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# Family Secrets and Relational Privacy: Protecting Not-So-Personal, Sensitive Information from Public Disclosure

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# Family Secrets and Relational Privacy: Protecting Not-So-Personal, Sensitive Information from Public Disclosure

## J. Lyn Entrikin\*

This Article seeks to map contemporary relational privacy issues in the context of the evolving "right of privacy" in the United States. Generally, the Article explains why the so-called "personal" right of informational privacy, whatever its legal foundations, cannot be realistically confined to an individual right given the dramatic scientific and technological developments in the twenty-first century. In particular, the Article proposes that both state and federal law must grapple with the inherently relational nature of privacy interests with respect to DNA profiles, which inherently implicate the privacy interests of one's biological relatives, whether known or unknown.

Part I summarizes the historical development of the right of privacy in the United States, as well as its relational aspects that predate recognition of the "personal" right of privacy. Part II explores the early recognition of the relational aspects of tortious invasion of privacy. Part III addresses the nature and scope of "personal privacy" interests expressly recognized in federal statutes regulating freedom of information and privacy with respect to public records. Part IV explains the constitutional foundations of the American right of privacy, including the conceptual relationship between

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informational privacy and autonomous decision-making privacy. Part V discusses relational privacy interests in the context of DNA databanks, whether used for criminal investigations or genealogical research. The Article concludes by conceptualizing the ever-expanding American right of privacy to encompass at least close family members whose privacy may be implicated when sensitive information about a relative is at risk of public disclosure without family members' knowledge or consent.

A rapidly developing technology is furnishing ever more effective means of invading privacy, and the situation has been viewed with increasing alarm.<sup>1</sup>

[*T*]*he most beautiful quality of law is that it is never finished.*<sup>2</sup>

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<sup>&</sup>lt;sup>1</sup> Harry D. Krause, *The Right to Privacy in Germany – Pointers for American Legislation*?, 1965 DUKE L.J. 481, 481; *see, e.g.*, David H. Kaye, *The Genealogy Detectives: A Constitutional Analysis of "Familial Searching"*, 50 AM. CRIM. L. REV. 109, 163 (2013) (conceding that "a database of expanded profiles of convicted offenders used for full-match and near-miss [criminal investigation] trawls will cause anguish to family members when it links close relatives to crimes, and if and when it exposes genetic relationships (or their absence) . . . kept as family secrets"); Erin Murphy, *Relative Doubt: Familial Searches of DNA Databases*, 109 MICH. L. REV. 291, 315–16 (2010) (discussing sensitive issues of family privacy surrounding the use of DNA databases for criminal investigations); *see also* Monica Rodriguez, *You Discovered Your Genetic History. Is it Worth the Privacy Risk?*, FORTUNE (Sept. 10, 2018, 4:51 PM), https://fortune.com/2018/09/10/genetic-history-test-privacy-risk/.

 <sup>&</sup>lt;sup>2</sup> Leon Green, *Basic Concepts: Persons, Property, Relations*, 24 A.B.A. J.
 65, 69 (1938) [hereinafter Green, *Basic Concepts*].

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### INTRODUCTION

Members of a traditional family share a unique configuration of sub-cellular biological material known as deoxyribonucleic acid more commonly known as DNA—that provides modern technology a window into the most personal of family relationships and secrets.<sup>3</sup> For decades, law enforcement organizations have developed and maintained DNA databanks using samples taken from crime scenes, convicted felons, and even arrestees.<sup>4</sup> More recently, commercial genealogy companies have heavily promoted the voluntary collection of saliva samples to locate close and distant relatives with statistically similar DNA profiles through a process called DNA matching.<sup>5</sup> Law enforcement investigations have recently solved a

<sup>4</sup> "The advent of DNA technology is one of the most significant scientific advancements of our era. The full potential for use of genetic markers in medicine and science is still being explored, but the utility of DNA identification in the criminal justice system is already undisputed." Maryland v. King, 569 U.S. 436, 442, 461 (2013) (5-4 decision) (holding that routinely taking DNA cheek swabs from felony arrestees at booking and uploading results to state law enforcement DNA databases to assist in investigating cold cases do not qualify as an unreasonable search for Fourth Amendment purposes because "the Court must give great weight both to the significant government interest at stake in the identification of arrestees and to the unmatched potential of DNA identification to serve that interest.").

DNA was first used for law enforcement purposes in 1986 to prosecute a criminal case in England. *Id.* at 442 (citing JOHN M. BUTLER, FUNDAMENTALS OF FORENSIC DNA TYPING 5 (2009)). In 2008, a routine DNA swab taken from a young man during a driving incident identified the driver as a close match with a DNA sample collected at the 1983 crime scene of a rape and murder. James Sturcke, *Man Jailed for Life over 1983 Murder of Colette Aram*, GUARDIAN (Jan. 25, 2010), https://www.theguardian.com/uk/2010/jan/25/paul-hutchinson-jailed-colette-aram. The arrest led investigators to identify the young man's father as the perpetrator of the crime twenty-five years earlier. *Id.* The murderer pleaded guilty in 2009 but died in prison eight months later from a self-inflicted drug overdose. *Colette Aram Murderer Paul Hutchinson Died from Overdose*, BBC NEWS (Oct. 25, 2011), https://www.bbc.com/news/uk-england-nottinghamshire-15452142.

<sup>5</sup> See, e.g., How It Works: It's Just Saliva. No Blood. No Needles., 23ANDME, https://www.23andme.com/howitworks/?vip=true (last visited March 10, 2020); see also Natalie Ram, DNA by the Entirety, 115 COLUM. L. REV. 873, 877 (2015) [hereinafter Ram, DNA by the Entirety] ("DNA's shared nature complicates the

<sup>&</sup>lt;sup>3</sup> See Deoxyribonucleic Acid (DNA) Fact Sheet, NAT'L HUM. GENOME RES. INST., https://www.genome.gov/about-genomics/fact-sheets/Deoxyribonucleic-Acid-Fact-Sheet (last updated Nov. 13, 2019).

number of "cold cases" using this type of "familial searching" in genealogy databases to locate relatives with shared DNA profiles<sup>6</sup> and by contacting those individuals to ask whether they have any relatives who might match the DNA collected from crime scenes.<sup>7</sup>

usual individualistic rules that have characterized the law governing DNA."); Natalie Ram, *The U.S. May Soon Have a De Facto National DNA Database*, SLATE (Mar. 19, 2019, 7:30 AM), https://slate.com/technology/2019/03/national-dnadatabase-law-enforcement-genetic-genealogy.html [hereinafter Ram, *U.S. DNA Database*] ("Since April 2018, law enforcement investigations stemming from DNA searches in consumer genetics databases have led to nearly three dozen arrests. In every case, those ultimately arrested . . . were identified through partial matches between crime scene DNA samples and the genetic profiles of oftendistant relatives shared on consumer [genealogy] platforms . . . .").

<sup>6</sup> Familial Searching: What Is Familial Searching?, NAT'L INST. JUST., https://projects.nfstc.org/fse/13/13-0.html (last visited March 13, 2020).

Familial searching is a process by which a DNA profile of interest in a criminal case is searched against the database. If there are no direct matches, it is then searched again in an attempt to find DNA profiles that are similar to the profile of interest and could belong to a close relative of the person who left the DNA at the crime scene. There are two parts to the process. First, the software ranks candidate offender relatives in order of likelihood that they are closely related to the person who left the DNA. There will always be an appreciable number of candidates on this list. Next, all of the offender candidates' samples are subjected to additional DNA typing, using existing Y-chromosome testing. This testing can strongly establish the existence of a close familial relationship (typically father-son or brother-brother) between the person who left the evidence and the offender in the database.

Id.

<sup>7</sup> E.g., Hayley Compton & Caroline Lowbridge, *How Familial DNA Trapped a Murderer for the First Time*, BBC NEWS (Sept. 23, 2018), https://www.bbc.com/news/uk-england-nottinghamshire-45561514 (describing an early use of "familial DNA searching" to locate close relatives of a rapist and murderer in England and reporting that the technique was first used in 2002 by a team led by Frances Bates to solve a manslaughter case); Camila Domonoske, *Suspect in Decade-Old Serial Rapes Arrested, with Help of Genealogy Database*, NPR (Aug. 23, 2018, 11:54 AM), https://www.npr.org/2018/08/23/641208167/ suspect-in-decade-old-serial-rapes-arrested-with-help-of-to-genealogy-database (explaining how law enforcement solved the cold case of the "Ramsey Street Rapist" in Fayetteville, North Carolina); Laurel Wamsley, *In Hunt for Golden State Killer, Investigators Uploaded His DNA to Genealogy Site*, NPR (Apr. 27, 2018, 7:31 PM), https://www.npr.org/sections/thetwo-way/2018/04/27/606624218/in-

What legal rights, if any, does a person have after voluntarily contributing DNA to a commercial or noncommercial database? Can the contributor prevent law enforcement from using DNA collected after an arrest if the arrestee is later exonerated?<sup>8</sup> Does a

While the results presented on this Site are intended solely for genealogical research, we are unable to guarantee that users will not find other uses, including both current and new genealogical and non-genealogical uses. For example, some of these possible uses of Raw Data, personal information, and/or Genealogy Data by any registered user of GEDmatch include but are not limited to . . . [f]amilial searching by third parties such as law enforcement agencies *to identify the perpetrator of a crime*, or to identify remains.

You understand that future genealogical and non-genealogical uses may be developed, including uses that GEDmatch cannot predict or foresee. If you find any of these current or future uses unacceptable, do not provide Raw Data to GEDmatch, and remove any of your Raw Data already provided to this Site.

GEDmatch.com Terms of Service and Privacy Policy, GEDMATCH, https://www.gedmatch.com/tos.htm (last updated Dec. 9, 2019) (emphasis added). Verogen, Inc. acquired the GEDmatch website on December 9, 2019. See Press Release, Verogen, Inc., Gedmatch Partners with Genomics Firm (Dec. 9, 2019), https://verogen.com/gedmatch-partners-with-genomics-firm/; see also Nila Bala, We're Entering a New Phase in Law Enforcement's Use of Consumer Genetic Data, SLATE (Dec. 19, 2019, 7:30 AM), https://slate.com/technology/2019/12/gedmatch-verogen-genetic-genealogy-law-enforcement.html ("With no legal regulations providing clarity on how and when genetic genealogy should be used to fight crime, we have left private entities in charge of the decision-making. And with Verogen taking over GEDmatch, we have new reasons to be concerned."); Jennifer Lynch, Genetic Genealogy Company GEDmatch Acquired by Company with Ties to FBI & Law Enforcement—Why You Should Be Warried, EFE (Dep. 10, 2010), https://www.off.org/doenlinks/2010/12/genetic

*Worried*, EFF (Dec. 10, 2019), https://www.eff.org/deeplinks/2019/12/geneticgenealogy-company-gedmatch-acquired-company-ties-fbi-law-enforcementwhy.

 $^{8}$  *Cf.* Am. Civil Liberties Union v. U.S. Dep't of Justice, 655 F.3d 1, 18–19 (D.C. Cir. 2011) ("[I]t is one thing to disclose the identities of targets who were eventually convicted in public proceedings; but the privacy calculus becomes increasingly more significant if disclosure extends to those who were acquitted, or

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hunt-for-golden-state-killer-investigators-uploaded-his-dna-to-genealogy-site (describing how investigators identified the "Golden State Killer" in California using familial DNA searching on GEDmatch, a website inviting voluntary contributions of DNA samples). The Terms of Service and Privacy Policy for GEDmatch, now owned and operated by Verogen, Inc., display the following statement:

contributor, for example, have any legal right to prevent the use of that information by law enforcement officials for genetic genealogy testing to identify close or distant relatives who may be suspected of perpetrating crimes?<sup>9</sup> What about insurance companies, which might be interested in accessing commercial DNA databases to identify genetic markers that represent a heightened inherited risk for certain diseases, such as breast cancer and alcohol or drug addiction?<sup>10</sup>

This Article seeks to map these issues in the context of the "right of privacy" as it has developed in the United States. In particular, I propose that to address the privacy issues surrounding the use of DNA, the law should recognize the inherently relational nature of privacy interests with respect to DNA profiles.<sup>11</sup> More generally, the Article explains why the so-called "personal" right of informational privacy, whatever its legal foundations, cannot be realistically confined to the individual any longer. In fact, a handful of cases decided over the last two decades reflect a growing judicial awareness that privacy rights cannot be so narrowly cabined, especially given the dramatic scientific and technological developments in the twentyfirst century's global community.

Part I of this Article summarizes the historical development of the right of privacy in the United States, as well as its relational aspects that predate recognition of the "personal" right of privacy beginning in the early twentieth century. Part II explores the early recognition of the relational aspects of tortious invasion of privacy

to those whose activities were never the focus of public attention, such as uncharged investigative subjects, witnesses, or bystanders.").

<sup>&</sup>lt;sup>9</sup> See Domonoske, supra note 7 (referring to "genetic genealogy testing" as the process of "look[ing] for *partial* matches in DNA [that has] been uploaded to public genealogy sites by people looking to find relatives"); Rodriguez, supra note 1 (reporting on the results of one person's efforts to track down her estranged father using genealogy databases).

<sup>&</sup>lt;sup>10</sup> See Michelle Andrews, Genetic Tests Can Hurt Your Chances of Getting Some Types of Insurance, NPR (Aug. 7, 2018, 9:00 AM), https://www.npr.org/sections/health-shots/2018/08/07/636026264/genetic-testscan-hurt-your-chances-of-getting-some-types-of-insurance; Fergus Walsh, DNA Test Reveals 80 Markers for Inherited Cancer Risk, BBC NEWS (Mar. 27, 2013), https://www.bbc.com/news/health-21945812.

<sup>&</sup>lt;sup>11</sup> See Ram, DNA by the Entirety, supra note 5, at 898–906 (explaining scientific reasons why DNA is "immutably and involuntarily" shared among biological relatives).

as the cause of action developed beginning in the early years of the twentieth century. Part III addresses the nature and scope of "personal privacy" interests expressly recognized in federal freedom of information and privacy statutes. Part IV explains the constitutional foundations of the American right of privacy, including the loose (and somewhat overlapping) relationship between the two primary aspects of privacy interests: informational privacy and decisional privacy. Part IV also evaluates and critiques recent cases in the Ninth Circuit holding that relatives have a privacy right, grounded in substantive due process, to limit dissemination of sensitive information that relates to the death of a loved one.<sup>12</sup> Part V discusses relational privacy interests in the context of DNA databanks, whether used for criminal investigations or genealogical research. The Article concludes by summarizing the ever-expanding view of the American right of privacy to encompass at least close family members whose privacy may be implicated when sensitive information about a relative is at risk of public disclosure or dissemination without knowledge or consent of family members.<sup>13</sup>

United States military law relating to government contracts narrowly defines "sensitive information" to mean "confidential commercial, financial, or proprietary information, technical data, or other privileged information." 10 U.S.C. § 129d(b)(2) (2018); *see also* 10 U.S.C. § 2367(g) (defining "sensitive information"); 38 U.S.C. § 5727(19) (2018) (defining "sensitive personal

 $<sup>^{12}</sup>$  *E.g.*, Marsh v. Cty. of San Diego, 680 F.3d 1148, 1157–60 (9th Cir. 2012) (holding that while surviving mother had a substantive due process right to relational privacy supporting her 42 U.S.C. § 1983 claim against county prosecutor for disclosing to the press an autopsy photo of her deceased toddler son, qualified immunity vindicated defendants because the constitutional right was not clearly established at the time of disclosure).

<sup>&</sup>lt;sup>13</sup> While some nations have expressly defined "sensitive information" in privacy statutes or regulations, U.S. law does not provide a general definition for that term. *See, e.g., Privacy Act 1988* (Cth) pt II div 1 s 6 (Austl.) (defining "sensitive information" broadly to include genetic and biometric information); Data Protection Act 2018, c. 12, § 3 (Eng.) (defining terms consistent with the European Union's General Data Protection Regulation); cf. Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c F.31 (Can.) (defining "personal information"); Council Regulation 2016/679, Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the Protection of Natural Persons with Regard to the Processing of Personal Data and on the Free Movement of Such Data, and Repealing Directive 95/46/EC (General Data Protection Regulation), 2016 O.J. (L 119) [hereinafter GDPR] (discussing "personal data").

## I. AMERICAN RIGHT OF PRIVACY AND RELATED "QUASI-PROPERTY" INTERESTS

With few exceptions, civil liability for invasion of privacy in the United States has traditionally focused on the interests of the individual.<sup>14</sup> In 1890, Samuel Warren and future Supreme Court justice Louis Brandeis urged courts to openly recognize an individual's "right to be let alone"<sup>15</sup> in what would become one of the most

### Id.

The federal Freedom of Information Act does not define "sensitive information" but does define "record" to mean "any item, collection, or grouping of information *about an individual* that is maintained by an agency, including, but not limited to, his education, financial transactions, medical history, and criminal or employment history and that contains his name, or the identifying number, symbol, or other identifying particular assigned to the individual, such as a finger or voice print or a photograph . . . ." 5 U.S.C. § 552a(a)(4) (2018) (emphasis added).

information" for purposes of veterans' benefits); *cf*. Perkey v. Dep't of Motor Vehicles, 721 P.2d 50, 61 (Cal. 1986) (Bird, C.J., concurring) (describing "personal and sensitive" information).

Individuals are constantly faced with requests for personal and sensitive information from a wide variety of government agencies and private organizations. In many cases, this information is essential to the provision of needed services . . . . The collection and storage of fragmentary bits of information and their use for narrowly specified purposes do not necessarily pose a serious threat to individual privacy, provided there are adequate safeguards against misuse and unwarranted disclosure.

<sup>&</sup>lt;sup>14</sup> See, e.g., James P. Nehf, *Recognizing the Societal Value in Information Privacy*, 78 WASH. L. REV. 1, 6 (2003) ("[I]nformation privacy legislation in the United States has placed heavy reliance on individuals policing their own data records and protecting their own information from unintended use."); Neil M. Richards & Daniel J. Solove, *Privacy's Other Path: Recovering the Law of Confidentiality*, 96 GEO. L.J. 123, 127 (2007) ("American privacy law has centered around the individual's inviolate personality . . . ."); *cf.* Tiffany R. Jones & Larry Peterman, *Whither the Family and Family Privacy?*, 4 TEX. REV. L. & POL. 193, 201 (1999) (making the case that "recent thinking, especially as it is reflected in court decisions, diminishes [the historical focus of American thought on] family distinction and privacy, preferring instead individualized conceptions of privacy").

<sup>&</sup>lt;sup>15</sup> Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 197 (1890) (considering whether existing law afforded "a principle which can properly be invoked to protect the privacy of the *individual*; and, if it does, what the nature and extent of such protection is") (emphasis added).

influential American law review articles of all time.<sup>16</sup> They inventoried early cases that tentatively marked the boundaries of a personal right to control dissemination of private information and images.<sup>17</sup>

Beginning soon after the turn of the twentieth century, states one by one started recognizing a private tort action to vindicate intentional invasions of personal privacy.<sup>18</sup> Some states enacted statutes.<sup>19</sup> Most addressed the issue by judicial declaration.<sup>20</sup> The personal right of privacy began as a matter of state law and developed

20 See, e.g., Melvin v. Reid, 297 P. 91, 91–92 (Cal. Dist. Ct. App. 1931); Pavesich v. New England Life Ins. Co., 50 S.E. 68, 68 (Ga. 1905); Kunz v. Allen, 172 P. 532, 532–33 (Kan. 1918). Professor Thomas Cooley has been credited with coining the term "the right to be let alone." E.g., Glancy, supra note 16, at 3 n.13; Warren & Brandeis, supra note 15, at 195 n.4. However, Cooley used the term in a very different sense analogous to individual liberty. Among several classifications of rights, he referred to the right of "personal immunity" as "the right to be let alone." THOMAS M. COOLEY, A TREATISE ON THE LAW OF TORTS OR THE WRONGS WHICH ARISE INDEPENDENT OF CONTRACT 29 (Callaghan & Co. 1879). That right, he explained, was a corollary of one's duty to refrain from injuring (or attempting to injure) anyone else. Id.; cf. Obergefell v. Hodges, 135 S. Ct. 2584, 2599–602 (2015) (grounding same-sex couples' fundamental constitutional right to marry in part on the "individual autonomy" protection of the Due Process Clause, while explaining that "decisions concerning marriage are among the most intimate that an individual can make" and referring to the constitutional right "to enjoy intimate association," to family relationships and autonomy as "a central part of the liberty protected by the Due Process Clause," and to "the right of samesex couples to marry [as] part of the liberty promised by the Fourteenth Amendment") (citations omitted); ANITA L. ALLEN, UNPOPULAR PRIVACY: WHAT MUST WE HIDE? 9–11 (2011) (arguing that a nation that prizes personal *liberty* must impose mandatory *privacy* protections, whether or not the general citizenry desires them).

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<sup>&</sup>lt;sup>16</sup> See, e.g., SAMANTHA BARBAS, NEWSWORTHY: THE SUPREME COURT BATTLE OVER PRIVACY AND PRESS FREEDOM 64 (2017) (referring to the Warren and Brandeis article as a "legal landmark"); Dorothy J. Glancy, *The Invention of the Right to Privacy*, 21 ARIZ. L. REV. 1, 1, 3 (1979) (crediting Warren and Brandeis with having invented "a categorical description of the right to privacy").

<sup>&</sup>lt;sup>17</sup> Warren & Brandeis, *supra* note 15, at 207–11.

<sup>&</sup>lt;sup>18</sup> See Kyle Sammin, Honor and Dignity: The Common Law of Privacy, North and South, 1890-1967, 23 J. S. LEGAL HIST. 93, 97–107 (2015).

<sup>&</sup>lt;sup>19</sup> See, e.g., N.Y. CIV. RIGHTS LAW §§ 50–51 (Consol. 1909) (originally enacted 1903).

incrementally in jumps and starts.<sup>21</sup> And the nature and scope of privacy rights varied substantially from one state to the next, although invasion of privacy has always been categorized as an intentional tort.<sup>22</sup> By 1957, one jurist described the still-developing right of privacy as "a haystack in a hurricane,"<sup>23</sup> calling to mind the familiar English idiom "tempest in a teapot."<sup>24</sup>

#### Disposition of Human Remains A.

With respect to privacy issues surrounding the death of a loved one, courts in the nineteenth-century United States began acknowledging the special interests and emotional vulnerability of a decedent's next of kin.<sup>25</sup> This trend reflected a significant departure from

<sup>21</sup> One author writing in the early 1930s declined to speculate "what the scope of the right to privacy should be, or to discuss the various necessary limitations involved in the recognition of a right of such a vague nature as freedom from the publication of one's features, doings or personal history." S. G. P., Torts: The Right to Privacy and the Pursuit of Happiness, 20 CALIF. L. REV. 100, 100 (1931). "The right even in the jurisdictions where it has been recognized is a nebulous one[,] and there has been but a slight development of the law concerning it." Id.

<sup>&</sup>lt;sup>22</sup> See, e.g., Marich v. MGM/UA Telecomms., Inc., 7 Cal. Rptr. 3d 60, 63 (Ct. App. 2003) ("The elements of both the statutory invasion of privacy and common law invasion of privacy include intentional conduct.").

<sup>&</sup>lt;sup>23</sup> Ettore v. Philco Television Broad. Corp., 229 F.2d 481, 485 (3d Cir. 1956). The court observed that the still-young right of privacy already had a broad and multi-faceted reach, having "read of the right of privacy, of invasion of property rights, of breach of contract, of equitable servitude, of unfair competition; and ... even suggestions of unjust enrichment." Id. at 485; see id. at 485 n.7 (referencing various examples); see also Paul v. Davis, 424 U.S. 693, 713 (1976) (acknowledging that the Court's "right of privacy' cases . . . defy[] categorical description").

<sup>&</sup>lt;sup>24</sup> See The Scotch Poets, Hogg and Campbell—Hynde and Theodric, 17 BLACKWOOD'S EDINBURGH MAG. 109, 112 (1825) (critiquing a Campbell poem describing "strife in the elements" by describing the passage as "[a] tempest in a teapot!").

<sup>&</sup>lt;sup>25</sup> See, e.g., Meagher v. Driscoll, 99 Mass. 281, 285 (1868). Responding to a claim for wrongfully disinterring the corpse of plaintiff's decedent and reburying it in a "charity lot," the Massachusetts court stated that "the natural injury to the feelings of the plaintiff may be taken into consideration . . . . We know of no rule of law which requires the mental suffering of the plaintiff, or the misconduct of the defendant, to be disregarded." Id.; see also Pierce v. Proprietors of Swan Point Cemetery, 10 R.I. 227 (1872).

tradition. English common law had recognized no property interest on behalf of surviving family members in a human corpse, reasoning that the disposition of human remains was primarily an ecclesiastical matter.<sup>26</sup> English criminal law provided the exclusive remedy for

> That there is no right or property in a dead body, using the word in its ordinary sense, may well be admitted. Yet the burial of the dead is a subject which interests the feelings of mankind to a much greater degree than many matters of actual property. There is a duty imposed by the universal feelings of mankind to be discharged by some one towards the dead; a duty, and we may also say a right, to protect from violation; and a duty on the part of others to abstain from violation; it may therefore be considered as a sort of *quasi* property, and it would be discreditable to any system of law not to provide a remedy in such a case.

Pierce, 10 R.I. at 237–38.

See Pierce, 10 R.I. at 237 n.1; Meagher, 99 Mass. at 284 (holding that an heir has no property interest in his ancestors' bodies or ashes); Larson v. Chase, 50 N.W. 238, 239 (Minn. 1891) ("The doctrine that a corpse is not property seems to have had its origin in the dictum of Lord Coke, ... where, in asserting the authority of the church, he says: 'It is to be observed that in every sepulchre that hath a monument two things are to be considered, viz., the monument, and the sepulture or burial of the dead. The burial of the cadaver that is caro data vermibus [flesh given to worms] is nullius in bonis, and belongs to ecclesiastical cognizance; but as to the monument action is given, as hath been said, at the common law, for the defacing thereof.""); see also Erin Colleran, My Body, His Property?: Prescribing a Framework to Determine Ownership Interests in Directly Donated Human Organs, 80 TEMP. L. REV. 1203, 1205-07 (2007); J. F. H., Note, The Nature of Rights in a Dead Body, 74 U. PA. L. REV. 404, 404 (1926) (stating that there were no property rights in a corpse at common law); Francis L. Wellman, Note, Law of Burial. – Quasi Property in Corpse. – Right to Dispose of Remains Before Burial, and After Burial, 14 AM. L. REV. 57, 59 (1880) ("By the common law though the heir has a property [interest] in the monuments and escutcheons of his ancestors, yet he has none in their bodies or ashes; nor can he bring any civil action against such as indecently, at least, if not impiously, violate and disturb their remains when dead and buried."). But cf. Snyder v. Snyder, 60 How. Pr. 368, 369–70 (N.Y. Sup. Ct. 1880) ("It is asserted in many cases, following the Roman law, that the exclusive right of burial and the right to select the place of burial rests, in the absence of any testamentary direction on the part of the deceased, in the next of kin.").

The primary reason for the English courts' refusal to recognize a property right in a human corpse was that the duty to ensure a dignified disposition of the body fell on the church; burials were considered matters of ecclesiastical cognizance. *See* R. S. Guernsey, *The Ownership of Corpse Before Burial*, 10 CENT. L.J. 303, 303–04 (1880).

the removal of human remains from a burial site.<sup>27</sup> And early common law courts in both England and America, skeptical of the potential for fraudulent claims, were not inclined to award recovery for mental anguish alone.<sup>28</sup>

In early America, however, equity jurisprudence found ways to remedy the emotional distress of surviving family members by acknowledging a property right of sorts to control the manner of disposition of a human corpse.<sup>29</sup> It was not uncommon in early America for creditors to seize a corpse as security against the unpaid debts of the decedent; and body-snatchers, motivated by greed, sometimes stole human corpses and held them for ransom.<sup>30</sup> Perhaps for those reasons, equity courts began to consider a decedent's corpse as an asset of the estate—a quasi-property interest within the jurisdiction of equity.<sup>31</sup> These early judicial remedies were all the more

<sup>29</sup> See PROSSER AND KEETON ON TORTS 63 (W. Page Keeton et al. eds., 5th ed. 1984) (expressing skepticism regarding the "property" right as "something evolved out of thin air to meet the occasion, and . . . in reality the personal feelings of the survivors are being protected, under a fiction likely to deceive no one but a lawyer"); *e.g.*, Weld v. Walker, 130 Mass. 422, 423 (1881) ("Neither the husband nor the next of kin have, strictly speaking, any right of property in a dead body; but controversies between them as to the place of its burial are in this country, where there are no ecclesiastical courts, within the jurisdiction of a court of equity.").

<sup>30</sup> CHRISTINE QUIGLEY, THE CORPSE: A HISTORY 277–79 (2005); *see* Wellman, *supra* note 26, at 59 (describing ancient laws of Egypt and parts of Europe treating a human corpse as legal security for debts and referring to Massachusetts and Rhode Island statutes forbidding the practice).

<sup>31</sup> Joseph R. Long, *Equitable Jurisdiction to Protect Personal Rights*, 33 YALE L.J. 115, 115–16 (1923) (acknowledging a general rule that "the test of equity jurisdiction" is "the existence of a property right needing protection," but critiquing the premise that an equity court has "no jurisdiction to protect personal rights where no property rights are involved"). Some courts have recognized that the constructive "property right" with respect to human remains was merely a legal fiction to redress surviving family members' emotional distress, for which they had no remedy under common law. *See, e.g.*, Colavito v. New York Organ Donor Network, Inc., 438 F.3d 214, 224 (2d Cir. 2006) (applying New York law).

The courts that have declined to treat this sort of claim as as-

serting a valid property right have explained that it should have

<sup>&</sup>lt;sup>27</sup> See Pierce, 10 R.I. at 237 n.1 (citing relevant cases).

<sup>&</sup>lt;sup>28</sup> See infra note 32 and accompanying text; see also Culpepper v. Pearl St. Bldg., Inc., 877 P.2d 877, 883 (Colo. 1994) ("[T]here is no property right in a dead body . . . .").

remarkable for the time. A remedy for emotional harm alone, especially in the absence of physical injury, was highly unusual in the nineteenth century.<sup>32</sup>

In the mid-nineteenth century, most courts granted the primary right to determine how and where to bury human remains to the

> been brought as a claim for emotional distress—which indeed is the gravamen of the injury bereaved families seek to redress in such circumstances .... But because the mishandling of a corpse is presumed to be emotionally distressing even though there is no physical impact on the plaintiff, courts have created the legal fiction of the "quasi-property right" ... to permit recovery in such cases.

Id.

<sup>32</sup> See, e.g., Calvert Magruder, Mental and Emotional Disturbance in the Law of Torts, 49 HARV. L. REV. 1033, 1035 (1936) (noting that English and American common law "has been reluctant to recognize the interest in one's peace of mind as deserving of general and independent legal protection, even as against intentional invasions"). Magruder traced this principle back to English common law. *Id.* at 1033 ("Mental pain or anxiety the law cannot value, and does not pretend to redress, when the unlawful act complained of causes that alone.") (quoting *Lynch v. Knight*, 9 H. L. Cas. 577, 598 (1861)). His premise, novel for its time, was that United States courts had recognized a tort action claiming damages for emotional distress independent of any other tort claim, as long as the "mental distress [was] of an aggravated sort, resulting from an outrageous aggression by the defendant upon the plaintiff's peace of mind." *Id.* at 1064; *see also* William L. Prosser, *Intentional Infliction of Mental Suffering: A New Tort*, 37 MICH. L. REV. 874, 874– 75 (1939).

The American Law Institute later recognized the tort of emotional distress, but not until 1948. RESTATEMENT OF TORTS § 46 (AM. LAW INST. Supp. 1948); *see* RESTATEMENT (SECOND) OF TORTS § 46 (AM. LAW INST. 1965) (outlining the elements of "Outrageous Conduct Causing Severe Emotional Distress"); RESTATEMENT (THIRD) OF TORTS: PHYSICAL AND EMOTIONAL HARM §§ 45–47 (AM. LAW INST. 2012) (defining "emotional harm" to mean "impairment or injury to a person's emotional tranquility"). The independent tort action to remedy emotional distress, like the claim for invasion of privacy, arose from academic scholarship rather than the courts. *See* John J. Kircher, *The Four Faces of Tort Law: Liability for Emotional Harm*, 90 MARQ. L. REV. 789, 797 (2007). Kircher acknowledged that long before the tort of outrage was recognized in the United States, courts granted remedies for "mental distress associated with intentional mistreatment of dead bodies or burial rights." *Id.* at 796 (referencing Gostkowski v. Roman Catholic Church of the Sacred Hearts of Jesus & Mary, 186 N.E. 798, 800 (N.Y. 1933)).

decedent's surviving spouse.<sup>33</sup> The decedent's close family members could seek equitable remedies against private parties for interfering with a gravesite or grave goods—often known in early America as "grave-robbing" or "body-snatching."<sup>34</sup> By the end of the

*Id.; see also* Weld v. Walker, 130 Mass. 422, 424 (1881) (holding that surviving widower had implied right to remove decedent's remains from original place of burial in proximity to her siblings and move it to a suitable burial plot of his own choosing); Pierce v. Proprietors of Swan Point Cemetery, 10 R.I. 227, 235 (1872) (recognizing widow's right to remove decedent's body from original burial place over objection of decedent's only child); Foley v. Phelps, 37 N.Y.S. 471, 473 (App. Div. 1896) (recognizing, as a matter of first impression, a widow's tort claim against the defendant for unlawfully conducting an unauthorized autopsy over her objection after husband died in tragic accident).

By the common law, and stricti juris, the proposition [that no property right exists in a dead body] may be maintainable. A long line of judicial decisions appear to have established a general doctrine to that effect; but courts of equity have frequently interfered to protect the remains of the dead, and courts of law have also afforded remedies . . . wherever any element of trespass to property, real or personal, was associated with the molestation of the remains of the dead. In more recent times the obdurate common-law rule has been very much relaxed, and changed conditions of society, and the necessity for enforcing that protection which is due to the dead, have induced courts to re-examine the grounds upon which the common-law rule reposed, and have led to modifications of its stringency. The old cases in England were decided when matters of burial, and the care of the dead, were within the jurisdiction of the ecclesiastical courts, and they are no longer absolutely controlling.

Id.

<sup>34</sup> For example, during the nineteenth century, medical schools often secured cadavers for purposes of teaching anatomy by disinterring recently buried corpses, which led to a public outcry. MICHAEL SAPPOL, A TRAFFIC OF DEAD BODIES: ANATOMY AND EMBODIED SOCIAL IDENTITY IN NINETEENTH-CENTURY AMERICA 3–5 (2002); *Grave Robbing*, OHIO HIST. CENT.,

<sup>&</sup>lt;sup>33</sup> See, e.g., Durell v. Hayward, 75 Mass. 248, 249 (1857) (rejecting a claim by the mother of a female decedent against decedent's widower for removing a gravestone erected by the mother and replacing it with one selected by widower).

The indisputable and paramount right, as well as duty, of a husband, to dispose of the body of his deceased wife by a decent sepulture in a suitable place, carries with it the right of placing over the spot of burial a proper monument or memorial in accordance with the well known and long established usage of the community.

nineteenth century, some state courts recognized comparable common law rights for the violation of which surviving close relatives could claim money damages.<sup>35</sup>

Tort remedies for interfering with the survivors' rights to dispose of a dead body survive today in many jurisdictions.<sup>36</sup> The *Restatement (Second) of Torts* expressly recognized a cause of action

To deter the practice of grave-robbing, enterprising inventors patented devices such as the "coffin torpedo." *See, e.g.*, Coffin-Torpedo, U.S. Patent No. 208,627 (filed June 29, 1878) (issued Oct. 8, 1878). The invention's purpose was as follows:

to provide a means which shall successfully prevent the unauthorized resurrection of dead bodies; and with this end in view [the] invention consists of a peculiarly-constructed torpedo, adapted to be readily secured to the coffin and the body of the contained corpse in such manner that any attempt to remove the body after burial will cause the discharge of the cartridge contained in the torpedo and injury or death of the desecrator of the grave.

Id.

<sup>35</sup> See, e.g., Larson v. Chase, 50 N.W. 238, 240 (Minn. 1891) ("[I]t would be a reproach to the law if a plaintiff's right to recover for mental anguish resulting from the mutilation or other disturbance of the remains of his dead should be made to depend upon whether in committing the act the defendant also committed a technical trespass upon plaintiff's premises, while everybody's common sense would tell him that the real and substantial wrong was not the trespass on the land, but the indignity to the dead.").

