⁸ The definition of “biometric information” varies across jurisdictions. In California, for example, biometric information refers to

an individual’s physiological, biological, or behavioral characteristics, including an individual’s [DNA], that can be used, singly or in combination with each other or with other identifying data, to establish individual identity. Biometric information includes, but is not limited to, imagery of the iris, retina, fingerprint, face, hand, palm, vein patterns, and voice recordings, from which an identifier template, such as a faceprint, a minutiae template, or a voiceprint, can be extracted, and keystroke patterns or rhythms, gait patterns or rhythms, and sleep, health, or exercise data that contain identifying information.

While the existence of state statutes emphasizes the importance of genetic privacy protection, most of these statutes do not provide actionable private causes of action,²⁴⁹ and thus private suits based on state genetic privacy statutes are scarce.²⁵⁰

See Bryan Cave Leighton Paisner, *Is the CCPA's Definition of "Biometric Information" Broader than the Definition Used by Other States?*, JDSUPRA (Apr. 13, 2020), <https://www.jdsupra.com/legalnews/is-the-ccpa-s-definition-of-biometric-64996/> (citing to Cal. Civil Code 1798.140(b)). In Illinois, however, biometric information means any information, regardless of how it is captured, converted, stored, or shared, based on an individual's biometric identifier used to identify an individual." *Id.* (noting that Illinois' definition of biometric information excludes "information derived from items or procedures excluded under the definition of biometric identifiers) (citing to 40 ILCS 14/10). Further, Illinois limits biometric identifiers to retina or iris scans, fingerprints, voiceprints, or scans of hand or face geometry;

Biometric identifiers do not include writing samples, written signatures, photographs, human biological samples used for valid scientific testing or screening, demographic data, tattoo descriptions, or physical descriptions such as height, weight, hair color, or eye color. Biometric identifiers do not include donated organs, tissues, or parts as defined in the Illinois Anatomical Gift Act or blood or serum stored on behalf of recipients or potential recipients of living or cadaveric transplants and obtained or stored by a federally designated organ procurement agency. Biometric identifiers do not include biological materials regulated under the Genetic Information Privacy Act. Biometric identifiers do not include information captured from a patient in a health care setting or information collected, used, or stored for health care treatment, payment, or operations under the federal Health Insurance Portability and Accountability Act of 1996. Biometric identifiers do not include an X-ray, roentgen process, computed tomography, MRI, PET scan, mammography, or other image or film of the human anatomy used to diagnose, prognose, or treat an illness or other medical condition or to further validate scientific testing or screening.

Id.

²⁴⁹ Ian Ballon et al., Practice Note, *US Privacy Litigation: Overview*, PRAC. L., [https://1.next.westlaw.com/Document/Iaadd478afba611e79bf099c0ee06c731/View/FullText.html?transition-Type=UniqueDocItem&contextData=\(sc.Default\)&userEnteredCitation=Practical+Law+Practice+w-012-7012#co_pp_sp_219005_W-012-7012](https://1.next.westlaw.com/Document/Iaadd478afba611e79bf099c0ee06c731/View/FullText.html?transition-Type=UniqueDocItem&contextData=(sc.Default)&userEnteredCitation=Practical+Law+Practice+w-012-7012#co_pp_sp_219005_W-012-7012) (last visited Jan. 12, 2023). States that provide for private causes of action include Alaska, Illinois, Maryland, New Jersey, New Mexico, Oregon, and Utah. *See* Alaska Stat. Ann. § 18.13.020; 410 ILCS 513/40; Md. Code Ann., Com. Law § 14-4406; N.J.S.A. § 10:5-49(c); NMSA 1978, § 24-21-6; Or. Rev. Stat. § 192.541; Utah Code § 26-45-105.

²⁵⁰ Ballon et al., *supra* note 249.

C. Arbitration as a Barrier to Protection

The lack of judicial guidance on this issue is due, in large part, to arbitration agreements that bind users of sites such as Ancestry and 23andMe.²⁵¹ While there is available case law concerning the compulsion to arbitrate such matters, courts have thus far ruled in favor of the companies, and not the private users, and have upheld the arbitration clauses.²⁵²

1. Ancestry's Arbitration Provision

Ancestry's Terms contain a separate section entirely dedicated to "Dispute Resolution, Arbitration and Class Action Waiver."²⁵³ By consenting to Ancestry's Terms, Users agree that they must first try to resolve any concern or dispute about Ancestry's Services informally by contacting Ancestry.²⁵⁴ The term "dispute," as indicated under the Terms, is "intended to be as broad as legally permissible."²⁵⁵

²⁵¹ See Ancestry Terms, *supra* note 62, at § 10.1; see also 23andMe Terms, *supra* note 69, at § 5.

