

# Strict Liability for Genetic Privacy Violations in the Age of Big Data

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## I. INTRODUCTION

The ethical issues implicated by the misuse of genetic information have been smoldering for over half a century, and the age of big data has turned them into a five-alarm fire. In recent years, medical researchers and commercial enterprises have been using technological advancements to develop a variety of innovative ways to use genetic information. For example, it is becoming increasingly common for people to learn more about their health and family history by paying direct-to-consumer (“DTC”) companies to analyze their genetic data.<sup>1</sup> DTC companies store the results of these tests electronically and often share them with pharmaceutical companies conducting medical research on some of the world’s most serious diseases.<sup>2</sup> The research conducted with this data could yield tremendous benefits, but it also raises very serious privacy concerns. This is so because although DTC companies remove a significant amount of personal information from the genetic data shared with third parties, some personal characteristics—e.g., age, sex, birthplace, and more—must remain attached to the genetic sample for it to be useful in medical studies.<sup>3</sup> As researchers have demonstrated, the identity of “supposedly anonymous genetic samples” can be revealed relatively easily.<sup>4</sup>

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1. Monica Rodriguez, *You Discovered Your Genetic History. Is it Worth the Privacy Risk?*, FORTUNE (Sept. 10, 2018), <http://fortune.com/2018/09/10/genetic-history-test-privacy-risk/> (stating the two leading companies in the field have “experienced serious booms in business” in the last few years).

2. *Id.*

3. *Id.* (quoting Hank Greely, director of Center for Law and Biosciences at Stanford).

4. See Peter Pitts, *The Privacy Delusions of Genetic Testing*, FORBES (Feb. 15, 2017, 1:26 PM), <https://www.forbes.com/sites/realspin/2017/02/15/the-privacy-delusions-of-genetic-testing/#69afbb251bba> (noting the relative ease with which anonymized genetic data can be deanonymized); Adam Tanner, *Harvard Professor Re-identifies Anonymous Volunteers in DNA Study*, FORBES (Apr. 25, 2013, 3:47 PM), <https://www.forbes.com/sites/adamtanner/2013/04/25/harvard-professor-re-identifies-anonymous-volunteers-in-dna-study/#7869482392c9> (discussing research-

Many people would not be alarmed if secure medical laboratories used their semi-anonymized genetic data, but the reality is far more concerning. Hackers frequently attack large dossiers of health information, like those maintained by DTC companies, because such information is very valuable on the black market and guarded by low levels of security.<sup>5</sup> If this genetic information is sold to unauthorized

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ers' ability to identify the identity of people who provided genetic samples even though the data had been stripped of some personal information).

5. See, e.g., Katherine Drabiak-Syed, *Lessons From Havasupai Tribe v. Arizona State University Board of Regents: Recognizing Group, Cultural, and Dignitary Harms as Legitimate Risks Warranting Integration into Research Practice*, 6 J. HEALTH & BIOMEDICAL L. 175, 215 (2010) (describing the high value medical researchers place on genetic data); Angela Chen, *Why a DNA Data Breach Is Much Worse Than a Credit Card Leak*, THE VERGE (June 6, 2018, 3:54 PM), <https://www.theverge.com/2018/6/6/17435166/myheritage-dna-breach-genetic-privacy-bioethics> ("Though the hackers [targeting MyHeritage] only accessed encrypted emails and passwords—so they never reached the actual genetic data—there's no question that this type of hack will happen more frequently as consumer genetic testing becomes more and more popular."); Jamie Ducharme, *A Major Drug Company Now Has Access to 23andMe's Genetic Data. Should You Be Concerned?*, TIME: HEALTH (July 26, 2018), <http://time.com/5349896/23andme-glaxo-smith-kline/> ("When information moves from one place to another, there's always a chance for it to be intercepted by unintended third parties."); Caroline Humer & Jim Finkle, *Your Medical Record Is Worth More to Hackers Than Your Credit Card*, REUTERS (Sept. 24, 2014, 1:25 PM), <https://www.reuters.com/article/us-cybersecurity-hospitals/your-medical-record-is-worth-more-to-hackers-than-your-credit-card-idUSKCN0HJ21I20140924> (describing the value of genetic data to hackers); *MyHeritage Statement About a Cybersecurity Incident*, MYHERITAGE BLOG (June 4, 2018), <https://blog.myheritage.com/2018/06/myheritage-statement-about-a-cybersecurity-incident/> [hereinafter *MyHeritage Statement*] (discussing the fact that in June 2018, hackers compromised the accounts of over 92 million of MyHeritage's customers); *NHS Cyber-Attack: GPs and Hospitals Hit by Ransomware*, BBC NEWS (May 13, 2017), <https://www.bbc.com/news/health-39899646> [hereinafter *NHS Cyber-Attack*] (detailing a large-scale cyber-attack on NHS entities in Europe); Charles Ornstein, *Fines Remain Rare Even as Health Data Breaches Multiply*, PROPUBLICA (Feb. 27, 2015, 12:15 PM), <https://www.propublica.org/article/fines-remain-rare-even-as-health-data-breaches-multiply>; Pitts, *supra* note 4 (observing that large depositories of valuable genetic information "are obvious targets" that are guarded by low levels of security); Antonio Regalado, *23andMe Sells Data for Drug Search*, MIT TECH. REV. (June 21, 2016), <https://www.technologyreview.com/s/601506/23andme-sells-data-for-drug-search/> (reporting that DTC companies have begun coordinating with drug makers to estab-

parties, used as blackmail, or held for ransom, the autonomy of the individuals associated with the genetic data could be significantly harmed.<sup>6</sup>