<sup>36</sup> *E.g.*, Smith v. City of Artesia, 772 P.2d 373, 375 (N.M. 1989) (quoting Infield v. Cope, 270 P.2d 716, 719 (N.M. 1954)) (noting that while "no special rule provides relatives a right of privacy in the body of a deceased person[,]... New Mexico has granted relatives of a decedent a [limited] cause of action for mistreatment of a corpse ... derived from the common law notion of 'a quasi-property right in a dead body vesting in the nearest relatives of the deceased and arising out of their duty to bury their dead"); Kirksey v. Jernigan, 45 So. 2d 188, 189 (Fla. 1950) (holding that impact rule did not bar mother's claim against undertaker for tortious interference with her child's body without her consent; acknowledging that "tortious interference with rights involving dead human bodies" naturally results in "mental anguish to the surviving relatives[,]" which "is frequently the only injurious consequence to follow from it.").

https://ohiohistorycentral.org/w/Grave-robbing (last visited Feb. 15, 2020); *see also Foley*, 37 N.Y.S. at 472 (noting that in 1854, New York enacted a statute expressly barring a hospital, over objection of "relatives or friends of the deceased," from dissecting the corpse of a patient who had died in the hospital, or delivering a corpse to someone else for that purpose).

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for tortious interference with a dead body.<sup>37</sup> The superseding *Re-statement (Third) of Torts: Physical and Emotional Harm*, finalized in 2012, continues to recognize the claim, but now treats it as a sub-category of tortious infliction of emotional distress.<sup>38</sup>

<sup>37</sup> See Restatement (Second) of Torts § 868 (Am. Law Inst. 1979) ("One who intentionally, recklessly or negligently removes, withholds, mutilates or operates upon the body of a dead person or prevents its proper interment or cremation is subject to liability to a member of the family of the deceased who is entitled to the disposition of the body."). In limiting the claim to the family member "who is entitled to the disposition of the body," id. § 868 cmt. a, the Restatement recognizes a family member's tort action for intentional, reckless, or negligent interference with the decedent's body, which some courts have characterized as a "quasi-property" right. E.g., Cochran v. Securitas Sec. Servs. USA, Inc., 59 N.E.3d 234, 243 (Ill. App. Ct. 2016) ("This cause of action has its roots in the early recognition of a quasi-property right in a decedent's body by his next of kin."), aff'd, 93 N.E.3d 493 (Ill. 2017). The Restatement further acknowledges the questionable nature of the property classification, observing that "the technical right has served as a mere peg upon which to hang damages for the mental distress inflicted upon the survivor; and in reality the cause of action has been exclusively one for the [survivor's] mental distress." RESTATEMENT (SECOND) OF TORTS § 868 cmt. a.

<sup>&</sup>lt;sup>38</sup> The *Restatement (Third) of Torts* recognizes that the claim is essentially one for negligent, reckless, or intentional infliction of emotional distress. See RESTATEMENT (THIRD) OF TORTS: PHYSICAL AND EMOTIONAL HARM § 47 cmt. b, Reporter's Note cmt. f (AM. LAW INST. 2012) (addressing liability for negligent conduct directly inflicting emotional harm on another). The Reporter's Note explains that the rule in subsection (b) originated in cases dealing with negligent mishandling of corpses and negligent transmission of information about death or terminal illness, and the rule has since been expanded in many states to include "other activities or undertakings." Id. (citing Kaufman v. W. Union Tel. Co., 224 F.2d 723 (5th Cir. 1955) as "what appears to be the last of the negligent telegraphtransmission cases"); see also Jackson v. McKay-Davis Funeral Home, Inc., 830 F. Supp. 2d 635, 653, 655 (E.D. Wis. 2011) (denying summary judgment to defendant funeral home on claim by decedent's widow and daughter for negligent handling of human remains and negligent infliction of emotional distress, noting that "the negligent handling [of human remains] cases have developed in tandem with the tort of negligent infliction of emotional distress"); RESTATEMENT (THIRD) OF TORTS: PHYSICAL AND EMOTIONAL HARM § 46 (AM. LAW INST. 2012) (addressing liability for outrageous intentional or reckless conduct causing severe emotional distress).

## B. Names and Reputations of Decedents and Surviving Relatives

In the late nineteenth century, at about the same time Warren and Brandeis published their groundbreaking law review article, surviving family members began seeking equitable remedies for conduct they perceived as sullying the names and reputations of their deceased relatives and, by implication, their own.<sup>39</sup>

Among the earliest cases was *Schuyler v. Curtis*.<sup>40</sup> decided by the New York Court of Appeals in 1895. The plaintiff, a nephew of the female decedent who had died fourteen years earlier, sought to enjoin the defendants' plans to erect a statue honoring his deceased aunt without the consent of the "immediate members of the [decedent's] family."<sup>41</sup> The plan was to display the statue at the Chicago World's Fair in the same room as a statue depicting Susan B. Anthony, an early ardent feminist.<sup>42</sup> The nephew asserted various concerns about the plans, including a complaint that the circulars promoting the statue had inaccurately credited the decedent for certain philanthropic actions during her lifetime.<sup>43</sup> He also alleged that these were activities for which the decedent would not have wanted publicity, and that she would have rejected any apparent affiliation with Susan B. Anthony.<sup>44</sup> But the plaintiff's primary rationale for litigating the issue was "to establish a principle[] that the right of privacy should be respected."45

The court rejected the nephew's claim.<sup>46</sup> It reasoned that any right of privacy on the part of the decedent had died with her, and the surviving family members had no claim against the promoters

<sup>&</sup>lt;sup>39</sup> For a concise summary of early state cases addressing the right of privacy, see Sammin, *supra* note 18, at 97–107.

<sup>&</sup>lt;sup>40</sup> 42 N.E. 22, 22 (N.Y. 1895).

<sup>&</sup>lt;sup>41</sup> *Id.* at 24.

<sup>&</sup>lt;sup>42</sup> Id. at 23; see, e.g., Barbara Babcock, Women's Rights, Public Defense, and the Chicago World's Fair, 87 CHI.-KENT L. REV. 481, 482, 486–87 (2012) (describing Susan B. Anthony's role in the fair's promotion of women's suffrage and recognition of women's contributions to the labor force).

<sup>&</sup>lt;sup>43</sup> *Schuyler*, 42 N.E. at 24.

<sup>&</sup>lt;sup>44</sup> *Id.* at 24–25. The court was unpersuaded that the planned display would suggest that the decedent had in any way sympathized with Ms. Anthony's advocacy of the nascent "wom[e]n's rights movement." *Id.* at 27.

<sup>&</sup>lt;sup>45</sup> *Id.* at 25.

<sup>&</sup>lt;sup>46</sup> *Id.* at 26.

for failing to secure the family's consent to erect the statue depicting the decedent.<sup>47</sup>

<sup>47</sup> The court explained its reasoning for rejecting the claim, which asserted what would later become known in academic circles as a relational right of privacy:

Whatever the rights of a relative may be, they are not, in such case as this, rights which once belonged to the deceased, and which a relative can enforce in her behalf and in a mere representative capacity; as, for instance, an executor or administrator, in regard to the assets of a deceased. It is not a question of what right of privacy Mrs. Schuyler had in her lifetime. The plaintiff does not represent that right. Whatever right of privacy Mrs. Schuyler had died with her. Death deprives us all of rights, in the legal sense of that term; and, when Mrs. Schuyler died, her own individual right of privacy, whatever it may have been, expired at the same time. The right which survived (however extensive or limited) was a right pertaining to the living only. It is the right of privacy of the living which it is sought to enforce here. That right may in some cases be itself violated by improperly interfering with the character or memory of a deceased relative, but it is the right of the living, and not that of the dead, which is recognized .... We hold that in this class of cases there must, in addition, be some reasonable and plausible ground for the existence of [the survivors'] mental distress and injury. It must not be the creation of mere caprice nor of pure fancy, nor the result of a supersensitive and morbid mental organization, dwelling with undue emphasis upon the exclusive and sacred character of this right of privacy . . . . The fact that Mrs. Schuyler is dead alters the case, and the plaintiff and other relatives must show some right of their own violated . . . .

Id. at 25–26 (emphasis added).

The court's reasoning has been followed by other courts in analogous cases decided throughout the twentieth century and beyond. *See, e.g.*, Young v. That Was the Week That Was, 312 F. Supp. 1337, 1341 (N.D. Ohio 1969) ("[T]he right of privacy is personal and can only be asserted by the individual whose privacy has been invaded. It dies with him and cannot be claimed by his estate. Neither can it be asserted by the anguished or outraged relatives and friends of the subject individual, who may have been disturbed by the disclosure or exploitation."), *aff'd*, 423 F.2d 265 (6th Cir. 1970); Atkinson v. John E. Doherty & Co., 80 N.W. 285, 287 (Mich. 1899) (rejecting claim that defendants used decedent's photograph to market cigars without consent; holding that "a court of equity has no power to restrain a libelous publication"); *see also* Cannady v. St. Vincent Infirmary Med. Ctr., 423 S.W.3d 548, 552 (Ark. 2012) (quoting RESTATEMENT (SECOND) OF TORTS § 652I cmt. b (AM. LAW INST. 1977)) (rejecting a mother's

In 1940, the New York Court of Appeals revisited the issue.<sup>48</sup> The court dismissed a claim by a widow and her children, who alleged that a newspaper article had erroneously described their decedent as a confessed murderer and identified the plaintiffs as his survivors.<sup>49</sup> The court held that "a libel or slander upon the memory of a deceased person which makes no direct reflection upon his relatives gives them no cause of action for defamation."<sup>50</sup>

In 1952, the California Supreme Court addressed an invasion of privacy claim against local law enforcement officials after the plaintiffs' son was acquitted for the misdemeanor offense of unlawful assembly.<sup>51</sup> The parents claimed that the prosecution's publicity had negatively affected the father's practice as an attorney and CPA.<sup>52</sup> The court refused to recognize the parents' claim that their privacy had been violated as an incident of the prosecutor's allegedly wrongful prosecution of their son.<sup>53</sup> For the same reason, in 1959, a federal district court in Illinois held that a decedent's son had no claim for

- <sup>48</sup> Rose v. Daily Mirror, 31 N.E.2d 182 (N.Y. 1940).
- <sup>49</sup> *Id.* at 182–83.
- <sup>50</sup> *Id.* at 182.

<sup>51</sup> Coverstone v. Davies, 239 P.2d 876, 881 (Cal. 1952). The court was unable to identify any cases allowing a plaintiff to recover "where defendant's alleged wrongful act was directed toward a third person, and only as an incident to that act was it claimed that plaintiff's privacy had been invaded." *Id.* 

<sup>52</sup> *Id.* at 880.

<sup>53</sup> The court reasoned that recognizing such a privacy claim would open the floodgates to litigation by involuntary public figures:

Neither reason nor authority indicates that there should be an extension of liability to cover such a situation. Such a rule would open the courts to persons whose only relation to the asserted wrong is that *they are related to the victim of the wrong-doer* and were therefore brought unwillingly into the limelight. Every defamation, false imprisonment, and malicious prosecution would then be an actionable invasion of the privacy of the relatives of the victim.

Id. at 881 (emphasis added).

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claim on behalf of her deceased daughter for invasion of privacy, referencing *Re-statement (Second) of Torts* in part for proposition that "[i]n the absence of statute, the action for the invasion of privacy cannot be maintained after the death of the individual whose privacy is invaded").

libel of his own name on the basis of defendant's alleged libel of the plaintiff's deceased father.<sup>54</sup>

Similarly, modern courts have generally rejected "relational" claims by relatives for defaming the names or reputations of their decedents.<sup>55</sup> In some cases, courts rely on state survival statutes that expressly exclude reputational claims. Thus, a decedent's heirs may not vindicate defamatory statements concerning a decedent unless the claim is asserted before the direct victim's death.<sup>56</sup>

## C. "Personal" Nature of the Right of Privacy

As the intentional tort of invasion of privacy evolved throughout the twentieth century,<sup>57</sup> the right of privacy was considered personal to the individual whose right was violated.<sup>58</sup> The only exception was

<sup>&</sup>lt;sup>54</sup> Insull v. N.Y. World-Telegram Corp., 172 F. Supp. 615, 636 (N.D. Ill.) (applying Illinois law), *aff'd*, 273 F.2d 166 (7th Cir. 1959).

<sup>&</sup>lt;sup>55</sup> See, e.g., Gonzales v. Times Herald Printing Co., 513 S.W.2d 124, 126 (Tex. Civ. App. 1974) (holding that plaintiff-widow had no claim against defendant-newspaper for reporting that her husband's body was found in an area known for drug trafficking, unless she personally had been subject of alleged defamatory statements).

<sup>&</sup>lt;sup>56</sup> E.g., Fitch v. Voit, 624 So. 2d 542, 543–44 (Ala. 1993) (citing Smith v. Doss, 37 So. 2d 118, 121 (Ala. 1948), and quoting Abernathy v. Thornton, 83 So. 2d 235, 237 (Ala. 1955)) ("As to the issue of privacy, the trial judge concluded correctly that the right of privacy is a personal right, and that this Court has not recognized a 'relational right of privacy,' under which the plaintiffs make their claim."); *see also* Lamonaco v. CBS, Inc., No. CIV. A. 93-1975(DRD), 1993 WL 556536, at \*3 (D.N.J. July 29, 1993) (noting that "the tendency of most courts to invoke and then dismiss [a claim for] relational privacy without ever defining it"), *aff'd*, 27 F.3d 557 (3d Cir. 1994). *But see* Weller v. Home News Publ'g. Co., 271 A.2d 738, 740 (N.J. Super. Ct. Law Div. 1970) (holding that, while New Jersey law does not generally recognize a survivor's claim implicating a relational right of privacy, state survival statute preserved decedent's own claim against defendant for falsely portraying her as a fictional charity patient).

<sup>&</sup>lt;sup>57</sup> Cox Broad. Corp. v. Cohn, 420 U.S. 469, 488 (1975) (noting that "the [twentieth] century has experienced a strong tide running in favor of the so-called right of privacy"). By 1971, nearly every jurisdiction had recognized a claim for invasion of privacy in one form or another. *Id.* (citing WILLIAM L. PROSSER, LAW OF TORTS 804 (4th ed. 1971)).

<sup>&</sup>lt;sup>58</sup> See Leon Green, *The Right of Privacy*, 27 ILL. L. REV. 237, 238–39, 253, 256–57 (1932) (noting that interests identified in the privacy cases qualify as "interests of personality," rather than "property interests" or "interests in relations with other persons," and listing "privacy" as one of several "interests of

the variation on the privacy right that would later become known as the "right of publicity"—the right to prevent a third party's commercial misappropriation of a person's name or likeness without consent.<sup>59</sup> Over time, this version of the privacy tort was increasingly recognized as a right that could be vindicated by the individual during her lifetime—and even after death by her surviving heirs under limited circumstances.<sup>60</sup> The right of publicity, also known as the

<sup>59</sup> See, e.g., Hart v. Elec. Arts, Inc., 717 F.3d 141, 151 (3d Cir. 2013) (explaining that right of publicity "protect[s] the property interest that an individual gains and enjoys in his identity through his labor and effort"); Carson v. Here's Johnny Portable Toilets, Inc., 698 F.2d 831, 836 (6th Cir. 1983) (concluding that defendant had violated Johnny Carson's right of publicity under Michigan law by intentionally appropriating for commercial use the phrase "Here's Johnny," which evoked the celebrity's persona as the host of a long-running late-night television program).

<sup>60</sup> *Compare, e.g.*, Guglielmi v. Spelling-Goldberg Prods., 603 P.2d 454, 462 (Cal. 1979) (refusing to permit a claim for violation of right of publicity for using the identity of Rudolph Valentino, a deceased celebrity, in a film), *and* Groucho Marx Prods., Inc. v. Day & Night Co., 689 F.2d 317, 323 (2d Cir. 1982) (holding that "California [law in 1982] would not recognize a descendible right of publicity that protects against an original play using a [deceased] celebrity's likeness and

personality," including "physical integrity," "feelings or emotions," "capacity for activity or service," "name," "likeness," and "history"); RESTATEMENT (SECOND) OF TORTS § 652I (AM. LAW INST. 1977) ("Except for the appropriation of one's name or likeness, an action for invasion of privacy can be maintained only by a living individual whose privacy is invaded."); id. § 652I cmt. a ("The right protected by the action for invasion of privacy is a personal right, peculiar to the individual whose privacy is invaded. The cause of action is not assignable, and it cannot be maintained by other persons such as members of the individual's family, unless their own privacy is invaded along with his."); see also, e.g., United States v. Leon, 468 U.S. 897, 910 (1984) (quoting Alderman v. United States, 394 U.S. 165, 174-75 (1969)) (stating that Fourth Amendment rights are personal and may not be vicariously asserted); Whalen v. Roe, 429 U.S. 589, 605 (1977) (referring to "the individual's interest in [informational] privacy"); Moore v. Charles B. Pierce Film Enters., Inc., 589 S.W.2d 489, 491 (Tex. Civ. App. 1979) (restricting recovery for invasion of privacy to "the person about whom facts have been wrongfully published, unless the Legislature sees fit to establish a right of action in the relatives of such a person."); Francis S. Chlapowski, Note, The Constitutional Protection of Informational Privacy, 71 B.U. L. REV. 133, 158 (1991) ("The interest in informational privacy—the right to control personal information-belongs with the individual."); cf. Maritote v. Desilu Prods., Inc., 345 F.2d 418, 420 (7th Cir. 1965) (applying Illinois law and observing that "[i]t is anomalous to speak of the privacy of a deceased person.").

tort of misappropriation of name and likeness,<sup>61</sup> evolved to become what is today a heritable right in many, if not most, of the states that recognize it.<sup>62</sup> But the other variations on the common law right of privacy presumably terminated immediately upon the death of the individual whose "personal" privacy right was allegedly violated.<sup>63</sup>

<sup>61</sup> See RESTATEMENT (SECOND) OF TORTS § 652C cmt. a (AM. LAW INST. 1977) (noting that the right of publicity "is in the nature of a property right").

<sup>62</sup> See State ex rel. Elvis Presley Int'l Mem'l Found. v. Crowell, 733 S.W.2d 89, 99 (Tenn. Ct. App. 1987) ("The legal literature has consistently argued that the right of publicity should be descendible. A majority of the courts considering this question agree."). In some states, the right of publicity is descendible not by judicial declaration, but rather statutory enactment. *E.g.*, CAL. CIV. CODE 3344.1(a)–(b) (West 2012); 42 PA. STAT. AND CONS. STAT. ANN. § 8316(b)(3) (West 2007).

<sup>63</sup> The general common law rule is that, "[e]xcept for the appropriation of one's name or likeness, an action for invasion of privacy can be maintained only by a living individual whose privacy is invaded." RESTATEMENT (SECOND) OF TORTS § 652I (AM. LAW INST. 1977); *id.* § 652I cmt. b ("In the absence of a statute, the action for the invasion of privacy cannot be maintained after the death of the individual whose privacy is invaded."); *see, e.g.*, Swickard v. Wayne Cty. Med. Exam'r, 475 N.W.2d 304, 309 (Mich. 1991).

comedic style."), *with, e.g.*, Herman Miller, Inc. v. Palazzetti Imports & Exports, Inc., 270 F.3d 298, 326 (6th Cir. 2001) ("We believe that the weight of authority indicates that the right of publicity is more properly analyzed as a property right and, therefore, is descendible."), *and* Martin Luther King, Jr., Ctr. for Soc. Change, Inc. v. Am. Heritage Prods., Inc., 296 S.E.2d 697, 705 (Ga. 1982) (holding that "the right of publicity survives the death of its owner and is inheritable and devisable.").

If a state's own constitution independently recognizes a right of privacy, state courts have held that those rights do not expire as a matter of law at the time of death. For example, in *Weaver v. Myers*, the Florida Supreme Court held that "[d]eath does not retroactively abolish [Florida's] constitutional protections for privacy that existed at the moment of death." 229 So. 3d 1118, 1127–28 (Fla. 2017) (4-3 decision). The majority struck down as unconstitutional statutory amendments to the state's medical malpractice laws that had required the release of a deceased patient's medical records to "prying [defense] lawyers, insurance companies, experts, and doctors" and authorized ex parte, "secret" interviews of decedent's medical providers. *Id.* at 1140–41; *see also* Brian W. Boelens, Weaver v. Myers: *The Future of Ex Parte Communication in Florida Medical Malpractice*, FLA. B.J., July–Aug. 2018, at 22, 26.

## II. EARLY RECOGNITION OF "RELATIONAL" PRIVACY INTERESTS

### A. Scholarly Recognition

As early as 1916, Roscoe Pound addressed relational interests of individuals within the nuclear family,<sup>64</sup> as distinguished from

[T]he law has to give effect to the right of the one party to the relation against the other and enforce the corresponding [relational] duty toward the former, and also to give effect to the right of each against the whole world not to have the relation interfered with by outsiders.

*Id.* at 179. This latter aspect of family interests—the family unit's rights against external interference—is the underpinning of relational privacy rights. For example, early American common law claims for alienation of affections and loss of consortium implicitly acknowledged relational interests in maintaining the integrity of the domestic family unit. *See id.* at 188–89. Another example is the common law concept of coverture, by which a married woman had no legal identity apart from her husband. *See* Jones & Peterman, *supra* note 14, at 215. In the last half of the nineteenth century, most states abolished coverture by enacting "married women's statutes" following the lead of New York, the first state to do so in 1848. *See* J. Lyn Entrikin, *The Death of Common Law*, 42 HARV. J.L. & PUB. POL'Y 351, 458–59 (2019).

However, these traditional notions of "family" privacy focused on protecting family autonomy rather than protecting against invasion of privacy by the misuse or misappropriation of family-related information. *See* Jones & Peterman, *supra* note 14, at 216; *see also, e.g.*, Wisconsin v. Yoder, 406 U.S. 205, 232 (1972) (referring to the "enduring American tradition" of parents' autonomy to educate their own children); Prince v. Massachusetts, 321 U.S. 158, 166 (1944) (striking down Massachusetts statutes regulating child labor based on respect for "the private realm of family life which the state cannot enter"); Pierce v. Soc'y of the Sisters of the Holy Names of Jesus & Mary, 268 U.S. 510, 534–35 (1925) (striking down Oregon law requiring public education for "unreasonably interfer[ing] with the liberty of parents and guardians to direct the upbringing and education of children"); Meyer v. Nebraska, 262 U.S. 390, 401 (1923) (deferring to parental authority to control education of their children).

Similar family autonomy interests, and by extension reproductive autonomy, were the underpinnings of major Supreme Court cases. *See* Carey v. Population

<sup>&</sup>lt;sup>64</sup> Roscoe Pound, *Individual Interests in the Domestic Relations*, 14 MICH. L. REV. 177, 177 (1916) [hereinafter Pound, *Domestic Relations*] (focusing on "individual interests of the individual parties to domestic relations in the maintenance and integrity thereof and with the securing of these interests both against the world at large and between the parties"). Pound viewed the family as an economic and social unit. He explained,

individual interests of "personality."<sup>65</sup> He explained that these relational interests are "wider than the individual personality [and] involve more than the individual body and life, and yet they are intimately related thereto."<sup>66</sup> Pound sought to distinguish relational rights from "interests of personality" of the sort modern legal thought characterizes as "personal" rights.<sup>67</sup>

American scholars have acknowledged the so-called "relational" right of privacy, albeit not uniformly.<sup>68</sup> Beginning in the

While the Court has departed from its traditional focus on family privacy in favor of personal and individual privacy in its decisional autonomy jurisprudence, the Supreme Court's concerns about protecting family and relational privacy continue to reverberate in its informational privacy cases. *See infra* Part IV.A (distinguishing privacy rights with respect to decisional autonomy from privacy rights with respect to disclosure of sensitive personal information).

<sup>65</sup> Roscoe Pound, *Interests of Personality*, 28 HARV. L. REV. 343, 349 (1915) [hereinafter Pound, *Personality*].

<sup>66</sup> Pound, *Domestic Relations*, *supra* note 64, at 177.

<sup>67</sup> See Pound, Personality, supra note 65, at 350. While recognizing that "[a]ll classifications are more or less arbitrary," Pound's 1915 article sorted "individual interests" into three subcategories: "(a) interests of personality, — the individual physical and spiritual existence; (b) domestic interests, — the expanded individual life; and (c) interests of substance, — the individual economic life." *Id.* at 349 (internal quotation marks omitted). From a historical perspective, Pound surmised that individual interests were relatively late in coming as distinguished from "group rights." *Id.* "This culminated in the eighteenth century in a working out of individual interests as distinguished from public interests, to which our bill of rights, in which the natural rights of the individual are solemnly asserted against the state, still bear witness." *Id.* 

<sup>68</sup> See, e.g., Ian Kerr, Schrödinger's Robot: Privacy in Uncertain States, 20 THEORETICAL INQUIRIES L. 123, 130 (2019) ("[T]he moniker of relational privacy has been used to mean different things . . . ."); Robert H. Sloan & Richard Warner, *Relational Privacy: Surveillance, Common Knowledge, and Coordination*, 11 U.

Servs., Int'l, 431 U.S. 678, 693, 699–70 (1977) (unmarried minors' "right to privacy in connection with decisions affecting procreation"); Eisenstadt v. Baird, 405 U.S. 438, 445–46 (1972) (unmarried women's right to use contraceptives); Roe v. Wade, 410 U.S. 113, 162–63 (1973) (women's right to choose abortion, in consultation with their physicians, during first trimester of pregnancy); Griswold v. Connecticut, 381 U.S. 479, 485–86 (1965) (married couples' right to use contraceptives). But the evolution of reproductive autonomy has departed from what was once a family-focused theme in favor of a woman's individual procreational autonomy. *See, e.g.*, Planned Parenthood of Cent. Mo. v. Danforth, 428 U.S. 52, 58 (1976) (holding that not even a pregnant woman's husband could interfere with her decision to terminate a pregnancy within the first twelve weeks).

1930s, Leon Green, then Dean of Northwestern University Law School, published a series of five articles on various categories of "relational interests."<sup>69</sup> The first of these focused on relational interests within the family.<sup>70</sup> The author devoted several pages to the relational interest of surviving family members with respect to the "personality" of a decedent,<sup>71</sup> acknowledging that courts considering those claims routinely focused on the "mental suffering of the surviving relative as the chief element of recovery."<sup>72</sup> Green concluded that harm to these relational family interests, which he defined as "hurt to one member of a family by reason of conduct

<sup>72</sup> *Id.* at 486.

ST. THOMAS J.L. & PUB. POL'Y 1, 7 (2017) (defining relational privacy as "a variety of informational privacy," meaning "the ability to determine for yourself when others may collect and how they may use your information," and explaining that "[i]nformational privacy is relational when control over the flow of information is exercised collectively by a group, not unilaterally by individuals"); see also Stuart Hargreaves, 'Relational Privacy' & Tort, 23 WM. & MARY J. WOMEN & L. 433, 463 (2017) ("[R]elational privacy accepts . . . that privacy has . . . a role to play both in creating a personal zone of freedom from unwanted outside interference, [and] as a means of protecting one's interactions within a broader community . . . . "); Bert-Jaap Koops et al., A Typology of Privacy, 38 U. PA. J. INT'L L. 483, 528 (2017) (discussing relational privacy as a cluster of "privacy of relations"); Radhika Rao, Property, Privacy, and the Human Body, 80 B.U. L. REV. 359, 388–89 (2000) [hereinafter Rao, Property, Privacy] (citing Radhika Rao, Reconceiving Privacy: Relationships and Reproductive Technology, 45 UCLA L. REV. 1077, 1078 (1998) [hereinafter Rao, Reconceiving Privacy] (referring to right of relational privacy as one component of constitutionally protected privacy that "casts a mantle of immunity from state interference around certain intimate and consensual relationships")); Sonia M. Suter, All in the Family: Privacy and DNA Familial Searching, 23 HARV. J.L. & TECH. 309, 364 (2010) (referring to relational privacy as "protect[ing] the sanctity of the family by working to support the relationships that are constitutive of the family").

<sup>&</sup>lt;sup>69</sup> Leon Green, *Relational Interests*, 29 ILL. L. REV. 460 (1934) [hereinafter Green, *Relational Interests* (1934)]; Leon Green, *Relational Interests*, 29 ILL. L. REV. 1041 (1935); Leon Green, *Relational Interests*, 30 ILL. L. REV. 1 (1935); Leon Green, *Relational Interests*, 30 ILL. L. REV. 314 (1935); Leon Green, *Relational Interests*, 31 ILL. L. REV. 35 (1936); *see also* Green, *Basic Concepts, supra* note 2, at 65 (distinguishing interests in person and property, the focus of early common law actions, from interests in "*relations with other persons*," which he characterized as "an entirely new group of interests").

<sup>&</sup>lt;sup>70</sup> Green, *Relational Interests* (1934), *supra* note 69, at 464.

<sup>&</sup>lt;sup>71</sup> *Id.* at 485–90.

[directed] towards some other member,"<sup>73</sup> warranted legal protection to the same extent as other interests.<sup>74</sup>

Even earlier, the venerable William Blackstone had acknowledged "*relative* rights; or such as are incident to persons considered as members of society, and connected to each other by various ties and relations."<sup>75</sup> Of these "relative rights," distinguished from the "absolute" rights of the individual, Blackstone identified four specific categories of rights in private relations: "husband and wife, parent and child, guardian and ward, master and servant."<sup>76</sup>

But none of these early scholars expressly identified what would come to be known as "relational privacy" or "familial privacy" interests with respect to disclosures of sensitive information. That terminology would develop much later in the twentieth century.<sup>77</sup> In

In the law of relative rights, Blackstone was primarily interested in presenting English society as a set of hierarchies of persons. Each hierarchy had a function, and each was composed of complex social roles heavily regulated by common law and statute. Two of the hierarchies . . . had the function of exercising the powers of the state, and Blackstone identified them as public. At the other extreme, there were the "domestic" or "economical" hierarchies of employment and family. As with the state hierarchies, Blackstone described these in terms of clusters of legal rules all related to the functions and ranks of the people involved, but here those were private, and he so identified them. In the middle were *people* in *public* relations, with some private and some public functions.

*Id.* at 288–89 (emphasis in original); *see also* Jones & Peterman, *supra* note 14, at 200 n.36 (citing 1 WILLIAM BLACKSTONE, COMMENTARIES \*422) ("The original sense of family privacy descended from the common law.").

<sup>77</sup> See, e.g., ALAN F. WESTIN, PRIVACY AND FREEDOM 38–39, 42 (1967). Westin, a renowned privacy scholar, recognized the need for "emotional release through privacy" at times of "loss, shock, or sorrow." *Id.* at 36. "In such moments

<sup>&</sup>lt;sup>73</sup> *Id.* at 490.

<sup>&</sup>lt;sup>74</sup> *Id.* at 460; *see also* Green, *Basic Concepts, supra* note 2, at 66 (distinguishing relational interests from interests of personality and property on the basis that "[t]heir value lies in the fact that one person has an interest in the welfare and conduct of some other person"); Pound, *Domestic Relations, supra* note 64, at 196.

<sup>&</sup>lt;sup>75</sup> 3 WILLIAM BLACKSTONE, COMMENTARIES \*138–39.

<sup>&</sup>lt;sup>76</sup> *Id.*; *see* Duncan Kennedy, *The Structure of Blackstone's Commentaries*, 28 BUFF. L. REV. 205, 273–75 (1979) (explaining Blackstone's distinctions between absolute and relative rights of persons).

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fact, the American Law Institute's ("ALI") articulation of common law "personal" privacy rights in the first two versions of the *Restatement of Torts* stymied the conceptual development of relational privacy rights recognized by early common law.<sup>78</sup>

### B. *The* Restatement of Torts *and the Influence of William Prosser*

The first *Restatement of Torts* was published in 1939.<sup>79</sup> It separately acknowledged claims for "interference with a dead body"<sup>80</sup> and "interference with privacy."<sup>81</sup> Both, however, were articulated

<sup>78</sup> See Neil M. Richards & Daniel J. Solove, *Prosser's Privacy Law: A Mixed Legacy*, 98 CALIF. L. REV. 1887, 1903, 1905 (2010) (explaining that Prosser's rendition of privacy claims took hold in the first and second Restatement of Torts and was "clear and orderly[,]" a contrast to the "characteristic creativity and *ad hoc* nature of the common law").

<sup>80</sup> *Id.* § 868 ("A person who wantonly mistreats the body of a dead person or who without privilege intentionally removes, withholds or operates upon the dead body is liable to the member of the family of such person who is entitled to the disposition of the body."). The *Restatement* commentary explained that "[t]he cause of action is primarily for mental suffering caused by the improper dealing with the body [and] includes also the right to recover damages for physical harm resulting from such mental suffering." *Id.* § 868 cmt. b; *see supra* text accompanying notes 35–37.

<sup>81</sup> RESTATEMENT OF TORTS § 867 (AM. LAW INST. 1939) ("A person who unreasonably and seriously interferes with another's interest in not having his affairs known to others or his likeness exhibited to the public is liable to the other."). Comment b to this section explained that the claim "has not been recognized until recently, not only because it normally involves nothing more than mental distress, but also because there is not a clear line of demarcation between what should and what should not be permitted." *Id.* § 867 cmt. b. Comment d elaborated on the nature and scope of the nascent privacy claim, focusing on its concern with offensive informational disclosures:

society provides comfort both through communal support by gatherings of friends and through respect for the privacy of the individual and his intimates." *Id.; see also* Rao, *Reconceiving Privacy, supra* note 68, at 1104 (distinguishing the "individual right of privacy—the right to be left alone, and the relational right of privacy—the right to connect with others"); Note, *The Relational Right of Privacy Theory—Recovery on the Basis of Conduct Directed at a Deceased or Living Relative, Friend or Associate*, 21 RUTGERS L. REV. 74, 74 (1966) (comprehensively analyzing early cases dealing with "what is called a 'relational right of privacy" and noting that use of the term "relational . . . perhaps heaps ambiguity upon ambiguity").

<sup>&</sup>lt;sup>79</sup> RESTATEMENT OF TORTS (AM. LAW INST. 1939).

as *personal* rights: the first limited to the "*member* of the family of such [deceased] person who is entitled to the disposition of the body,"<sup>82</sup> and the second limited to an individual whose "interest in not having his affairs known to others or his likeness exhibited to the public" is "unreasonably and seriously interfere[d] with."<sup>83</sup> At the same time, another section of the *Restatement of Torts* expressly foreclosed any claim for conduct, regardless of intention, that caused "only mental or emotional disturbance to another."<sup>84</sup>

[L]iability exists only if the defendant's conduct was such that he should have realized that it would be offensive to persons of ordinary sensibilities. It is only where the intrusion has gone beyond the limits of decency that liability accrues. These limits are exceeded where intimate details of the life of one who has never manifested a desire to have publicity are exposed to the public, or where photographs of a person in an embarrassing pose are surreptitiously taken and published. On the other hand, there is no invasion of a right of privacy in the description of the ordinary goings and comings of a person or of weddings, even though intended to be entirely private, or of other publications to which people do not ordinarily seriously object. In determining liability, the knowledge and motives of the defendant, the sex, station in life, previous habits of the plaintiff with reference to publicity, and other similar matters are considered. A distinction can be made in favor of news items and against advertising use. It is only when the defendant should know that the plaintiff would be justified in feeling seriously hurt by the conduct that a cause of action exists. If these conditions exist, however, the fact that the plaintiff suffered neither pecuniary loss nor physical harm is unimportant.

- Id. § 867 cmt. d.
  - <sup>82</sup> Id. § 868 (emphasis added).
  - <sup>83</sup> *Id.* § 867.
  - <sup>84</sup> *Id.* § 46.

The interest in mental and emotional tranquillity and, therefore, in freedom from mental and emotional disturbances is not, as a thing in itself, regarded as of sufficient importance to require others to refrain from conduct intended or recognizably likely to cause such a disturbance. *Conduct, either of act or omission, which is intended or likely to cause only mental or emotional distress is not tortious.* Therefore, it cannot subject the actor to liability no matter what its consequences.

Id. § 46 cmt. c (emphasis added).

William Prosser, selected in 1955 as the reporter for the *Restate-ment (Second) of Torts*,<sup>85</sup> was highly influential in formulating American common law privacy rights. In 1977, the four familiar variations on the right of privacy found their origins in the second *Restatement*,<sup>86</sup> which largely tracked the definitions Prosser had articulated in a 1960 law review article.<sup>87</sup> Prosser acknowledged that one of the four privacy tort variations, intrusion on seclusion, was essentially vindicating the same injury as a claim for intentional infliction of mental distress, which many courts had already recognized as a separate, limited basis for tort liability.<sup>88</sup>

But the *Restatement (Second) of Torts* expressly disclaimed any *relational* privacy interest. Section 652I, captioned "Personal Character of Right of Privacy," clarified that as a general rule, only the person then living whose privacy has been violated could maintain

<sup>87</sup> William L. Prosser, *Privacy*, 48 CALIF. L. REV. 383, 422–23 (1960) (outlining the "four distinct and only loosely related torts").

<sup>88</sup> See id. at 422 (citing William L. Prosser, *Insult and Outrage*, 44 CALIF. L. REV. 40, 52 (1956)); William L. Prosser, *Intentional Infliction of Mental Suffering: A New Tort*, 37 MICH. L. REV. 874, 884 (1939).

(1) One who by extreme and outrageous conduct intentionally or recklessly causes severe emotional distress to another is subject to liability for such emotional distress, and if bodily harm to the other results from it, for such bodily harm.

(2) Where such conduct is directed at a third person, the actor is subject to liability if he intentionally or recklessly causes severe emotional distress (a) to a member of such person's immediate family who is present at the time, whether or not such distress results in bodily harm, or (b) to any other person who is present at the time, if such distress results in bodily harm.