²⁵² See *Tompkins v. 23andMe, Inc.*, 840 F.3d 1016, 1026 (9th Cir. 2016) (holding that "[u]nder California law, a portion of prevailing party clause in arbitration provision found in genetic testing service provider's terms of service agreement that shifted arbitrators' fees to the losing party was not substantively unconscionable, as would support customers' claim that the provision was unenforceable; there was no indication that the arbitration fees were unaffordable for customers or would thwart their ability to arbitrate their dispute").

²⁵³ See Ancestry Terms, *supra* note 62, at § 10.1.

²⁵⁴ *Id.* (including a hyperlink to contact Ancestry, which directs Users to a support page. See *AncestrySupport*, ANCESTRY.COM, https://support.ancestry.com/s/phonesupport?language=en_US&gl=1*1vdlstds*_ga*MTIwODgwMTM2OC4xNjcwNjk4Mjc1*_ga_4QT8FMEX30*MTY3MDgwNzU3MC4zLjEuMTY3MDgwODU0MC42MC4wLjA (last visited Dec. 11, 2022)).

²⁵⁵ *Id.* (providing that the broad definition of "dispute" within the Terms "includes, but is not limited to, all disputes between [User] and any other person on whose behalf [User] ha[s] interacted with Ancestry, on the one hand, and Ancestry, including any of its parents, subsidiaries, predecessors, successors, assigns, or affiliates, on the other, that arise out of or relate in any way to the Terms, this arbitration agreement, or [User's] interactions or relationship with Ancestry. Further, if [User] ha[s] or will use Ancestry's Services or otherwise interact with Ancestry on behalf of a minor or other individual for whom [User is] the parent or legal guardian, [User] agree[s], on the minor's or other person's behalf, that any dispute arising out of or relating to such use of Ancestry's Services or other interaction with Ancestry will be subject to arbitration, as set forth herein, and subject to the other agreements set forth

With respect to its Terms, Ancestry's arbitration provision states that Ancestry and its Users agree that the Terms affect interstate commerce, and that "the Federal Arbitration Act governs the interpretation and enforcement of these arbitration provisions."²⁵⁶ Further, the Arbitration Rules provide, in relevant part:

Arbitration will be conducted by JAMS in accordance with the JAMS Streamlined Arbitration Procedure Rules for claims that do not exceed \$250,000 and the JAMS Comprehensive Arbitration Rules and Procedures for claims exceeding \$250,000 in effect at the time the arbitration is initiated, excluding any rules or procedures governing or permitting class actions. Where no disclosed claims or counterclaims exceed \$25,000 (excluding any claim for attorneys' fees), the dispute shall be resolved by the submission of documents only/desk arbitration unless the arbitrator finds good cause for a live hearing.²⁵⁷

With respect to class action lawsuits in particular, Ancestry does not permit class action disputes as a form of dispute resolution.²⁵⁸

Ancestry's arbitration provision further grants an arbitrator the "exclusive authority to resolve all disputes arising out of or relating to the interpretation, applicability, enforceability, or formation of these

herein (including, but not limited to, the Class Action Waiver); [User] further represent[s] that [User] ha[s] the authority to enter such agreement on the minor's or other person's behalf.").

²⁵⁶ See *id.*; see also 9 U.S.C. § 1 et seq. (Federal Arbitration Act).

²⁵⁷ See Ancestry Terms, *supra* note 62, at § 10.1.1. JAMS is "the world's largest private alternative dispute resolution (ADR) provider." JAMS, *About*, JAMSADR.COM, <https://www.jamsadr.com/about/> (last visited Dec. 11, 2022). See also JAMS Arbitrators & Arbitration Services, *Streamlined Arbitration Rules & Procedures*, JAMSADR.com (June 1, 2021), <https://www.jamsadr.com/rules-streamlined-arbitration/>; JAMS Arbitrators & Arbitration Services, *JAMS Comprehensive Arbitration Rules & Procedures*, JAMSADR.COM (June 1, 2021), <https://www.jamsadr.com/rules-comprehensive-arbitration/>.