Although only a few once recognized these and other risks posed by the pervasive use of genetic data in a variety of contexts, awareness of this issue is now on the rise. During a press conference in November 2017, U.S. Senate Minority Leader Chuck Schumer acknowledged that there is a real risk that the genetic information of DTC companies' customers could be misused.<sup>7</sup> Many agree with Senator Schumer. Included among the list of those concerned about this issue are several academics who believe tort law should be used to protect the interest people have in ensuring that their genetic information remains private.<sup>8</sup> One of tort law's two primary goals is to

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lish lucrative sharing arrangements). See *infra* notes 48–55 and accompanying text, for a more detailed discussion of the risks hackers pose to genetic privacy.

6. See Chen, *supra* note 5; see also *Hospital Computer System Held for Ransom, Bitcoin Demanded*, CBS NEWS (Jan. 13, 2018, 1:22 PM), <https://www.cbsnews.com/news/indiana-hancock-regional-hospital-system-held-for-ransom-bitcoin-demanded/> [hereinafter *Bitcoin Demanded*] (reporting, after an Indiana hospital was hacked, it was held for ransom for “an unspecified amount of bitcoin”). See *infra* Part I, for a more detailed description of the ways genetic privacy violations can harm individual autonomy.

7. Michael Schulson, *Spit and Take: Genetic Testing Data Can Be Subpoenaed, Stolen, and Sold as a Commodity. So Why is the Industry Booming?*, SLATE (Dec. 29, 2017, 12:04 PM), <https://slate.com/technology/2017/12/direct-to-consumer-genetic-testing-has-tons-of-privacy-issues-why-is-the-industry-booming.html>.

8. See, e.g., Ifeoma Ajunwa, *Genetic Testing Meets Big Data: Tort and Contract Law Issues*, 75 OHIO ST. L.J. 1225, 1242–52, 1259–61 (2014) (evaluating various tort remedies, including strict liability, that could be used to protect people's genetic privacy); Jorge L. Contreras, *Genetic Property*, 105 GEO. L.J. 1, 9 (2016) (suggesting liability rules are the most appropriate means of protecting people's genetic data from abusive research practices); June Mary Z. Makdisi, *Genetic Privacy: New Intrusion a New Tort?*, 34 CREIGHTON L. REV. 965, 966 (2001) (discussing liability for violations of genetic privacy); Elizabeth R. Pike et al., *Finding Fault? Exploring Legal Duties to Return Incidental Findings in Genomic Research*, 102 GEO. L.J. 795, 814–15 (2014) (discussing the merits of a no-fault regime in the genetic data context); Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737, 746 (2004) (contending that liability rules better promote compensation goals of tort law than property rules do). See generally Guido Calabresi & A. Douglas Melamed, *Property Rules, Liability Rules, and Inalienability: One View of the Cathedral*, 85 HARV. L.

deter risky behavior.<sup>9</sup> The other primary goal is to compensate people who have been injured by the actions of others.<sup>10</sup> The tort of invasion of privacy has been identified as an appropriate tool to accomplish these goals and address the misuse of genetic information.<sup>11</sup>

This Article acknowledges that the tort of invasion of privacy is an appropriate vehicle for addressing genetic privacy violations. But if tort law is to accomplish this goal in the age of big data, the doctrine must undergo a bit of a facelift. This is so because the current state of tort law imposes doctrinal barriers on genetic privacy plaintiffs.<sup>12</sup> Although these barriers can take several forms, a common theme underpins them: plaintiffs are permitted to receive compensation only when imposing liability succeeds in deterring future

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REV. 1089, 1092–93 (1972) (arguing that for reasons related to both efficiency and distributive goals, a liability regime is preferable to a property rule in some contexts).

9. See generally Mark A. Geistfeld, *The Coherence of Compensation-Deterrence Theory in Tort Law*, 61 DEPAUL L. REV. 383 (2012) (describing the central debate over the appropriate roles that deterrence and compensation are to play in tort theory).

10. See Geistfeld, *supra* note 9, at 415 (“Courts and commentators regularly analyze tort law in terms of the functions of compensation and deterrence.”). Liability standards adhere to this hallmark of tort law if they are efficient—that is, tort law imposes liability and encourages people to take precautions against risky behavior when the burden of doing so is less than the cost of an accident. See, e.g., *McCarty v. Pheasant Run, Inc.*, 826 F.2d 1554, 1556 (7th Cir. 1987).

11. See, e.g., Ajunwa, *supra* note 8, at 1245–48; Makdisi, *supra* note 8, at 966; Elizabeth R. Pike, *Securing Sequences: Ensuring Adequate Protections for Genetic Samples in the Age of Big Data*, 37 CARDOZO L. REV. 1977, 1983–85 (2016) [hereinafter Pike, *Securing Sequences*] (describing the various ways that modern technology creates challenges to the goal of securing genetic privacy); Suter, *supra* note 8, at 74.