RESTATEMENT (SECOND) OF TORTS § 46 (AM. LAW INST. 1965).

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<sup>&</sup>lt;sup>85</sup> Laurence H. Eldredge, *In Memoriam: William Lloyd Prosser*, 23 HASTINGS L.J. xxxii, xxxv (1972).

<sup>&</sup>lt;sup>86</sup> RESTATEMENT (SECOND) OF TORTS §§ 652A–E (AM. LAW INST. 1977). They include (a) unreasonable intrusion on seclusion, (b) appropriation of another's name or likeness, (c) unreasonable publicity given to another's private life, or (d) publicity that unreasonably casts another in a false light. *Id.* § 652A. The *Restatement (Second) of Torts* continued to recognize a tort claim for interference with a dead body, but expanded it to include unintentional conduct, setting it apart from the four privacy torts. *See* RESTATEMENT (SECOND) OF TORTS § 868 (AM. LAW INST. 1977) ("One who intentionally, recklessly or negligently removes, withholds, mutilates or operates upon the body of a dead person or prevents its proper interment or cremation is subject to liability to a member of the family of the deceased who is entitled to the disposition of the body.").

a cause of action for invasion of privacy.<sup>89</sup> The only exception was misappropriation of a person's name or likeness, which could be vindicated by a decedent's surviving family members.<sup>90</sup>

### C. Judicial Recognition

The right to personal privacy is not confined... to the right to control information about oneself....Congress' use of the term "personal privacy" [in FOIA] permit[s] family members to assert their own privacy rights against public intrusions long deemed impermissible under the common law and in our cultural traditions.<sup>91</sup>

By the last third of the twentieth century, surviving family members increasingly sought civil remedies for perceived invasions of privacy that contemporary common law had treated as personal to the decedent.<sup>92</sup> In 1965, the United States Court of Appeals for the Seventh Circuit, interpreting Illinois law, considered whether the widow and son of Al Capone had a relational privacy interest sufficient to support a claim against television broadcasters and

The right protected by the action for invasion of privacy is a personal right, peculiar to the individual whose privacy is invaded. The cause of action is not assignable, and it cannot be maintained by other persons such as members of the individual's family, unless their own privacy is invaded along with his. The only exception to this rule involves the appropriation to the defendant's own use of another's name or likeness.

<sup>&</sup>lt;sup>89</sup> See, e.g., Fasching v. Kallinger, 510 A.2d 694, 702 (N.J. Super. Ct. App. Div. 1986) (citing with approval RESTATEMENT (SECOND) OF TORTS § 652I (AM. LAW INST. 1977)) (declining to recognize a cause of action by an immediate family member of a decedent for invasion of relational privacy for publicizing private information about decedent).

<sup>&</sup>lt;sup>90</sup> See RESTATEMENT (SECOND) OF TORTS § 652I (AM. LAW INST. 1977)) ("Except for the appropriation of one's name or likeness, an action for invasion of privacy can be maintained only by a living individual whose privacy is invaded."). Comment a elaborates:

*Id.* § 652I cmt. a (citing *id.* § 652C cmt. a).

<sup>&</sup>lt;sup>91</sup> Nat'l Archives & Records Admin. v. Favish, 541 U.S. 157, 165–67 (2004) (internal quotation marks omitted).

<sup>&</sup>lt;sup>92</sup> See generally Robert P. Kennedy, Note, *The Right to Privacy in the Name, Reputation and Personality of a Deceased Relative*, 40 NOTRE DAME LAW. 324, 324 (1965) (reviewing relevant case law).

producers for portraying their deceased relative.<sup>93</sup> The court rejected the claim, relying on an analogous Illinois precedent holding that the right of privacy did not support a surviving mother's claim to redress her mental anguish caused by the defendant's publicizing her son's murder when the publication did not relate specifically to the mother.<sup>94</sup>

In 1969, a federal court applying Ohio law rejected a class action asserted by surviving family members against a popular television production for defaming their recently deceased relative.<sup>95</sup> The litigation was filed after the program published the following account memorializing an elderly woman who had died just two weeks earlier: "Mrs. Katherine Young of Syracuse, New York, who died at 99 leaving 5 sons, 5 daughters, 67 grandchildren, 72 great-grandchildren, and 73 great-grandchildren, gets our First Annual Booby Prize in the Birth Control Sweepstakes."<sup>96</sup> In rejecting the claim, the court acknowledged that a few early cases had recognized "a so-called 'relational' right of privacy."<sup>97</sup> However, the court discounted those cases, summarily reasoning that most were "not recent, and their

<sup>&</sup>lt;sup>93</sup> Maritote v. Desilu Prods., Inc., 345 F.2d 418, 419 (7th Cir. 1965).

<sup>&</sup>lt;sup>94</sup> *Id.* (citing Bradley v. Cowles Magazines, Inc., 168 N.E.2d 64, 65, 66 (Ill. App. Ct. 1960)).

<sup>&</sup>lt;sup>95</sup> Young v. That Was the Week That Was, 312 F. Supp. 1337, 1337–38, 1343 (N.D. Ohio 1969) (granting summary judgment on the basis that surviving family members had no cause of action under Ohio law), *aff'd*, 423 F.2d 265 (6th Cir. 1970).

<sup>&</sup>lt;sup>96</sup> *Id.* at 1338.

<sup>97</sup> Id. at 1341 n.2. As examples of these "few cases," the court cited Smith v. Doss, 37 So. 2d 118, 121 (Ala. 1948); Fitzsimmons v. Olinger Mortuary Ass'n, 17 P.2d 535, 535 (Colo. 1932); Bazemore v. Savannah Hospital, 155 S.E. 194, 195 (Ga. 1930); Douglas v. Stokes, 149 S.W. 849, 850 (Ky. 1912); and Schuyler v. Curtis, 42 N.E. 22, 24 (N.Y. 1895). Young, 312 F. Supp. at 1341 n.2. All of these cases sought remedies for surviving family members whose decedents allegedly had been subjected to unwanted publicity. In some of these cases the plaintiffs prevailed. See, e.g., Fitzsimmons, 17 P.2d at 537 (holding that plaintiff widow stated a claim that mortician violated its contractual agreement that nothing would be done to outrage feelings of ordinary person or unnecessarily inflict humiliation and mental suffering); Bazemore, 155 S.E. at 194 (holding that parents stated a claim against hospital, photographer, and newspaper for unauthorized publication and distribution of photograph of their deceased child); Douglas, 149 S.W. at 850 (upholding jury verdict in lawsuit by parents of deceased Siamese twins against photographer).

authority, even in the states which decided them, is questionable."<sup>98</sup> On appeal, the Sixth Circuit affirmed, expressly rejecting the appellants' alternative argument that even if the decedent's personal privacy right had expired at death, the survivors should be able to sue for "invasion of their own privacy and the privacy of the descendants whom they undertake to represent by class action."<sup>99</sup> The court concluded that "no such right of action exists under the averments of the complaint in the present case."<sup>100</sup>

In 1975, the United States Supreme Court addressed the issue in the more typical context of a criminal investigation.<sup>101</sup> The plaintiff's seventeen-year-old daughter, a rape victim, had died as a result of the injuries she had sustained.<sup>102</sup> Her father sued a broadcaster, as authorized by a Georgia statute, for revealing the name of his daughter as the rape victim, claiming the disclosure had invaded his own right of privacy.<sup>103</sup> The Georgia Supreme Court upheld his claim.<sup>104</sup> But the United States Supreme Court reversed, reasoning that the broadcasting company's reporter was exercising his First and Fourteenth Amendment rights by publishing information that he had lawfully gathered from court records and proceedings open to the general public.<sup>105</sup>

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<sup>105</sup> Cox Broad. Corp., 420 U.S. at 496–97. "Appellee has not contended that the name was obtained [improperly] or that it was not on an official court document open to public inspection. Under these circumstances, the protection of freedom of the press... bars the State of Georgia from making appellants' broadcast the basis of civil liability." *Id.* The Court did not disclaim the father's privacy

<sup>&</sup>lt;sup>98</sup> *Young*, 312 F. Supp. 1341 n.2 (citing Waters v. Fleetwood, 91 S.E.2d 344, 346–48 (Ga. 1956)).

<sup>&</sup>lt;sup>99</sup> *Young*, 423 F.2d at 266.

<sup>&</sup>lt;sup>100</sup> *Id*.

<sup>&</sup>lt;sup>101</sup> Cox Broad. Corp. v. Cohn, 420 U.S. 469, 471 (1975).

 $<sup>^{102}</sup>$  Id.

 $<sup>^{103}</sup>$  Id. at 474 (noting that the original action was brought under GA. CODE ANN. § 26-9901 (1972)).

<sup>&</sup>lt;sup>104</sup> Cox Broad. Corp. v. Cohn, 200 S.E.2d 127, 131 (Ga. 1973) (acknowledging the "head-on collision between the tort of public disclosure and First Amendment rights of freedom of speech and press"), *rev'd*, 420 U.S. 469 (1975). As a state law claim, *Cox Broadcasting* did not involve a request under the federal FOIA statute for access to public records held by a federal agency. Instead, a father asserted a claim based on a Georgia statute that barred disclosure of a rape victim's identity, which the defendant broadcaster challenged as unconstitutional. *Id.* at 133–34.

A Florida appellate court in 1981 addressed a claim by surviving family members after an author had published a book including information about their deceased relative.<sup>106</sup> The family claimed a

interests protected by the Georgia statute, but implicitly reasoned that First Amendment considerations with respect to public records outweighed any privacy concerns of family survivors. *See id.* at 494–95.

[E]ven the prevailing law of invasion of privacy generally recognizes that the interests in privacy fade when the information involved already appears on the public record. The conclusion is compelling when viewed in terms of the First and Fourteenth Amendments and in light of the public interest in a vigorous press. The Georgia [statutory] cause of action for invasion of privacy through public disclosure of the name of a rape victim imposes sanctions on pure expression—the content of a publication—and not conduct or a combination of speech and nonspeech elements that might otherwise be open to regulation or prohibition. The publication of truthful information available on the public record contains none of the indicia of those limited categories of expression, such as 'fighting' words, which [are not entitled to First Amendment protection].

By placing the information in the public domain on official court records, the State must be presumed to have concluded that the public interest was thereby being served. Public records by their very nature are of interest to those concerned with the administration of government, and a public benefit is performed by the reporting of the true contents of the records by the media. The freedom of the press to publish that information appears to us to be of critical importance to our type of government in which the citizenry is the final judge of the proper conduct of public business. In preserving that form of government the First and Fourteenth Amendments command nothing less than that the States may not impose sanctions on the publication of truthful information contained in official court records open to public inspection.

*Id.* (citations omitted). In effect, the Court struck down as unconstitutional a state statute restricting disclosure of rape victims' identities, with the result that any state law limiting free access to public information risks a challenge based on the First and Fourteenth Amendment freedom of the press. *But cf.* Weaver v. Myers, 229 So. 3d 1118, 1141–42 (Fla. 2017) (4-3 opinion) (upholding analogous state privacy claim on behalf of decedent's estate grounded in Florida Constitution, which protects confidentiality of decedent's medical records).

<sup>106</sup> Loft v. Fuller, 408 So. 2d 619, 624 (Fla. Dist. Ct. App. 1981). *Loft* cited the Georgia Supreme Court decision in *Cohn* as one of several cases illustrating the rationale that "relatives of the deceased have their own privacy interest in

violation of the right of privacy under both Florida statutory and common law.<sup>107</sup> Although the court rejected the relatives' claim because they had not asserted "any independent violation of their own privacy rights," the court refused to reject all relational privacy claims out of hand.<sup>108</sup> As the court explained in dicta,

> We are wary of a blanket rule barring all relatives of a deceased from bringing a common law invasion of privacy action simply because the relatives were not directly involved in the publicity [pertaining to the decedent]. However, ... such relatives must shoulder a heavy burden in establishing a cause of action. When there are unusual circumstances, ... it may be that a defendant's conduct towards a decedent will be found to be sufficiently egregious to give rise to an independent cause of action in favor of members of decedent's immediate family.<sup>109</sup>

But in 1998, in *Reid v. Pierce County*, the Washington Supreme Court recognized a common law relational privacy interest in several decedents' immediate relatives, holding that they could assert claims against county officials for misappropriating photographs of the decedents' corpses and displaying them to third parties.<sup>110</sup> The photographs had been taken during forensic investigations or during

protecting their rights in the character and memory of the deceased[,] as well as the right to recover for their own humiliation and wounded feelings caused by the publication." Id. While noting that the Supreme Court had reversed Cohn "on other grounds," the Florida court did not address the potential conflict between its dicta and the First Amendment. Id.

<sup>&</sup>lt;sup>107</sup> Id. at 621 (citing FLA. STAT. § 540.08 (1977)). The claim did not assert a privacy right grounded in the Florida Constitution, which did not expressly grant a personal right of privacy until four years after the 1976 publication of the book that was the source of the family's privacy claims. See FLA. CONST. art. I, § 23 ("Right of Privacy.--Every natural person has the right to be let alone and free from governmental intrusion into the person's private life except [that] [t]his section shall not be construed to limit the public's right of access to public records and meetings as provided by law.").

<sup>&</sup>lt;sup>108</sup> *Loft*, 408 So. 2d at 624.

<sup>109</sup> Id.

<sup>110</sup> Reid v. Pierce Cty., 961 P.2d 333, 342 (Wash. 1998).

autopsies.<sup>111</sup> The court reasoned that if the defendants had *physically* interfered with the corpses, liability certainly would have attached under the state's precedents.<sup>112</sup> The court also cited a Washington statute declaring that autopsy reports were confidential and generally prohibiting their disclosure to third parties, with limited exceptions such as the decedent's personal representative, family members, and attending physician.<sup>113</sup> Rejecting as "counterintuitive" the county's argument that the relatives' claims were meritless "no matter how egregious the act,"<sup>114</sup> the court concluded that "immediate relatives of a decedent [that] is grounded in maintaining the dignity of the deceased."<sup>115</sup> The Washington Supreme Court's holding in *Reid* has been followed by appellate courts in Delaware and Tennessee as a matter of state common law.<sup>116</sup>

<sup>116</sup> See Lawson v. Meconi, 897 A.2d 740, 743, 747 (Del. 2006) (holding that state statutes barring public disclosure of autopsy report and other death-related information created privacy right on the part of decedent's widow) (citing DEL. CODE. ANN. tit. 29, §§ 4707(e), 4710(b), 4710(c)) (2003); Harris v. Horton, 341 S.W.3d 264, 272 (Tenn. Ct. App. 2009) ("Plaintiffs may have a protectable privacy interest in photographs of their deceased relative . . . consonant with prior Tennessee cases holding that the family of a decedent has a protectable interest in

<sup>&</sup>lt;sup>111</sup> *Id.* at 335. A concurring judge in a later California case addressing a similar issue narrowly characterized the right recognized in *Reid* and analogous cases as "a familial right of privacy *in autopsy photographs*." Catsouras v. Dep't of Cal. Highway Patrol, 104 Cal. Rptr. 3d 352, 391 (Ct. App. 2010) (Aronson, J., concurring) (emphasis added).

<sup>&</sup>lt;sup>112</sup> *Reid*, 961 P.2d at 339–40 (citing Gadbury v. Bleitz, 233 P. 299 (Wash. 1925); Wright v. Beardsley, 89 P. 172 (Wash. 1907)).

<sup>&</sup>lt;sup>113</sup> *Id.* at 341 (quoting WASH. REV. CODE § 68.50.105 (1987)).

<sup>&</sup>lt;sup>114</sup> *Id.* at 342.

<sup>&</sup>lt;sup>115</sup> *Id.* at 342–43. The court reasoned that the county's actions had been "sufficiently egregious to enable the families of the deceased to maintain their own action." *Id.* at 342. While the plaintiffs in *Reid* also asserted a claim for violation of the state constitutional right of privacy, the court declined to address that issue, reasoning "that Plaintiffs may obtain adequate relief under the common law and that such actions are better addressed under the common law invasion of privacy action." *Id.* at 343. Notably, however, the *Reid* court expressly approved the dicta in *Loft v. Fuller*, in which a Florida appellate court had declined to foreclose a relational right of privacy claim if "a defendant's conduct towards a decedent [is] sufficiently egregious to give rise to an independent cause of action in favor of members of decedent's immediate family." *Id.* at 342 (quoting with approval Loft v. Fuller, 408 So. 2d 619, 624 (Fla. Dist. Ct. App. 1981)).

The various state court decisions addressing "relational privacy" are difficult to harmonize, and, at least so far, not even the American Law Institute has attempted to do so. The *Restatement (Third) of Torts*, parts of which were published in final form in 2012, now expressly acknowledges a claim for *negligent* infliction of emotional

making certain that the decedent's remains are not disturbed or mutilated.") (citing with approval *Reid*, 961 P.2d at 335–36, 341, 342), *overruled on other grounds by* Rogers v. Louisville Land Co., 367 S.W.3d 196, 205 n.6 (Tenn. 2012).

In *Lawson*, the Delaware Supreme Court reversed the trial court's decision rejecting the widow's claim, reasoning as follows:

In providing the statutory protections that have been invoked by Mrs. Lawson, the General Assembly has recognized concepts that have been respected in almost all civilizations from time immemorial: "[f]amily members have a personal stake in honoring and mourning their dead and objecting to unwarranted public exploitation that, by intruding upon their own grief, tends to degrade the rites and respect they seek to accord to the deceased person who was once their own."

Lawson, 897 A.2d at 747–48 (quoting Nat'l Archives & Records Admin. v. Favish, 541 U.S. 157, 168 (2004)).

But other state courts have declined to follow Reid. E.g., Cannady v. St. Vincent Infirmary Med. Ctr., 423 S.W.3d 548, 553-54 (Ark. 2012) (rejecting mother's claim that decedent's right of privacy survived according to Arkansas's survival statute, but holding that decedent's tort of outrage claim did survive and that mother could assert a claim for outrage on her own behalf as a "relational wrong"). In Cannady, the defendant hospital's employees had pled guilty to felony violations of 42 U.S.C. § 1320(d)(6) (2006) (the federal Health Insurance Portability and Accountability Act ("HIPAA")), which prohibits obtaining or disclosing "individually identifiable health information." 423 S.W.3d at 549. The plaintiff's counsel apparently did not argue that the mother had a derivative privacy right against the hospital based on its employees' federal criminal convictions. See id. at 550–54. However, nearly all courts that have considered the issue have held that HIPAA does not authorize a private cause of action to enforce its privacy protections, even by a direct victim of the violation. E.g., Dodd v. Jones, 623 F.3d 563, 569 (8th Cir. 2010) ("HIPAA does not create a private right of action."); cf. Gonzaga Univ. v. Doe, 536 U.S. 273, 278, 290-91 (2002) (holding that Family Educational Rights and Privacy Act of 1974 creates no privacy rights that an aggrieved individual can enforce in a private cause of action).

On remand, the *Cannady* trial court denied the hospital's summary judgment motion on the mother's tort of outrage claim. Cannady v. St. Vincent Infirmary Med. Ctr., 537 S.W.3d 259, 262–63 (Ark. 2018). The hospital argued in part that "[the decedent's mother] was not present when the allegedly outrageous conduct occurred." *Id.* at 262. Although the trial court certified the issue for immediate appeal, the Arkansas Supreme Court demurred, holding that the interlocutory order was non-appealable. *Id.* at 266.

distress without regard to physical harm under two broad sets of circumstances.<sup>117</sup> First, a defendant may be liable for emotional harm as a result of actions that place the plaintiff "in danger of immediate bodily harm."<sup>118</sup> Second, a defendant may be liable for a plaintiff's emotional harm resulting from conduct "in the course of specified categories of activities, undertakings, or *relationships* in which negligent conduct is especially likely to cause serious emotional harm."<sup>119</sup> The relevant comments demonstrate that the second set of circumstances is broad enough in scope to cover the series of cases addressing negligent handling of corpses or negligent transmission of death-related information.<sup>120</sup>

But what of the relational right of privacy claim of the nature recognized by the Washington Supreme Court in *Reid v. Pierce County*?<sup>121</sup> Many other courts have rejected an asserted relational or familial right of privacy that survives the decedent, citing the *Restatement (Second) of Torts*, published in final form in 1977.<sup>122</sup> The

Historically, the rule stated in Subsection (b) originated in cases involving telegrams announcing death or illness or caring for or handling a corpse .... Even in the case of mishandling corpses, one of the classic categories for permitting recovery of negligently inflicted emotional harm, *courts have had to supervise and limit those relatives who can sue for emotional harm*.... Now the rule has been extended by many jurisdictions to cover other activities or undertakings."

*Id.* (emphasis added) (citations omitted); *cf. Cannady*, 423 S.W.3d at 553 (holding that decedent's mother had no survival claim for invasion of a "relational right of privacy" against hospital for its employees' unlawful access to photographs in decedent's medical records, but mother could pursue a tort of outrage claim on her own behalf as a "relational wrong").

<sup>121</sup> See supra notes 110–16 and accompanying text.

<sup>122</sup> See RESTATEMENT (SECOND) OF TORTS § 652I (AM. LAW INST. 1977) ("Except for the appropriation of one's name or likeness, an action for invasion of privacy can be maintained only by a living individual whose privacy is invaded."); *e.g.*, Boyd v. Thomson Newspaper Publ'g Co., 6 Media L. Rep. (BNA) 1020, 1023 (W.D. Ark. 1980) (predicting that Arkansas courts would reject a claim grounded in a relational privacy interest); *Cannady*, 423 S.W.3d at 552–53 (rejecting claim that mother had a relational right of privacy that survived

<sup>&</sup>lt;sup>117</sup> RESTATEMENT (THIRD) OF TORTS: PHYSICAL AND EMOTIONAL HARM § 47 (AM. LAW INST. 2012).

<sup>&</sup>lt;sup>118</sup> *Id.* § 47(a).

<sup>&</sup>lt;sup>119</sup> *Id.* § 47(b) (emphasis added).

<sup>&</sup>lt;sup>120</sup> *Id.* cmt. f.

*Restatement (Third) of Torts*, now underway, has yet to address the issue.<sup>123</sup> Moreover, the four aspects of the right of privacy recognized by the *Restatement (Second) of Torts* all purport to limit the tortious cause of action to *intentional* invasions of privacy.<sup>124</sup> The question remains whether a court would recognize a common law claim for negligent or reckless invasion of privacy, akin to the one the *Restatement (Third) of Torts* recognizes for infliction of emotional distress with various degrees of culpability.<sup>125</sup>

In January 2019, the ALI approved development of the next part of the *Restatement (Third) of Torts*, which will address both defamation and privacy claims.<sup>126</sup> The next iteration is likely to address significant issues, perhaps including the scope of relational privacy

As this Article went to press, the ALI website describes the forthcoming installment of the *Restatement (Third) of Torts*, on "Defamation and Privacy," as "address[ing] torts dealing with personal and business reputation and dignity, including defamation, business disparagement, and *rights of privacy*. Among other issues, the updates will cover the substantial body of new issues relating to the internet." *Restatement of the Law Third, Torts, supra* (emphasis added).

<sup>124</sup> See Restatement (Second) of Torts § 652A(2) (Am. Law Inst. 1977).

<sup>125</sup> See supra note 38 and accompanying text.

<sup>126</sup> Restatement of the Law Third, Torts, supra note 123. Currently underway is the Restatement (Third) of Torts: Intentional Torts to Persons, but that component reportedly does not address privacy rights. See Kenneth W. Simons & W. Jonathan Cardi, Restating the Intentional Torts to Persons: Seeing the Forest and the Trees, 10 J. TORT L. 1, 15 (2018) (acknowledging that the intentional torts of defamation and invasion of privacy are not addressed in Restatement (Third) of Torts: Intentional Torts to Persons).

decedent) (citing RESTATEMENT (SECOND) OF TORTS § 652I). *But cf. In re* Estate of Reynolds, 327 P.3d 213, 218 (Ariz. Ct. App. 2014) (citing ARIZ. REV. STAT. ANN. § 14-3110 (2014)) (holding that a surviving daughter's Mother's Day tribute to her deceased parent did not violate decedent's right of publicity, which had survived her death notwithstanding Arizona survival statute that expressly excluded privacy claims).

<sup>&</sup>lt;sup>123</sup> As of this writing, the American Law Institute ("ALI") has either issued or embarked upon four subcomponents of the *Restatement (Third) of Torts* that supersede relevant parts of the *Restatement (Second) of Torts*: Products Liability, Apportionment of Liability, Liability for Physical and Emotional Harm, and Liability for Economic Harm. *See Restatement of the Law Third, Torts: Defamation and Privacy*, AM. LAW INST., https://www.ali.org/projects/show/torts-defamation-and-privacy/#\_status (last visited Feb. 24, 2020) [hereinafter *Restatement of the Law Third, Torts*]. Other Restatements address aspects of the right of privacy in particular settings, such as employment. *E.g.*, RESTATEMENT OF EMPLOYMENT LAW ch. 7 (AM. LAW INST., Tentative Draft No. 5, 2012) (addressing "Employee Privacy and Autonomy").

interests. But most likely the next installment will not be soon in coming.<sup>127</sup> Time will tell, but in the meantime, courts will continue to struggle with relational aspects of privacy interests in a rapidly advancing technological age.<sup>128</sup>

## III. FEDERAL FREEDOM OF INFORMATION ACT AND FEDERAL PRIVACY ACT PROTECTION OF "PERSONAL" PRIVACY

The federal Freedom of Information Act ("FOIA"),<sup>129</sup> and many comparable state open records acts,<sup>130</sup> indirectly recognize "personal privacy" interests with respect to otherwise "public" records<sup>131</sup> but do not articulate the source, nature, or scope of those privacy

<sup>&</sup>lt;sup>127</sup> See Project Life Cycle, AM LAW INSTI., https://www.ali.org/projects/project-life-cycle/ (last visited Feb. 24, 2020) (outlining the many steps of the process from project announcement to project completion).

<sup>&</sup>lt;sup>128</sup> See, e.g., Peterson v. Moldofsky, No. 07-2603-EFM, 2009 WL 3126229, at \*1–2 (D. Kan. Sept. 29, 2009) (acknowledging a mother's claim for intentional infliction of emotional distress against her daughter's former paramour, who had emailed sexually explicit photos of the daughter to her mother and other family members). The court found little precedent or persuasive secondary authority for this "revenge porn" issue. See id. at \*4 ("Today, unlike 1977, the year that the American Law Institute officially adopted the Restatement (Second), due to the advent of the Internet, 'the barriers of creating publicity are slight.' Consequently . . . the Restatement offers little to no assistance to the Court in its effort to resolve the present matter.") See generally Eric Goldman & Angie Jin, Judicial Resolution of Nonconsensual Pornography Dissemination Cases, 14 I/S: J.L. & POL'Y INFO. SOC'Y 283, 292–93 (2018); Elizabeth Williams, Cause of Action for Internet Posting of "Revenge Porn", 72 CAUSES OF ACTION 2D 537 (2016) (discussing the causes of action through which a victim of "revenge pornography" may obtain civil redress).

<sup>&</sup>lt;sup>129</sup> 5 U.S.C. § 552 (2018).

<sup>&</sup>lt;sup>130</sup> E.g., ARK. CODE. ANN. §§ 25-19-101 to -111 (2019); KAN. STAT. ANN. §§ 45-215 to -223 (2019). While state open-records acts and the federal FOIA serve similar public policy goals, state and federal acts reflect "stark differences in scope and utility." Christopher P. Beall, Note, *The Exaltation of Privacy Doctrines over Public Information Law*, 45 DUKE L.J. 1249, 1251 (1996).

<sup>&</sup>lt;sup>131</sup> Just what constitutes "public" information is a conundrum in its own right. *See* Woodrow Hartzog, *The Public Information Fallacy*, 99 B.U. L. REV. 459, 465 (2019) ("[N]obody knows what 'public' means, because it has no set definition in law or policy.").

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interests.<sup>132</sup> In general, FOIA statutes provide that all "agency records" maintained by executive branch agencies must be disclosed upon request—subject to certain restrictions and express exemptions.<sup>133</sup> The exemptions are many, but two of them are particularly relevant to personal privacy.<sup>134</sup>

<sup>133</sup> The courts have acknowledged that FOIA's "remedial purpose was to pierce the veil of administrative secrecy and to open agency action to the light of public scrutiny." Rose v. Dep't of Air Force, 495 F.2d 261, 263 (2d Cir. 1974), aff'd, 425 U.S. 352 (1976); see also Alirez v. N.L.R.B., 676 F.2d 423, 425 (10th Cir. 1982) (emphasis added) (citations omitted) (noting that FOIA's "basic policy" favors disclosure and, accordingly, the Act "is to be broadly construed in favor of disclosure . . . and, unless requested material in the possession of a federal agency falls within one of the statutory exemptions structured to protect *spec*ified confidentiality and privacy interests, it must be made available on demand to any member of the general public .... These statutory exemptions are to be narrowly construed with all doubts resolved in favor of disclosure ...."); Lauren Bemis, Balancing a Citizen's Right to Know with the Privacy of an Innocent Family: The Expansion of the Scope of Exemption 7(C) of The Freedom of Information Act Under National Archives & Records Administration v. Favish, 25 J. NAT'L ASS'N ADMIN. L. JUDGES 507, 508 (2005) (noting that FOIA was designed as "a full-disclosure statute"). FOIA places the burden on the agency "to show that certain pieces of information should not be released," expressly limiting the circumstances under which an agency is authorized to withhold information. Id. Those circumstances include when "the agency reasonably foresees that disclosure would harm an interest protected by an exemption described in subsection (b)." 5 U.S.C. § 552(a)(8)(A)(i)(I).

<sup>134</sup> 5 U.S.C. § 552(b)(6) ("personnel and medical files and similar files the disclosure of which *would constitute a clearly unwarranted invasion of personal privacy*") (emphasis added); *id.* § 552(b)(7) ("records or information compiled for law enforcement purposes, but only to the extent that the production of such law enforcement records or information . . . (C) *could reasonably be expected to constitute an unwarranted invasion of personal privacy*") (emphasis added). While both exemptions purport to protect "personal privacy") (emphasis added). While both exemptions purport to protect "personal privacy," the Supreme Court has carefully distinguished the language of the two exemptions, interpreting Exemption 7(C) to provide considerably more agency discretion to withhold sensitive information that could infringe on personal privacy interests. *See, e.g., Favish*, 541 U.S. at 165–66; News-Press v. U.S. Dep't of Homeland Sec., 489 F.3d 1173, 1198 (11th Cir. 2007) (noting that while amendments to Exemption 7(C) eased

<sup>&</sup>lt;sup>132</sup> See, e.g., Michael Hoefges et al., Privacy Rights Versus FOIA Disclosure Policy: The "Uses and Effects" Double Standard in Access to Personally-Identifiable Information in Government Records, 12 WM. & MARY BILL RTS. J. 1, 3 (2003) (observing that FOIA's privacy exemptions appear "to place the public interest in full public disclosure of government-held information in an adversarial relationship with the individual privacy interest in nondisclosure").

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The first exception pertains to "personnel and medical files and similar files the disclosure of which would constitute a *clearly unwarranted* invasion of personal privacy."<sup>135</sup> The second pertains to "records or information compiled for law enforcement purposes," which an agency may withhold from disclosure "only to the extent

the burden on a federal law enforcement agency to justify withholding a record from disclosure on that basis, "Congress . . . steadfastly refused to yield as to Exemption 6" for personnel, medical, and similar records that would lead to a "clearly unwarranted invasion of personal privacy").

<sup>&</sup>lt;sup>135</sup> 5 U.S.C. § 552(b)(6) (emphasis added); *see, e.g.*, Bibles v. Oregon Nat. Desert Ass'n, 519 U.S. 355, 355–56 (1997) (per curiam) (reversing Ninth Circuit's holding that 5 U.S.C. § 552(b)(6) did not justify the Bureau of Land Management ("BLM") decision to withhold its mailing list from respondent environmental association, which had asserted "a perceived public interest in 'providing [persons on the BLM's mailing list] with additional information") (alteration in original). The Court observed that while the asserted reasons for requesting disclosure of public information are irrelevant, "the *only* relevant public interest in the FOIA balancing analysis is the extent to which disclosure of the information sought would shed light on an agency's performance of its statutory duties or otherwise let citizens know what their government is up to." *Id.* at 355–56 (internal quotation marks and alterations omitted) (emphasis in original). Releasing the mailing list to an environmental advocacy group, the Court reasoned, would not advance the public policy goals underlying FOIA. *Id.* 

The Ninth Circuit directed the trial court on remand to dismiss the association's FOIA claim seeking the agency's mailing list, presumably on the basis that its disclosure would impose a clearly unwarranted invasion of personal privacy under 5 U.S.C. § 552(b)(6). Oregon Nat. Desert Ass'n v. Bibles, 125 F.3d 1282, 1282 (9th Cir. 1997). Such a finding strains credulity, given the limited "personal" information contained in the mailing list. *See* Oregon Nat. Desert Ass'n v. Bibles, 83 F.3d 1168, 1169 (9th Cir. 1996) (noting that the claim sought "the names and addresses of persons who receive the BLM's newsletter [that] provide[d] information about the BLM's activities and plans affecting the Oregon desert"), *rev'd*, 519 U.S. 355 (1997).

The Supreme Court's reasoning in *Bibles* rested on a *narrow* interpretation of FOIA's disclosure mandate by confining it to its purported policy rationale favoring government transparency, while at the same time *broadly* interpreting the exemption under § 552(b)(6) authorizing BLM to withhold the mailing list. *See Bibles*, 519 U.S. at 355–56. The Court's interpretation thus directly conflicted with the longstanding practice of narrowly construing FOIA's "limited exemptions" in favor of disclosure, consistent with the statute's "dominant objective." *E.g.*, John Doe Agency v. John Doe Corp., 493 U.S. 146, 152 (1989) (citations omitted).

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that the production . . . *could reasonably be expected to constitute an unwarranted* invasion of personal privacy."<sup>136</sup>

Does this federal statutory disclosure mandate that yields to perceived "personal privacy" interests refer to the federal *constitutional* right of privacy? Or do the FOIA exemptions instead recognize a federal *statutory* right of privacy by negative implication? Or does the statutory term "invasion of personal privacy" refer to privacy rights protected by *state law*, whether constitutional, statutory, or common law?<sup>137</sup> If the latter, how is a federal agency—or a federal

To the extent required to prevent a *clearly unwarranted invasion of personal privacy*, an agency may delete identifying details when it makes available or publishes an opinion, statement of policy, interpretation, staff manual, instruction, or copies of records referred to in subparagraph (D) [with certain records to be made available for public inspection in electronic format]. However, in each case the justification for the deletion shall be explained fully in writing, and the extent of such deletion shall be indicated on the portion of the record which is made available or published, unless including that indication would harm an interest protected by the exemption in subsection (b) under which the deletion is made. If technically feasible, the extent of the deletion shall be indicated at the place in the record where the deletion was made.

5 U.S.C. § 552(a)(2)(E) (emphasis added).

<sup>137</sup> Several states have incorporated privacy rights into their respective state constitutions. *E.g.*, CAL. CONST. art. I, § 1 ("All people are by nature free and independent and have inalienable rights. Among these are enjoying and defending life and liberty, acquiring, possessing, and protecting property, and pursuing and obtaining safety, happiness, and privacy."); FLA. CONST. art. I, § 23 ("Every natural person has the right to be let alone and free from governmental intrusion into the person's private life except as otherwise provided herein. This section shall not be construed to limit the public's right of access to public records and meetings as provided by law."); LA. CONST. art. I, § 5 ("Every person shall be secure in his person, property, communications, houses, papers, and effects against unreasonable searches, seizures, *or invasions of privacy.*") (emphasis added); WASH. CONST. art. I, § 7 ("No person shall be disturbed in his private affairs, or his home invaded, without authority of law."); *see also* Am. Acad. of Pediatrics

<sup>&</sup>lt;sup>136</sup> 5 U.S.C. § 552(b)(7)(C) (emphasis added); *see, e.g.*, U.S. Dep't of Justice v. Reporters Comm. for Freedom of Press, 489 U.S. 749, 771 (1989) (reaffirming that "whether an invasion of privacy is *warranted* cannot turn on the purposes for which the request for information is made"). Similar to the language in § 552(b)(7)(C), the otherwise mandatory disclosure subsections of FOIA generally provide the following:

reviewing court—to determine which state's substantive privacy law applies? These questions have no clear answers, and courts appear to take a multitude of different approaches in interpreting the scope of the FOIA "personal privacy" exemptions.<sup>138</sup>

Moreover, some significant federal precedents suggest that one or perhaps both of FOIA's "personal privacy" exemptions from disclosure incorporate an expansive "relational" perspective on privacy—in contrast to state common law privacy rights, which are generally thought to protect only *individual* privacy.<sup>139</sup> This Part considers those perplexing and confounding issues.