²⁵⁸ See Ancestry Terms, *supra* note 62, at § 10.1.3 ("No Class Actions"). Ancestry's Terms includes a Class Action Waiver provision which states that "[t]he parties each agree that each party may only resolve disputes with the other on an individual basis and may not bring a claim as a plaintiff or a class member in a class, consolidated, or representative action." *Id.* (noting that the Class Action Waiver provision "applies both to disputes resolved in arbitration and to any disputes that are resolved in court, to the extent such disputes arise").

Terms or the Privacy Statement,”²⁵⁹ and that he shall further “be empowered to grant whatever relief would be available in a court under law or equity.”²⁶⁰

With respect to jurisdiction, the arbitration provision states that:

Arbitration may take place in the county where [the User] resides at the time of filing. [The User] and Ancestry further agree to submit to the personal jurisdiction of any federal or state court in San Francisco County, California in order to compel arbitration, to stay proceedings pending arbitration, or to confirm, modify, vacate, or enter judgment on the award entered by the arbitrator.²⁶¹

While Ancestry’s arbitration provision has a seemingly broad reach, its Terms also contain language designating the controlling law for those claims that may not fall within the scope of arbitration:

If you access the Services on our websites in the United States, the laws of the State of Utah and as applicable, those of the United States of America, govern these Terms and the use of the Services. You agree that all claims not subject to arbitration and brought in the United States will be subject to the exclusive jurisdiction of the courts of competent jurisdiction located in the State of Utah. . . [i]f you access the Services on our websites anywhere outside the United States, the laws of Ireland govern these Terms.²⁶²

The arbitration provision expressly includes three exceptions to arbitration.²⁶³ The first exception provides in relevant part:

Each party to this agreement shall have the option to resolve any dispute, if it qualifies, in the small claims court with jurisdiction over your place of residence. If any dispute involves claims for both (1) monetary

²⁵⁹ *Id.* at § 10.1.1 (emphasis added).

²⁶⁰ *Id.* (noting further that “[t]he arbitrator’s award shall be written and shall be binding on the parties and may be entered as a judgment in any court of competent jurisdiction”).

²⁶¹ *Id.*

²⁶² *Id.* at § 10.3 (“Controlling Law”).

²⁶³ *Id.* at § 10.1 (“Dispute Resolution, Arbitration and Class Action Waiver”).

damages or relief and (2) equitable or injunctive relief, each party shall have the option to resolve the claims for monetary relief or damages in small claims court, and any claim for equitable or injunctive relief shall be resolved in arbitration pursuant to this agreement.²⁶⁴

The second exception to Ancestry's arbitration provision provides "[b]oth [a User] and Ancestry may bring a suit in court in the state of Utah only for a claim of patent or copyright infringement. In this case, [both the User and Ancestry] waive any right to a jury trial."²⁶⁵ The third and final state exception to Ancestry's arbitration agreement states "[i]f it qualifies, [a User] may bring a claim to the attention of a relevant federal, state, or local agency that may seek relief against [Ancestry] on [the User's] behalf."²⁶⁶ This exception is vague and seemingly broadens the scope of claims that can be brought against Ancestry outside of arbitration.²⁶⁷

2. *23andMe's Arbitration Provision*

23andMe's arbitration provision can be found within its Terms of Service.²⁶⁸ Its arbitration rules mirror those within Ancestry's arbitration provision,²⁶⁹ and further grant the arbitrator the same exclusive authority to resolve disputes that fall within its arbitration provision.²⁷⁰ However, unlike Ancestry, whose controlling law falls within the legal jurisdiction of the State of Utah,²⁷¹ 23andMe's Terms are governed by

²⁶⁴ *Id.* at § 10.1(1).

²⁶⁵ *Id.* at § 10.1(2).

²⁶⁶ *Id.*

²⁶⁷ *See id.* at § 10.1(3).

²⁶⁸ *See* 23andMe Terms, *supra* note 69, at § 5 ("Dispute Resolution and Arbitration").

²⁶⁹ *Id.* at § 5(b) (providing that "the parties' relationship with each other and/or [the User's] use of the Services shall be finally settled by binding arbitration administered on a confidential basis by JAMS, in accordance with the JAMS Streamlined Arbitration Rules and Procedures, excluding any rules or procedures governing or permitting class actions").