12. See 1 AM. LAW INST., REPORTERS’ STUDY: ENTERPRISE RESPONSIBILITY FOR PERSONAL INJURY 30–32 (1991). Since the early 1980s, many tort law scholars, judges, and practitioners have admonished that the primary goal of tort law is to conduct economic analyses focused on “liability incentives for the [deterrence] of future injuries.” *Id.* at 31 (footnote omitted). See generally WILLIAM M. LANDES & RICHARD A. POSNER, *THE ECONOMIC STRUCTURE OF TORT LAW* (1987) (arguing that tort law is inefficient if it imposes liabilities exceeding the level to which they succeed in raising the deterrence of risky behavior among would-be defendants); STEVEN SHAVELL, *ECONOMIC ANALYSIS OF ACCIDENT LAW* (1987) (same).

acts of that kind.<sup>13</sup> As a result of these barriers, plaintiffs cannot receive compensation if imposing liability on the actor causing their injury would not accomplish a greater level of deterrence. This reality is unacceptable, and it must be addressed.

The solution I propose is to circumvent these doctrinal barriers. Holding those routinely attending to genetic data strictly liable for any and all actions that cause genetic privacy violations can accomplish this goal. A strict liability regime will ensure that victims of genetic privacy violations are not faced with the sort of insurmountable doctrinal barriers currently afflicting tort law. Strict liability will also provide deterrence against risky behavior. This Article will defend my proposal by proceeding in five parts.

Part II provides a brief overview of how technological advancements are rapidly increasing threats to the confidentiality of people's genomic information. Part III explains how doctrinal barriers prohibit victims of genetic privacy violations from receiving compensation for their injuries, and Part IV illustrates how these barriers prevent victims of these genetic privacy violations from receiving compensation for their genetic data's misuse. Part V suggests that a strict liability regime can avoid the aforementioned encumbrances, provide compensation for victims of genetic privacy violations, and adequately deter risky behavior. Part VI identifies a few challenges available to critics of this Article's proposal and details how those objections are laid to rest.

## II. THE PERVASIVE USE OF GENETIC INFORMATION: A CAUSE FOR CONCERN

Our genes, which are made up of deoxyribonucleic acid ("DNA"), instruct proteins in our bodies to perform a variety of different functions.<sup>14</sup> One role played by these proteins is to assist in the

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13. See LANDES & POSNER, *supra* note 12, at 16; Virginia E. Nolan & Edmund Ursin, *Enterprise Liability and the Economic Analysis of Tort Law*, 57 OHIO ST. L.J. 835, 848–50 (1996) [hereinafter Nolan & Ursin, *Enterprise Liability*] (discussing Posner's influence on tort scholarship).

14. NAT'L INST. OF GEN. MED. SCI., U.S. DEP'T HEALTH & HUMAN SERVS., *THE NEW GENETICS* 4 (2010), <https://www.nigms.nih.gov/education/Booklets/the-new-genetics/Documents/Booklet-The-New-Genetics.pdf>.

formation of cells.<sup>15</sup> Each cell contains a full set of chromosomes, which are structures possessing genetic information that is highly particularized to each individual.<sup>16</sup> In fact, although “any two individuals’ DNA are 99.9% identical, the variations within the remaining 0.1% are responsible for the diversity among human beings.”<sup>17</sup> In short, genes—a complete set of which is called a genome—contain sensitive information that makes each individual unique.<sup>18</sup> Not only can genes tell us a lot about an individual’s cellular makeup, they can also provide information about the specific types of cells or chromosomes that coincide with particular medical conditions.<sup>19</sup> Simply by looking for specific types of mutations in someone’s genes, we can tell if a person has—or has a propensity for—Huntington’s disease, cystic fibrosis, schizophrenia, sickle cell anemia, and many other conditions.<sup>20</sup> Because of the critical role that genes play in the development of various conditions, it is no surprise that genetic data are highly sought after resources to better understand various diseases.

In 2015, the U.S. government launched a large-scale effort to improve the ability of researchers to understand, prevent, and treat some of the most serious diseases.<sup>21</sup> This project, known as the Precision Medicine Initiative (“PMI”), will collect the genetic information of around one million Americans.<sup>22</sup> The PMI builds on the Human Genome Project, which was a decade-long research initiative to collect and study genetic data.<sup>23</sup> That project, completed in 2003, dra-

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15. *Id.*

16. *Id.* at 6.

17. Sarah Washburn, *Controlling Your DNA: Privacy Concerns in Genomic Testing and the Uncertainty of Federal Regulation and Legislation*, 18 DEPAUL J. HEALTH CARE L. 1, 3 (2016).

18. *Id.* at 4.

19. *Id.*

20. *Id.*; see also Mads G. Henriksen et al., *Genetics of Schizophrenia: Overview of Methods, Findings and Limitations*, 11 FRONTIERS HUM. NEUROSCIENCE 1, 1 (2017) (noting that genetics constitute a factor in the risk of developing schizophrenia).