#### A. Personnel, Medical, and Similar Records: Exemption 6

In 1996, in a closely divided *en banc* opinion, the Federal Court of Appeals for the District of Columbia Circuit addressed whether a federal agency had acted properly when it withheld an audiotape recording of the astronauts' voices during the tragic launch of the Challenger space shuttle from the press.<sup>140</sup> The applicable federal FOIA exemption pertained to "personnel and medical files and similar files the disclosure of which would constitute a clearly unwarranted invasion of personal privacy."<sup>141</sup> The lower court had held

v. Lungren, 940 P.2d 797, 808 (Cal. 1997) ("[I]n many contexts, the scope and application of the state constitutional right of privacy is broader and more protective of privacy than the federal constitutional right of privacy as interpreted by the federal courts."). *See generally* Jeffrey M. Shaman, *The Right of Privacy in State Constitutional Law*, 37 RUTGERS L.J. 971, 988 (2006) ("State constitutional conceptions of privacy independent of the federal model began to emerge at a relatively early date."); *Privacy Protections in State Constitutions*, NAT'L CONFERENCE OF STATE LEGISLATURES (Nov. 7, 2018), http://www.ncsl.org/research/telecommunications-and-information-technology/ privacy-protections-in-state-constitutions.aspx.

<sup>&</sup>lt;sup>138</sup> *Compare*, *e.g.*, N.Y. Times Co. v. NASA, 920 F.2d 1002, 1004–10 (D.C. Cir. 1990), *with*, *e.g.*, McCambridge v. City of Little Rock, 766 S.W.2d 909, 913–16 (Ark. 1989).

<sup>&</sup>lt;sup>139</sup> But cf. McCambridge, 766 S.W.2d at 915 (recognizing that City's intended disclosure of criminal investigation photos and documents, including personal letters relating to son's murder-suicide, implicated his mother's asserted federal constitutional privacy right against disclosure; but mother's informational privacy interests, while "very high," were outweighed by government's "highly valued governmental interest" in disclosure under Arkansas FOIA).

<sup>&</sup>lt;sup>140</sup> N.Y. Times Co. v. NASA, 920 F.2d 1002, 1003–04 (D.C. Cir. 1990) (6-5 opinion on rehearing *en banc*).

<sup>&</sup>lt;sup>141</sup> 5 U.S.C. § 552(b)(6); *see supra* note 135 and accompanying text.

that disclosure was mandatory because the audio recording did not qualify as a personnel, medical, or similar file to which the exemption expressly applied.<sup>142</sup>

The disputed recording had captured the last remarks by the seven ill-fated astronauts just before the Challenger space shuttle exploded with all of them aboard.<sup>143</sup> The National Aeronautics and Space Administration ("NASA") claimed that giving the press a copy of the audiotape would subject the astronauts' surviving family members "to hearing the voices of their loved ones, an intrusion on their grief which would certainly exacerbate feelings of hurt and loss."<sup>144</sup> NASA responded to the FOIA request by supplying a transcribed readout of the tape, but the *New York Times* wanted a copy of the audio recording itself.<sup>145</sup>

A slim majority of the en banc court of appeals held that the audio recording met the threshold test of the FOIA exemption. The court reasoned that the recording *pertained* to particular persons, and therefore NASA had the statutory authority to withhold it from disclosure, even if the astronauts *personally* were not the subjects of the recording.<sup>146</sup> The majority directed the trial court to give NASA an opportunity on remand to establish that releasing the recording would indeed invade the privacy of either the decedents themselves or their surviving families.<sup>147</sup> The majority rejected the dissenters' argument that, to avoid the FOIA disclosure mandate, NASA needed to establish that the recording included personal information about the surviving family members, who argued that disclosure would implicate their own personal privacy interests.<sup>148</sup> The dissenters, reasoning that the subject of the recording was the safety of the Challenger space shuttle, not the personal lives of the ill-fated astronauts, concluded that NASA's rationale for withholding it from the

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<sup>&</sup>lt;sup>142</sup> *N.Y. Times Co.*, 920 F.2d at 1003. The district court therefore did not initially address whether the recording's disclosure would have amounted to a "clearly unwarranted invasion of privacy." *Id.* at 1004.

<sup>&</sup>lt;sup>143</sup> *Id.* at 1004.

 $<sup>^{144}</sup>$  *Id*.

<sup>&</sup>lt;sup>145</sup> *Id.* 

<sup>&</sup>lt;sup>146</sup> *Id.* at 1009–10.

<sup>&</sup>lt;sup>147</sup> *Id*.

<sup>&</sup>lt;sup>148</sup> *Id.* at 1007–09.

press did not satisfy the precondition for invoking the FOIA exemption.<sup>149</sup>

On remand, NASA persuaded the district court that the surviving family members' "personal privacy" interests outweighed the public interest in disclosing the audio recording, which would amount to a clearly unwarranted invasion of the family members' privacy.<sup>150</sup> In reaching that conclusion, the district court expressly acknowledged that the Supreme Court had narrowly interpreted the public interest in disclosure of government records protected by FOIA's mandate.<sup>151</sup>

#### B. *Criminal Investigation Records: Exemption* 7(*C*)

The most significant case that expansively interpreted the federal FOIA disclosure exemption for criminal investigation records<sup>152</sup> was the 2004 Supreme Court decision in *National Archives* & *Records Administration v. Favish.*<sup>153</sup> Allan J. Favish, a California lawyer, filed a federal FOIA request with the National Archives seeking photographs of the corpse of Vince Foster, who had died in 1993 as an apparent victim of a self-inflicted gunshot wound during his tenure as President Clinton's Deputy White House Counsel.<sup>154</sup>

<sup>&</sup>lt;sup>149</sup> See id. The majority and dissenting opinions of the D.C. Circuit on rehearing *en banc* reflect the controversy inherent in the language Congress used in drafting the FOIA privacy exemptions: Do they purport to protect *individual* "personal privacy," consistent with the traditional understanding of personal privacy rights? Or do they reasonably extend to "personal privacy" interests of the individual subject's *family members? See id.* at 1006 (reasoning that the threshold for invoking Exemption 6 "was set at a low level"); *see also id.* at 1010–11 (Edwards, J., dissenting) ("The majority now holds that if an identifiable individual is somehow connected with a Government file, that file automatically becomes a 'similar file' under Exemption 6. That is not what the statute says.").

<sup>&</sup>lt;sup>150</sup> N.Y. Times Co. v. NASA, 782 F. Supp. 628, 633 (D.D.C. 1991).

<sup>&</sup>lt;sup>151</sup> *Id.* at 632 (citing U.S. Dep't of Justice v. Reporters Comm. for Freedom of Press, 489 U.S. 749, 773 (1989)).

<sup>&</sup>lt;sup>152</sup> 5 U.S.C. § 552(b)(7)(C) (2018).

<sup>&</sup>lt;sup>153</sup> 541 U.S. 157 (2004). The Court's decision cited with approval the district court's opinion on remand in *New York Times Co. v. NASA*, in particular its focus on the privacy interests of the astronauts' surviving family members. *Id.* at 170–71.

<sup>&</sup>lt;sup>154</sup> See id. at 161. See generally KENNETH W. STARR, REPORT ON THE DEATH OF VINCENT W. FOSTER, JR., BY THE OFFICE OF INDEPENDENT COUNSEL IN RE: MADISON GUARANTY SAVINGS & LOAN ASSOCIATION 1–28 (1997),

The relevant federal agencies had denied the FOIA request, asserting that releasing the death scene photographs would amount to an "unwarranted invasion of personal privacy."<sup>155</sup> Although the decedent's own "personal privacy" was certainly not at stake, Vince Foster's surviving family members intervened, objecting to the photographs' release.<sup>156</sup>

The Court held that the statutory exemption relating to unwarranted invasions of "personal" privacy for disclosure of criminal investigation records was broad enough to extend to Foster's surviving family members because they had objected to releasing photographs showing the condition of Foster's body at the scene of his death.<sup>157</sup> The Court reasoned,

> [W]e think it proper to conclude from Congress' use of the term "personal privacy" that it intended to permit family members to assert their own privacy rights against public intrusions long deemed impermissible under the common law and in our cultural traditions. This does not mean that the family is in the same position as the individual who is the subject of the disclosure. We have little difficulty, however, in finding in our case law and traditions the right of family members to direct and control disposition of the body of the deceased and to limit attempts to exploit pictures of the deceased family member's remains for public purposes .... Family members have a personal stake in honoring and mourning their dead and objecting to unwarranted public exploitation that, by intruding upon their own grief, tends to degrade the

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https://digitalcommons.law.ggu.edu/cgi/viewcontent.cgi?article=1007&context=federal documents.

See id. at 160 (quoting 5 U.S.C. § 552(b)(7)(C) (2000) and explaining that it "excuses from disclosure 'records or information compiled for law enforcement purposes' if their production 'could reasonably be expected to constitute an unwarranted invasion of personal privacy").

<sup>&</sup>lt;sup>156</sup> *See id.* at 167.

<sup>157</sup> Id. at 165.

rites and respect they seek to accord to the deceased person who was once their own.<sup>158</sup>

The Court reiterated that the privacy right attributed to Foster's family members was a *statutory* right by implication, foreclosing any inference that it rested on a constitutionally protected privacy right.<sup>159</sup>

We have observed that the statutory privacy right protected by [FOIA] Exemption 7(C) goes beyond the common law and the Constitution . . . . It would be anomalous to hold in the instant case that the statute provides even less protection [for personal privacy] than does the common law.<sup>160</sup>

<sup>160</sup> *Id.* at 170 (emphasis added) (citations omitted); *see also* Marzen v. Dep't of Health & Human Servs., 825 F.2d 1148, 1152 (7th Cir. 1987) (observing that "the privacy interest protected under FOIA extends beyond the common law").

What is unclear, however, is just what the federal courts mean by the "common law" privacy interest beyond which the FOIA exemptions purportedly reach. Of course, the federal courts have no power to create federal common law. Erie R.R. Co. v. Tompkins, 304 U.S. 64, 78 (1938) ("There is no federal general common law."). And until a century ago, most states did not recognize a "common law" right of privacy. 1 J. THOMAS MCCARTHY, THE RIGHTS OF PUBLICITY AND PRIVACY 836–37 (2d ed. 2010) (explaining that the "rights of privacy and publicity were unknown to the early common law of England or the United States" and that Georgia in 1905 was the first state to judicially recognize the right of privacy). Even fewer recognized a state constitutional right of privacy until the latter part of the twentieth century. *See* Ken Gormley, *One Hundred* 

<sup>&</sup>lt;sup>158</sup> *Id.* at 167–68 (emphasis added).

<sup>&</sup>lt;sup>159</sup> See id. at 170 (citing U.S. Dep't of Justice v. Reporters Comm. for Freedom of Press, 489 U.S. 749, 762 n.13 (1989)). In *Reporters Committee*, however, the Court had *distinguished* the scope of FOIA's "personal privacy" protections from those protected by state common law and the Constitution, suggesting that the FOIA statutory privacy protections are significantly narrower. *See Reporters Comm. for Freedom of Press*, 489 U.S. at 763 (referring to "the individual's control of information concerning his or her person"). In the footnote cited in *Favish*, the *Reporters Committee* majority observed that "[t]he question of the statutory meaning of privacy under the FOIA is, of course, *not the same* as the question whether a [common law] tort action might lie for invasion of privacy or the question whether an individual's interest in privacy is protected by the Constitution." *Id.* at 762 n.13 (emphasis added).

*Years of Privacy*, 1992 WIS. L. REV. 1335, 1423 (1992) ("Few of the states recognized anything approaching an identifiable right of privacy under their own constitutions during the first two centuries of this nation's history."). *But cf.* Griswold v. Connecticut, 381 U.S. 479, 486 (1965) (recognizing a constitutional right to marital privacy, "a right of privacy older than the Bill of Rights—older than our political parties, older than our school system").

The Court has declared that FOIA's several express exemptions from compelled agency disclosure were "plainly intended to set up concrete, workable standards for determining whether particular material may be withheld or must be disclosed." Envtl. Prot. Agency v. Mink, 410 U.S. 73, 79 (1973). However, in the years since FOIA's first enactment in 1966, the Supreme Court has been characteristically nebulous in mapping the boundaries of FOIA's informational "right of privacy," articulating its legal foundations, and explaining how it applies. See, e.g., FCC v. AT&T Inc., 562 U.S. 397, 408-10 (2011) (holding that federal courts have interpreted FOIA's "personal privacy" exemptions to apply to an "individual's right of privacy"; thus, FOIA's personal privacy protection "against disclosure of law enforcement information . . . does not extend to corporations") (emphasis added) (citations omitted); *Reporters Comm.*, 489 U.S. at 777–79, 779 n.22 (holding that balancing private and public interests to determine whether to disclose criminal investigation records does not require an "ad hoc," individualized approach; rather, a categorical approach employing "discrete categor[ies] of exempt information" represents a "workable" rule that advances FOIA policy favoring expedited disclosure) (citations omitted); U.S. Dep't of State v. Washington Post Co., 456 U.S. 595, 599, 602 (1982) ("House and Senate Reports . . . suggest that Congress' primary purpose . . . was to protect individuals from the injury and embarrassment that can result from the unnecessary disclosure of personal information .... When disclosure of information which applies to a *particular indi*vidual is sought from Government records, courts must determine whether release of the information would constitute a clearly unwarranted invasion of that person's privacy.") (emphasis added); id. at 602 n.5 (explaining that (1) information exempted from mandatory disclosure in "similar files" is not "limited to [that] containing intimate details about individuals such as might also be contained in personnel or medical files," and (2) scope of exemption may extend to information contained in public records if disclosure could result in a "clearly unwarranted invasion of personal privacy"); Dep't of Air Force v. Rose, 425 U.S. 352, 372 (1976) ("Congress sought to construct an exemption [for personnel and medical records] that would require a balancing of the individual's right of privacy against the preservation of the basic purpose of the Freedom of Information Act 'to open agency action to the light of public scrutiny.' The device adopted to achieve that balance was the limited exemption, where privacy was threatened, for 'clearly unwarranted' invasions of personal privacy.") (emphasis added). But see Nat'l Archives & Records Admin. v. Favish, 541 U.S. 157, 167 (2004) (interpreting "personal privacy" in exemption for criminal investigation records to include privacy rights of family members "against public intrusions long deemed impermissible under the common law and in our cultural traditions," but sidestepping whether

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Thus, the so-called "right" of Vince Foster's immediate family members that the Court presumably recognized and enforced in *Favish* was expressly grounded solely in FOIA's disclosure exemption for information in criminal investigation records that, if released, could amount to an "unwarranted invasion of personal privacy."<sup>161</sup> While the Court disclaimed reliance on the federal Constitution as the source of the relational right of privacy, the *statutory* right of privacy the Court attributed to Foster's surviving family members was interpreted as broader than, but at least coterminous with, the *common law* right of privacy.<sup>162</sup> The question *Favish* left open was the nature, scope, and relational reach of the surviving family's statutory privacy "right" that the Court extrapolated from the FOIA exemption for certain information in criminal investigation records.<sup>163</sup>

Finally, the *Favish* Court held that under the circumstances, the surviving family's statutory privacy interests outweighed the requester's asserted public interest in favor of securing access to the photographs.<sup>164</sup> Therefore, the Court upheld the federal agencies'

<sup>&</sup>quot;the family is in the same position as the individual who is the subject of the disclosure").

<sup>&</sup>lt;sup>161</sup> 5 U.S.C. § 552(b)(7)(C) (2000).

<sup>&</sup>lt;sup>162</sup> *Favish*, 541 U.S. at 170.

<sup>163</sup> See 5 U.S.C. § 552(b)(7)(C); see also Jeffrey R. Boles, Documenting Death: Public Access to Government Death Records and Attendant Privacy Concerns, 22 CORNELL J.L. & PUB. POL'Y 237, 271 (2012). For example, had the National Archives elected to disclose the photographs of Foster's corpse over the objection of his widow and sister, the statutory privacy protection the Court extrapolated by negative implication from § 552(b)(7)(C) would not support a private cause of action by the survivors against the federal government for infringing their relational right of privacy. See Favish, 541 U.S. at 166. While the Privacy Act authorizes a private claim to redress a violation of that Act, 5 U.S.C. § 552a(g)(1) (2018), FOIA does not. See infra note 185 and accompanying text. And under the Privacy Act, surely the surviving family members could not have reasonably argued that the photos of the decedent they sought to withhold included information pertaining to them, either individually or collectively. See 5 U.S.C. § 552a(g)(1) (allowing an individual to bring a claim, not an individual's family).

<sup>&</sup>lt;sup>164</sup> See Favish, 541 U.S. at 174–75.

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decision invoking the judicially expanded Exemption (7)(C) to avoid the judicially narrowed FOIA disclosure mandate.<sup>165</sup>

# C. Distinguishing the Judicially Implied FOIA Privacy "Right" from Agency Discretion to Prevent Unwarranted Invasions of "Personal Privacy"

Various state and federal courts considering the scope of state common law and statutory privacy rights have distinguished *Favish* on the rationale that the FOIA privacy exemptions recognize a *federal* statutory right of privacy.<sup>166</sup> However, courts have not been inclined to rely on *Favish* to expand the purported statutory "right" the Court articulated. For example, the Supreme Court in 2011 declined

<sup>&</sup>lt;sup>165</sup> See id. at 170; see also Martin E. Halstuk & Bill F. Chamberlin, *The Free*dom of Information Act 1966-2006: A Retrospective on the Rise of Privacy Protection over the Public Interest in Knowing What the Government's Up to, 11 COMM. L. & POL'Y 511, 514 (2006) ("In effect, the Court has tipped the scales significantly in favor of a broadly construed and vaguely framed right to privacy over the public's right of access to government-held information.").

E.g., Showler v. Harper's Magazine Found., 222 F. App'x 755, 761-62 (10th Cir.), cert. denied, 552 U.S. 825 (2007) (distinguishing Favish as "rel[ying] on a statutory privacy right under the FOIA, not a cause of action for invasion of privacy" in rejecting survivors' Oklahoma privacy claim alleging wrongful photographing of decedent's open casket and later publishing and selling photographs); Graham v. Ala. State Emps. Ass'n, 991 So. 2d 710, 720 (Ala. Civ. App. 2007) ("Favish ... was interpreting and applying only the statute before it-the FOIA—not some general privacy right recognized or created by the United States Constitution or by the common law .... In this case, we are dealing with [state] statutes that do not include the same language found in the FOIA."); Mercer v. S.D. Attorney Gen. Office, 864 N.W. 2d 299, 304 (S.D. 2015) (holding Favish inapplicable absent any state statutory language similar to FOIA exemption that might result in "unwarranted invasion of personal privacy"); Lawson v. Meconi, No. 1183-N, 2005 WL 5755653, at \*6 (Del. Ch. May 27, 2005) (addressing widow's claim to enjoin release of autopsy information concerning spouse's accidental death; explaining that cases interpreting federal FOIA exemptions were "not dispositive as to whether [decedent's] common law right of privacy survives death, especially since . . . the overwhelming weight of authority . . . holds that it does not"); cf. Blethen Me. Newspapers, Inc. v. State, 871 A.2d 523, 533 (Me. 2005) (distinguishing Favish on its facts because "records requested in this case involve allegations of abuse alleged to have occurred twenty to seventy years ago [by now-deceased priests]," so the case posed no risk of "unwarranted public exploitation of grieving family members that was central to the outcome in Favish ").

to hold that FOIA's "personal privacy" exemptions extend to corporations.<sup>167</sup>

And yet the Chief Justice, writing for a unanimous Court, emphasized the *individual* nature of "personal privacy" recognized by FOIA Exemption 6. *See* AT&T, 562 U.S. at 408 ("Although the question whether Exemption 6 is limited to individuals has not come to us directly, we have regularly referred to that exemption as involving an 'individual's right of privacy.") (citations omitted). But that reasoning expressly undercuts the Court's 2004 (pre-Roberts) holding in *Favish*, which expansively interpreted "personal privacy" in Exemption 7(C) to encompass a decedent's close relatives. *See Favish*, 541 U.S. at 170.

On the other hand, the AT&T majority opinion explained that "'[p]ersonal' in the phrase 'personal privacy' conveys more than just 'of a person.' It suggests a type of privacy *evocative of human concerns*—not the sort usually associated with an entity like . . . AT&T." AT&T, 562 U.S. at 406 (emphasis added). Chief Justice Roberts cited *Favish* with apparent approval, specifically its reliance on a 1974 Department of Justice [DOJ] Memorandum issued soon after Congress enacted § 552(b)(7)(C). AT&T, 562 U.S at 409. The Court referred to the 1974 DOJ Memorandum as a "reliable guide" to interpreting FOIA. *Id*. (noting that Congress later reprinted the memorandum in a 1975 joint committee print).

Because the DOJ Memorandum sheds light on the Court's interpretation of Exemption 7(C), the relevant section is reprinted below. Although the Court is increasingly reluctant to rely on legislative history (especially *subsequent* legislative history) to interpret federal statutes, in this case it probably best explains why the Court has generously interpreted agency discretion to withhold public records from disclosure out of respect for a decedent's surviving "relatives or descendants."

#### (C) INVASION OF PRIVACY

Clause (C) [of § 552(b)(7)] exempts law enforcement investigatory records to the extent that their production would "constitute an unwarranted invasion of personal privacy." The comparable provision in [a Senate] amendment referred to "clearly unwarranted" invasions, but "clearly" was deleted by the Conference Committee.

<sup>&</sup>lt;sup>167</sup> FCC v. AT&T Inc., 562 U.S. 397, 409–10 (2011) (holding that the "protection in FOIA against disclosure of law enforcement information on the ground that it would constitute an unwarranted invasion of personal privacy does not extend to corporations"). Chief Justice Roberts included a helpful summary of the legislative history of the two FOIA exemptions, which were both designed to protect "personal privacy." *Id.* at 407–09; *see also* Nat'l Day Laborer Org. Network v. U.S. Immigration & Customs Enf't Agency, 811 F. Supp. 2d 713, 737–38 (S.D.N.Y. 2011) (as amended on reconsideration).

Except for the omission of "clearly," the language of clause (C) is the same as that contained in the original Act for [Exemption 6], the exemption for personnel, medical and similar files. Thus, in determining the meaning of clause (C), it is appropriate to consider the body of court decisions regarding [Exemption 6]—bearing in mind, of course, that the deletion of "clearly" renders the Government's burden somewhat lighter under the new provisions. In applying clause (C), it will also be necessary to take account of the Privacy Act of 1974, Public Law 93-579, which takes effect in September 1975.

The phrase "personal privacy" pertains to the privacy interests of individuals. Unlike clause (B), clause (C) does not seem applicable to corporations or other entities. The individuals whose interests are protected by clause (C) clearly include the subject of the [criminal] investigation and "any [other] person mentioned in the requested file." In appropriate situations, clause (C) also protects relatives or descendants of such persons.

While neither the legislative history nor the terms of the Act and the 1974 Amendments comprehensively specify what information about an individual may be deemed to involve a privacy interest, cases under [Exemption 6] have recognized, for example, that a person's home address can qualify. It is thus clear that the privacy interest does not extend only to types of information that people generally do not make public. Rather, in the present context it must be deemed generally to include information *about an individual* which he could reasonably assert an option to withhold from the public at large because of its intimacy *or its possible adverse effects upon himself or his family*.

When the facts indicate an invasion of privacy under clause (C), but there is substantial uncertainty whether such invasion is "unwarranted," a balancing process may be in order, in which the agency would consider whether the *individual's* [privacy] rights are outweighed by the public's interest in having the material available.

The Conference Report states (p. 13) that "disclosure of information about a person to that person does not constitute an invasion of his privacy." It must be noted, however, that *records concerning one individual may contain information affecting the privacy interests of others*. Of course, when information otherwise exempt [from disclosure] under clause (C) is sought by a requester claiming to be the subject of the information, the agency may require appropriate verification of identity. Regardless of what Congress may have intended in 1974, the plain language of FOIA's statutory exemptions from mandatory disclosure of public records does not come close to creating a statutory "right" of privacy for anyone, let alone an individual's relatives. If such a privacy "right" exists at all, it is nothing more than a creature of judicial "gloss" on the plain language of the statute.

Indeed, FOIA's personal privacy exemptions from mandatory disclosure expressly grant only *discretionary authority* to a federal agency holding public records to override what is otherwise a statutory *duty to disclose* those records upon request.<sup>168</sup> The exemptions qualify a federal agency's statutory duty to disclose, but they do not confer an independent right of privacy on anyone, including the person to whom the information directly and specifically pertains.<sup>169</sup> As virtually every court has held, the language that Congress employed in FOIA imposes a broad duty to disclose information in public records,<sup>170</sup> *unless* the agency exercises its statutory authority to withhold certain records (or parts of records) under the specific conditions outlined in each enumerated exemption.<sup>171</sup> Nor does either privacy exemption *prohibit* agency disclosure to protect

Attorney General's Memorandum on the 1974 Amendments to the FOIA, U.S. DEP'T JUST., https://www.justice.gov/oip/attorney-generals-memorandum-1974-amendments-foia (last updated July 23, 2014) (emphasis added) (citations omitted).

<sup>&</sup>lt;sup>168</sup> See, e.g., 5 U.S.C. § 552(a)(2)(E) (2018) (stating that an agency *may* delete information that can identify an individual).

<sup>&</sup>lt;sup>169</sup> See id.

<sup>&</sup>lt;sup>170</sup> E.g., Elec. Privacy Info. Ctr. v. Internal Revenue Serv., 910 F.3d 1232, 1235 (D.C. Cir. 2018) ("[T]he Freedom of Information Act . . . vests the public with a broad right to access government records.") (citing 5 U.S.C. § 552(a)(3)(A)) (2012); see 5 U.S.C. § 552(a) (2018) ("Each agency shall make available to the public information as follows: . . . .") (emphasis added); see also id. § 552(d) ("This section does not authorize withholding of information or limit the availability of records to the public, except as specifically stated in this section.") (emphasis added).

<sup>&</sup>lt;sup>171</sup> See FOIA Guide, 2004 Edition: Discretionary Disclosure and Waiver, U.S. DEP'T JUST., https://www.justice.gov/oip/foia-guide-2004-edition-discretionary-disclosure-and-waiver#N\_9 (last updated July 23, 2014) [hereinafter FOIA Guide] (explaining that because "FOIA's exemptions are discretionary, not mandatory, agencies may make 'discretionary disclosures' of exempt information, as a matter of their administrative discretion, where they are not otherwise prohibited from doing so"); *cf.* Chrysler Corp. v. Brown, 441 U.S. 281, 293 (1979) ("Congress did not design the FOIA exemptions to be mandatory bars to disclosure.").

anyone's personal privacy, regardless of whether the person or the person's family might object. As the Court explained in 1979,

[t]he organization of the Act is straightforward. Subsection (a), 5 U.S.C. § 552(a), places a *general obligation* on the agency to make information available to the public and sets out specific modes of disclosure for certain classes of information. Subsection (b), 5 U.S.C. § 552(b), which lists the exemptions, simply states that the specified material is not subject to the disclosure obligations set out in subsection (a). By its terms, subsection (b) demarcates the agency's obligation to disclose; *it does not foreclose disclosure*.<sup>172</sup>

Contrary to the Court's reasoning in *Favish*,<sup>173</sup> and the District of Columbia Circuit Court's interpretation in *New York Times Co. v. NASA*,<sup>174</sup> the longstanding interpretation of the federal FOIA exemptions is that they grant *discretionary authority* to federal agencies to withhold records from disclosure under specified circumstances, but they impose no *duty* to do so.<sup>175</sup> Absent a statutory duty

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<sup>&</sup>lt;sup>172</sup> Chrysler Corp., 441 U.S. at 291–92 (emphasis added); see also Doe v. Fed. Election Comm'n, 920 F.3d 866, 872 (D.C. Cir. 2019). But see Boles, supra note 163, at 246–47 (opining that "the [FOIA] exemptions direct an agency to withhold particular types of records if certain conditions are met" and that FOIA Exemptions 6 and 7(C) "block the release of government records to prevent unwarranted invasions of privacy") (emphasis added). In support of the statement that FOIA's exemptions direct an agency to withhold particular types of records, Boles cited Chrysler Corp., 441 U.S. at 293–94. See Boles, supra note 163, at 246 n.45. However, the Court in Chrysler Corp. expressly stated that FOIA privacy exemptions do not bar agency disclosure: "[T]he exemptions were only meant to permit the agency to withhold certain information, and were not meant to mandate nondisclosure." 441 U.S. at 293–94 (emphasis added).

<sup>&</sup>lt;sup>173</sup> See discussion supra Section III.B.

<sup>&</sup>lt;sup>174</sup> N.Y. Times Co. v. NASA, 920 F.2d 1002, 1003–04 (D.C. Cir. 1990).

<sup>&</sup>lt;sup>175</sup> See, e.g., Doe, 920 F.3d at 872. "FOIA is a disclosure statute. If an agency wrongly withholds information in the face of a proper FOIA request, it violates that statute. But if an agency discloses information pursuant to other statutory provisions or regulations, the agency cannot possibly violate FOIA." *Id.*; *see also Chrysler Corp.*, 441 U.S. at 293–94 (citing statements in congressional record reflecting that Congress intended exemptions to *permit* agencies to withhold certain kinds of information without *mandating* withholding).

to withhold information, FOIA creates no correlative privacy "right."<sup>176</sup> For that reason, under any reasonable interpretation of the statute's plain language, it is difficult to justify the Supreme Court's generous reading of the FOIA exemptions to support any so-called statutory "right" of privacy.<sup>177</sup> That is particularly true because FOIA expressly grants a federal agency the discretion to withhold information it reasonably foresees could (or would) pose an unwarranted invasion of "personal privacy."<sup>178</sup>

Moreover, the Supreme Court has acknowledged that the FOIA exemption from the disclosure mandate for information in medical, personnel, and similar records ("Exemption 6") offers even less agency discretion to withhold sensitive information than does the exemption for information in criminal investigation records ("Exemption 7(C)").<sup>179</sup> But notwithstanding the *Favish* Court's interpretation to the contrary, neither FOIA exemption confers a statutory right of personal privacy on anyone, let alone the relatives of a decedent whose common law personal privacy rights terminated at death.<sup>180</sup>

On the other hand, the federal Privacy Act of 1974, discussed in Section III.E, created a limited statutory privacy right to prevent government disclosure of individual information without the written consent of the person to whom that information pertains.<sup>181</sup> In fact, the Privacy Act's statement of legislative purpose expressly

<sup>&</sup>lt;sup>176</sup> As the next Subpart will explain, the Privacy Act of 1974 does arguably create a limited statutory "right" of personal privacy, but any such right is expressly subject to the disclosure mandate of FOIA. *See infra* notes 189, 207–11 and accompanying text.

<sup>&</sup>lt;sup>177</sup> *Cf. Favish*, 541 U.S. at 170 (holding that "FOIA recognizes surviving family members' *right to personal privacy* with respect to their close relative's deathscene images . . . consistent with the unanimous view of the Courts of Appeals and other lower courts that have addressed the question") (emphasis added).

<sup>&</sup>lt;sup>178</sup> See 5 U.S.C. §§ 552(b)(6), (b)(7)(C), (d) (2018) (explaining in subsection (d) that "[t]his section does not *authorize withholding* of information or limit the availability of records to the public, except as specifically stated in this section") (emphasis added).

<sup>&</sup>lt;sup>179</sup> See Favish, 541 U.S. at 166. "Exemption 7(C)'s comparative breadth is no mere accident in drafting. We know Congress gave special consideration to the language in Exemption 7(C) because it was the result of specific amendments to an existing statute." *Id.* 

<sup>&</sup>lt;sup>180</sup> See Chrysler Corp., 441 U.S. at 293–94; see also Doe, 920 F.3d at 872.

<sup>&</sup>lt;sup>181</sup> 5 U.S.C. § 552a (2018).

declared that "the right to privacy is a personal and fundamental right protected by the Constitution of the United States."<sup>182</sup> But Favish had nothing to do with the Privacy Act; it involved a FOIA request by a third party for Foster's death-scene photographs held by a federal agency.<sup>183</sup> Moreover, Foster's family members who supported the agency's decision to withhold the photographs were intervenors, not parties to the litigation.<sup>184</sup> That is because FOIA, unlike the Privacy Act, does not authorize a private cause of action against the government to protect anyone's privacy interests that might be implicated by mandatory disclosure of public records.<sup>185</sup> Instead, FOIA authorizes a claim only by the requester of a public record to enforce the FOIA disclosure mandate.<sup>186</sup> And, even if the agency exercises its statutory authority to withhold a public record under one of the privacy-related exemptions, the burden is on the agency itself-not a third party whose privacy might be implicated—to justify that discretionary decision.<sup>187</sup>

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The *Favish* Court's declaration that a statutory right of privacy exists based solely on the language of FOIA's two privacy-related exemptions simply lacks a sound legal footing. The majority opinion adopted a non-textual interpretation based on a 1974 Department

<sup>&</sup>lt;sup>182</sup> Privacy Act of 1974, Pub. L. No. 93-579, § 2(a)(4), 88 Stat. 1896, 1896 (1974) (codified at 5 U.S.C. § 552a) (emphasis added); *see also id.* § 2(b) (protecting individual privacy by authorizing an individual to preclude an agency from disclosing "records pertaining to him . . . without his consent; [and authorizing] civil suit for . . . willful or intentional [agency] action" that violates an individual's rights under the Act).

<sup>&</sup>lt;sup>183</sup> See Favish, 541 U.S. at 161. FOIA was enacted in 1966, predating the Privacy Act by several years. Halstuk & Chamberlin, *supra* note 165, at 512.

<sup>&</sup>lt;sup>184</sup> See Favish, 541 U.S. at 166–67.

<sup>&</sup>lt;sup>185</sup> See FOIA Guide, supra note 171.

<sup>&</sup>lt;sup>186</sup> 5 U.S.C. § 552(a)(4)(B) (2018).

On complaint, the district court of the United States . . . has jurisdiction to *enjoin the agency from withholding agency records* and to order the production of any agency records improperly withheld from the complainant. In such a case the court shall determine the matter de novo, and may examine the contents of such agency records in camera to determine whether such records or any part thereof shall be withheld under any of the exemptions set forth in subsection (b) of this section, and *the burden is on the agency to sustain its action*.

*Id.* (emphasis added).

<sup>&</sup>lt;sup>187</sup> See id.

of Justice Memorandum issued soon after Congress added Exemption 7(C) pertaining to medical, personnel, and similar records.<sup>188</sup>

While Congress arguably created a limited statutory "right of personal privacy" by enacting the 1974 Privacy Act, the federal courts have repeatedly acknowledged that an individual's qualified privacy right conferred by that Act is *expressly subject* to FOIA's *pre-existing* disclosure mandate.<sup>189</sup> Thus, only by a federal agency's discretionary act—and, if challenged by a requester, a federal court's endorsement of that discretion—does anyone enjoy privacy by an agency's nondisclosure of a public record based on either FOIA Exemption 6 or Exemption 7(C).<sup>190</sup>

# D. Judicial Interpretation of "Personal" Privacy to Encompass Surviving Relatives

While some courts have tread lightly in the wake of the Supreme Court's interpretation of FOIA's reference to "personal privacy" in favor of statutory relational privacy interests, the Ninth Circuit has not. In *Marsh v. County of San Diego*, Judge Kozinski, writing for the panel, expansively interpreted *Favish* to recognize a constitutional right to relational privacy grounded in substantive due process.<sup>191</sup> In doing so, the *Marsh* panel's dicta reached well beyond the reasoning expressed in *Favish* and the legislative history supporting the Supreme Court's holding.

In *Marsh*, a surviving mother filed a statutory tort claim against the county under 42 U.S.C. § 1983, objecting to the county's publication of photographs of her son's death scene and autopsy.<sup>192</sup>

<sup>&</sup>lt;sup>188</sup> See Favish, 541 U.S. at 169; Halstuk & Chamberlin, *supra* note 165, at 539-40 (noting that Congress added FOIA Exemption 7(C) in 1974).

<sup>&</sup>lt;sup>189</sup> See, e.g., Chrysler Corp., 441 U.S. at 293 n.14 (comparing FOIA and the Privacy Act).

<sup>&</sup>lt;sup>190</sup> See 5 U.S.C. § 552(a)(4)(B).

<sup>&</sup>lt;sup>191</sup> Marsh v. County of San Diego, 680 F.3d 1148, 1154 (9th Cir. 2012) ("For precisely the same reasons [cited by the Court in *Favish*], we conclude that this right is also protected by substantive due process.").

<sup>&</sup>lt;sup>192</sup> *Id.* at 1152 (noting that the basis for Marsh's claim was the Fourteenth Amendment's Due Process Clause); *see also* Williams v. Baker, 464 F. Supp. 2d 46, 49 (D. Me. 2006) ("A violation of an individual's [constitutional] right of privacy can form the basis for a cause of action under § 1983.") (citing Borucki v. Ryan, 827 F.2d 836, 847 (1st Cir. 1987)).

Declaring the issue a matter of first impression, the panel held that the common law right to non-interference with a family's remembrance of a decedent is so ingrained in tradition that it is constitutionally protected as a matter of substantive due process.<sup>193</sup> The court recognized family members' well-established common law privacy right to protect a loved one's death images from publication:

> The long-standing tradition of respecting family members' privacy in death images partakes of both types of privacy interests protected by the Fourteenth Amendment. First, the publication of death images interferes with "the individual interest in avoiding disclosure of personal matters . . . ." Few things are more personal than the graphic details of a close family member's tragic death. Images of the [decedent's] body usually reveal a great deal about the manner of death and the decedent's suffering during his final moments—all matters of private grief not generally shared with the world at large.