²⁷⁰ *Id.* ("The arbitrator, and not any federal, state or local court or agency, shall have exclusive authority to resolve all disputes arising out of or relating to the interpretation, applicability, enforceability or formation of [the Terms of Service], including, but not limited to, any claim that all or any part of these [Terms of Service] is void or voidable. The arbitrator shall be empowered to grant whatever relief would be available in a court under law or in equity.").

²⁷¹ *See* Ancestry Terms, *supra* note 62, at § 10.3 ("Controlling Law").

the laws of the State of California.²⁷² With respect to class actions, similar to Ancestry's, 23andMe's Terms of Service includes a Class Action and Class Arbitration Waiver.²⁷³

A notable difference between the arbitration provisions is that 23andMe includes a limitation on an arbitrator's authority to issue a public injunction:

[T]he arbitrator may not issue a public injunction and any such public injunction may be awarded only by a federal or state court. If either party seeks a public injunction, all other claims and prayers for relief must be adjudicated in arbitration first and any prayer or claim for a public injunction in federal or state court stayed until the arbitration is completed, after which the federal or state court can adjudicate the party's claim or prayer for public injunctive relief.²⁷⁴

Additionally, 23andMe's arbitration provision includes only two exceptions to its binding arbitration agreement.²⁷⁵ Aside from the parties' agreement to resolve all disputes through arbitration, additional relief may be sought by either party (i) in a small claims court for disputes or claims within the scope of that court's jurisdiction, and (ii) for any disputes relating to intellectual property rights, obligations, or any infringement claims.²⁷⁶

VI. PROPOSAL

There is a lack of legislation, regulation, oversight, and judicial guidance over genealogy sites such as Ancestry and 23andMe. Recognizing these clear issues, states have tried to implement policies that

²⁷² See 23andMe Terms, *supra* note 69, at § 6.

²⁷³ *Id.* at § 5(c) (“[The User] and [23andMe] each further agree that any arbitration shall be conducted in [their] respective individual capacities only and not as a class action, and [the User and 23andMe] each expressly waive [their] respective right to file a class action or seek relief on a class basis.”).

²⁷⁴ *Id.* (internal quotations omitted). A public injunction is “primarily for the benefit of the general public,” and its “evident purpose . . . is to remedy a public wrong [and] not to resolve a private dispute . . . any benefit to the plaintiff requesting such relief likely . . . would be incidental to the general public benefit of enjoining such a practice.” *McGill v. Citibank, N.A.*, 292 P.3d 85, 94 (Cal. 2017) (internal citations and quotations omitted).

²⁷⁵ See 23andMe Terms, *supra* note 69, at § 5(d) (“Exceptions”).

²⁷⁶ See *id.*

protect privacy interests while at the same time compromise with the concerns and requests of adoptees. Federal standards, or at the very least guidance, must be developed to ensure equal and adequate protection for all parties. There are several avenues in which this can be done, and they are not mutually exclusive.

First, the personal and genetic information collected by commercial entities—including, but not limited to genealogy sites—must be protected by federal law. This can be done either by amending current laws to include such entities within the scope of their protections, or by the enactment of new laws directly aimed at this type of data collection.

Second, although family law issues are traditionally reserved to the states, there should be some federal guidance with respect to access to adoption records. Adoption is rarely a transaction that occurs entirely in one state; families often adopt children from other states.²⁷⁷ With respect to interstate adoptions, while current laws dictate that prospective adoptive parents comply with the laws of the state where the child lives,²⁷⁸ it is critical to develop a national standard to ensure equality of rights amongst adoptees, adoptive families, and biological families nationwide. Without a national standard, the privacy interests of biological parents would largely depend on the states in which the child was adopted from, as well as where the adoptive family lives. To ensure that privacy interests are protected equally, regardless of jurisdiction, federal law must be enacted. This law must not encroach on states' rights, and thus should intend to protect privacy interests of all parties of closed adoptions but allow states the flexibility on implementation.

Third, it is important that a uniform standard of “good cause” be established at the federal level. The proposed federal statute should provide a standard to evaluate good cause when adoptees seek access to their birth records. While this standard can be broad, leaving interpretation up to the individual states, it is important to have a uniform test which governs instances in which it is applicable. While what constitutes “good cause” may vary from state-to-state, the circumstances under which such test would be applied should be uniform across the nation. Mere curiosity should not be enough, in any

²⁷⁷ See Children's Bureau, *How Do I Adopt a Child Living in Another State? How Do I Adopt Across State Lines*, U.S. DEP'T HEALTH & HUM. SERVS. (June 29, 2022), <https://www.acf.hhs.gov/cb/faq/adoption10>.