21. See *President Obama’s Precision Medicine Initiative*, NAT’L HUM. GENOME RES. INST. (Feb. 5, 2015), <https://www.genome.gov/27560828/february-5-2015-president-obamas-precision-medicine-initiative/>.

22. *Id.*

23. Brenda J. Wilson & Stuart G. Nicholls, *The Human Genome Project, and Recent Advances in Personalized Genomics*, 8 RISK MGMT. & HEALTHCARE POL’Y

matically improved the power of health-care professionals to diagnose, “treat, prevent, and cure diseases.”<sup>24</sup>

In addition to government-sponsored efforts to collect genomic information, private actors are also amassing large genetic databases. DTC companies, such as 23andMe, have begun offering genetic tests to consumers.<sup>25</sup> In exchange for a small fee, individuals can submit cheek swabs to DTC companies, which test those samples to provide customers with information about their ancestors, health, and more.<sup>26</sup> Medical researchers are using the data collected by DTC companies to study some of today’s most vexing diseases.<sup>27</sup>

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9, 9–10 (2015) (discussing the original Human Genome Project and how technological advancements are adding to this area of research); Samantha Olson, *Pres. Obama’s Precision Medicine Initiative, The Human Genome Project, and Your Individualized Genetic Data*, MED. DAILY (Sept. 16, 2015, 11:30 AM), <https://www.medicaldaily.com/pres-obamas-precision-medicine-initiative-human-genome-project-and-your-352678> (explaining how the funding made available by the Precision Medicine Initiative will accelerate the medical research made possible by the Human Genome Project).

24. See *An Overview of the Human Genome Project: What Was the Human Genome Project?*, NAT’L HUM. GENOME RES. INST., <https://www.genome.gov/12011238/an-overview-of-the-human-genome-project/> (last reviewed May 11, 2016) (quoting Francis Collins, director of NHGRI); see also Olson, *supra* note 23; Wilson & Nicholls, *supra* note 23, at 9–10.

25. See Pike, *Securing Sequences*, *supra* note 11, at 1983, 1995 (explaining how genetic privacy is made more difficult by advents in modern technology).

26. Lydia Ramsey, *I Tried 23andMe’s New Genetics Test—And Now I Know Why the Company Caused Such a Stir*, BUS. INSIDER (Dec. 23, 2015, 11:00 AM), <http://www.businessinsider.com/i-tried-the-new-23andme-genetic-test-2015-12/#a-few-days-after-ordering-my-box-arrived-it-was-colorful-and-so-inviting-that-i-couldnt-wait-to-open-it-up-1> (describing the business model of DTC genetic testing companies that collect and analyze samples from paying customers).

27. See Sarah Zhang, *Big Pharma Would Like Your DNA*, THE ATLANTIC (July 27, 2018), <https://www.theatlantic.com/science/archive/2018/07/big-pharma-dna/566240/>. GlaxoSmithKline (“GSK”) was careful to note that it would only receive anonymized data from 23andMe’s customers. Press Release, GSK, *GSK and 23andMe Sign Agreement to Leverage Genetic Insights for the Development of Novel Medicines* (July 25, 2018) [hereinafter *GSK and 23andMe*], <https://www.gsk.com/en-gb/media/press-releases/gsk-and-23andme-sign-agreement-to-leverage-genetic-insights-for-the-development-of-novel-medicines/> (stating 23andMe and GSK “have stringent security protections in place when it comes to [handling] information about research participants”).



Genetic data are not only being exploited in the medical research context—they are also being used to support the criminal justice system. Law enforcement agencies from all fifty states participate in a DNA collection program, known as the Combined DNA Index System (“CODIS”).<sup>28</sup> DNA collected through CODIS and other sources enters a database containing genetic information from specific categories of people, including convicted offenders, legal detainees, and arrestees.<sup>29</sup> CODIS has become a very effective tool for agencies in the criminal justice system. In fact, California authorities recently used DNA from one DTC company to identify and arrest the “Golden State Killer,” who committed a string of crimes and evaded authorities for decades.<sup>30</sup>

As these examples demonstrate, more and more people’s genetic data are being collected, stored in large databases, and used for a variety of purposes. Thanks to modern technology, these databases do not require physical samples. Cloud computing and compression technologies have made it possible for “an individual’s genetic sequence [to] be uploaded to the cloud and shared with a potentially limitless number of people.”<sup>31</sup> According to some predictions, by 2025 the genetic information of approximately one billion people will

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28. See *CODIS-NDIS Statistics*, FBI (last visited Mar. 10, 2019), <https://www.fbi.gov/services/laboratory/biometric-analysis/codis/ndis-statistics> [hereinafter *CODIS-NDIS Statistics*].