Brenda Marsh's toddler son died in 1983 as a result of physical injuries while in the care of Marsh's then-partner, Kenneth Marsh. *Marsh*, 680 F.3d at 1152. Kenneth Marsh served two decades in state prison for homicide before he was ultimately released. *Id.* After his release, Brenda married Kenneth Marsh, who was later awarded \$756,000 in compensation by the California Victim Compensation and Government Claims Board for the time he spent in prison. Mark Martin, \$756,900 for 21 Years Wrongly Held in Prison / Dead Child's Mom Always Said Convict Didn't Kill Her Son, SFGATE (Jan. 20, 2006, 4:00 AM), https://www.sfgate.com/news/article/756-900-for-21-years-wrongly-held-inprison-2506317.php ("The compensation would mark the ending of a story worthy of a Hollywood script.").

<sup>&</sup>lt;sup>193</sup> *Marsh*, 680 F.3d at 1154. A sister circuit described substantive due process claims as follows:

A substantive due process claim can be stated two different ways. One, substantive due process is violated when the state infringes "fundamental" liberty interests without narrowly tailoring that infringement to serve a compelling state interest. Two, substantive due process is offended when the state's actions either "shock[] the conscience" or "offend[] judicial notions of fairness ... or ... human dignity."

Riley v. St. Louis Cty. 153 F.3d 627, 631 (8th Cir. 1998) (alterations in original) (citations omitted) (quoting Weiler v. Purkett, 137 F.3d 1047, 1051 (8th Cir. 1998) (en banc)).

Second, a parent's right to control a deceased child's remains and death images flows from the well-established substantive due process right to family integrity.<sup>194</sup>

While the *Marsh* panel's dicta squarely declared that the surviving mother's asserted privacy rights were grounded in substantive due process, the court held that her § 1983 claim was nevertheless barred by qualified immunity because the new-found substantive due process right had not been "clearly established" at the time of the county's alleged violation.<sup>195</sup> The case was remanded to address a host of other state law claims, including intentional and negligent infliction of emotional distress.<sup>196</sup>

*Marsh* was wrongly decided, and it appears to be generating a circuit split on the issue of relational privacy interests that will require either Supreme Court intervention or congressional action to resolve.<sup>197</sup> *Favish* and the relational privacy rights the *Marsh* panel

<sup>195</sup> *Marsh*, 680 F.3d at 1159–60.

<sup>196</sup> See Marsh v. County of San Diego, No. 37201200099693CUCRCT, 2013 WL 12144732, at \*2 (Cal. Super. Ct. June 21, 2013).

<sup>&</sup>lt;sup>194</sup> Marsh, 680 F.3d at 1154 (quoting Whalen v. Roe, 429 U.S. 589, 599 (1977)); see also Roberts v. Bell, 281 F. Supp. 3d 1074, 1086 (D. Mont. 2018) (rejecting § 1983 claim by decedent's daughter and her children against the county for posting photographs on Facebook depicting decedent's death; acknowledging *Marsh* but concluding that the county's "alleged conduct [did] not rise to the level of a substantive due process violation"); Range v. Douglas, 763 F.3d 573, 588, 591–92 (6th Cir. 2014) (acknowledging *Marsh* but holding that county defendants' conduct did not rise to the level of deliberate indifference to plaintiffs' constitutionally protected rights that would "shock the conscience"). *But cf.* Olejnik v. England, 147 F. Supp. 3d 763, 778 (W.D. Wis. 2015) (declining to follow *Marsh*, noting that "[t]he Seventh Circuit has not recognized any constitutionally protected interest in the 'right to remembrance' or to the non-interference with a loved one's remains"; pointing out that the Supreme Court has expressly limited the scope of substantive due process rights) (citing Gen. Auto Serv. Station v. City of Chicago, 526 F.3d 991, 1000 (7th Cir. 2008)).

<sup>&</sup>lt;sup>197</sup> See, e.g., Granato v. Davis, 2014-Ohio-5572, 2014 WL 7224556, at \*1–5, \*15 (Ohio Ct. App. 2014) (rejecting a widow's substantive due process claim based on *Marsh* for interfering with her "right of sepulcher" stemming from coroner's failure to correctly identify decedent's body); *see also, e.g., Riley*, 153 F.3d at 630 & n.5 (describing the Missouri common law right of sepulcher as the nextof-kin's right "to perform a ceremonious and decent burial of the nearest relative—and an action for the breach of that right," which "typically involves a

recognized as the "long-standing tradition of respecting family members' privacy in death images" involved informational privacy interests—meaning the right to control the dissemination of personal information.<sup>198</sup> The Supreme Court has long distinguished informational privacy interests from decisional and autonomy privacy interests, such as reproductive decision making and parenting decisions about children's religious and academic education.<sup>199</sup> While both aspects of privacy have relational components, *Favish* and other FOIA cases addressed only informational privacy, the focus of this Article.

## E. Federal Privacy Act of 1974: Nondisclosure of Personal Information; Exceptions

American privacy law took a decided turn in favor of protecting personal *informational* privacy on the eve of 1975, when the federal Privacy Act of 1974<sup>200</sup> became law. The Act's expressed purpose was "to protect the privacy of *individuals* identified in information

<sup>199</sup> See, e.g., Whalen v. Roe, 429 U.S. 589, 598–600 (1977). "The cases sometimes characterized as protecting 'privacy' have in fact involved at least two different kinds of interests. One is the individual interest in avoiding disclosure of personal matters, and another is the interest in independence in making certain kinds of important decisions." *Id.*; *see also* Meyer v. Nebraska, 262 U.S. 390, 399 (1923) (freedom in raising and educating children); Doe v. Heck, 327 F.3d 492, 517–19 (7th Cir. 2003), *as amended on denial of reh*'g (May 15, 2003); Indus. Found. of the S. v. Tex. Indus. Acc. Bd., 540 S.W.2d 668, 679 (Tex. 1976).

> Several commentators have suggested that the right of privacy protected by the U.S. Constitution actually has two meanings: first, the ability of individuals to determine for themselves whether to undergo certain experiences or to perform certain acts—Autonomy; and second, the ability of individuals 'to determine for themselves when, how, and to what extent information about them is communicated to others'—the right to control information, or Disclosural privacy . . . . Most privacy cases decided by the Supreme Court to date have concerned autonomy. Little has been said of the constitutional dimensions of disclosural privacy.

Id. (emphasis added).

<sup>200</sup> Privacy Act of 1974, Pub. L. No. 93-579, 88 Stat. 1896, 1896 (1974) (codified as amended at 5 U.S.C. § 552a (2018)).

physical intrusion, mishandling, or manipulation of the deceased's body") (citations omitted). The *Riley* panel rejected the plaintiff's substantive due process claim. *Id.* at 631 ("We are generally hesitant to extend substantive due process into new arenas.").

<sup>&</sup>lt;sup>198</sup> *Marsh*, 680 F.3d at 1154.

systems maintained by Federal agencies, ... [by] regulat[ing] the collection, maintenance, use, and dissemination of information by such agencies."<sup>201</sup> In outlining the Act's purposes, Congress declared that "the right to privacy is a personal and fundamental right protected by the Constitution of the United States."<sup>202</sup> Read in historical context, Congress surely meant to declare a personal right to informational privacy, not decisional autonomy, which was still very much in judicial flux in the mid-1970s.<sup>203</sup>

The federal Privacy Act sought to ensure that a person to whom personal information pertains has the right to consent—or refuse consent—to a third party's request for personal information in any "record"<sup>204</sup> maintained by a federal agency.<sup>205</sup> As the Supreme

We are not unaware of the threat to privacy implicit in the accumulation of vast amounts of personal information in computerized data banks or other massive government files .... The right to collect and use such data for public purposes is typically accompanied by a concomitant statutory or regulatory duty to avoid unwarranted disclosures .... [I]n some circumstances that duty arguably has its roots in the Constitution ....

Whalen, 429 U.S. at 605.

<sup>204</sup> See 5 U.S.C. § 552a(a)(4) (2018) (defining "record" for purposes of the Privacy Act to mean "information *about an individual* that is maintained by an *agency*") (emphasis added)). "Agency" is separately defined to mean an agency in the executive branch. *See id.* § 552a(a)(1); *see also* 5 U.S.C. § 552(f)(1) (defining "agency"). Section 551(f)(1) expressly excludes Congress and the courts from the definition. *See id.* 

<sup>&</sup>lt;sup>201</sup> *Id.* § 2(a)(5) (emphasis added).

<sup>&</sup>lt;sup>202</sup> *Id.* § 2(a)(4).

<sup>&</sup>lt;sup>203</sup> See infra notes 214–15 (discussing the constitutional right to privacy with respect to decision-making autonomy). The 1974 Privacy Act predated *Whalen v. Roe* by three years. *Whalen* was the first Supreme Court case that acknowledged (in dicta) that informational privacy might have constitutional underpinnings.

<sup>&</sup>lt;sup>205</sup> 5 U.S.C. § 552a(b). "CONDITIONS OF DISCLOSURE.—No agency shall disclose any record . . . to any person, or to another agency, except pursuant to a written request by, or with the prior written consent of, the individual to whom the record pertains . . . ." *Id.* However, the Privacy Act lists 12 exceptions, including one that expressly makes the Act's *prohibition on disclosure* (absent the subject's written consent) subject to the *mandatory disclosure* provisions of 5 U.S.C. § 552. *See* 5 U.S.C. § 552a(b)(2) ("No agency shall disclose any record . . . unless disclosure of the record would be . . . required under section 552 of this title . . . ."). Thus, if a third party requests public information that is part of a federal agency "record," disclosure is mandatory under FOIA, *unless* one or more of the FOIA exemptions authorize withholding. *See* Cochran v. United States, 770 F.2d 949, 955 (11th Cir. 1985).

Court once described the Privacy Act of 1974, "Congress explicitly require[d] agencies to withhold records about an individual from most third parties unless the subject gives his permission."<sup>206</sup>

The interplay between the federal Privacy Act and the federal Freedom of Information Act is confusing at best.<sup>207</sup> While the Privacy Act generally *prohibits* disclosure of personal information in public records without the person's written consent, FOIA generally *mandates* disclosure of information in public records, whether personal or not.<sup>208</sup> Each statute enumerates several exceptions, often denominated "exemptions."<sup>209</sup> Privacy Act exemptions from the general rule of *nondisclosure* authorize a federal agency to *disclose* a record even without the subject's written consent.<sup>210</sup> In contrast, FOIA exemptions to the general rule of *disclosure* authorize a federal agency to *withhold* information from a requester under specified circumstances, notwithstanding the broad statutory mandate

[T]he relationship between the two acts is clearly established. Subsection (b)(2) of the Privacy Act expressly defers to the mandatory disclosure requirements of the FOIA by prohibiting the nonconsensual release of personal information unless the *information is required to be disclosed under the FOIA*.

<sup>&</sup>lt;sup>206</sup> Chrysler Corp. v. Brown, 441 U.S. 281, 293 n.14 (1979).

<sup>&</sup>lt;sup>207</sup> The convoluted drafting and codification of the two statutes, FOIA enacted in 1966 and the Privacy Act in 1974, are no doubt among the reasons the FOIA exemptions have generated so much litigation. *See Cochran*, 770 F.2d at 957 (referring to "the Privacy Act and the FOIA [as] two statutes between which there is great tension"); *see also* Julia P. Eckart, *The History of the Freedom of Information Act's Apparent Failure to Define "Record," and the Disconcerting Trend of Applying Electronic Discovery Protocols to the FOIA, 11 ALB. GOV'T L. REV. 313, 313 (2018) (referring to FOIA jurisprudence as "a convoluted and complex area of law" and noting that "this complexity began at the FOIA's inception"). <i>But see* Porter v. U.S. Dep't of Justice, 717 F.2d 787, 797 (3d Cir. 1983) ("[T]he [Privacy Act's] language in section 552a(b)(2) could hardly be clearer. This *nondisclosure* provision expressly *excepts disclosures* required under the Freedom of Information Act.") (emphasis added); *see also Cochran*, 770 F.2d at 954–55.

*Id.* (emphasis added). To this reader (and probably most other critical legal readers), the relationship between the two statutes and their many exceptions is hardly "clear."

<sup>&</sup>lt;sup>208</sup> See Cochran, 770 F.2d at 954–55, 955 n.7 (summarizing relevant legislative history).

<sup>&</sup>lt;sup>209</sup> See id. at 954.

<sup>&</sup>lt;sup>210</sup> See 5 U.S.C. § 552a(b).

favoring disclosure of information in a federal agency's records.<sup>211</sup> Reconciling the terms of the companion statutes is nothing short of a legal mindbender.<sup>212</sup>

To illustrate, assume that Requester A seeks an FBI record that contains personal information about Person B. Assume further that Person B declines to give written consent to the FBI to disclose the record to Requester A, which the Privacy Act requires as a precondition of disclosure. The FBI is nevertheless obligated by FOIA's general disclosure mandate to hand over the record to Requester A, *unless* one of the privacy-related FOIA exemptions applies and the FBI elects to invoke its discretion to withhold the record from Requester A. Even then, if Requester A challenges that decision, the FBI must shoulder the burden of defending its *discretionary decision* to withhold Person B's FBI record. Nothing in FOIA bars the FBI from disclosing the record to Requester A, even though it contains personal

<sup>&</sup>lt;sup>211</sup> See 5 U.S.C. § 552(b); Cochran, 770 F.2d at 954. The Privacy Act purports to address the potential for conflict in the two statutes' respective exemptions, 5 U.S.C. § 552a(t), but that subdivision, like the others, is hardly a model of legislative clarity.

<sup>(1)</sup> EFFECT OF OTHER LAWS.— No agency shall rely on any exemption contained in section 552 of this title [FOIA] to withhold from an individual any record which is otherwise accessible to such individual under the provisions of this section [the Privacy Act].

<sup>(2)</sup> No agency shall rely on any exemption in this section [the Privacy Act] to withhold from an individual any record which is otherwise accessible to such individual under the provisions of section 552 of this title [FOIA].

Id. When read together, these subsections support the congressional purpose favoring disclosure of public records. If an individual requester may otherwise obtain access to a record containing personal information under the Privacy Act, the agency cannot invoke one of the FOIA disclosure exemptions as a reason to withhold it. Id. § 552a(t)(1). Similarly, if an individual may obtain access to a public record under FOIA's disclosure mandate, the agency cannot invoke one of the Privacy Act's nondisclosure exemptions as a reason to withhold the record. Id. § 552a(t)(2); see Martin v. Office of Special Counsel, Merit Sys. Prot. Bd., 819 F.2d 1181, 1184 (D.C. Cir. 1987) ("The two acts explicitly state that access to records under each is available without regard to exemptions under the other."). This interpretation, as codified in § 552a(t), is also consistent with 5 U.S.C. § 552a(b)(2), which expressly makes the Privacy Act's general rule of nondisclosure subject to FOIA's mandatory *disclosure* provisions. See Doe v. U.S. Dep't of Justice, 790 F. Supp. 17, 19 n.1 (D.D.C. 1992). "It is well established that the Privacy Act and FOIA provide separate routes for obtaining information. Where . . . a person files requests under both Acts, an exemption must apply from each Act in order for the material to be withheld." Id. (citing 5 U.S.C. § 552a(t) (1988)).

#### IV. CONSTITUTIONAL CONSIDERATIONS

## A. Distinguishing Informational Privacy from Decisional Privacy Rights

When judges and scholars debate the constitutional right of privacy, they typically speak of either the implied Fourth Amendment right of individual privacy against unreasonable search and seizure,<sup>213</sup> or the right of autonomy to make personal decisions regarding intimate consensual conduct, procreation, childrearing, and the like.<sup>214</sup> Outside the law enforcement context, the Supreme Court has

<sup>212</sup> *Cf.* United States v. Saya, 247 F.3d 929, 940 (9<sup>th</sup> Cir. 2001) (coining the descriptive term "semantic mindbender" in referring to defendant's argument challenging his sentence as a career offender).

<sup>213</sup> *E.g.*, Carpenter v. United States, 138 S. Ct. 2206, 2223 (2018) (holding that allowing unrestricted government access to information of a "deeply revealing nature" in a wireless carrier's database of physical location information gleaned from cell phones was subject to Fourth Amendment protection, even if a third party had gathered the information); Maryland v. King, 569 U.S. 435, 465–66 (2013) (5-4 opinion) ("When officers make an arrest [for a serious offense] supported by probable cause . . . , taking and analyzing a cheek swab of the arrestee's DNA is, like fingerprinting and photographing, a legitimate police booking procedure that is reasonable under the Fourth Amendment."); Katz v. United States, 389 U.S. 347, 351 (1967) (expanding the Court's interpretation of the Fourth Amendment to protect not just places, but personal privacy as well, holding that what a person "seeks to preserve as private, even in an area accessible to the public, may be constitutionally protected").

<sup>214</sup> See, e.g., Obergefell v. Hodges, 135 S. Ct. 2584, 2597 (2015) (addressing the constitutional right to make "certain personal choices central to individual dignity and autonomy, including intimate choices that define personal identity and beliefs"); Jeffrey M. Shaman, *The Right of Privacy in State Constitutional Law*, 37 RUTGERS L.J. 971, 972 (2006) ("One of the more significant branches of the right of privacy concerns the right of an individual to make personal decisions about his or her life free from government control; that is, the right of individual autonomy."); *cf.* Rao, *Reconceiving Privacy, supra* note 68, at 1123 (1998) (positing that the constitutional right of privacy with respect to decisional autonomy should be reconceived "as a relational right that attaches to entire associations rather than to isolated individuals," a right that is "bounded by the countervailing interests of others [and] ends at the point when individuals within a protected

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information pertaining to Person B. On the other hand, if Person B *consents* to the release of the record to Requester A, the FBI cannot invoke one of the privacy exemptions in FOIA to withhold the record. In other words, § 552a(t) imposes additional constraints on an agency's discretion to withhold personal information that is otherwise available to third parties.

grappled with the "constitutional right of privacy"—generally meaning the right to autonomy in decision making—in a long line of decisions over the last several decades.<sup>215</sup>

In what was perhaps the first of these decisions, the Supreme Court considered whether a District of Columbia public utility commission violated public transit passengers' constitutional privacy right by broadcasting amplified radio programs in passenger cars.<sup>216</sup> The Court rejected the claim after balancing the complaining passengers' asserted privacy interests against the desires of other passengers who apparently enjoyed the radio broadcasts.<sup>217</sup>

<sup>215</sup> See supra note 214 and accompanying text; *infra* notes 216–39 and accompanying text.

<sup>216</sup> Pub. Utilities Comm'n of D.C. v. Pollak, 343 U.S. 451, 453, 463 (1952).

<sup>217</sup> *Id.* at 463–64. The Court's reasoning harkened back to the *Lochner* era, when it held that "[t]he supervision of such practices by the Public Utilities Commission in the manner prescribed in the District of Columbia meets the requirements both of substantive and procedural due process when it is not arbitrarily and capriciously exercised." *Id.* at 465. Justice Frankfurter wrote separately to express his admittedly biased reasons for recusing from the case: "My feelings are so strongly engaged as a victim of the practice in controversy that I had better not participate in judicial judgment upon it." *Id.* at 467 (Frankfurter, J., writing separately).

Justice Douglas dissented, noting first that the passengers' assertion of a Fifth Amendment liberty interest presented an issue of first impression. *Id.* (Douglas, J., dissenting). Perhaps in light of the post-World War II times, he wrote eloquently of the possibility that the government could require radio broadcasts on public transit systems to achieve ill motives:

> If liberty is to flourish, government should never be allowed to force people to listen to any radio program. The right of privacy

relationship assert contradictory interests"). On occasion, a court erroneously refers to a constitutional right of informational privacy, even in factual and legal contexts that implicate the constitutional right to decision-making autonomy. *See*, *e.g.*, Aid for Women v. Foulston, 441 F.3d 1101, 1116 (10th Cir. 2006) (enjoining enforcement of a Kansas statute requiring professionals to report minors' voluntary sexual activity with other minors after holding, as a matter of first impression, that "the right of *informational* privacy extends to minors") (emphasis added). The trial court's decision on remand was vacated as moot by the Tenth Circuit after the 2006 Kansas Legislature repealed the challenged statute. *See* Aid for Women v. Foulston, 427 F. Supp. 2d 1093, 1102 (D. Kan. 2006), *vacated*, No. 06-3187, 2007 WL 6787808 (10th Cir. Sept. 20, 2007) (citing Kan. Stat. Ann. § 38-1522 (repealed 2006)). *See generally* Aliya Haider, *Adolescents Under International Law: Autonomy as the Key to Reproductive Health*, 14 WM. & MARY J. WOMEN & L. 605 (2008).

However complete [a passenger's] right of privacy may be at home, it is substantially limited by the rights of others when its possessor travels on a public thoroughfare or rides in a public conveyance. Streetcars and busses are subject to the immediate control of their owner and operator and, by virtue of their dedication to public service, they are for the common use of all of their passengers. The Federal Government in its regulation of them is not only entitled, but is required, to take into consideration the interests of all concerned.<sup>218</sup>

#### B. Constitutional Basis for a Right to Informational Privacy

In a few cases, the Supreme Court has considered an asserted constitutional right to informational privacy<sup>219</sup>—specifically, a right to prevent government disclosure or misuse of sensitive personal information.<sup>220</sup> However, to date, the Court has never expressly

should include the right to pick and choose from competing entertainments, competing propaganda, competing political philosophies. If people are let alone in those choices, the right of privacy will pay dividends in character and integrity. The strength of our system is in the dignity, the resourcefulness, and the independence of our people. Our confidence is in their ability as individuals to make the wisest choice. That system cannot flourish if regimentation takes hold. The right of privacy, today violated, is a powerful deterrent to any one who would control men's minds.

*Id.* at 469 (Douglas, J., dissenting). However compelling Justice Douglas's concerns, the constitutional "right of privacy" he asserted is more closely aligned with the modern judicial conception of the First Amendment right of free expression, including a right *not* to listen or a right *not* to know, rather than general due process liberty interests. *Id.*; *see* Caroline Mala Corbin, *The First Amendment Right Against Compelled Listening*, 89 B.U. L. REV. 939, 980 (2009) ("[T]he [proposed] right against compelled listening is most strongly grounded in the First Amendment values of autonomy, self-realization, and self-determination.").

<sup>218</sup> *Pollak*, 343 U.S. at 464.

<sup>219</sup> Larry J. Pittman, *The Elusive Constitutional Right to Informational Privacy*, 19 NEV. L.J. 135, 150–67 (2018) (discussing the right to informational privacy and the recognition of such a right in Supreme Court case law).

<sup>220</sup> See, e.g., Whalen v. Roe, 429 U.S. 589, 607 (1977) (concluding that a state statute creating a centralized computer file of individuals taking certain

declared the existence of a right of informational privacy grounded in the federal Constitution.<sup>221</sup> In fact, as explained in more detail below, the Supreme Court's most recent opinion addressing the issue sidestepped it once again.<sup>222</sup>

Whalen v. Roe,<sup>223</sup> decided in 1977, is the Supreme Court case most often cited for the premise that the right to informational

prescription drugs impaired neither their interest in nondisclosure of personal information nor their interest in making personal decisions independently); *see also* Griswold v. Connecticut, 381 U.S. 479, 484–86 (1965) (reasoning that while the Constitution does not explicitly protect a general right to privacy, the Bill of Rights provisions create penumbras, or zones, that establish a right to privacy, including the right of marital privacy against state restrictions on access to contraception); Leiser v. Moore, 903 F.3d 1137, 1140 (10th Cir. 2018) (noting that the asserted "right not to have one's private affairs made public by the government [is] sometimes referred to as a right to informational privacy"); Ellen Wright Clayton et al., *The Law of Genetic Privacy: Applications, Implications, and Limitations*, 6 J.L. & BIOSCIENCES 1, 5 (2019) ("Informational privacy is a particularly important dimension of genetic privacy.").

<sup>221</sup> Lisa Anne Albinger, *Personal Information in Government Agency Rec*ords: Toward an Informational Right to Privacy, 1986 ANN. SURV. AM. L. 625, 626, 626 n.12 (1986); Guy J. Sternal, Comment, Informational Privacy and Public Records, 8 PAC. L.J. 25, 28 (1977).

<sup>222</sup> See, e.g., NASA v. Nelson, 562 U.S. 134, 138 (2011) (assuming, without deciding, that "the Constitution protects [an informational] privacy right of the sort mentioned in *Whalen* and *Nixon*"). Justice Scalia's concurring opinion was more forthright:

Like many other desirable things not included in the Constitution, "informational privacy" seems like a good idea—wherefore the People have enacted laws ... restricting government collection and use of information. But it is up to the People to enact those laws, to shape them, and, when they think it appropriate, to repeal them. A federal constitutional right to "informational privacy" does not exist.

Id. at 159-60 (Scalia, J., concurring).

<sup>223</sup> 429 U.S. 589 (1977). *Whalen* was a facial constitutional challenge to the New York Controlled Substances Act, which provided for a centralized database recording the names, addresses, and ages of anyone for whom a physician had prescribed certain pharmaceutical drugs. *Id.* at 591. Various prescribing physicians, patients, and associations sought to enjoin the Act's enforcement, claiming that it violated their constitutional "rights of privacy." *Id.* After taking pains to give a detailed description of the Act's legislative history and its provisions designed to prevent unauthorized disclosure of the collected information, the Court concluded, "The New York statute ... represents a considered attempt to deal with ... a problem" of vital local concern, and the statute "was a reasonable

privacy is grounded in the federal Constitution.<sup>224</sup> There, the Court acknowledged—in dicta—the possibility that informational privacy interests enjoy a constitutional foundation, but the Court declined to articulate the parameters of the asserted right.<sup>225</sup> Nor has the Court ever held that an asserted constitutional right to informational privacy was violated, although scholars have observed that the asserted right has "flourished by assumption over the decades [in the lower

Whalen, 429 U.S. at 605–06.

We are not unaware of the threat to privacy implicit in the accumulation of vast amounts of personal information in computerized data banks or other massive government files. . . . The right to collect and use such data for public purposes is typically accompanied by a concomitant statutory or regulatory duty to avoid unwarranted disclosures. *Recognizing that in some circumstances that duty arguably has its roots in the Constitution*, nevertheless New York's statutory scheme, and its implementing administrative procedures, evidence a proper concern with, and protection of, the individual's interest in privacy. We therefore need not, and do not, decide any question which might be presented by the unwarranted disclosure of accumulated private data whether intentional or unintentional or by a system that did not contain comparable security provisions [to those provided by the New York Controlled Substances Act].

*Id.* (emphasis added); *see also* Nixon v. Adm'r of Gen. Servs., 433 U.S. 425, 457–58, 465 (1977) (rejecting President Nixon's asserted claim to informational privacy with respect to presidential papers and recordings, which it held was "weaker than that found wanting in the recent decision of Whalen v. Roe"); *cf.* Pittman, *supra* note 219, at 156 (interpreting *Nixon* as providing "strong support that the Court affirmed the existence of a constitutionally protected right to informational privacy").

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exercise of New York's broad police powers." *Id.* at 597–98. Turning to the constitutional issues, the Court acknowledged that the New York statute was challenged on dual grounds: first, the asserted right of individuals to avoid disclosure of personal matters, and second, the interest in decisional autonomy. *Id.* at 599–600. The Court rejected both arguments, concluding that "neither the immediate nor the threatened impact of the patient-identification requirements in the New York [Act] on either the reputation or the independence of patients for whom Schedule II drugs are medically indicated is sufficient to constitute an invasion of any right or liberty protected by the Fourteenth Amendment." *Id.* at 603–05; *see id.* at 600.

<sup>&</sup>lt;sup>224</sup> See, e.g., Mary D. Fan, Constitutionalizing Informational Privacy by Assumption, 14 U. PA. J. CONST. L. 953, 955–56 (2012) (describing Whalen as "the genesis of the assumed right").

courts]."<sup>226</sup> One scholar who canvassed federal and state court decisions addressing the issue concluded that "the majority of the federal courts of appeals and a number of state courts have gone further [than the Supreme Court] and accorded the idea of informational privacy constitutional stature."<sup>227</sup>

In 2011, the Court revisited the issue.<sup>228</sup> Several contract employees who had worked for years at a NASA worksite challenged the government's recently adopted requirement that NASA complete and submit detailed employment questionnaires as part of the agency's background check process.<sup>229</sup> When first hired, the contract employees had not been required to complete the background check otherwise required for civil service employees.<sup>230</sup> But after the 9/11 Commission recommended improvements in security measures, President George W. Bush issued a directive imposing a new identification process for all federal employees, including contract employees.<sup>231</sup> The Department of Commerce, which houses NASA and its research facilities, complied with the presidential order by "mandating that contract employees with long-term access to federal facilities complete a standard background check."<sup>232</sup> The plaintiffs protested, arguing that the directive requiring them to disclose detailed personal information violated their constitutional right to informational privacy grounded in the Fifth Amendment.<sup>233</sup>

<sup>&</sup>lt;sup>226</sup> Fan, *supra* note 224, at 956; *see also id.* at 972 ("In producing decisions that could not quite decide if the constitutional right [to informational privacy] exists and offering a Rorschach blot of standards that might govern if it did, the Court punted to the lower courts to sort things out.").

<sup>&</sup>lt;sup>227</sup> *Id.* at 974–75, 974 n.121 (citing illustrative cases by various federal and state appellate courts); *e.g.*, Barry v. City of New York, 712 F.2d 1554, 1559 (2d Cir.), *cert. denied*, 464 U.S. 1017 (1983).

<sup>&</sup>lt;sup>228</sup> See NASA v. Nelson, 562 U.S. 134 (2011) (6-2 opinion; Kagan, J., not participating).

<sup>&</sup>lt;sup>229</sup> *Id.* at 138.

<sup>&</sup>lt;sup>230</sup> *Id.* at 139.

<sup>&</sup>lt;sup>231</sup> *Id.* at 139–40.

<sup>&</sup>lt;sup>232</sup> *Id.* at 140.

<sup>&</sup>lt;sup>233</sup> *Id.* at 142. The Court noted that all of the information gathered in the government's background check was subject to the nondisclosure provisions of the Privacy Act, 5 U.S.C. § 552a. *Nelson*, 562 U.S. at 142; *see supra* note 204–06 and accompanying text.

The Court rejected the claim, once again sidestepping whether the Constitution supports a right to informational privacy.<sup>234</sup> After carefully reiterating its dicta in both *Whalen* and *Nixon*, the Court concluded that none of its other decisions had "squarely addressed a constitutional right to informational privacy."<sup>235</sup> Following its reasoning in *Whalen*, the Court assumed, without deciding, the existence of the constitutional right but held that regardless of its hypothetical scope, the right "does not prevent the Government from asking reasonable questions of the sort included . . . in an employment background investigation that is subject to the Privacy Act's safeguards against public disclosure."<sup>236</sup>

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Justice Scalia concurred, joined by Justice Thomas, but they threw cold water (figuratively speaking) on the very notion that the Constitution protects informational privacy.<sup>237</sup> They declared bluntly that a "federal constitutional right to 'informational privacy' does not exist."<sup>238</sup> Thus, the Court declined to address the controversial issue any further than it already had in *Whalen* and *Nixon*, decided more than three decades earlier, and two justices disclaimed any constitutional basis whatsoever for the claimed right to informational privacy.<sup>239</sup>

In summary, Supreme Court precedents suggest that any federal right to informational privacy is grounded in the Privacy Act, not

<sup>238</sup> *Id.* at 160; *see also id.* at 169 (Thomas, J., concurring) ("I agree with Justice Scalia that the Constitution does not protect a right to informational privacy.... [T]he notion the Due Process Clause of the Fifth Amendment is a wellspring of unenumerated rights against the Federal Government strains credulity for even the most casual user of words.") (citations and internal quotation marks omitted).

<sup>&</sup>lt;sup>234</sup> Nelson, 562 U.S. at 159.

<sup>&</sup>lt;sup>235</sup> *Id.* at 146.

<sup>&</sup>lt;sup>236</sup> *Id.* at 148. The Court stressed that the plaintiffs had challenged only the collection of the information, not any risk of its improper dissemination to third parties. *Id.* at 156. Even if they had, the Court reasoned that all information gathered was subject to the Privacy Act's "protections against disclosure," which it considered sufficient to "evidence a proper concern" for the contract employees' individual privacy. *Id.* (citations omitted). The Court, however, failed to acknowledge that the Privacy Act's "safeguards" for personal information are expressly subject to FOIA's general disclosure mandate for information in public records. *See* 5 U.S.C. §§ 552(a), 552a(t).

<sup>&</sup>lt;sup>237</sup> *Id.* at 159–69 (Scalia, J., concurring).

<sup>&</sup>lt;sup>39</sup> See supra notes 223–38 and accompanying text.

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the Constitution, and certainly not FOIA.<sup>240</sup> The *Favish* Court incorrectly set the foundations of a federal right to informational privacy in FOIA's discretionary exemptions from the disclosure mandate. Instead, the narrow scope of the *federal* right to informational privacy—at least for now—rests exclusively on the limited protections granted by the Privacy Act of 1974, which are expressly subject to FOIA's disclosure requirements.

### C. First Amendment Constraints on Informational Privacy Rights

Even if a constitutional basis exists for the right to informational privacy, the Supreme Court has carefully circumscribed it, recognizing its inherent tension with the First Amendment freedom of speech,<sup>241</sup> freedom of the press,<sup>242</sup> and even the freedom of association.<sup>243</sup> For example, in 1975, the Court explained that invasion of privacy claims for disclosure and dissemination of information "most directly confront the constitutional freedoms of speech and press."<sup>244</sup>

Indeed, the Court has recognized that "the creation and dissemination of information are speech within the meaning of the First Amendment."<sup>245</sup> Thus, if any constitutional right to informational privacy exists, the Court would necessarily need to address its inherent conflicts with the many well-established individual rights

<sup>244</sup> *Cohn*, 420 U.S. at 488–89 ("[T]he century has experienced a strong tide running in favor of the so-called [common law] right of privacy.").

<sup>&</sup>lt;sup>240</sup> See Nat'l Archives & Records Admin. v. Favish, 541 U.S. 157, 172 (2004).

<sup>&</sup>lt;sup>241</sup> See, e.g., Snyder v. Phelps, 562 U.S. 443, 460 (2011).

<sup>&</sup>lt;sup>242</sup> See, e.g., Cox Broad. Corp. v. Cohn, 420 U.S. 469, 489 (1975).

<sup>&</sup>lt;sup>243</sup> See, e.g., NAACP v. State of Ala. *ex rel.* Patterson, 357 U.S. 449, 460 (1958) (setting aside lower court's contempt order and fine against NAACP for failure to produce its membership list, which infringed NAACP members' First Amendment freedom of association "for the advancement of beliefs and ideas[,] an inseparable aspect of the 'liberty' assured by the Due Process Clause of the Fourteenth Amendment"); *cf. Snyder*, 562 U.S. at 460 (holding that Maryland privacy and other common law rights of a deceased soldier's grieving father must yield to First Amendment rights lawfully exercised by anti-homosexual funeral picketers, regardless of the hateful content of defendants' message).

<sup>&</sup>lt;sup>245</sup> Sorrell v. IMS Health Inc., 564 U.S. 552, 570 (2011) (striking down on First Amendment grounds a Vermont statute restricting sale and dissemination of information held by private pharmacies that revealed individual physicians' drug-prescribing practices).

protected by the First and Fourteenth Amendments.<sup>246</sup> No doubt that is among the primary reasons, if not *the* primary reason, the Court has been reluctant to squarely address the issue.<sup>247</sup>

Given the wide gap that remains in the Court's informational privacy jurisprudence, lower federal courts are understandably mystified about how to resolve these increasingly complex issues.<sup>248</sup> State courts too are left to resort to their own state constitutions, statutes, or common law protections for informational privacy, without any clear guidance about First and Fourteenth Amendment constraints on those state rights.<sup>249</sup>

### D. Substantive Due Process and Privacy

In the early decades of the twentieth century, the Supreme Court resorted to the doctrine of "substantive due process" to strike down state regulatory statutes that a majority of the Court thought intruded too far into the Fourteenth Amendment liberty interests of

<sup>246</sup> See, e.g., A. Michael Froomkin, The Death of Privacy?, 52 STAN. L. REV. 1461, 1501, 1523–24 (2000) (explaining how First Amendment jurisprudence constrains effective legal responses to "privacy-destroying technologies," as illustrated by "the relatively limited protection against data acquisition provided by existing privacy rules"); Amy Gajda, Judging Journalism: The Turn Toward Privacy and Judicial Regulation of the Press, 97 CALIF. L. REV. 1039, 1061 (2009) ("By the 1960s, ... privacy and press rights had each gained sufficient strength that the tension [between them] could no longer be ignored."); see also Fla. Star v. B.J.F., 491 U.S. 524, 530 (1989) (acknowledging the "tension between the right which the First Amendment accords to a free press, on the one hand, and the protections which various statutes and common-law doctrines accord to personal privacy against the publication of truthful information, on the other"); Cohn, 420 U.S. at 490 (explaining that if a privacy tort claim seeks to redress publication of false or misleading personal information, the plaintiff must establish that information pertaining to a "matter[] of public interest" qualifies as a "knowing or reckless falsehood") (quoting Time, Inc. v. Hill, 385 U.S. 374, 387-88 (1967)).