²⁷⁸ *Id.*

jurisdiction, to violate the fundamental right to privacy of another individual. However, in instances where an adoptee can establish medical need—a definition which can be left to the judicial interpretation of state judges—flexibility can be awarded. This flexibility would ensure that adoptees are not entirely barred from accessing the necessary information to allow proper and adequate medical care. Further, if “good cause” is established, there should be limitations on the adoptees’ access to their adoption records to permit access to only such information that is relevant to their showing of need.

Fourth, I argue for the implementation of a national mutual consent registry, or in the alternative, nationally implemented search and consent procedures. Mutual consent registries and search and consent procedures facilitate the exchange of information between adoptees and biological parents in a way that respects and promotes the privacy interests of all parties. Mutual consent registries are passive in nature, generally prohibiting direct assistance to either the biological parent or the adoptee in searching for the other. Such registries are designed as a “short cut to waive the good cause requirement when both parties consent.”²⁷⁹ This method further helps avoid judicial congestion. Alternatively, search and consent procedures are a more active way to facilitate this exchange of information.²⁸⁰ Search and consent procedures designate assistance to adoptees in locating their biological parents.²⁸¹ If the biological parents are located, they are then given the option of whether to permit the disclosure of information or meet with their biological child.²⁸² Although they have a right of refusal, this method has the ability to place biological parents in difficult positions. If a biological parent refuses consent, adoptees thus would have to establish “good cause” to access their records.

Fifth, and finally, with respect to the mechanisms by which genealogy sites such as Ancestry and 23andMe function, I argue for further consideration of the privacy interests of non-users. It is no secret that these sites have significant impacts on individuals who are not themselves users, creating significant privacy implications with respect to that impact. Such companies need to take additional measures in their collection of information and data to better safeguard the

²⁷⁹ Kuhns, *supra* note 164, at 265.

²⁸⁰ *Id.* at 266.

²⁸¹ *Id.*

²⁸² *Id.*

privacy of individuals who do not personally use or benefit from these companies' services.

VII. CONCLUSION

The right to privacy is a fundamental right protected by the Constitution, as is the right of parents to direct their child's upbringing. Genealogy sites, and how they operate specifically with respect to closed adoptions, puts these fundamental rights in jeopardy. Genealogy sites, such as Ancestry and 23andMe, are unsupervised and unregulated. Without proper oversight, regulation, and enforcement, such sites permit individuals to bypass state and federal laws. Such actions should not only be impermissible, but prohibited by law, and deemed unconstitutional.

The right of privacy extends to all parties to a closed adoption, regardless of who is seeking access to confidential information within the adoption records. The right of parents to direct their child's upbringing extends to both the biological and adoptive parents. For biological parents, the right to direct the upbringing of their children permits them to voluntarily place their child up for adoption, whereas for adoptive parents, it allows them to direct the upbringing of the child they choose to adopt. An agreement by all parties to a closed adoption should fall within this constitutional right.

Our country's deep-rooted history supports the general concern for and interest in privacy protections. This long-held view suggests that, with respect to adoptions, the superior arguments in the debate regarding sealing adoption records are those which concern protecting privacy interests. With respect to privacy and adoption, despite recent trends, our country has historically sealed adoption records due in large part to privacy considerations.

This contrast between privacy and access to information, however, does not have to be so inflexible. With the proper judicial guidance or legal regulation, I believe that there is the potential to reach a compromise between the two sides of this debate. First, looking towards Restricted states, there are arguments that can overcome the strict protections over the confidential information within the adoption records. These arguments allow access to such information only in those circumstances under which it is warranted, such as for good cause. If there is "good cause" to unseal the record, or to access certain information within, that should be sufficient to promote justice and

properly and adequately protect the interests of all parties. It avoids enacting broad-reaching provisions which would allow for access regardless of need.

Mutual consent registries are also viable means to connect adoptees with their biological families as they only permit access or contact when there is an affirmative mutual consent. Employment of such mutual consent methods emphasizes the importance of decision-making—to think carefully before making such a decision as a closed adoption because some decisions cannot be undone. Mutual consent is likely the only ethical option that provides for a compromise to adoptees' requests to unseal adoption records as it best protects the interests of all parties to a closed adoption.