29. *Id.*

30. Mark Berman et al., *Authorities Used DNA, Genealogy Website, to Track Down ‘Golden State Killer’ Suspect Decades After Crimes*, WASH. POST (Apr. 26, 2018), [https://www.washingtonpost.com/news/post-nation/wp/2018/04/26/authorities-begin-racking-up-cases-against-golden-state-killer-suspect-ex-cop-turned-mechanic/?utm\\_term=.7ff550e2558e](https://www.washingtonpost.com/news/post-nation/wp/2018/04/26/authorities-begin-racking-up-cases-against-golden-state-killer-suspect-ex-cop-turned-mechanic/?utm_term=.7ff550e2558e). “Although investigative searches of DNA databases are routine, the Golden State Killer case marks one of the first times police have successfully used a database not created for law enforcement purposes in this way.” Natalie Ram, *Incidental Informants: Police Can Use Genealogy Databases to Help Identify Criminal Relatives—But Should They?*, 51 MD. B.J. 8, 9 (2018).

31. Pike, *Securing Sequences*, *supra* note 11, at 1984 (footnote omitted); see also Lawrence O. Gostin et al., *Virus Sharing, Genetic Sequencing, and Global Health Security*, 345 SCI. MAG. 1295, 1295–96 (2014) (explaining how genetic data can now be stored electronically without the need for physical samples to be preserved).

be stored electronically.<sup>32</sup> This is a tremendous accomplishment that significantly helps genetic researchers searching for ways to prevent and cure diseases. DTC companies are well aware that genetic information is very valuable to pharmaceutical companies and medical researchers.<sup>33</sup> “The long game” for DTC companies “is not to make money selling [genetic testing] kits . . . . Once you have the data, [the genetic testing company becomes] the Google of personalized health care.”<sup>34</sup> For this reason, DTC companies prompt customers to sign consent forms before shipping their samples to the lab.<sup>35</sup> These forms provide testing companies with “a royalty-free, worldwide, sub-licensable, transferable license to host, transfer, process, analyze, distribute, and communicate [the individual’s] [g]enetic [i]nformation.”<sup>36</sup> Such sharing agreements are becoming more common. For example, on July 25, 2018, GlaxoSmithKline (“GSK”)—a large pharmaceutical company—announced that it was paying 23andMe \$300 million for the right to use the DTC company’s customer data for genetic research.<sup>37</sup>

On one hand, massive amounts of genetic data in the hands of well-intentioned organizations could create significant medical breakthroughs. On the other hand, it has the potential to create very serious genetic privacy violations because the misuse of genetic information could occur even if careful efforts to safeguard these data are taken. For example, in 1997, researchers were able to identify patients whose health records had been anonymized and publicly displayed by

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32. See Robert Gebelhoff, *Sequencing the Genome Creates So Much Data We Don’t Know What To Do with It*, WASH. POST (July 7, 2015), <https://www.washingtonpost.com/news/speaking-of-science/wp/2015/07/07/sequencing-the-genome-creates-so-much-data-we-dont-know-what-to-do-with-it> (highlighting the far-reaching implications of researching genetic data).

33. Elizabeth Murphy, *Inside 23andMe Founder Anne Wojcicki’s \$99 DNA Revolution*, FAST COMPANY (Oct. 14, 2013), <https://www.fastcompany.com/3018598/for-99-this-ceo-can-tell-you-what-might-kill-you-inside-23andme-founder-anne-wojcickis-dna-r>.

34. *Id.* (quoting Patrick Chung, a 23andMe board member).

35. Schulson, *supra* note 7.

36. *Id.* (quoting the AncestryDNA consent form).

37. Zhang, *supra* note 27.

the State of Massachusetts for research purposes.<sup>38</sup> Although the data had been stripped of some identifiable information, the patients' sex, birthdate, and zip code remained attached to the data.<sup>39</sup> Using the information accompanying the records, researchers were able to cross-reference this information with other publicly available facts to reidentify some of the patients.<sup>40</sup> As people voluntarily disclose more personal information through social media and other online mediums, the chances that their anonymized genetic data will be reidentified through some cross-referencing procedure increases.<sup>41</sup> Responding to the challenges posed by reidentification, the National Institutes of Health issued new guidelines in 2014 for de-identifying the genetic data it posts online to share with researchers.<sup>42</sup> The problem with de-identification efforts, however, is that genetic data cannot ever be completely anonymized.<sup>43</sup> This is so because some personal information is needed to distinguish samples from each other and track important variables, such as age, sex, geographic location, and more.<sup>44</sup> The example concerning the patients in Massachusetts, and others like it that have occurred in recent years, demonstrates that anonymized genetic information's reidentification is possible and relatively easy.<sup>45</sup> Thus, research subjects' genetic privacy remains at

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38. Sejin Ahn, *Whose Genome Is it Anyway?: Re-Identification and Privacy Protection in Public and Participatory Genomics*, 52 SAN DIEGO L. REV. 751, 766–68 (2015).

39. *Id.* at 767.

40. *Id.* at 767–68.

41. *See id.* at 768.

42. Richard Van Noorden, *US Agency Updates Rules on Sharing Genomic Data*, NATURE (Sept. 1, 2014), <http://www.nature.com/news/us-agency-updates-rules-on-sharing-genomic-data-1.15800> (describing a variety of changes, including ones regarding the de-identifying process for genetic data, the National Institutes of Health made to its research publication procedures).

43. *See* Melissa Gymrek et al., *Identifying Personal Genomes by Surname Inference*, 339 SCI. 321, 321 (2013) (explaining how de-identified participants in genetic research can be reidentified by comparing publicly available genetic databases).