<sup>&</sup>lt;sup>247</sup> See Froomkin, supra note 246, at 1523–24.

<sup>&</sup>lt;sup>248</sup> See Pittman, supra note 219, at 167–82 (discussing the federal courts' various interpretations of informational privacy).

<sup>&</sup>lt;sup>249</sup> See Fan, supra note 224, at 974–75 & n.121 (citing illustrative cases by various federal and state appellate courts); see also, e.g., Barry v. City of New York, 712 F.2d 1554, 1559 (2d Cir.), cert. denied, 464 U.S. 1017 (1983).

commercial businesses and even families.<sup>250</sup> But since the midtwentieth century, the Supreme Court has repeatedly discredited *Lochner* and its articulation of substantive due process as a rationale for striking down state statutes on federal constitutional grounds.<sup>251</sup>

In *Obergefell v. Hodges*, the Supreme Court came perhaps as close as it has in several decades to deciding a case on substantive due process grounds.<sup>252</sup> A sharply divided Court held that same-sex couples have a constitutional right to marry.<sup>253</sup> Justice Kennedy, writing for a slim majority, cobbled together a host of constitutional interests, including the constitutional right to autonomy in relational

 $<sup>^{250}</sup>$  *E.g.*, Muller v. State of Oregon, 208 U.S. 412, 421 (1908) (upholding Oregon statute restricting working hours of women to a 10-hour workday, reasoning "that [a] woman's physical structure and the performance of maternal functions place her at a disadvantage in the struggle for subsistence").

<sup>[</sup>T]here is a limit to the valid exercise of the police power by the state .... Otherwise the 14th Amendment would have no efficacy and the legislatures of the states would have unbounded power, and it would be enough to say that any piece of legislation was enacted to conserve the morals, the health, or the safety of the people; such legislation would be valid, no matter how absolutely without foundation the claim might be.

Lochner v. New York, 198 U.S. 45, 56 (1905), *abrogated by* W. Coast Hotel Co. v. Parrish, 300 U.S. 379 (1937); *see* David E. Bernstein, Lochner *Era Revisionism, Revised:* Lochner *and the Origins of Fundamental Rights Constitutionalism,* 92 GEO. L.J. 1, 10–11 (2003) (explaining that the *Lochner* era spanned from approximately 1897 to the mid-1930s, when "the Court was dominated by Justices who expanded *Lochner* by voting to limit the power of government in both economic and noneconomic contexts").

<sup>&</sup>lt;sup>1</sup> See, e.g., Ferguson v. Skrupa, 372 U.S. 726, 730 (1963).

The doctrine that prevailed in *Lochner*... and like cases—that due process authorizes courts to hold laws unconstitutional when they believe the legislature has acted unwisely—has long since been discarded. We have returned to the original constitutional proposition that courts do not substitute their social and economic beliefs for the judgment of legislative bodies, who are elected to pass laws.

*Id.*; *see also* Obergefell v. Hodges, 135 S. Ct. 2584, 2616 (2015) (Roberts, C.J., dissenting) ("The need for restraint in administering the strong medicine of substantive due process is a lesson this Court has learned the hard way.").

<sup>&</sup>lt;sup>252</sup> See Obergefell, 135 S. Ct. at 2616, 2618–19.

<sup>&</sup>lt;sup>253</sup> *Id.* at 2607 ("The Court, in this decision, holds same-sex couples may exercise the fundamental right to marry in all States.").

decision-making,<sup>254</sup> that support the "fundamental right to marry" protected by the Fourteenth Amendment.<sup>255</sup> However, the majority carefully avoided holding that the right was grounded in substantive due process, notwithstanding the dissenters' rather hyperbolic protestations to the contrary.<sup>256</sup>

More recently, however, the Court held that even the fundamental right of same-sex couples to marry must yield to First Amendment protections for the exercise of religious freedom, at least when a private businessperson asserts religious beliefs as the reason for declining to transact business with a same-sex couple who plans to marry.<sup>257</sup> Thus, in any constitutional analysis, the courts must strike

[T]he right to marry is a fundamental right inherent in the liberty of the person, and under the Due Process and Equal Protection Clauses of the Fourteenth Amendment couples of the same-sex may not be deprived of that right and that liberty. The Court now holds that same-sex couples may exercise the fundamental right to marry. No longer may this liberty be denied to them.

### Id.

<sup>257</sup> See Masterpiece Cakeshop, Ltd. v. Colo. Civil Rights Comm'n, 138 S. Ct. 1719, 1732 (2018) (Kennedy, J.) "[T]hese disputes must be resolved with tolerance, without undue disrespect to sincere religious beliefs, and without subjecting gay persons to indignities when they seek goods and services in an open market." *Id.* 

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<sup>&</sup>lt;sup>254</sup> *Id.* at 2597–98 (Kennedy, J., writing for a 5-4 majority) ("[T]hese liberties [protected by the Due Process Clause of the Fourteenth Amendment] extend to certain personal choices central to individual dignity and autonomy, including intimate choices that define personal identity and beliefs.") (citing Eisenstadt v. Baird, 405 U.S. 438, 453 (1972); Griswold v. Connecticut, 381 U.S. 479, 484–86 (1965)).

<sup>&</sup>lt;sup>255</sup> *Obergefell*, 135 S. Ct. at 2604–05.

<sup>&</sup>lt;sup>256</sup> See id. at 2618–19 (Roberts, C.J., dissenting) (referring to the majority's "aggressive application of substantive due process [that] breaks sharply with decades of precedent and returns the Court to the unprincipled approach of *Lochner*"); *id.* at 2632 n.1 (Thomas, J., dissenting) ("[T]he majority clearly uses equal protection only to shore up its substantive due process analysis, an analysis both based on an imaginary constitutional protection and revisionist view of our history and tradition."). Justice Thomas opined that "[i]n its haste to reach a desired result, the majority misapplies a clause focused on 'due process' to afford substantive rights, disregards the most plausible understanding of the 'liberty' protected by that clause, and distorts the principles on which this Nation was founded." *Id.* at 2640 (Thomas, J., dissenting).

a balance among rights that are inherently in tension with one another.<sup>258</sup>

Returning to the Ninth Circuit's decision in *Marsh* articulating a relational right of informational privacy grounded in substantive due process, discussed *supra* in Section III.D, the rationale in that case is questionable. The Supreme Court's decisions have closely cabined, if not dismissed altogether, substantive due process as a constitutional foundation for striking down state laws.<sup>259</sup> Judge Kozinski's substantive due process reasoning in *Marsh* directly contradicted the Supreme Court's informational privacy jurisprudence.

# V. RELATIONAL PRIVACY INTERESTS AND DNA BIOBANKS<sup>260</sup>

[A] family history belongs to a collective of individuals, each one of whom has an informational privacy

<sup>&</sup>lt;sup>258</sup> See supra notes 241–49 and accompanying text (discussing First Amendment constraints on the recognition of a constitutional right of informational privacy).

<sup>&</sup>lt;sup>259</sup> See, e.g., Olejnik v. England, 147 F. Supp. 3d 763, 778 (W.D. Wis. 2015) (declining to follow *Marsh* in part because it "represents an expansion in substantive due process law not augured in Seventh Circuit precedent"; noting that "[t]he Supreme Court . . . has been reluctant to enlarge the list of rights protected by substantive due process . . . .") (citing Washington v. Glucksberg, 521 U.S. 702, 720 (1997)).

<sup>260</sup> DNA biobanks collect and link DNA samples with health information for research purposes. Kelly E. Ormond et al., The Views of Participants in DNA Biobanks, 1 STAN. J.L., SCI. & POL'Y 80, 81-82 (2010). More than just a database, a "biobank" is a unique type of repository that collects, stores, processes, and distributes biospecimens, such as DNA and other tissue samples, along with the associated data. Karen J. Maschke, Biobanks: DNA and Research, in FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS 11, 11-12 (Mary Crowley ed., 2008). DNA biobanks are largely unregulated in the United States. See id. at 12 ("Because the United States has no comprehensive regulatory framework that addresses these issues, there is confusion about when the rules governing research with humans apply to research with biospecimens and their data."); cf. Sarah Zhang, What Happens When You Put 500,000 People's DNA Online, (Nov. 6, 2017), ATLANTIC https://www.theatlantic.com/science/archive/2017/11/what-happens-when-you-put-500000-peoples-dnaonline/543747/.

## *interest in the security of the information and a spatial privacy interest in not knowing information.*<sup>261</sup>

Recent developments with respect to the public availability of genetic information pose serious risks for informational privacy rights—whatever their source—not only for individuals, but also their family members.<sup>262</sup> In 2003, the scientific community announced that the Human Genome Project had successfully "mapped" the entire human genome.<sup>263</sup> Currently underway is the Personal Genome Project, initiated in 2005, which seeks to collect individual genomic data from volunteers for the purpose of sharing it with the public "for the greater good."<sup>264</sup>

The potential impact of the uses of genetic information on families, in addition to individuals, is often perceived as being unique to this area of inquiry. Indeed, this is frequently held out to be the case irrespective of the kind of genetic knowledge involved. The implications of this are far-reaching. The historical focus of both ethics and law in the United Kingdom and the United States - as paradigm examples of communities nurtured in the Western liberal tradition – has been the rights of the individual to determine for herself the course of her life, with minimal interference by others. This notion is challenged by increased availability of genetic information. At least, this is so if we take as our premise that genetic information relates not only to the person from whom it is derived, but also to blood relatives of that person. . . . [W]e cannot ignore the fact that genetic information derived from [a genetic] sample might also reveal information about the relatives of the sample source.

*Id.*; *see also id.* at 3 ("[I]ndividual genetic information can unlock many secrets within the wider genetic family.").

<sup>263</sup> International Consortium Completes Human Genome Project, NAT'L HUM. GENOME RES. INST. (Apr. 14, 2003), https://www.genome.gov/11006929/2003-release-international-consortium-completes-hgp. The Institute reported that "[t]he finished sequence produced by the Human Genome Project covers about 99 percent of the human genome's gene-containing regions, and it has been sequenced to an accuracy of 99.99 percent." *Id*.

<sup>264</sup> *The Personal Genome Project*, PERS. GENOME PROJECT, https://www.personalgenomes.org/us#about (last visited Mar. 18, 2020). For the national locus of

<sup>&</sup>lt;sup>261</sup> GRAEME LAURIE, GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS 146 (2002).

<sup>&</sup>lt;sup>262</sup> As scholars have noted, mapping the human genome, along with the increasing availability and affordability of direct-to-consumer genetic testing, has unprecedented implications for family privacy. *See, e.g., id.* at 93.

The public interest in the results and implications of genome mapping is arguably widespread.<sup>265</sup> For example, the Public Broad-casting Service recently announced a forthcoming Ken Burns documentary titled *The Gene: An Intimate History*,<sup>266</sup> based on a best-selling book by the same name.<sup>267</sup> Direct-to-consumer genetic test-ing<sup>268</sup> will soon become a billion-dollar commercial enterprise that is projected to grow rapidly in coming years both in the United States and abroad.<sup>269</sup> For example, the DNA database maintained by Ancestry, the largest commercial service offering genetic testing in

<sup>265</sup> See, e.g., Jamie Ducharme, A Major Drug Company Now Has Access to 23andMe's Genetic Data. Should You Be Concerned?, TIME (July 26, 2018), https://time.com/5349896/23andme-glaxo-smith-kline/.

<sup>266</sup> Ken Burns Presents The Gene: An Intimate History, PBS, https://www.pbs.org/show/gene/ (last visited Mar. 18, 2020).

<sup>267</sup> See Siddhartha Mukherjee, The Gene: An Intimate History (2016).

<sup>269</sup> See Direct-to-Consumer Genetic Testing Market to Hit \$2.5 Bn by 2024: Global Market Insights, Inc., CISION PR NEWSWIRE (Dec. 11, 2018, 6:00 AM), https://www.prnewswire.com/news-releases/direct-to-consumer-genetictesting-market-to-hit-2-5-bn-by-2024-global-market-insights-inc--830436085.html.

> In 2010, with whole-genome sequencing becoming increasingly affordable, the promise of large-scale human genomic research studies involving hundreds, thousands, and even hundreds of thousands of individuals is rapidly becoming a reality. The next generation of human genomic research will occur on a scale that would have been nearly unfathomable [in 2000], when the publication of the Human Genome Project's first draft results was still pending.

Jeantine E. Lunshof et al., *Personal Genomes in Progress: From the Human Genome Project to the Personal Genome Project*, 12 DIALOGUES CLINICAL NEUROSCIENCE 47, 47 (2010); *see also International Consortium Completes Human Genome Project, supra* note 263 ("The international consortium announced the first draft of the human sequence in June 2000.").

the global project, see *The Harvard Personal Genome Project*, HARV. MED. SCH., https://pgp.med.harvard.edu/ (last visited Mar. 18, 2020). The project "invite[s] willing participants to publicly share their personal data for the greater good" for the purpose of "creating public genome, health, and trait data." *The Personal Genome Project, supra*.

<sup>&</sup>lt;sup>268</sup> See, e.g., RB Altman, Direct-to-Consumer Genetic Testing: Failure Is Not an Option, 86 CLINICAL PHARMACOLOGY & THERAPEUTICS 15, 15 (2009). "[D]irect-to-consumer (DTC) genetic testing . . . has arisen precisely because genotyping is sufficiently inexpensive and straightforward that it is easy for a company to set up shop. The cat is out of the bag: genotyping is already a commodity, and full-genome sequencing is well on the way." *Id*.

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the United States, includes DNA samples submitted by more than fifteen million "DNA customers."<sup>270</sup> So great is the public interest in using DNA data to trace family history that some commentators have referred to the "genealogy craze" that has fueled public demand for these services.<sup>271</sup>

The rapid proliferation of DNA biobanks by nonprofit organizations and commercial enterprises is a direct result of increasingly affordable DNA sequencing.<sup>272</sup> While some commentators long ago anticipated the privacy issues associated with massive collections of DNA samples,<sup>273</sup> only a few legal scholars paid heed to the multi-

Genomic information can wield considerable influence, affecting the decisions of health care professionals, patients and their families, employers, insurers, and the justice system. How does society control this information without stifling the real potential for human good that it offers? The answer to this question must be in recognizing that trade-offs are inevitable. Permitting

<sup>&</sup>lt;sup>270</sup> Ancestry Surpasses 15 Million DNA Customers, ANCESTRY (May 31, 2019), https://blogs.ancestry.com/ancestry/2019/05/31/ancestry-surpasses-15-million-dna-customers/; see Antonio Regalado, More than 26 Million People Have Taken an At-Home Ancestry Test, MIT TECH. REV. (Feb. 11, 2019), https://www.technologyreview.com/s/612880/more-than-26-million-people-have-taken-an-at-home-ancestry-test/.

<sup>&</sup>lt;sup>271</sup> E.g., Ashley Barnwell, *The Genealogy Craze: Authoring an Authentic Identity Through Family History Research*, 10 LIFE WRITING 261, 261–62 (2013); Neil Genzlinger, *TV's Genealogy Craze Yields Game Shows and Paper Chases but Also Interesting Lessons*, N.Y. TIMES (Apr. 1, 2016), https://www.ny-times.com/2016/04/02/arts/television/tvs-genealogy-craze-yields-game-shows-and-paper-chases-but-also-interesting-lessons.html.

<sup>&</sup>lt;sup>272</sup> See, e.g., C.W. Knetsch et al., DNA Sequencing, in MOLECULAR DIAGNOSTICS PART 1: TECHNICAL BACKGROUNDS AND QUALITY ASPECTS 339, 339 (E. van Pelt-Verkuil et al. eds., 2019) (noting the "substantial reductions in the cost of DNA sequencing" over the last 15 years); James W. Hazel & Christopher Slobogin, Who Knows What, and When?: A Survey of the Privacy Policies Proffered by U.S. Direct-to-Consumer Genetic Testing Companies, 28 CORNELL J.L. & PUB. POL'Y 35, 57 (2018). See generally The Cost of Sequencing a Human Genome, NAT'L HUM. GENOME RES. INST., https://www.genome.gov/about-genomics/fact-sheets/Sequencing-Human-Genome-cost (last updated Oct. 30, 2019) (explaining the rapidly declining costs of both whole-genome sequencing and targeted, or partial, genome sequencing).

<sup>&</sup>lt;sup>273</sup> A few commentators foresaw the privacy risks to close family members of disclosing highly sensitive personal information. *See, e.g.*, Lawrence O. Gostin, *Genetic Privacy*, 23 J.L., MED. & ETHICS 320, 327–28 (1995).

dimensional risks to relational privacy associated with the rapid expansion of commercial DNA biobanks.<sup>274</sup>

This Part explores some of the developing privacy issues implicating relational privacy, all of which warrant further research and analysis. We have a pressing need for scholars and policymakers to develop innovative legal approaches to balance legitimate privacy interests against both the "public good" and the proprietary commercial interests associated with collecting, storing, accessing, and disseminating DNA data. Because of its unique implications for identifying known and unknown genetic relatives, revealing family secrets, and affecting family relationships, genomic information in the developing era of biotechnology turns out to be not so "personal" to the *individual* after all. How policymakers balance the respective interests in genetic data may prove to be one of the most confounding issues of our time.

A. Direct-to-Consumer Genetic Testing: Contract Rights and Informed Consent

[T]he popular definition of privacy as an individual control over personal information, does not result in the protection of the interests commonly expressed

the Human Genome Initiative to proceed unabated will have costs in personal privacy.

Id.; see also, e.g., Graeme T. Laurie, Challenging Medical-Legal Norms: The Role of Autonomy, Confidentiality, and Privacy in Protecting Individual and Familial Group Rights in Genetic Information, 22 J. LEGAL MED. 1, 10–11 (2001); Leornard L. Riskin & Phillip P. Reilly, Remedies for Improper Disclosure of Genetic Data, 8 RUTGERS-CAMDEN L.J. 480, 488 (1977); Note, The Relational Right of Privacy Theory—Recovering on the Basis of Conduct Directed at a Deceased or Living Relative, Friend or Associate, 21 RUTGERS L. REV. 74, 75 (1966) (suggesting that the "distinct legal interest" in relational privacy arguably warrants common law protection, whether or not the relative to whom the defendant directs the "encroaching acts" is living or dead).

<sup>&</sup>lt;sup>274</sup> See, e.g., Suter, supra note 68, at 362–63 (discussing implications for relational aspects of family privacy); Michael Avery, Landry v. Attorney General: *DNA Databanks Hold A Mortgage on Privacy Rights*, 44 Bos. B.J. 18, 18 (2000) ("The personal information disclosed [by DNA analysis] may violate the privacy not only of the subject whose DNA is analyzed, but also that of close relatives.").

# regarding genetic databases and therefore needs to be redrawn.<sup>275</sup>

In the United States, the most common approach to protecting consumers' privacy rights in genomic data is rooted in traditional contract law.<sup>276</sup> An individual willing to pay for commercial genetic testing services can simply purchase a testing kit for a modest fee and mail in a DNA sample, generally a small tube of the individual's saliva.<sup>277</sup> Several weeks later, the direct-to-consumer genetic testing provider sends back the individual's digitized DNA profile, which may take various forms depending on the consumer's purposes for seeking the information.<sup>278</sup>

Commercial genetic testing providers generally market their DNA analysis services with a strong assurance of privacy.<sup>279</sup> But as a practical and legal matter, the provider's fine-print "terms and conditions" govern the scope of the consumer's "informed consent."<sup>280</sup>

<sup>278</sup> See id. at 167–68 (describing results); Jackson Ryan, *What AncestryDNA Taught Me About DNA, Privacy and the Complex World of Genetic Testing*, CNET (Mar. 22, 2019, 5:00 AM), https://www.cnet.com/news/ancestrydna-taught-me-about-my-dna-privacy-and-the-complex-world-of-genetic-testing/ (describing the process of submitting a DNA sample and receiving results).

<sup>279</sup> See, e.g., Privacy Is in Our DNA, 23ANDME, https://www.23andme.com/privacy/?%20vip=true (last visited Mar. 18, 2020) ("Everyone deserves a secure, private place to explore and understand their genetics. At 23andMe, we put you in control of deciding what information you want to learn and what information you want to share. See our privacy statement for more info."); Origins, ANCESTRY, https://www.ancestry.com/cs/origins (last visited Mar. 18, 2020) ("Your privacy and security are at the core of everything we do. From the second you open your kit to the minute you get your results, you're in control of your DNA data.").

<sup>280</sup> E.g., Ancestry Terms and Conditions, ANCESTRY, https://www.ancestry.com/cs/legal/termsandconditions (last visited Mar. 18, 2020) [hereinafter

<sup>&</sup>lt;sup>275</sup> Salvör Nordal, *Privacy*, *in* THE ETHICS AND GOVERNANCE OF HUMAN GENETIC DATABASES: EUROPEAN PERSPECTIVES 181, 182 (Matti Häyry et. al eds., 2007).

<sup>&</sup>lt;sup>276</sup> See Dana A. Elfin, DNA Testing? You Might Want to Wait for More Legal Protection, BLOOMBERG L. (Jan. 7, 2019, 5:40 AM), https://news.bloomber-glaw.com/pharma-and-life-sciences/dna-testing-you-might-want-to-wait-for-more-legal-protection.

<sup>&</sup>lt;sup>277</sup> ADAM RUTHERFORD, A BRIEF HISTORY OF EVERYONE WHO EVER LIVED: THE HUMAN STORY RETOLD THROUGH OUR GENES 167 (2017) (describing similar features shared by direct-to-consumer genetic testing kits).

The concept of informed consent has a long history in United States tort law.<sup>281</sup> From a privacy perspective, the notion of "informed consent" represents the intersection between the right of personal autonomy (to make intimate decisions about one's body or interpersonal relationships) and the right of informational privacy (to regulate both the subject's access to relevant information and its disclosure to third parties).<sup>282</sup>

The terms and conditions that apply to direct-to-customer genealogical services, which appear only online, also set out any restrictions on the service provider's authority to retain the consumer's DNA sample. More importantly, the terms and conditions also govern whether the service provider may either disclose or sell the DNA data to third parties, which may occur with or without the individual's informed consent.<sup>283</sup> Ancestry's "Privacy Statement"

<sup>281</sup> See Martin R. Struder, *The Doctrine of Informed Consent: Protecting the Patient's Right to Make Informed Health Care Decisions*, 48 MONT. L. REV. 85, 86–88 (1987). The traditional notion of "informed" consent developed in response to paternalistic medicine—physicians making decisions they believed were in the patient's best interest and often without fully informing the patient. See Jørgen Husted, *Autonomy and a Right Not to Know, in* THE RIGHT TO KNOW AND THE RIGHT NOT TO KNOW: GENETIC PRIVACY AND RESPONSIBILITY 24, 32–33 (Ruth Chadwick et al. eds., 2d ed. 2014). Some contemporary scholars have proposed the more modern concept of "open consent" to describe the willingness of individual participants to include their DNA profiles in a public domain database with open access, without any guarantee of privacy or confidentiality. *See, e.g.*, Jeantine E. Lunshof et al., *From Genetic Privacy to Open Consent*, 9 NATURE REVIEWS GENETICS 406, 406 (2008).

<sup>282</sup> See supra notes 198–99 (distinguishing privacy right to autonomous decision making from privacy right to control access to and disclosure of personal information).

<sup>283</sup> See Jacob Brogan, Who Owns Your Genetic Data After a Home DNA Test?, SLATE (May 23, 2017, 2:18 PM), https://slate.com/technology/2017/05/ances-trydnas-terms-and-conditions-sparked-a-debate-about-ownership-of-genetic-material.html (discussing the ownership implications of terms and conditions).

More than 12 million Americans have sent in their DNA to be analyzed to companies like 23andMe and AncestryDNA. The spit-in-tube DNA you send in is anonymized and used for

Ancestry Terms and Conditions]; Terms of Service, 23ANDME, https://www.23andme.com/about/tos/ (last updated Sept. 30, 2019) [hereinafter 23andMe Terms of Service] ("In order to use the Services, you must first agree to the TOS [Terms of Service]. You may not use the Services if you do not accept the TOS.").

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assures customers that "[a]t Ancestry<sup>®</sup>, your privacy is a top priority."<sup>284</sup> But its terms and conditions include an indemnity provision, by which the customer expressly waives any claim against Ancestry for invasion of privacy, among other specified tort claims.<sup>285</sup> If an Ancestry consumer does assert a claim, mandatory arbitration provisions apply.<sup>286</sup> And the customer must pay a fee of \$250 to initiate the arbitration process, which far exceeds the cost of the basic genetic testing service.<sup>287</sup> Terms and conditions for direct-to-consumer

genetic drug research and both sites have been selling the data to third-party companies . . . for some time. . . . Both companies say this is not without consent.

When you sign up to share your DNA with Ancestry, you opt-in for "informed consent research." However, you have the ability to opt out of this when you first agree to the service. Both 23andMe and Ancestry said that they will not share genetic information freely, without a court order, but people are welcome to share the information online themselves sometimes in order to find lost relatives or biological parents.

Nicole Martin, *How DNA Companies Like Ancestry and 23andMe Are Using Your Genetic Data*, FORBES (Dec. 5, 2018, 2:49 PM), https://www.forbes.com/sites/ni-colemartin1/2018/12/05/how-dna-companies-like-ancestry-and-23andme-are-us-ing-your-genetic-data/#1b6bbfa36189.

<sup>284</sup> *Your Privacy*, ANCESTRY, https://www.ancestry.com/cs/legal/ privacystatement (last visited Mar. 19, 2020).

<sup>285</sup> Ancestry Terms and Conditions, supra note 280 ("In addition, you release Ancestry from all claims, demands, actions, or suits in connection with your User Provided Content, including any liability related to our use or non-use of your User Provided Content, claims for defamation, invasion of privacy, right of publicity, emotional distress or economic loss."); see Clayton et al., supra note 220, at 18 ("[C]onsumers typically agree to terms and conditions that contain exclusion clauses that limit a company's liability or provisions that limit the remedies and damages available to the consumer.") (citing Andelka M. Phillips, *Reading the Fine Print When Buying Your Genetic Self Online: Direct-to-Consumer Genetic Testing Terms and Conditions*, 36 NEW GENETICS & SOC'Y 273, 282 (2017)).

<sup>286</sup> Ancestry Terms and Conditions, supra note 280 ("If any dispute between us is not resolved within 30 days after contacting us, then you and Ancestry agree that we will resolve it through final and binding arbitration . . . .").

<sup>287</sup> *Id.* ("<u>Fees</u>: You will be required to pay \$250 to initiate an arbitration against us. If the arbitrator finds the arbitration to be non-frivolous, Ancestry will pay all other fees invoiced by JAMS, including filing fees and arbitrator and hearing expenses. You are responsible for your own attorneys' fees unless the arbitration rules and/or applicable law provide otherwise."). As of March 2020, the undiscounted retail cost of an AncestryDNA genetic test is \$99. *Your DNA Reveals* 

genetic testing services also often allow access to customers' genomic data by third parties, including law enforcement.<sup>288</sup>

While the direct-to-consumer genetic testing industry is booming, it remains largely unregulated.<sup>289</sup> For certain kinds of healthrelated diagnostic tests, specifically those offered by 23andMe, the Food and Drug Administration has asserted regulatory authority over genetic testing services.<sup>290</sup> But on the whole, the direct-to-consumer genetic testing is essentially self-regulating with respect to genetic data collection and dissemination.<sup>291</sup>

[T]he rapidly growing use of consumer and other genetic testing services will soon make third-party access to an individual's genetic data commonplace and nearly unavoidable. Courts should act now . . . to protect the important Fourth Amendment interests implicated when the government seeks to access genetic data in third-party hands.

Id.

<sup>289</sup> Clayton et al., *supra* note 220, at 19.

290 Id. at 16-18; see Catherine M. Sharkey, Direct-to-Consumer Genetic Testing: The FDA's Dual Role as Safety and Health Information Regulator, 68 DEPAUL L. REV. 343, 358–59 (2019) (describing the FDA's evolving "hybrid" regulatory model); Direct-to-Consumer Tests, U.S. FOOD & DRUG ADMIN., https://www.fda.gov/medical-devices/vitro-diagnostics/direct-consumer-tests (last updated Dec. 20, 2019); see also Lindsey Jones, FDA Regulation Defines Business Strategy in Direct-to-Consumer Genetic Testing, BIOTECH CONNECTION BAY AREA (Oct. 30, 2017), https://biotechconnectionbay.org/view-points/fdaregulation-defines-business-strategy-in-direct-to-consumer-genetic-testing (explaining the various ways the FDA has regulated the industry, including current and future developments). "As the field of genomics advances, genetic and genomic tests are becoming more common .... Yet most genetic tests today are not regulated, meaning that they go to market without any independent analysis to verify the claims of the seller." Regulation of Genetic Tests, NAT'L HUM. GENOME RES. INST., https://www.genome.gov/about-genomics/policy-issues/Regulationof-Genetic-Tests (last updated Nov. 20, 2019) (explaining the limited scope of federal regulation).

<sup>291</sup> See Jean-Raphaël Champagne & Eliane Ellbogen, Genetic Testing and Privacy: What is the Code to Regulating Ours?, FASKEN (Sept. 13, 2018), https://www.fasken.com/en/knowledge/2018/09/privacy-cybersecuritybulletin-genetic-testing-and-privacy/ (noting that the growth in the industry is in

More than Ever Before—From Your Origins to Your Family's Health, ANCESTRY, https://www.ancestry.com/dna/ (last visited Mar. 19, 2020).

<sup>&</sup>lt;sup>288</sup> See Hazel & Slobogin, *supra* note 272, at 54–57; Natalie Ram, *Genetic Privacy After* Carpenter, 105 VA. L. REV. 1357, 1424 (2019) [hereinafter Ram, *Genetic Privacy*].

A 2018 study of the direct-to-consumer genetic testing industry concluded that customers are generally provided insufficient information to make an informed decision about whether to purchase ge-

> [T]he privacy policies of genetic testing companies are evidence of a larger problem with e-commerce, big data, and the internet of things. Arguably all of these industries might benefit from enhanced consumer privacy protections. . . . The goal should be achieving the right balance between consumer protection and informed consent so that privacy can be protected without unduly inhibiting the personal and research benefits that come from the free flow of genetic information.<sup>293</sup>

netic testing services from a particular testing provider.<sup>292</sup> The study

The industry is beginning to respond, in part to deflect policymakers' concerns about whether and how to regulate these services.<sup>294</sup> In 2018, an American privacy protection think tank known as the "Future of Privacy Forum" issued "best practices" guidelines for the direct-to-consumer genetic testing industry.<sup>295</sup> Those

concluded,

part due to the "lack of government regulation in countries where the majority of these companies are located, notably the United States and China"); Clayton et al., *supra* note 220, at 18. Some states have enacted statutes that regulate various aspects of these services, but limited federal regulation means that state regulations may have little practical effect on nationwide genetic testing services, especially if their terms and conditions include choice-of-law provisions and onerous waiver and arbitration clauses. *See generally* Helen C. Dick, Note, *Risk and Responsibility: State Regulation and Enforcement of the Direct-to-Consumer Genetic Testing Industry*, 6 ST. LOUIS U. J. HEALTH L. & POL'Y 167, 184, 189 (2012).

<sup>See Hazel & Slobogin, supra note 272, at 66.
Id</sup> 

<sup>&</sup>lt;sup>293</sup> *Id.* 

<sup>&</sup>lt;sup>294</sup> See, e.g., Champagne & Ellbogen, *supra* note 291.

<sup>&</sup>lt;sup>295</sup> See FUTURE OF PRIVACY FORUM, PRIVACY BEST PRACTICES FOR CONSUMER GENETIC TESTING SERVICES 1–2 (2018), https://fpf.org/wp-content/uploads/2018/07/Privacy-Best-Practices-for-Consumer-Genetic-Testing-Services-FINAL.pdf. The guidelines include detailed provisions for seeking a customer's express consent for collecting, analyzing, sharing, or reporting genetic data. *Id.* at 4–6.

guidelines encourage consumer education on the implications and consequences of genetic testing.<sup>296</sup> Several major companies have signaled their willingness to follow the guidelines, which are designed to ensure that industry practices are responsive to the increasingly complex privacy issues relating to genetic testing.<sup>297</sup> And in 2019, three of those genetic testing companies—Ancestry, 23andMe, and Helix—joined forces as the Coalition for Genetic Data Protection to support best practices and to "promote the industry in Washington as lawmakers put more scrutiny on their privacy practices."<sup>298</sup>

As the industry continues to expand and the technology becomes more accessible, it is vital that the industry acknowledges and addresses the risks posed to *individual* privacy when Genetic Data is generated in the consumer context. Given the potential benefits that consumer genetic and personal genomic testing can provide to Consumers and society, it is important that this data is subject to privacy controls and used responsibly.

*Id.* at 1 (emphasis added). Note that nothing in this purpose statement acknowledges the inherent privacy implications for *nonconsenting* genetic relatives of those individuals who, knowingly or not, give the genetic test provider "informed" consent to digitize their own DNA profiles. *Id.* 

<sup>296</sup> See id. at 10 ("Companies should inform Consumers about the basics of genetics and genetic testing; the risks, benefits, and limitations of genetic testing; and the appropriate interpretation and use of results.").

<sup>297</sup> Carson Martinez, *Privacy Best Practices for Consumer Genetic Testing Services*, FUTURE PRIVACY F. (July 31, 2018), https://fpf.org/2018/07/31/privacy-best-practices-for-consumer-genetic-testing-services/ (listing 23andMe, Ances-try, Helix, MyHeritage, Habit, African Ancestry, and Living DNA as having pledged to comply).

<sup>298</sup> Alex Gangitano, *DNA Testing Companies Launch New Privacy Coalition*, HILL (June 25, 2019, 6:00 AM),

https://thehill.com/regulation/lobbying/450124-dna-testing-companies-launchnew-privacy-coalition. *But see* David Lazarus, *Column: DNA-Testing Firms Are Lobbying to Limit Your Right to Genetic Privacy*, L.A. TIMES (July 2, 2019, 5:00 AM), https://www.latimes.com/business/lazarus/la-fi-lazarus-dna-genetic-

privacy-20190702-story.html (reporting that the coalition is actually run by a prominent lobbying firm that seeks to shape privacy laws and largely abides by an "honor system"). *See generally About CGDP*, COALITION FOR GENETIC DATA PROTECTION (last visited Mar. 12, 2019),

https://geneticdataprotection.com/about/ ("While we recognize the significant opportunities genetic testing and research present, we also support and advocate for reasonable and uniform privacy regulation that will ensure the responsible and ethical handling of every person's genetic data.").

While voluntary guidelines are a step in the right direction, they may not be enough to ensure that consumers are well informed about their rights to control access to their genetic data, including the rights they *expressly waive*—probably unknowingly—when purchasing genetic testing services and their digitized results.<sup>299</sup> If indeed the industry is not willing to self-regulate to better protect the privacy interests of consumers, Congress should step in with federal legislation to fill the void.<sup>300</sup>

But any yet-to-be-devised federal regulatory framework should also address the relational implications of the *individual* customer's "informed consent." The customer's decision implicates the privacy of genetic relatives, including those then unknown to the customer. Biological relatives' genetic identity and privacy are inherently compromised because of the proliferation of partial DNA matching techniques, not only in private DNA databases, but also in federal

<sup>&</sup>lt;sup>299</sup> See Terms and Conditions May Apply, YOUTUBE (July 13, 2013), https://www.youtube.com/watch?v=fzDgBITDaRY

<sup>(</sup>cautioning consumers about carefully reading lengthy terms and conditions posted online and stating that "[a]nything digitized is not private, and that's frightening"); see also Lily Rothman, New Documentary Tackles Online Privacy, TIME (July 11, 2013), http://entertainment.time.com/2013/07/11/new-documentary-tackles-online-privacy/ (reviewing the documentary film Terms And Conditions May Apply).