44. *See* Mats G. Hansson et al., *The Risk of Re-Identification Versus the Need to Identify Individuals in Rare Disease Research*, 24 EUR. J. HUM. GENETICS 1553, 1554 (2016).

45. Ahn, *supra* note 38, at 767–69 (discussing multiple examples of genetic research where reidentification of research participants was made possible through the cross-referencing of personal information).

risk even though institutions make good-faith efforts to safeguard people's genetic data.<sup>46</sup>

In addition to unintentional misuses of genetic information, intentional genetic privacy violations could occur. It may surprise some to learn that the worth of genetic data and other forms of health information is "10 times more than [a] credit card number on the black market."<sup>47</sup> Although many people assume the genetic data they provide to researchers, law enforcement officials, or DTC companies remains safe and secure in a database somewhere, the reality is far more concerning.<sup>48</sup> Hackers frequently attack large dossiers of health information, such as those maintained by DTC companies. Over 1,000 cyber-attacks on large dossiers of sensitive health-care information have occurred in the last few years.<sup>49</sup> In June 2018, hackers compromised the accounts of over 92 million customers of the DNA-testing service provided by MyHeritage.<sup>50</sup> These databases are targets because the health-care industry is extremely lucrative and guarded by low levels of cyber security.<sup>51</sup> "Hacks are inevitable. . . . [G]enetic depositories are obvious targets."<sup>52</sup> Once hackers obtain sensitive information, they may wish to sell the data to insurance companies or pharmaceutical research organizations.<sup>53</sup> Existing laws prevent insurance companies from denying coverage based on genetic conditions,<sup>54</sup> and companies would not knowingly purchase data from hackers. "But it can be unclear where the data comes from, and there will always be underground markets through which this information could"

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46. Gymrek et al., *supra* note 43, at 321.

47. Humer & Finkle, *supra* note 5.

48. Pitts, *supra* note 4.

49. See, e.g., *NHS Cyber-Attack*, *supra* note 5; Ornstein, *supra* note 5.

50. *MyHeritage Statement*, *supra* note 5.

51. Humer & Finkle, *supra* note 5 (explaining that providing health care is an industry that is worth approximately \$3 trillion in the United States); see also Drabiak-Syed, *supra* note 5, at 215 (describing the high value medical researchers place on genetic data); Regalado, *supra* note 5 (reporting that DTC companies have begun coordinating with drug makers to establish lucrative sharing arrangements).

52. Pitts, *supra* note 4.

53. Chen, *supra* note 5.

54. See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008). Title I of GINA prohibits insurance companies from using a person's genetic information to make decisions about eligibility for health care. *Id.*

significantly impair individual autonomy if sold to unauthorized parties, used as blackmail, or held for ransom.<sup>55</sup> To see how harms from the hack of a genetic database could occur, consider the following hypothetical of a woman named Deborah.<sup>56</sup>

Deborah was adopted and has no knowledge of her biological parents.<sup>57</sup> She is an athletic person who was a star of her college rowing club. A good portion of her personal identity is based on the pride she takes in her past athletic accomplishments and continued physical fitness. Despite the identity she presents to the people around her, she has been diagnosed with hidradenitis suppurativa (“HS”), which is a “chronic, recurrent, and debilitating inflammatory skin condition.”<sup>58</sup> Deborah conceals her skin condition by wearing long sleeves and pants. She decides to learn more about her condition and genealogical background by using genetic testing, so she purchases a testing kit and sends her samples to a DTC company.<sup>59</sup> The result of the test reveals that Deborah carries the HS gene.<sup>60</sup> Then, the company Deborah paid to test her genes is the target of a cyber-attack. The hackers obtain Deborah’s genetic data—along with the genetic information of many of the company’s other customers—and sell the data to various companies offering services to treat HS.<sup>61</sup> Subsequently, Deborah begins to receive brochures from these treatment companies.<sup>62</sup> Debo-

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55. Chen, *supra* note 5; see also *Bitcoin Demanded*, *supra* note 6 (reporting on a hospital in Indiana, which hackers demanded an “unspecified amount” from after its electronic health records were compromised and held for ransom).

56. This example is derived from hypotheticals provided by Sejin Ahn and Ifeoma Ajunwa. See Ahn, *supra* note 38, at 752–55 (discussing a scenario where a hacker obtained a DTC customer’s genetic information and disclosed it without the customer’s consent); Ajunwa, *supra* note 8, at 1228–31 (same).

57. See Ahn, *supra* note 38, at 752; Ajunwa, *supra* note 8, at 1228.

58. Erika Yue Lee et al., *What is Hidradenitis Suppurativa?*, 63 CANADIAN FAM. PHYSICIAN 114, 114 (2017), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5395382/pdf/0630114.pdf>.

59. See Ahn, *supra* note 38, at 753; Ajunwa, *supra* note 8, at 1228.

60. See Ajunwa, *supra* note 8, at 1228.

61. See Ahn, *supra* note 38, at 753–54 (discussing the possibility of a hacker obtaining the genetic information of DTC customers); Ajunwa, *supra* note 8, at 1228–29 (same); see also Schulson, *supra* note 7 (explaining that genetic information provided to DTC companies can be bundled and sold to entities willing to pay for such information).

62. See Ajunwa, *supra* note 8, at 1229–30.

rah's neighbors see the pamphlets because they are delivered to her apartment complex and are left hanging out of the mailbox next to her door.<sup>63</sup>

The hackers in this hypothetical could hold Deborah's genetic information for ransom and threaten to disclose it to her employer, neighbors, or friends. Moreover, this hypothetical illustrates how the misuse of genetic data can be very traumatic and harmful to a person's autonomy, which is the primary focus of this Article.<sup>64</sup> Deborah's individual autonomy was harmed when the brochures disclosed information about her genes that she wanted to remain private. Autonomy is a complex concept, but it is generally founded on the following principles: (1) respect for a people's ability to make their own choices; (2) respect for the choices people make; and (3) respect for the importance of having an environment in which to make free choices.<sup>65</sup> In the genetic data context, the capacity to make one's own choices involves the ability to decide when, and to whom, sensitive personal information is disclosed.<sup>66</sup> Misusing a person's genetic information undermines that person's autonomy by failing to demonstrate respect for their right to exercise control over certain sensitive facts' dissemination.<sup>67</sup> The ability to maintain control over such information plays an important role in our ability to autonomously con-

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63. See *id.* at 1230.

64. The concept of autonomy has a rich history in the biomedical context. For a more robust discussion of human dignity, autonomy, and genetic data, see a 2003 article by Roger Brownsword, *An Interest in Human Dignity as the Basis for Genomic Torts*, 42 WASHBURN L.J. 413 (2003). See also Edward J. Bloustein, *Privacy as an Aspect of Human Dignity: An Answer to Dean Prosser*, 39 N.Y.U. L. REV. 962 (1964) (discussing the merits of conceiving privacy as an interest in human dignity); Makdisi, *supra* note 8 (evaluating the merits of viewing genetic data through a human dignity and privacy lens).

65. See Brownsword, *supra* note 64, at 416. Brownsword provides a nice overview of discussions concerning human dignity and autonomy in the genetic data context.

66. See Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31, 49 (Mark A. Rothstein ed., 1997) (explaining how the contents of a person's DNA contain information that is highly particularized to an individual).

67. See *id.* at 43; Bloustein, *supra* note 64, at 971, 974, 984.

struct and maintain our individual identities.<sup>68</sup> For example, Deborah is able to maintain the identity of a physically fit person by often donning her rowing-club shirt in public while also wearing long sleeves and pants to conceal her skin condition. The unwanted disclosure of Deborah's skin condition to members of her community constituted an intrusion on her right to control the dissemination of sensitive information about herself. "Western culture defines individuality as including the right to be free from certain types of intrusions."<sup>69</sup> Genetic privacy violations are precisely the sort of intrusions that harm our ability to exercise autonomy by maintaining our individual identities in the communities we live in.

Unfortunately, doctrinal barriers afflicting the current state of tort law prevent people like Deborah from receiving adequate compensation for genetic privacy violations. These barriers can be explained in large part by the fact that contemporary tort law too often requires fault for the imposition of liability. Part III will explain the origins of fault-based tort law in greater detail.

### III. THE SOURCE OF DOCTRINAL BARRIERS: FAULT-BASED TORT LAW

Tort law can be broadly described as having two main goals: deterring harms and compensating those who have been injured by others.<sup>70</sup> Contemporary tort law affords compensation only when in-

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68. See Bloustein, *supra* note 64, at 963. These identities are formed autonomously when people are able to control the facts about themselves that are known to those in their community. See generally SISSELA BOK, *SECRETS: ON THE ETHICS OF CONCEALMENT AND REVELATION* 18–24 (1982) (discussing the need for secrecy in social life).

69. Bloustein, *supra* note 64, at 973.

70. See, e.g., Geistfeld, *supra* note 9, at 389, 415; John C. P. Goldberg, *Twentieth-Century Tort Theory*, 91 GEO. L.J. 513, 525 (2003) (footnotes omitted); Daniel W. Shuman, *The Psychology of Deterrence in Tort Law*, 42 U. KAN. L. REV. 115, 118 (1993). Geistfeld notes that although there is no universal consensus about the most correct rationale underlying tort law, the compensation-deterrence rationale emerges from the interpretive examination of tort law. Geistfeld, *supra* note 9, at 384; Goldberg, *supra*, at 521–22 (noting that many scholars express deep disagreements about the rationale underlying tort law); see also SAUL LEVMORE & CATHERINE M. SHARKEY, *FOUNDATIONS OF TORT LAW* 249 (Roberta Romano ed., 2d ed. 2009) (contending that tort law aims to deter risky behavior and promote fundamental fairness). To be sure, within compensation-deterrence theory, there are varying opinions as to whether one of these goals should take priority over the other. See

juries occur as the result of fault, which generally refers to behavior that is “thought to be in need of deterrence.”<sup>71</sup> Because fault principles dominate contemporary tort theory, tort law’s deterrence goals have received a disproportionate amount of attention relative to compensation aims.<sup>72</sup> To understand how deterrence has come to play such a central role in tort law, it is useful to appreciate how social, political, and economic changes in the nineteenth century had a significant effect on the doctrine. The developments during that period played a large part in shaping tort law’s evolution throughout the twentieth century and up to present day.