See Sarah F. Sunderman, The Need for Regulation of Direct-to-Consumer Genetic Testing in the United States: Assessing and Applying the German Policy Model, 12 WASH. U. GLOBAL STUD. L. REV. 357, 373, 378 (2013) (calling for the United States to "follow Germany's example by requiring satisfactory genetic counseling and enacting standardized laboratory procedure requirements" but not Germany's requirement that only physicians trained in genetic counseling may order genetic testing); Caroline F. Wright et al., Regulating Direct-to-Consumer Genetic Tests: What Is All the Fuss About?, 13 GENETICS MED. 295, 295, 300 (2011) (reporting "a lack of consensus as to the extent to which regulators should be involved, what minimum standards should and could be required across an international and predominantly internet-based market, and the role of legislation versus self-governance or voluntary guidance within an appropriate regulatory framework"; and recommending five "overarching principles" of regulation); cf. L. Kalokairinou et al., Legislation of Direct-to-Consumer Genetic Testing in Europe: A Fragmented Regulatory Landscape, 9 J. COMMUNITY GENETICS 117, 119 (2018) (reviewing regulations adopted by numerous European nations to regulate, restrict, or prohibit direct-to-consumer genetic testing).

and state forensic DNA databases.<sup>301</sup> As commentators have observed, "it is *not possible* to rely on individual informed consent to do all the ethical work in the context of developments such as genetic databases."<sup>302</sup>

# B. Forensic and Genetic Genealogy: Cold Cases and Partial DNA Matches

Familial searching builds on one of the most basic facts of genetics: DNA is shared among family members. As a result, a forensic DNA profile 'not only reveal[s] extensive genetic information about the individual whose "genetic fingerprint" is on file, but also about his or her close relatives.' Familial searching uses this principle to infer that someone whose DNA is a close, but not perfect, match to a

<sup>301</sup> See, e.g., Henry T. Greely et al., Family Ties: The Use of DNA Offender Databases to Catch Offenders' Kin, 34 J.L. MED. & ETHICS 248, 249, 255–59 (2006) (considering the legal and policy implications of using partial matches in forensic DNA databases to identify and investigate relatives, while acknowledging that "[t]he legal and policy implications of this kind of [familial forensic DNA searching] have been discussed only rarely and briefly"); Natalie Ram, The Mismatch Between Probable Cause and Partial Matching, 118 YALE L.J. POCKET PART 182, 183 (2009) ("[B]ecause close genetic relatives have similar 'genetic motifs,' a partial match between a crime scene sample and a stored genetic profile may also implicate family members."); Mary McCarthy, Note, Am I My Brother's Keeper?: Familial DNA Searches in the Twenty-First Century, 86 NOTRE DAME L. REV. 381, 398 (2011); Heather Murphy, Sooner or Later Your Cousin's DNA Is Going to Solve a Murder, N.Y. TIMES (Apr. 15, 2019), https://www.nytimes.com/2019/04/25/us/golden-state-killer-dna.html; Heather Murphy, How Your DNA Could Solve a Murder, WEEK (May 19, 2019), https://theweek.com/articles/841864/how-dna-could-solve-murder ("If you are an American, it is likely that your name can be extrapolated even if you have never taken a DNA test. In the hands of an advanced genealogical sleuth, often all that is needed to identify someone from a drop of saliva, blood, or semen are the DNA profiles of two third cousins.").

<sup>&</sup>lt;sup>302</sup> Ruth Chadwick, *The Philosophy of the Right to Know and the Right Not to Know, in* THE RIGHT TO KNOW AND THE RIGHT NOT TO KNOW: GENETIC PRIVACY AND RESPONSIBILITY *supra* note 281, at 13, 21–22 (emphasis in original).

# crime scene sample might be related to the of-fender.<sup>303</sup>

In 2018, DNA evidence was used to identify the elusive Golden State Killer as Joseph James DeAngelo.<sup>304</sup> He was arrested and prosecuted for committing a series of heinous rapes and murders during the 1970s and 1980s in six counties surrounding Sacramento, California.<sup>305</sup> Investigators uploaded the killer's DNA profile, generated by analyzing decades-old crime scene tissue samples, to a public domain genealogy website known as GEDmatch,<sup>306</sup> and then traced the DNA profile to two distant cousins using "partial match"

formed consent to such an exception.").

306 See Zoë Corbyn, How Taking a Home Genetics Test Could Help Catch a Murderer, GUARDIAN (Dec. 1, 2018, 12:00 PM), https://www.theguardian.com/science/2018/dec/01/how-home-dna-tests-are-solving-cold-casesgolden-state-killer (describing the controversy surrounding the use of the public domain GEDmatch database to identify the Golden State Killer). Once the story broke in the media in April 2018, the owner of GEDmatch, Curtis Rogers, faced a small exodus of users for allowing law enforcement access to the database without subscribers' consent. See id. In May 2019, GEDmatch changed its policy to disallow law enforcement use of the database unless a subscriber expressly opts in to permit that use. See Natalie Ram, The Genealogy Site That Helped Catch the Golden State Killer is Grappling with Privacy, SLATE (May 29, 2019, 7:30 AM), https://slate.com/technology/2019/05/gedmatch-dna-privacy-update-law-enforcement-genetic-geneology-searches.html; Judy G. Russell, GEDmatch Reverses Course, LEGAL GENEALOGIST (May 19, 2019), https://www.legalgenealogist.com/2019/05/19/gedmatch-reverses-course/ ("The change came after a firestorm over the decision of the site owners . . . to allow an exception to their published terms of use in a Utah case without informing site users or obtaining in-

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<sup>&</sup>lt;sup>303</sup> Suter, *supra* note 68, at 311 (citing Michelle Hibbert, *DNA Databanks: Law Enforcement's Greatest Surveillance Tool?*, 34 WAKE FOREST L. REV. 767, 782 (1999); Alice A. Noble, *DNA Fingerprinting & Civil Liberties*, 34 J.L. MED. & ETHICS 149, 150 (2006)).

<sup>&</sup>lt;sup>304</sup> See Wamsley, supra note 7.

<sup>&</sup>lt;sup>305</sup> See Darrell Smith, Golden State Killer/East Area Rapist Suspect in Court as His Lawyers Call for Long Delay, SACRAMENTO BEE (Aug. 22, 2019, 3:39 PM), https://www.sacbee.com/news/local/crime/article234280297.html. As this Article went to press, DeAngelo offered to plead guilty in exchange for a life sentence. He faces the death penalty if convicted. Michael Levenson & Heather Murphy, Golden State Killer Suspect Offers to Plead Guilty, N.Y. TIMES (Mar. 4, 2020), https://www.nytimes.com/2020/03/04/us/golden-state-killer-trial.html.

methodology.<sup>307</sup> Having narrowed down the possible suspects to one male with the expertise of a genetic genealogist,<sup>308</sup> investigators secured a paper cup DeAngelo had discarded, analyzed the DNA from the saliva sample, and found a direct match with the stored DNA that police had taken from the Golden State Killer's crime scenes.<sup>309</sup>

Law enforcement investigators have used DNA as a forensic tool for decades.<sup>310</sup> Beginning in the mid-1990s, the Federal Bureau

<sup>310</sup> See generally, e.g., Hibbert, supra note 303, at 773–78.

<sup>307</sup> See Adhiti Bandlamudi, Tactics Used to Find Golden State Killer Raise Privacy and Legal Questions, NPR (Apr. 27, 2018, 4:22 PM), https://www.npr.org/2018/04/27/606580162/tactics-used-to-find-golden-statekiller-raise-privacy-and-legal-questions (explaining how law enforcement compared DNA crime scene samples to online digitized DNA profiles uploaded by DeAngelo's genetic relatives to GEDmatch, a public domain genealogy website, to identify DeAngelo without first securing a search warrant); Partial Matches: CODIS Searches and Partial Matches, Cont., NAT'L INST. JUST., https://projects.nfstc.org/fse/12/12-03.html (last visited Mar. 13, 2020) ("A partial match occurs when the [individual DNA database profile] is excluded as the perpetrator because it does not match the crime scene profile, but the analyst identifies a sufficient number of alleles in common between the [individual DNA profile] and crime scene profile to believe that a family member [of the individual] may be the true perpetrator."); Jeremy W. Peters, New Rule Allows Use of Partial DNA Matches. N.Y. TIMES (Jan. 24, 2010), https://www.nytimes.com/2010/01/25/nyregion/25dna.html\_(reporting the adoption of a New York rule in December 2009 allowing partial DNA matches to identify perpetrators and quoting forensic experts as explaining that "[s]ince family members share genetic traits, a partial DNA match allows investigators to narrow searches to relatives of people whose DNA is already in the state database"); see also Ram, Genetic Privacy, supra note 288, at 1359-60 (explaining the forensic use of partial match methodology); Ram, DNA by the Entirety, supra note 5, at 882 ("[S]ource-excluding partial matches may . . . inculpate the offender's close genetic relatives as possible perpetrators of a crime.").

<sup>&</sup>lt;sup>308</sup> See Corbyn, supra note 306. While the two distant cousins were each genetically related to DeAngelo, they were not related to one another. See *id*. Tracing them to the killer required a genetic genealogist to research the respective family histories of both distant cousins to identify an intermarriage between the two family lines. See *id*. Once that marriage was identified, other records led to a family with four offspring, including one male. See *id*. Ms. Corbyn explains more about the genetic genealogy process of "triangulation" in her *Guardian* article. See *id*.

<sup>&</sup>lt;sup>309</sup> Roberta Estes, *The Golden State Killer and DNA*, DNAEXPLAINED (Apr. 30, 2018), https://dna-explained.com/2018/04/30/the-golden-state-killer-and-dna/.

of Investigation ("FBI") and its state counterparts built DNA profile databases using samples taken from convicted criminals, crime scenes, and unidentified human remains.<sup>311</sup> The "familial searching" methodology using partial DNA matches was first used in the mid-2000s.<sup>312</sup> In 2006, investigators in the United Kingdom used the technique to identify the "Dearne Valley Shoe Rapist," who had committed a series of offenses two decades earlier using a unique modus operandi—tying up the victims with their stockings and then absconding with their stiletto heels.<sup>313</sup>

In February 2005, a variation of familial searching was used to identify, prosecute, and eventually convict the "BTK Killer," who had eluded police in Wichita, Kansas, for decades.<sup>314</sup> He was identified after he sent local police a message on a floppy computer disk, which was digitally traced to a local church's computer. Police narrowed the investigation to Dennis Rader, who attended the church.<sup>315</sup> To confirm his identify, investigators obtained a warrant to recover a biological tissue sample taken from Rader's daughter, Kerri Rawson, during a routine diagnostic test at a university health clinic.<sup>316</sup> The BTK Killer's identity was confirmed by the partial match of his daughter's DNA with the perpetrator's crime scene

After visiting two of the forty-three individuals with partial matches, a police officer knocked on the door of June Lloyd and told her, "We're running a cold case investigation and there are some similarities between your DNA and the offender's DNA. Do you mind telling me, have you got any brothers?"

<sup>315</sup> *Id.* at 48.

<sup>316</sup> *Id.* 

<sup>&</sup>lt;sup>311</sup> See id.; see also DNA Identification Act of 1994, Pub. L. No. 103-322, § 210304, 108 Stat. 2065, 2069 (1994) (codified as amended at 34 U.S.C. § 12592).

<sup>&</sup>lt;sup>312</sup> See, e.g., Suter, *supra* note 68, at 310 ("[I]n 2006, investigators turned to a new technology called familial searching to identify local individuals in the DNA database whose genetic profile closely matched the crime scene evidence, suggesting they might be related to the rapist.").

<sup>&</sup>lt;sup>313</sup> See id.

*Id.* To her surprise, June Lloyd's only brother, James Lloyd, turned out to be the rapist. *Id.* He was later convicted for four rapes and two attempted rapes. *Id.* 

<sup>&</sup>lt;sup>314</sup> See Mark Hansen, *How the Cops Caught BTK: Playing to a Serial Killer's Ego Helped Crack the Case*, A.B.A. J., Apr. 2006, at 44, 45, 47–48. "BTK Killer" was the moniker adopted by the unidentified serial murderer himself based on his modus operandi: to "bind, torture, and kill" his victims. *Id.* at 45.

DNA.<sup>317</sup> At the age of twenty-six, Rawson learned from an FBI agent, who visited her home unannounced, that her beloved father was the serial killer known as BTK, whom police had been searching for since the mid-1970s.<sup>318</sup>

Familial searching like that used to confirm the identity of the BTK Killer raises other ethical and legal questions, such the rightful owner of a biological tissue sample taken from a medical patient. *See* Suter, *supra* note 68, at 251. The ethical and legal issues concerning excised human tissue were the subject of a best-selling book telling the story of Henrietta Lacks, a young mother who died of cervical cancer in 1951. *See* REBECCA SKLOOT, THE IMMORTAL LIFE OF HENRIETTA LACKS 3 (2010). While Lacks was still living, and apparently without her express consent, tissue samples were taken from her tumor by a Johns Hopkins University Hospital physician. *See id.* at 33. The tumor cells were later used to develop a cell line that has been the source of numerous innovative therapeutic medical interventions, all highly lucrative. *See id.* at 99–104. Her surviving spouse and children were never told by anyone in the medical community, and they never shared in the profits derived by medical researchers from the resulting "HeLa" cell line. *See id.* at 194–95.

Courts have seldom addressed disputes about the ownership rights to biological tissue samples. See, e.g., Ram, DNA by the Entirety, supra note 5, at 891. The few that have done so address the question from a variety of perspectives, but no court has held that the individual from whom the tissue is taken retains any ownership interests. See, e.g., Wash. Univ. v. Catalona, 490 F.3d 667, 673-74 (8th Cir. 2007) (applying Missouri law to hold that medical research participants made an "informed decision" and expressly intended to make a gift of their biological materials, and the University accepted them); Moore v. Regents of Univ. of Cal., 793 P.2d 479, 497 (Cal. 1990) (applying California law to find that tissue donor failed to state a claim against University and its physician for conversion of tissue samples, but he could pursue his claims against his physician for breach of fiduciary duty and failure to obtain his informed consent); see also E. RICHARD GOLD, BODY PARTS: PROPERTY RIGHTS AND THE OWNERSHIP OF HUMAN BIOLOGICAL MATERIALS 23-40 (1996) (discussing *Moore* and the "property debate" over biological tissue). See generally Gary E. Marchant, Property Rights and Benefit-Sharing for DNA Donors?, 45 JURIMETRICS 153, 153 (2005) (challenging the "traditional assumption" that "the donors of genetic material used in research act altruistically and are entitled to no property rights or direct benefit-sharing in the fruits of the research").

But in the context of DNA testing, the issue is not who owns the tissue sample itself, but rather who controls the use and dissemination of the DNA *profile*—the

<sup>&</sup>lt;sup>317</sup> *Id. See generally* KERRI RAWSON, A SERIAL KILLER'S DAUGHTER: MY STORY OF FAITH, LOVE, AND OVERCOMING (2019).

<sup>&</sup>lt;sup>318</sup> See RAWSON, supra note 317, at 6–7; see also A Serial Killer's Daughter: Watch the Trailer, THOMAS NELSON, https://www.thomasnelson.com/p/a-serialkillers-daughter/#trailer (last visited Mar. 13, 2020) (promoting the book release).

In 2013, the Supreme Court held that taking a DNA sample from an arrestee, even if only for identification purposes, qualifies as a Fourth Amendment "search."<sup>319</sup> However, the Court held that no warrant was necessary to conduct a relatively non-intrusive DNA cheek swab search in a hospital setting after the defendant had been arrested for a serious felony offense for which he was later convicted.<sup>320</sup> Some courts have followed similar reasoning to uphold

319 See Maryland v. King, 569 U.S. 435, 446 (2013) ("It can be agreed that using a buccal swab on the inner tissues of a person's cheek in order to obtain DNA samples is a search.").

<sup>320</sup> *Id.* at 451 (analogizing the use of DNA for identifying an arrestee to "the accepted use of fingerprint databases," while acknowledging that DNA provides "unparalleled accuracy" and that "DNA collected from arrestees is an irrefutable identification of the person from whom it was taken").

information derived from an individual's biological tissue. See Suter, supra note 68, at 332–34 (highlighting the importance that information can have on protecting "personhood interests"). The ability or inability to control that information raises serious privacy implications for the DNA subject and arguably her biological relatives, whether known or unknown. See, e.g., United States v. Comprehensive Drug Testing, Inc., 513 F.3d 1085, 1104 (9th Cir. 2008) (acknowledging in dicta professional baseball players' "strong privacy interests" in urine specimens and associated drug test results); Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1269 (9th Cir. 1998) (upholding invasion of privacy claim by government employees whose blood and urine samples were tested for sickle cell anemia and syphilis without their consent); Havasupai Tribe of Havasupai Reservation v. Ariz. Bd. of Regents, 204 P.3d 1063, 1076 (Ariz. Ct. App. 2008) (stating in dicta that "invasions of privacy relating to tissue samples such as the Tribe described in its claim notices naturally give rise to subjective personal injury, even when, as here, the samples are given voluntarily"); Doe v. High-Tech Inst., Inc., 972 P.2d 1060, 1064 (Colo. App. 1998) (upholding invasion of privacy claim by student whose blood sample was tested for HIV virus without his consent), as modified on denial of reh'g (Aug. 6, 1998).

Similarly, when law enforcement seizes tissue samples to create DNA profiles, inchoate and abstract informational privacy issues are implicated-of the sort that cannot be resolved by concepts of property law and economics. See, e.g., Birchfield v. North Dakota, 136 S. Ct. 2160, 2177 (2016) (holding that police may administer a breath test, but not a blood test, during a warrantless search incident to an arrest for drunk driving; analogizing a blood sample to a DNA sample "from which a wealth of additional, highly personal information could potentially be obtained," while a breath test leaves nothing for police to retain); United States v. Davis, 690 F.3d 226, 243–44 (4th Cir. 2012) (observing that "an analysis required to obtain a DNA profile . . . generally qualifies as a search, because an individual retains a legitimate expectation of privacy in the information obtained from the testing").

body-tissue samples taken from a broad array of criminal offenders or *suspects*, including "nonviolent felons, misdemeanants, and even arrestees."<sup>321</sup> On the other hand, the Fourth Circuit has held that a DNA profile generated from a tissue sample taken from a crime *victim*'s clothing at the scene is an unconstitutional search.<sup>322</sup> The court reasoned that a crime victim has a higher expectation of privacy than a criminal suspect.<sup>323</sup>

The Justice Department has recently initiated a proposed rule amendment that would effectively require DNA testing of non-U.S. citizens. In October 2019, the Trump Administration announced its intent to take DNA samples from immigrants detained when crossing the United States border.<sup>324</sup> That new policy suggests that

324 See Bobby Allyn & Joel Rose, Justice Department Announces Plan to Collect DNA From Migrants Crossing the Border, NPR (Oct. 21, 2019, 5:20 PM), https://www.npr.org/2019/10/21/772035602/justice-department-announces-planto-collect-dna-from-migrants-crossing-the-bord. A current Department of Justice regulation provides that "[a]ny agency of the United States that arrests or detains individuals or supervises individuals facing charges shall collect DNA samples from individuals who are arrested, facing charges, or convicted, and from non-United States persons who are detained . . . . " 28 C.F.R. § 28.12(b) (2019) (emphasis added). "Non-United States persons" are defined as "persons who are not United States citizens and who are not lawfully admitted for permanent residence." Id. However, the DNA sampling requirements "do not include, except to the extent provided by the Secretary of Homeland Security . . . aliens with respect to whom the Secretary ..., in consultation with the Attorney General, determines that the collection of DNA samples is not feasible because of operational exigencies or resource limitations." Id. § 28.12(b)(4). The proposed new rule would rescind subsection (b)(4). See DNA-Sample Collection from Immigration Detainees, 84 Fed. Reg. 56397, 56398 (proposed Oct. 22, 2019) (to be codified at 28 C.F.R. § 28.12). The proposed rule would effectively require DNA sampling from most non-citizen detainees except those lawfully admitted for permanent residence. See id. The justification for amending the rule was explained, in part, as follows:

<sup>&</sup>lt;sup>321</sup> Suter, *supra* note 68, at 311.

<sup>&</sup>lt;sup>322</sup> See Davis, 690 F.3d at 246 ("[A] victim retains a privacy interest in his or her DNA material, even if it is lawfully in police custody.").

<sup>&</sup>lt;sup>323</sup> See id. at 245–46 (noting that "a court's constitutional analysis may differ depending on whether the person is an arrestee or a 'free person,'" and that "extraction of DNA and the creation of a DNA profile result in a sufficiently separate invasion of privacy that such acts must be considered a separate search... even when there is no issue concerning the collection of the DNA sample") (citations omitted).

federal courts will soon confront thornier questions about the propriety, under the Fourth Amendment, of DNA sampling by immigration law enforcement officers without individualized suspicion of criminal activity.<sup>325</sup> The most troubling aspect of the Justice Department's rationale for amending the rule is its expressed assumption that immigrants, other than those who enter lawfully for permanent residence, *categorically* pose a risk of criminal activity as great as federal arrestees or convicted offenders.<sup>326</sup> Moreover, categorical

> [In 2010,] Secretary of Homeland Security Janet A. Napolitano advised . . . that categorical DNA collection from aliens in this class was not feasible, on the grounds described in § 28.12(b)(4). However, subsequent developments have resulted in fundamental changes in the cost and ease of DNA-sample collection. DNA-sample collection from persons taken into or held in custody is no longer a novelty. Rather, pursuant to the mandate of § 28.12(b), it is now carried out as a routine booking measure, parallel to fingerprinting, by Federal agencies on a government-wide basis. The established DNA-collection procedures applied to persons arrested or held on criminal charges can likewise be applied to persons apprehended for immigration violations.

Id. at 56398-99.

[The] proposed rule's removal of the authorized exception to DNA collection for certain detained aliens appearing in 28 CFR 28.12(b)(4) will help to ensure that . . . DNA technology will be consistently utilized to further public safety and the interests of justice in relation to immigration detainees, as has long been the case in relation to [federal] criminal arrestees, defendants, and convicts . . . .

#### Id. at 56400.

325 See Carpenter v. United States, 138 S. Ct. 2206, 2221 (2018) ("The Court usually requires 'some quantum of individualized suspicion' before a search or seizure may take place."") (quoting United States v. Martinez-Fuerte, 428 U.S. 543, 560-61 (1976)); see also United States v. Davis, 690 F.3d 226, 244 (4th Cir. 2012) ("[O]ur precedent and . . . decisions of our sister circuits . . . uniformly recognize that persons who have not been arrested [such as crime victims] have a greater privacy interest in their DNA than would persons who have been arrested . . . .").

<sup>326</sup> See DNA-Sample Collection from Immigration Detainees, 84 Fed. Reg. at 56399.

> [D]istinguishing the treatment of criminal arrestees and immigration detainees with respect to DNA identification is largely artificial, in that most immigration detainees are held on the

DNA testing of non-U.S. citizens at the border will undoubtably advance the Trump Administration's ability to identify, investigate, and prosecute a detainees' *relatives* who may have already immigrated to the United States, whether lawfully or unlawfully.

As this Article went to press, law enforcement access to private DNA databases took yet another turn. As noted above, GEDmatch took steps in May 2019 to protect the privacy of non-consenting subscribers by barring law enforcement access to their DNA profiles while allowing consenting subscribers to expressly opt in.<sup>327</sup> Nevertheless, in late October 2019, a Florida trial court judge issued a search warrant that authorized a detective to search the entire GEDmatch database, including the DNA profiles of subscribers who had not consented to law enforcement access.<sup>328</sup> Reporters sought a comment from New York University Law Professor Erin Murphy, who noted that "[t]he company made a decision to keep law enforcement out, and that's been overridden by a court. It's a signal that no genetic information can be safe." <sup>329</sup>

basis of conduct that is itself criminal. Aliens who are apprehended following illegal entry have likely committed crimes under the immigration laws, such as 8 U.S.C. [§§] 1325(a) and 1326, for which they can be prosecuted. . . . The practical difference between criminal arrestees and immigration detainees, for purposes of DNA-sample collection, has been further eroded through policies favoring increased prosecution for immigration violations.

*Id.* Of course, "policies favoring increased prosecution for immigration violations" are code words for the Trump Administration's onerous policies deterring immigration. *See, e.g.*, Priscilla Alvarez, *ICE Ramps up DNA Testing for Migrant Families Along the Southern Border*, CNN (July 22, 2019, 6:51 PM), https://www.cnn.com/2019/07/22/politics/ice-deploys-dna-testing-at-border/index.html ("The implementation of DNA testing along parts of the US-Mexico border is part of a concerted effort by the Trump administration to crack down on illegal immigration, as the number of apprehensions at the border continue to outpace recent years.").

<sup>327</sup> See Russell, supra note 306.

<sup>328</sup> Kashmir Hill & Heather Murphy, Your DNA Profile is Private? A Florida Judge Just Said Otherwise, N.Y. TIMES (Nov. 5, 2019), https://www.ny-times.com/2019/11/05/business/dna-database-search-warrant.html?auth=login-email&login=email.

<sup>329</sup> *Id.*; *see also* Scott Simon, *Privacy and DNA Tests*, NPR (Nov. 9, 2019, 8:12 AM), https://www.npr.org/2019/11/09/777888000/privacy-and-dna-tests (interviewing Professor Erin Murphy regarding the privacy ramifications of the Florida search warrant).

As this discussion demonstrates, forensic familial searching using partial DNA matches has become a powerful law enforcement tool. If extended to private DNA databases, whether public domain or proprietary, the use of forensic genealogy significantly expands the universe of DNA profiles accessible to law enforcement. That universe potentially includes millions of individuals who are merely genetically related to a suspect, arrestee, or detainee, but who are not themselves suspected of any criminal activity.

The possible public benefits of solving "cold cases" using these techniques should neither eclipse nor overshadow the serious privacy implications. Those who willingly share DNA with proprietary genealogy databases are most likely unaware that without clear restrictions, criminal investigators have the ability to access their DNA profiles, without customers' knowledge, for use in identifying genetic relatives who are (or may be) suspected of criminal conduct. The latest move by the Trump Administration threatens to further expand the DNA universe accessible to law enforcement, raising the specter that the United States will one day have a "de facto" national DNA database from which none of us—including our genetic identities—can ever escape.<sup>330</sup>

[Law enforcement use of consumer genetics platforms for the] identification of individuals who are not directly included in a genetic database runs afoul of any given reason [justifying] law enforcement use of such databases [as] legally and ethically acceptable. These individuals have not previously been arrested or convicted of a crime. Nor have they "volunteered" their DNA on a consumer genetics platform. Instead, like millions of ordinary Americans, these individuals are identifiable to police through the genetic data of their kin. Few genetic relationships, however, are voluntary. Even if parents can be said to voluntarily choose to have children, children plainly do not choose their parents. Nor do we choose our siblings, cousins, or more distant relatives—if we even know who they are.

*Id.*; *cf.* Havasupai Tribe of Havasupai Reservation v. Ariz. Bd. of Regents, 204 P.3d 1063, 1076 (Ariz. Ct. App. 2008) (discussing Native American tribe's privacy interests when members' blood samples were used for population research beyond the scope of written consent); Donna M. Gitter, *The Ethics of Big Data in Genomics: The Instructive Icelandic Saga of the Incidentalome*, 18 WASH. U. GLOBAL STUD. L. REV. 351, 354 (2019) (providing a fascinating account of the ethical and legal issues arising from a DNA database, built by a private firm under a twelve-year government license, that included virtually all Icelandic citizens).

<sup>&</sup>lt;sup>330</sup> See Ram, U.S. DNA Database, supra note 5.

# C. Assisted Reproductive Technology: Balancing a Child's Right to Know, a Donor's Right to Anonymity, and the Parents' Right to Keep Family Secrets

When author Dani Shapiro was in her mid-fifties, her husband decided to order a DNA profile from a popular genealogical testing service to learn more about his family's medical history.<sup>331</sup> He prompted her to do the same, and she agreed. Little did she know that the results would reveal a family secret that her deceased parents had taken to their graves several years before. Shapiro's only sibling was an older half-sister Susie, born to their father and his first wife years before he married Shapiro's mother. While she never felt close to her mother, Shapiro had always been particularly fond of her late father, who had descended from a long line of European Ashkenazi Jews. Shapiro took pride in the religious and ethnic heritage she shared with her father, and she treasured the family mementos and stories about her paternal ancestors.

Several weeks after sending in her saliva sample, Shapiro's DNA profile arrived. The results showing her statistically-probable ethnicity raised some nagging questions. She contacted her half-sister Susie to inquire whether she had ever had a genetic test and learned that she had. Susie located her own DNA profile and emailed it to Shapiro. To her shock, a side-by-side comparison of the two DNA profiles unequivocally reflected that the two women were not half-sisters after all. The only plausible conclusion that would reconcile the results was that Shapiro was not the biological child of her father.

Shapiro then remembered a fleeting conversation with her mother decades before when Shapiro was twenty-five years old. Her father had recently died in a car accident, and her mother was still recovering from the serious injuries she had suffered in the same accident. In response to Shapiro's question about something her mother had let slip in a casual conversation with an acquaintance, her mother mentioned that Shapiro had been conceived by means of artificial insemination at a "world-famous institute" after her parents had difficulty conceiving a child. Her mother, then in her late 30s,

<sup>&</sup>lt;sup>331</sup> See generally DANI SHAPIRO, INHERITANCE: A MEMOIR OF GENEALOGY, PATERNITY, AND LOVE (2019). The author's story, briefly summarized in this section, is well documented in the book.

had suffered a series of miscarriages, and her father was told he had "slow sperm." Shapiro's mother described how the doctor had carefully monitored her ovulation cycles to identify the optimum moment for conception, and then summoned her father away from work to provide a sperm sample for his wife's insemination procedure. Eventually her mother became pregnant and gave birth to Shapiro in the late 1950s.

Over the nearly three decades since that conversation with her mother, Shapiro had adjusted to the idea that she had been conceived with the assistance of a then-experimental clinical procedure. The family's traditional religious beliefs would never have entertained the possibility that Shapiro's conception was not the product of her father's own sperm sample. But now, she was stunned to learn from her DNA profile that she was not the half-sister of her father's only other child.

Shapiro would soon learn from comparing her own DNA results against the online database that she had a biological first cousin with an unfamiliar name. After a flurry of activity over the next twentyfour hours, Shapiro and her husband were able to trace her DNA results against partial matches from family trees that others had uploaded to the genealogy website. She also found an obituary online. With the help of a genealogist friend, Shapiro was able to narrow down the possible candidates who might be her biological father to the two uncles of her biological first cousin. One turned out to be a retired surgeon who had graduated from medical school in the 1950s in the same city where the "world-famous" fertility institute had been located.

After Shapiro and her husband tracked the surgeon down online, they found an internet video of a presentation he had given at an Oregon college. To their shock, the retired surgeon's facial features, coloring, and mannerisms were nearly mirror-images of Shapiro's own.

The rest of Shapiro's story details the personal identity upheaval and mixed emotions she experienced over many months as a result of learning that her long-deceased beloved father was not her biological father after all. Her experience raises questions about whether a child conceived by artificial insemination has a right to know her origins, and whether she has a right to know the identity of her biological parents and their medical history. It also raises

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serious issues about her biological father's right to remain anonymous, consistent with the assurances sperm donors typically receive by sperm banks in exchange for a waiver of parental rights and a disclaimer of parental responsibilities for the prospective child.

Shapiro eventually worked up the courage to contact her biological father by email, expressing her desire to meet him. Long married with a family of his own, the retired surgeon at first politely declined. But many months later, after she reached out again, he reconsidered. Ultimately, Shapiro's biological father and his wife agreed to meet Shapiro and her husband over lunch at a neutral location, and they have enjoyed a cordial relationship since then.

Dani Shapiro's 2019 book, *Inheritance: A Memoir of Geneal*ogy, Paternity, and Love,<sup>332</sup> chronicles her devastating emotional reaction when she learned from her DNA results what she probably never expected to learn nor ever wanted to know: that she was not the biological daughter of her long-deceased father, but rather the offspring of her parents' decision to conceive by artificial insemination. For a long time after she learned the truth, she felt betrayed by both her parents and the family secret they had kept from her about her true identity. But eventually, she came to realize that they had both wanted a child of their own so much that after her birth, they had simply refused to consciously acknowledge that she was not her father's biological child.

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The various methods of biological procreation that some scholars have aptly called "collaborative reproduction" raise a number of provocative issues about the potentially conflicting rights of the participants.<sup>333</sup> Most scholarship to date has focused on the prospective

<sup>&</sup>lt;sup>332</sup> *Id.; see also* Grow Through It, *Dani Shapiro on Growing Through a Family Secret*, YOUTUBE (Feb. 20, 2019), https://www.youtube.com/

watch?v=g61SQM3ppwo (describing the "crisis of personhood" Shapiro experienced after learning the truth—that secrets are "corrosive and toxic" and that "we can be formed by what we don't know as well as what we do know"); Politics and Prose, *Dani Shapiro*, *"Inheritance"*, YOUTUBE (July 13, 2019), https://www.youtube.com/watch?v=yNUsQvhj-xg (book promotional interview).

<sup>&</sup>lt;sup>333</sup> See, e.g., John Lawrence Hill, What Does It Mean to Be A "Parent"? The Claims of Biology as the Basis for Parental Rights, 66 N.Y.U. L. REV. 353, 357 (1991).

parents' rights to procreational autonomy,<sup>334</sup> and the possible tension between those rights and the interests of third-party contributors of biological material.<sup>335</sup> Third-party contributors facilitate couples' nontraditional procreational choices by contributing gametes or embryos,<sup>336</sup> or, in the case of surrogacy parenting, by providing a

*Id.* at 355 & tbl.10 (representing the various combinations of collaborative reproduction).

334 See, e.g., Allison Morse, Good Science, Bad Law: A "Multiple Balancing" Approach to Adjudication, 46 S.D. L. Rev. 410, 425–26, 425 n.83 (2001) (noting that, among many others, relational interests are aspects of the right of privacy and citing cases in support); Rao, Reconceiving Privacy, supra note 68, at 1102-03 ("Privacy should be viewed as a relational right that 'afford[s] the formation and preservation of certain kinds of highly personal relationships a substantial measure of sanctuary from unjustified interference by the State."") (quoting Roberts v. U.S. Jaycees, 468 U.S. 609, 618 (1984)); John A. Robertson, Assisted Reproductive Technology and the Family, 47 HASTINGS L.J. 911, 915 (1996) (positing that the fundamental constitutional right to procreational privacy should apply equally to ART); see also supra notes 198–99 and accompanying text (distinguishing the right to make autonomous decisions about exercising fundamental rights such as marriage and procreation and the more nebulous legal foundations for the right to informational privacy); cf. Sirpa Soini et al., The Interface Between Assisted Reproductive Technologies and Genetics: Technical, Social, Ethical and Legal Issues, 14 EUROPEAN J. HUM. GENETICS 588, 591, 601 (2006) (observing that genetic tests potentially have "far-reaching repercussions for the patients, and sometimes for immediate and extended family," and that "[g]enerally agreed principles on the extent and quality of the family history asked from a prospective donor do not exist").

<sup>335</sup> See, e.g., Glenn Cohen, The Constitution and the Rights Not to Procreate, 60 STAN. L. REV. 1135, 1148–67 (2008); I. Glenn Cohen, The Right Not to Be a Genetic Parent, 81 S. CAL. L. REV. 1115, 1145–61 (2008); Browne Lewis, Two Fathers, One Dad: Allocating the Paternal Obligations Between the Men Involved in the Artificial Insemination Process, 13 LEWIS & CLARK L. REV. 949, 972–79 (2009).

<sup>336</sup> Recent calls have been made for the Commission on Uniform State Laws to study the need for a uniform law or model legislation that would regulate the disposition of human embryos and gametes. *See, e.g.*, Richard Vaughn, *Uniform* 

We now live in an era where a child may have as many as five different "parents." These include a sperm donor, an egg donor, a surrogate or gestational host, and two nonbiologically related individuals who intend to raise the child. Indeed, the process of procreation itself has become so fragmented by the variety and combinations of collaborative-reproductive methods that there are a total of sixteen different reproductive combinations, in addition to traditional conception and childbirth.

natural environment for bringing an implanted embryo to a healthy birth.<sup>337</sup>

But scholarship is relatively sparse with respect to the *informational* privacy rights of either the offspring<sup>338</sup> of assisted

Some courts have treated preserved embryos differently than other kinds of human tissue.

Courts have always struggled with characterizing embryos in disputes over their possession or use; the context of the dispute matters and often leads directly to the outcome. A number of courts have considered them a special kind of property or in some cases, *sui generis*, stating they are deserving of special treatment; in the divorce context most courts have considered them a unique form of joint or marital property that could not simply be valued and divided down the middle, with equal shares going to each party.

Id. at 68 (citing and discussing cases).

<sup>337</sup> See generally Pamela Laufer-Ukeles, *Collaborative Family-Making: From Acquisition to Interconnection*, 64 VILL. L. REV. 223, 224 (2019).

338 For examples of scholarship about the offspring of ART, see generally Helen M. Alvaré, The Case for Regulating Collaborative Reproduction: A Children's Rights Perspective, 40 HARV. J. LEGIS. 1 (2003); Pamela Laufer-Ukeles, The Lost Children: When the Right to Children Conflicts with the Rights of Children, 8 L. & ETHICS HUM. RTS. 219 (2014); J. Brad Reich & Dawn Swink, You Can't Put the Genie Back in the Bottle: Potential Rights and Obligations of Egg Donors in the Cyberprocreation Era, 20 ALB. L.J. SCI. & TECH. 1 (2010); Jennifer L. Rosato, The Children of ART (Assisted Reproductive Technology): Should the Law Protect Them from Harm?, 2004 UTAH L. REV. 57; Catherine A. Clements, What About the Children? A Call for Regulation of Assisted Reproductive Technology, 84 IND. L.J. 331 (2009); cf. Kathryn Webb Bradley, Surrogacy and Sovereignty: Safeguarding the Interest of Both the Child and the State, 43 N.C. J. INT'L L. 1 (2018). Scholars in other fields, however, have recognized the unique effects on children who are conceived by ART and on their interrelationships with parents and gamete donors. See generally, e.g., Susan Golombok et al., Children Conceived by Gamete Donation: Psychological Adjustment and Mother-Child Relationships at Age 7, 25 J. FAM. PSYCHOL. 230 (2011).

Laws Needed to Regulate Abandoned Embryos, INT'L FERTILITY L. GROUP (Aug. 26, 2019, 4:10 PM), https://www.iflg.net/laws-needed-abandoned-embryos/; Memorandum from JEB UFL Chair Barbara Atwood & Reporter Linda Elrod to Unif. L. Comm'n Comm. on Scope & Program (Nov. 30, 2018), https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?Document-FileKey=324180e7-0408-9fdf-28a6-bdec13bb7fbb (citing *In re* Marriage of

Rooks, 429 P.3d 579 (Colo. 2018); Gary A. Debele & Susan L. Crockin, *Legal Issues Surrounding Embryos and Gametes: What Family Law Practitioners Need to Know*, 31 J. AM. ACAD. MATRIM. LAW. 55 (2018)).

reproductive technology ("ART"),<sup>339</sup> or third-party contributors such as gamete donors or surrogate mothers.<sup>340</sup> As one author has observed,

[t]here are multiple levels of secrecy and disclosure in the donor world. First, many donor-conceived offspring simply do not know that they are donor-conceived. A second level concerns the layers of secrecy between offspring, donors, and parents who have used donor gametes. The secrecy that pervades this world is the product of cultural norms and contracts, not constitutional principles or legislative decision making. While donors and parents may have signed agreements pertaining to anonymity, very few court opinions have interpreted the validity, and applicability, of these documents.<sup>341</sup>

United States caselaw is even more sparse than legal scholarship pertaining to the respective informational privacy interests of the various participants in collaborative reproduction. The California Supreme Court tangentially addressed the issue in 2000 in the context of a discovery dispute.<sup>342</sup> Acknowledging that the case

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<sup>&</sup>lt;sup>339</sup> The two principal types of ART are in vitro fertilization ("IVF") and donorassisted artificial insemination ("AID"). *See* JUDITH DARR, THE NEW EUGENICS: SELECTIVE BREEDING IN AN ERA OF REPRODUCTIVE TECHNOLOGIES 9–13 (2017). Together, IVF and AID account for three percent of the births in the United States. *Id.* at 9. AID alone accounts for some 60,000 births annually. *Id.* at 8.

<sup>&</sup>lt;sup>340</sup> See Alvaré, supra note 338, at 1, 42–44 (noting that while interests of children warrant consideration in analyzing parents' rights to elect these alternatives, "the effects on children born through collaborative reproduction are, at best, unknown because so few studies have addressed the topic"); Terra Ziporyn, 'Artificial' Human Reproduction Poses Medical, Social Concerns, 255 J. AM. MED. ASS'N 13, 14 (1986) (describing issues pertaining to donor privacy).

<sup>&</sup>lt;sup>341</sup> Naomi Cahn, *The New Kinship*, 100 GEO. L.J. 367, 391 (2012) [hereinafter Cahn, *The New Kinship*]; *see* Sonia M. Suter, *Giving in to Baby Markets: Regulation Without Prohibition*, 16 MICH. J. GENDER & L. 217, 261 (2009) ("From the inception of artificial insemination, anonymity and secrecy have been the norm.").

<sup>&</sup>lt;sup>342</sup> See Johnson v. Superior Court, 95 Cal. Rptr. 2d 864 (Ct. App. 2000), *disapproved on other grounds by* Williams v. Superior Court, 398 P.3d 69 (Cal. 2017).

presented an issue of first impression, the court defined the issue in terms of the parties' respective privacy rights:

whether parents and their child, conceived by the sperm of an anonymous sperm donor, may compel the donor's deposition and production of documents in order to discover information relevant to their action against the sperm bank for selling sperm that [allegedly] transmitted [a specific genetic disorder] to the child.<sup>343</sup>

The court concluded that the "alleged sperm donor" was required to "submit to a deposition and answer questions, as well as produce documents . . . but that his identity should remain undisclosed to the fullest extent possible."<sup>344</sup> The court reasoned that the fertility clinic's contract with the donor assuring his anonymity conflicted with public policy by going "too far in precluding disclosure of the donor's identity and related information under *all* circumstances."<sup>345</sup> While the court also recognized the sperm donor's constitutional "right of privacy in his medical history and his identity," any such right did not preclude the court from compelling his deposition and production of the records requested by the plaintiffs.<sup>346</sup>

At least for now, protecting donor anonymity appears to remain the default practice in the United States.<sup>347</sup> But recent scholarship demonstrates that the international trend clearly favors laws that not only permit children to access relevant information about their biological parentage, but also prohibit gamete donors from remaining anonymous.<sup>348</sup>

<sup>348</sup> See Gaia Bernstein, Unintended Consequences: Prohibitions on Gamete Donor Anonymity and the Fragile Practice of Surrogacy, 10 IND. HEALTH L. REV. 291, 292–93, 300 (2013) (explaining that "U.S. law does not prohibit anonymous gamete donation").

<sup>&</sup>lt;sup>343</sup> *Id.* at 867.

<sup>&</sup>lt;sup>344</sup> *Id*.

<sup>&</sup>lt;sup>345</sup> *Id.* at 873 (emphasis in original).

<sup>&</sup>lt;sup>346</sup> *Id.* at 875 (referring to the right of privacy granted by the California Constitution, which is "broader than the implied federal right to privacy").

<sup>&</sup>lt;sup>347</sup> See Ashley Fetters, *Finding the Lost Generation of Sperm Donors*, ATLANTIC (May 18, 2018), https://www.theatlantic.com/family/archive/2018/05/sperm-donation-anonymous/560588/.

A few U.S. scholars have acknowledged that alternative reproductive technologies implicate the right of relational or family privacy,<sup>349</sup> the boundaries of which are said to be "delineated by the countervailing interests of others within the protected relationship."<sup>350</sup> While adopted children face similar personal identity and

Id. at 299. See generally Maya Sabatello, Disclosure of Gamete Donation in the United States, 11 IND. HEALTH L. REV. 29, 29 (2014) (considering whether the United States should follow the international trend favoring reversal of the policy of anonymity for gamete donors). Countries that bar anonymous gamete donations include Austria, Australia (only the states of Victoria, Western Australia, and New South Wales), Finland, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United Kingdom. Bernstein, supra, at 300. In Canada, the issue has raised controversy about whether gamete donors' option to remain anonymous discriminates against children conceived by artificial insemination by barring them from knowing their family history and allowing the destruction of records that would help identify biological parents. See Vanessa Gruben & Angela Cameron, Donor Anonymity in Canada: Assessing the Obstacles to Openness and Considering a Way Forward, 54 ALBERTA L. REV. 665, 665 (2017) ("Donor anonymity has been hotly debated in Canada."). See generally Matt Malone, Gamete Donor Anonymity in Canada: An Overview of Potential Policy Solutions, 38 WINDSOR REV. LEGAL & SOC. ISSUES 71, 78 (2017).

<sup>349</sup> See, e.g., Alvaré, supra note 338, at 1, 42–44 (discussing the Supreme Court's recognition that constitutional rights of some family members necessarily implicate other family members' interests (citing, among others, Smith v. Org. of Foster Families for Equality & Reform, 431 U.S. 816, 846 (1977); Michael H. v. Gerald D., 491 U.S. 110, 124 n.4 (1989); Roe v. Wade, 410 U.S. 113, 159 (1973); Planned Parenthood of Se. Pennsylvania v. Casey, 505 U.S. 833, 871 (1992)).

<sup>350</sup> Rao, *Reconceiving Privacy, supra* note 68, at 1106; *see* Rao, *Property, Privacy, supra* note 68, at 399 ("Privacy not only guarantees individuals a certain degree of autonomy over their bodies, but it also safeguards the freedom to create and maintain intimate and consensual relationships apart from the state."); Lainie M. C. Dillon, *Conundrums with Penumbras: The Right to Privacy Encompasses Non-Gamete Providers Who Create Preembryos with the Intent to Become Parents*, 78 WASH. L. REV. 625, 628 (2003) (arguing that "the constitutional right to privacy broadly protects intimate decisions related to procreation, marriage and

Prohibiting gamete donor anonymity is a growing global trend. In jurisdictions prohibiting anonymity, egg and sperm donors are not anonymous. Instead, typically, when the child reaches the age of eighteen he can find out the identity of the egg or sperm donor – his genetic parent. The main goal driving the movement toward an open identity system are beliefs that children need to develop their own identity, and that possession of information regarding their genetic origins is crucial for that purpose.

family history issues, children conceived by ART are born into uniquely complex family relationships. They are typically the genetic offspring of one legal parent but not the other, and the child also shares a genetic identity with a third-party donor whom the child may never know.<sup>351</sup>

family life," and therefore "a non-gamete provider's intimate decision to create preembryos falls squarely within the zone of privacy protected by the federal Constitution"); Lucy R. Dollens, Artificial Insemination: Right of Privacy and the Difficulty in Maintaining Donor Anonymity, 35 IND. L. REV. 213, 223, 227 (2001) (asserting that because ART conception "occurs within the confines of a close and personal association, it is afforded constitutional protection by the [associational] right of privacy," and addressing the right of a sperm donor to remain anonymous) (citing Johnson, 95 Cal. Rptr. 2d at 875); cf. Pamela Laufer-Ukeles, The Relational Rights of Children, 48 CONN. L. REV. 741, 769 (2016) (advocating that "any conception of individualized rights of children that does not also consider the interests of parents and society in providing care for children does not appropriately reflect the nature of childhood, parent-child relationships, and children as rights-holders"; and that "only through a relationship-focused perspective can children's rights be accurately calibrated, and parent and state interests be appropriately limited"); Susan L. Crockin & Gary A. Debele, Ethical Issues in Assisted Reproduction: A Primer for Family Law Attorneys, 27 J. AM. ACAD. MATRIM. LAW. 289, 297 (2015) (noting that, unlike other means of conception, "IVF separates the woman from the conceptus and thus introduces a novel element into any discussion of [constitutional] procreative rights"); John A. Robertson, Procreative Liberty and Harm to Offspring in Assisted Reproduction, 30 AM. J.L. & MED. 7, 20 (2004) (noting that reproductive rights are not absolute but rather subject to restriction for cause, and that "[r]estricting ARTs might be marginally more acceptable [than regulating] coital reproduction," while acknowledging many disputes about acceptable reasons for banning or restricting ART).

Some legal scholars have addressed the issue from a comparative perspective. *See, e.g.,* Gaia Bernstein, *Regulating Reproductive Technologies: Timing, Uncertainty, and Donor Anonymity,* 90 B.U. L. Rev. 1189, 1207 (2010) (analyzing data from Sweden, United Kingdom, and Victoria (Australia) as jurisdictions that prohibit anonymity for sperm and egg donors). *See generally* Andreas S. Voss, *The Right to Privacy & Assisted Reproductive Technologies: A Comparative Study of the Law of Germany and the U.S.,* 21 N.Y.L. SCH. J. INT'L & COMP. L. 229, 232 (2002) (comparing United States and Germany law on "the development of the right to privacy and its potential to solve new problems caused by modem assisted reproductive technologies").

<sup>351</sup> See Radhika Rao, Assisted Reproductive Technology and the Threat to the Traditional Family, 47 HASTINGS L.J. 951, 959 (1996); see also Vasanti Jadva, Why Search for a Sperm Donor Online? The Experiences of Women Searching for and Contacting Sperm Donors on the Internet, 21 HUM. FERTILITY 112, 118 (2018).

The dearth of legal scholarship addressing the informational rights of ART children is surprising given its clinical use in the United States for several decades,<sup>352</sup> as well as its increasingly frequent use by prospective parents.<sup>353</sup> Artificial insemination was first used in the 1950s to assist human procreation, although at first the practice was condemned by religious leaders and some judges.<sup>354</sup> ART came into general use for human reproduction in the United States in the 1970s, when a "thriving sperm-bank industry" led to the "commercialization" of artificial insemination.<sup>355</sup> The first "test-tube baby" conceived by IVF was born in 1978.<sup>356</sup> At first, artificial insemination was used primarily to allow infertile couples to bear children, or to prevent conception of children who would be carriers

Id.

<sup>356</sup> DARR, *supra* note 339, at 5.

<sup>&</sup>lt;sup>352</sup> See generally JUDITH DAAR, REPRODUCTIVE TECHNOLOGIES AND THE LAW 26–38 (2d ed. 2013) (summarizing the historical development of ART); Kara W. Swanson, *Adultery by Doctor: Artificial Insemination*, 1890–1945, 87 CHI.-KENT L. REV. 591, 595–62 (2012).

<sup>&</sup>lt;sup>353</sup> E.g., Jenna Casolo et al., Assisted Reproductive Technologies, 20 GEO. J. GENDER & L. 313, 354 (2019) (referring to "[t]he increasing popularity and success rates of ART").

<sup>&</sup>lt;sup>354</sup> DARR, *supra* note 339, at 28 (noting that in 1953 researchers reported pregnancies using frozen sperm samples) (citing R. Bunge & J. Sherman, *Fertilizing Capacity of Frozen Human Spermatazoa*, 172 NATURE 767 (1953)); CARL ZIMMER, SHE HAS HER MOTHER'S LAUGH: THE POWERS, PERVERSIONS, AND POTENTIAL OF HEREDITY 502 (2018) (explaining that the Pope declared artificial insemination adulterous, and an Illinois judge opined that a child conceived by a mother using donor sperm had been born out of wedlock); Hollace S.W. Swanson, *Donor Anonymity in Artificial Insemination: Is It Still Necessary?*, 27 COLUM. J.L. & SOC. PROBS. 151, 157 (1993) (explaining that courts considered donor-conceived children "illegitimate" as not born "in wedlock") (citing Doornbos v. Doornbos, 139 N.E.2d 844 (Ill. App. Ct. 1956)).

<sup>&</sup>lt;sup>355</sup> W. Ombelet & J. Van Robays, *Artificial Insemination History: Hurdles and Milestones*, 7 FACTS, VIEWS & VISION OBGYN 137, 142 (2015); *see* DARR, *supra* note 339, at 5.

Beginning with the birth of Louise Brown in 1978, the first child conceived through in vitro fertilization (IVF), assisted reproduction has grown and evolved, becoming an indispensable player in contemporary family life. In three-plus decades, ART has blossomed from a nascent technology into a multi-billiondollar industry responsible for the births of over five million children worldwide.

of genetic diseases linked to the male sex chromosome.<sup>357</sup> More recently, however, it has become more common for single women or lesbian couples to conceive children by artificial insemination using donor sperm, known in the medical community as AID.<sup>358</sup> The field of assisted reproduction technology in the United States, in contrast to other nations, remains largely unregulated.<sup>359</sup>

A comprehensive discussion of the many fascinating privacy issues surrounding ART is beyond the scope of this Article. But Dani Shapiro's personal experience, detailed in *Inheritance*, illustrates how readily accessible DNA profiles stored in commercial databases can reveal long-held family secrets. If and when revealed, those secrets have the capacity to dramatically up-end an individual's sense of personal identity,<sup>360</sup> to potentially raise conflicting emotions about predeceased loved ones that can never be resolved,<sup>361</sup> and to dramatically alter a person's intimate personal and familial relationships.<sup>362</sup> On the other hand, her parents' careful efforts to keep the family secret that a third party might have been her biological father effectively prevented both Shapiro and the sperm donor from learning intimate information about each other's identity, family history, and medical history, and from building a meaningful relationship of their own.

The story illustrates the inherent complexities of commercialized DNA profiles at a time when family configurations have long since exceeded the boundaries of the traditional nuclear family. And it poses questions about whether closely held family secrets are

<sup>&</sup>lt;sup>357</sup> Ombelet & Van Robays, *supra* note 355, at 137.

<sup>&</sup>lt;sup>358</sup> *Id*.

<sup>&</sup>lt;sup>359</sup> See Naomi Cahn, The New "ART" of Family: Connecting Assisted Reproductive Technologies & Identity Rights, 2018 U. ILL. L. REV. 1443, 1447 [hereinafter Cahn, The New "ART"] ("There are few laws in the United States directly concerned with donor conception, apart from health and safety regulations relating to gamete testing and parentage determinations for a donor-conceived child or a child born through surrogacy."); Cahn, The New Kinship, supra note 341, at 386 ("Gamete donation remains a largely private transaction that is handled through contract and intention with virtually no substantive regulation."); Sabatello, supra note 348, at 31 ("[A]ssisted reproductive technologies . . . are hardly regulated in the United States.").

<sup>&</sup>lt;sup>360</sup> See SHAPIRO, supra note 331, at 60–61.

<sup>&</sup>lt;sup>361</sup> See id. at 99–102.

<sup>&</sup>lt;sup>362</sup> See id. at 105–09.

permanently at risk of inadvertent disclosure, and if so, the potential ramifications for individuals and families.

In the past few years, a growing number of scholars have questioned the practice of keeping children who have been conceived by collaborative reproduction techniques from learning truthful and complete information about their families and medical histories.<sup>363</sup> Those who promote full disclosure assert that children have a "right to know" the circumstances of their conception, as well as healthrelated information about the gamete donors who enabled their conception.<sup>364</sup> On the other hand, the United States' tradition of secrecy favors the rights of sperm donors to remain anonymous—also known as the right to be forgotten—with respect to search results in internet databases.<sup>365</sup>

<sup>364</sup> See, e.g., Sabatello, supra note 348, at 31; see also Barbara Prainsack, *DIY* Genetics: The Right to Know Your Own Genome, in THE RIGHT TO KNOW AND THE RIGHT NOT TO KNOW: GENETIC PRIVACY AND RESPONSIBILITY, supra note 281, at 100, 104–13 (considering the right to know one's genomic information balanced against the right not to know and the right to be forgotten); Samuel W. Royston, *The Right to Be Forgotten: Comparing U.S. and European Approaches*, 48 ST. MARY'S L.J. 253, 254 (2016) (referring to the "'right to be forgotten' paradox").

<sup>365</sup> See Graeme Laurie, Privacy and the Right Not to Know: A Plea for Conceptual Clarity, in THE RIGHT TO KNOW AND THE RIGHT NOT TO KNOW: GENETIC PRIVACY AND RESPONSIBILITY, supra note 281, at 38, 38–39 (discussing comparable rights under international law, for example, with respect to an individual's right not to know one's genetic status); R. Andorno, The Right Not to Know: An

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<sup>363</sup> See, e.g., Sabatello, supra note 348, at 31; Naomi Cahn, Do Tell! The Rights of Donor-Conceived Offspring, 42 HOFSTRA L. REV. 1077, 1079 (2014) ("While the basic constitutional parameters support family privacy, respect for familial autonomy does not pre-empt the possibilities for reforms affecting donorconceived people's interests."); Pino D'Orazio, Half of the Family Tree: A Call for Access to a Full Genetic History for Children Born by Artificial Insemination, 11 J. HEALTH & BIOMEDICAL L. 249, 276 (2006) (advocating that children conceived by AID should have the legal right to access non-identifying donor information pertaining to genetic and medical history); Michele Goodwin, A View from the Cradle: Tort Law and the Private Regulation of Assisted Reproduction, 59 EMORY L.J. 1039, 1099 (2010); Guido Pennings, The Right to Privacy and Access to Information About One's Genetic Origins, 20 MED. & L. 1, 13–14 (2001); Sara Cotton et al., Model Assisted Reproductive Technology Act, 9 J. GENDER, RACE & JUST. 55, 79–80 (2005) (proposing that "[p]arents of a child and the child born as a result of assisted reproductive technology shall have unlimited access to nonidentifying information held by the registry about the gamete or embryo donor").

The slow but steady trend in the United States appears to be following the lead of many other nations that have recognized the rights of donor-conceived children to information about their genetic heritage, at least once they reach adulthood.<sup>366</sup> For example, the 2017 Uniform Parentage Act requires clinics to record donor information as well to give donors the option of remaining anonymous or allowing disclosure.<sup>367</sup> Even if a donor elects anonymity, the clinic must make a good faith attempt to provide the child with nonidentifying information about the donor, and to notify the donor if the child requests information in order to allow the donor to reconsider the nondisclosure election.<sup>368</sup>

The latest iteration of the Uniform Parentage Act provision was apparently modelled after a 2011 Washington state statute, the first of its kind in the United States, that expressly permitted a child conceived by artificial insemination to access the donor's medical information when the child reached age eighteen, even if the donor had opted to remain anonymous.<sup>369</sup> The Washington Legislature

<sup>369</sup> See id. at 1447–48 (citing WASH. REV. CODE § 26.26.750(2)(b) (2017)).

Autonomy Based Approach, 30 J. MED. ETHICS 435, 435 (2004) (arguing that "autonomy', understood in a wide sense, provides a theoretical basis for a right not to know one's genetic status"); Gitter, *supra* note 330, at 368 ("In the field of biomedical research, the principle of autonomy, or self-determination, suggests that each individual has the right not to know selected information about herself."); Bartha Maria Knoppers, *Introduction: From the Right to Know to the Right Not to Know*, 42 J.L., MED. & ETHICS 6, 6 (2014) ("Respect for the autonomy of research participants recognizes that all individuals have the right to make their own decisions.").

The European Union Court of Justice introduced the "right to be forgotten" in interpreting the since-superseded E.U. Data Protection Regulation. Royston, *supra* note 364, at 256. The right to be forgotten allows an E.U. citizen to petition an internet search engine to remove links to personal information that would harm one's reputation. *Id.* In the European Union, "personal privacy trumps freedom of information." Leslie E. Minora, Comment, *U.S. Courts Should Not Let Europe's* "*Right to Be Forgotten" Force the World to Forget*, 89 TEMP. L. REV. 609, 609 (2017). But in the United States, freedom of expression and the free exchange of information generally weigh more heavily in the balance than privacy interests. *Id.* As has been observed, "[E.U.] law highlights the stark value clash between freedom of expression in the United States and personal privacy in the EU." *Id.* 

<sup>&</sup>lt;sup>366</sup> See, e.g., Cahn, *The New "ART"*, *supra* note 359, at 1447–49 (highlighting examples of state legislation regarding donor-identifying information).

<sup>&</sup>lt;sup>367</sup> *Id.* at 1448 (citing UNIF. PARENTAGE ACT § 903).

<sup>&</sup>lt;sup>368</sup> *Id.* (citing UNIF. PARENTAGE ACT § 903).

repealed the statute effective January 1, 2018, at the same time it enacted the Uniform Parentage Act.<sup>370</sup> California<sup>371</sup> and Vermont<sup>372</sup> also enacted the Uniform Parentage Act in 2018, and other states have since introduced it in bill form.<sup>373</sup>

It remains to be seen whether state laws in the United States will follow the lead of other nations by providing ART offspring the right to obtain health-related information concerning gamete donors.

### D. California Consumer Privacy Protection Act

On January 1, 2020, a sweeping statute took effect in California that addresses the right to informational privacy.<sup>374</sup> Specifically, the California Consumer Privacy Act<sup>375</sup> creates new rights for consumers to control access to and dissemination of the personal information businesses collect and maintain about them.<sup>376</sup> The Act, which reportedly "gives nearly 40 million people in [California] the strongest data privacy rights in the country," was introduced on the initiative of Alastair MacTaggart, Founder and Chair of Californians for Consumer Privacy.<sup>377</sup> MacTaggart did so after several internet

<sup>&</sup>lt;sup>370</sup> See WASH. REV. CODE § 26.26A.903 (2018); see also Raegen Rasnic, State's Parentage Act Gets Major Makeover, KING COUNTY B. ASS'N (Feb. 1, 2019), https://www.kcba.org/For-Lawyers/Bar-Bulletin/PostId/690/states-parentage-act-gets-major-makeover.

<sup>&</sup>lt;sup>371</sup> Cal. A.B. § 2684, ch. 876 (2018).

<sup>&</sup>lt;sup>372</sup> Vt. H.B. § 562, Act 162 (2018).

<sup>&</sup>lt;sup>373</sup> 2017 Parentage Act Enactment Map, UNIF. L. COMM'N, https://www.uniformlaws.org/committees/community-home?CommunityKey=c4f37d2d-4d20-4be0-8256-22dd73af068f (last visited Mar. 17, 2020).

<sup>&</sup>lt;sup>374</sup> See CAL. CIV. CODE §§ 1798.100–199 (West, Westlaw current with urgency legislation through Ch. 3 of 2020 Reg. Sess.).

<sup>&</sup>lt;sup>375</sup> *Id.* 

<sup>&</sup>lt;sup>376</sup> California Consumer Privacy Act (CCPA): Background on the CCPA & the Rulemaking Process, CAL. DEP'T JUST., https://oag.ca.gov/privacy/ccpa (last visited Mar. 23, 2020) (soliciting public comments to rule modifications by March 27, 2020).

<sup>&</sup>lt;sup>377</sup> Letter from Alastair Mactaggart, Bd. Chair & Founder of Californians for Consumer Privacy (Sept. 25, 2019), https://www.caprivacy.org/post/a-letterfrom-alastair-mactaggart-board-chair-and-founder-of-californians-for-consumerprivacy (reporting that a new and stronger initiative was filed on November 19, 2019, that is slated to appear on the California general election ballot in November 2020). As Mactaggart explained,

service providers had blocked proposed state legislation that would have reigned in the commercial exploitation of users' personal information.<sup>378</sup>

What this new law comes down to is giving consumers the right to take back control over their information from thousands of giant corporations. This is about power: the more a company knows about you, the more power it has to shape your daily life. That power is exercised on the spectrum ranging from the benign, such as showing you a shoe ad, to the consequential, like selecting your job, your housing, or helping to shape what candidate you support in an election.

*Id.*; *see* Letter from Alastair Mactaggart, Bd. Chair & Founder of Californians for Consumer Privacy, to Cal. Att'y Gen. Transmitting the Proposed Cal. Privacy Rights Act of 2020 (Nov. 4, 2019), https://oag.ca.gov/system/files/initia-tives/pdfs/19-0021A1%20%28Consumer%20Privacy%20-%20Version%203%29\_1.pdf.

<sup>378</sup> The California Consumer Privacy Act defines "personal information" broadly:

"Personal information" means information that identifies, relates to, describes, is reasonably capable of being associated with, or could reasonably be linked, directly or indirectly, with a particular consumer *or household*. Personal information includes, but is not limited to, the following if it identifies, relates to, describes, is capable of being associated with, or could be reasonably linked, directly or indirectly, with a particular consumer or *household*:

(A) Identifiers such as a real name, alias, postal address, unique personal identifier, online identifier, Internet Protocol address, email address, account name, social security number, driver's license number, passport number, or other similar identifiers.

(B) Any categories of personal information described in subdivision (e) of Section 1798.80.

(C) Characteristics of protected classifications under California or federal law.

(D) Commercial information, including records of personal property, products or services purchased, obtained, or considered, or other purchasing or consuming histories or tendencies.(E) Biometric information.

(F) Internet or other electronic network activity information, including, but not limited to, browsing history, search history, and information regarding a consumer's interaction with an internet web site, application, or advertisement.

(G) Geolocation data.

The Act authorizes the California Attorney General to adopt regulations after seeking public comment.<sup>379</sup> As this Article went to press, the proposed regulations have been published for notice and comment.<sup>380</sup> Among other things, the regulations would bar a business from using personal information for any purpose other than those the business disclosed to the consumer at the time of collecting the data.<sup>381</sup> In addition, a consumer would have the right to "opt out" from the sale of the consumer's personal information,<sup>382</sup> to know what kind of personal information a business collects and maintains,<sup>383</sup> and to request deletion of the consumer's personal information.<sup>384</sup>

(H) Audio, electronic, visual, thermal, olfactory, or similar information.

(I) Professional or employment-related information.

(J) Education information, defined as information that is not publicly available personally identifiable information as defined in the Family Educational Rights and Privacy Act (20 U.S.C. Sec. 1232g; 34 C.F.R. Part 99).

(K) Inferences drawn from any of the information identified in this subdivision to create a profile about a consumer reflecting the consumer's preferences, characteristics, psychological trends, predispositions, behavior, attitudes, intelligence, abilities, and aptitudes.

CAL. CIV. CODE § 1798.140(0)(1) (emphasis added). Certainly, this definition appears to be sufficiently broad to encompass genetic information, at least to the extent it implicates relational privacy interests of individuals who reside within the same "household" as the individual whose "personal" information has been collected and maintained by a business. *See id.* 

<sup>379</sup> CAL. CIV. CODE § 1798.185(a) ("On or before July 1, 2020, the Attorney General shall solicit broad public participation and adopt regulations to further the purposes of this title, including, but not limited to, the following areas . . . ."); *see also California Attorney General Publishes Privacy Regulations, Seeks Public Comment*, EPIC.ORG (Feb. 11, 2020), https://epic.org/2020/02/california-attorney-general-pu.html.

<sup>380</sup> See California Consumer Privacy Act (CCPA): Background on the CCPA & the Rulemaking Process, supra note 376 (soliciting public comments to rule modifications by Mar. 27, 2020).

<sup>381</sup> Chapter 20. California Consumer Privacy Act Regulations: Text of Initial Proposed Regulations, CAL. DEP'T JUST., https://oag.ca.gov/sites/all/files/ag-web/pdfs/privacy/ccpa-proposed-regs.pdf (last visited Mar. 17, 2020) (to be codified at CAL. CODE REGS. tit. 11, § 999.305(a)(3)).

- <sup>382</sup> *Id.* (to be codified at CAL. CODE REGS. tit. 11, § 999.306).
- <sup>383</sup> *Id.* (to be codified at CAL. CODE REGS. tit. 11, § 999.308(b)(1)).
- <sup>384</sup> *Id.* (to be codified at CAL. CODE REGS. tit. 11, § 999.308(b)(2)).

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It remains to be seen whether other states will follow California's lead by enacting state statutes that regulate the collection, maintenance, and retention of personal and relational information. Even more speculative is how future courts may interpret and apply state privacy statutes to address the increasingly complex relational privacy issues generated by digitized "personal" information.

### E. European Union General Data Privacy Regulation

The General Data Privacy Regulation ("GDPR"),<sup>385</sup> which took effect on May 25, 2018,<sup>386</sup> has global implications for informational privacy, even for businesses headquartered outside the European Union. It implements the European Union Charter of Fundamental Rights, which expressly provides that E.U. citizens have the right to "the protection of personal data concerning him or her."<sup>387</sup> While the GDPR does not apply directly to U.S. citizens, its broad privacy protections govern any internet service provider that reaches E.U. citizens. Because so many technology-oriented businesses with a global reach operate outside the European Union, the GDPR indirectly benefits citizens of the United States and other countries.<sup>388</sup>

1. Everyone has the right to the protection of personal data concerning him or her.

2. Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.

3. Compliance with these rules shall be subject to control by an independent authority.

Id. art. 8.

<sup>388</sup> "The GDPR gives EU data subjects legal control and individual redress rights related to access and use of their data anywhere in the world." 3 ROBERT L. HAIG, COMMERCIAL LITIGATION IN NEW YORK STATE COURTS § 27:37 (4th ed. 2019).

<sup>&</sup>lt;sup>385</sup> GDPR, *supra* note 13.

<sup>&</sup>lt;sup>386</sup> See Gergana Sivrieva, *The Equifax Breach Amid a Lawless Landscape: Changes Are Afoot for Privacy & Data Security Due to the European Union's General Data Protection Regulation*, 64 WAYNE L. REV. 553, 562–63 (2018) (summarizing the GDPR). "In every category, the GDPR exhibits provisions that are substantially more favorable to EU consumers than the protections offered to consumers by U.S. statutes." Id.

<sup>&</sup>lt;sup>387</sup> Charter of Fundamental Rights of the European Union, Dec. 18, 2000, 2000 O.J. (C 364) 10.

But even the far-reaching GDPR raises serious issues about relational privacy interests because of its restrictive definition of "personal data." That definition is couched in terms that relate to a "data subject," which is defined in turn to mean an "identifiable natural person."<sup>389</sup>

> <sup>•</sup>[P]ersonal data' means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person . . . .<sup>390</sup>

European scholars have already called for reform by redefining the meaning of "data subject" to recognize the broad implications of digital data-sharing—not only for individuals, but also for family members, biological relatives, and even members of the same racial, ethnic, or population group as the "data subject."<sup>391</sup>

#### CONCLUSION

The "relational" right of privacy needs a much sounder footing in U.S. constitutional, statutory, and common law. As articulated and defined by U.S. scholars and jurists since the early twentieth century, relational privacy interests have been unduly limited to a shared desire to protect grieving family members from suffering further emotional distress as a result of disclosing information pertaining to the death of their loved ones.<sup>392</sup>

<sup>&</sup>lt;sup>389</sup> GDPR, supra note 13, art. 4(1) (defining "personal data"). See generally P.T.J. Wolters, The Enforcement by the Data Subject Under the GDPR, 22 J. INTERNET L. 21 (2019); P.T.J. Wolters, The Control by and Rights of the Data Subject Under the GDPR, 22 J. INTERNET L. 6, 12–13 (2018).

<sup>&</sup>lt;sup>390</sup> GDPR, *supra* note 13, art. 4(1).

<sup>&</sup>lt;sup>391</sup> See generally, e.g., Ugo Pagallo, *The Group, the Private, and the Individual: A New Level of Data Protection?, in* GROUP PRIVACY: NEW CHALLENGES OF DATA TECHNOLOGIES 159 (Linnet Taylor et al. eds., 2017).

<sup>&</sup>lt;sup>392</sup> See supra Part II.

The American Law Institute will have the opportunity to clarify these issues in developing the next installment of the *Restatement* (*Third*) of Torts. But Congress and state legislatures will need to revisit the disclosure exemptions in FOIA and related state statutes that allow agencies to withhold public records from disclosure to protect "unwarranted invasions of personal privacy."<sup>393</sup> The traditional meaning of "personal privacy," the term Congress employed in FOIA exemptions to support a balancing test, relates to a right that belongs to a living individual.<sup>394</sup> Surviving family members who desire protection from mental anguish as a result of disclosing records pertaining to the death of their loved ones seek to prevent a "relational wrong"<sup>395</sup>—but one that implicates interests in preventing infliction of emotional distress, not invasion of personal privacy.

The dramatic ongoing developments in mapping the human genome and collecting and disseminating genetic data demand that legal scholars and policymakers revisit relational privacy concepts with respect to burgeoning DNA biobanks. The increasing accessibility of genetic data, unlike most medical and health care data, raises complex privacy issues. Those issues not only require balancing the interests of the individual against the needs of the public, but also the sometimes conflicting interests of other family members.<sup>396</sup> To date, social values have generally favored the collection and dissemination of genetic data to enable medical research for the "public good." But little attention has focused on the serious risks to group and family privacy of unregulated collection, use, and dissemination of genomic data.<sup>397</sup>

Each person's genome, or full complement of DNA, is unique, but the specific variants within an individual's genome may be

<sup>&</sup>lt;sup>393</sup> See supra Part III.

<sup>&</sup>lt;sup>394</sup> See supra Part III.

<sup>&</sup>lt;sup>395</sup> Cannady v. St. Vincent Infirmary Med. Ctr., 423 S.W.3d 548, 549, 553 (Ark. 2012).

<sup>&</sup>lt;sup>396</sup> See, e.g., PATRICIA KUSZLER ET AL., GENETIC TECHNOLOGIES AND THE LAW: CASES AND MATERIALS 78–79 (2007). "[U]nlike much of a patient's medical history, the implications of genetic information are simultaneously uniquely personal and necessarily familial. This 'dual ownership' aspect of genetic information poses unique challenges for physicians as they attempt to reconcile competing duties to safeguard patient confidentiality and promote the welfare of others." *Id.* 

<sup>&</sup>lt;sup>397</sup> See, e.g., Clayton et al., supra note 220, at 5.

These complex legal and policy issues warrant further attention as legislatures and other policymakers confront competing legal interests of those whose rights are implicated by the widespread collection and sharing of genetic information. This Article seeks to open the long-overdue scholarly debate in the United States about how best to resolve these challenging public policy issues and their implications for family relationships. The genealogical genie has escaped from the bottle, and we have no time to waste.<sup>398</sup>

Finally, the United States can no longer avoid these far-reaching global privacy issues, which are growing more complex by the minute with the rapid development of digitized information technology. The U.S. Supreme Court should expressly recognize a constitutionally-based right to relational information privacy—rather than ducking the issue by attempting to ground those rights in circular reasoning based on explicit privacy-based FOIA exemptions. And legal scholars around the world, together with international human rights tribunals, must work collaboratively on cross-border legislative solutions to what has become a global relational privacy challenge.

widely shared with biological relatives or even across the entire human population. This mixed character of the genome—as a uniquely individual assemblage of widely shared common elements—imbues it with a dual private and public significance that confounds any discussion of policy addressing genetic privacy.

Id. at 2.

<sup>&</sup>lt;sup>398</sup> See Rothman, supra note 299 ("We're up against a pretty big foe and time is running out") (quoting Cullen Hoback, director of the 2013 documentary film *Terms and Conditions May Apply*).