#### A. *The Roots of Fault-Based Tort Law*

For much of the nineteenth century, the character of a typical tort suit consisted of hyper-localized disputes, such as a person striking his neighbor.<sup>73</sup> During this time, fault was requisite for liability.<sup>74</sup> The fault principle held actors accountable when they violated—either intentionally or negligently<sup>75</sup>—the behavioral norms governing

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Goldberg, *supra*, at 525 n.53. A full discussion of the compensation-deterrence debate is outside the scope of this Article.

71. Shuman, *supra* note 70, at 119.

72. See James A. Henderson, Jr., *Why Negligence Dominates Tort*, 50 UCLA L. REV. 377, 377, 380, 404 (2002) (linking fault and negligence in tort law and explaining that negligence is at the core of American tort law); see also Goldberg, *supra* note 70, at 527 (describing how “compensation-deterrence” tort law theorists view the primary goals of tort law to be deterring harms caused by negligence and compensating victims of such negligent behavior).

73. Goldberg, *supra* note 70, at 523–24.

74. Jeremiah Smith, *Sequel to Workmen’s Compensation Acts*, 27 HARV. L. REV. 344, 344 (1914). “Fault liability makes wrongful agency,” which is defined as negligent behavior that does not comport with accepted standards, “the fundamental basis of responsibility for harm.” See Gregory C. Keating, *The Theory of Enterprise Liability and Common Law Strict Liability*, 54 VAND. L. REV. 1285, 1286 (2001).

75. Henderson, *supra* note 72. Henderson also observes that “‘fault’ is synonymous with negligence.” *Id.* at 380. It should be noted, however, that some scholars believe strict liability was the dominant tort theory prior to the nineteenth century before becoming overtaken by fault in that century. Joseph H. King, Jr., *A Goals-Oriented Approach to Strict Tort Liability for Abnormally Dangerous Activities*, 48 BAYLOR L. REV. 341, 343–44 (1996). Multiple explanations exist as to why strict liability dominated early common law. *Id.* Likewise, many explanations are



the communities in which the parties to the suit resided.<sup>76</sup> For example, one of these conventional norms might stipulate that a person does not exercise a reasonable level of care if he swings his walking cane above waist level in a public space. If defendant (“D”) injures plaintiff (“P”) by failing to observe this standard, and some exigent circumstance does not excuse D’s act, he is liable for the injury.<sup>77</sup> In such instances, the cost of the harm is shifted from the injured person to the party at fault.<sup>78</sup> A consequence of this tort system was that if D caused an injury to P, but D’s behavior did not violate any behavioral norm, liability was not imposed, and P would bear the cost of the injury.<sup>79</sup>

During this time, some exceptions to the fault principle existed. One such exception was the doctrine of strict liability, which

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available as to why fault-based liability came to replace strict liability during the nineteenth century. *See id.* at 344–45.

76. Geistfeld, *supra* note 9, at 388; Keating, *supra* note 74, at 1286; King, *supra* note 75, at 344.

77. *See, e.g.,* Brown v. Kendall, 60 Mass. (6 Cush.) 292 (1850) (holding that a man using a cane to break up a dog fight in a park was not liable for the injury caused by his cane striking another person because the defendant was acting in response to exigent circumstances and injured the plaintiff by accident).

78. *See* Goldberg, *supra* note 70, at 522–23 (observing that if judges and juries determined that a D was at fault, the D would be required to provide the P with redress); Virginia E. Nolan & Edmund Ursin, *The Deacademification of Tort Theory*, 48 U. KAN. L. REV. 59, 69 (1999) [hereinafter Nolan & Ursin, *The Deacademification*]. The fault-based scheme of “tort law was a reflection of a laissez-faire economic philosophy that favored . . . individual responsibility.” King, *supra* note 75, at 345.

79. King, *supra* note 75, at 344. Several explanations are available for the dominance of fault-based law during this period. Some argue that fault principles are the natural result of the social evolution away from tort laws designed to promote peaceful interactions and toward a more modern society governed by moral norms—in the latter society, law is designed to promote popular conceptions of fairness instead of merely keeping the peace. *Id.* King notes:

Others speculate that the fault requirement grew out of a perceived double standard that allowed recovery without fault for direct injuries but required fault for indirect ones. Perhaps the most convincing explanation for the explicit rise of the fault system in tort law was the perceived need to protect fledgling industries during the early years of the industrial revolution.

*Id.* at 344–45.

holds actors causing an accident liable regardless of fault.<sup>80</sup> Strict liability only applied in very specific circumstances during the late nineteenth century.<sup>81</sup> These circumstances included vicarious liability for employers.<sup>82</sup> Vicarious liability holds employers strictly liable for the torts committed by their employees during the course of the employees' duties at work.<sup>83</sup> Abnormally dangerous activities—like handling explosive devices or keeping wild animals—were other circumstances where strict liability was appropriate.<sup>84</sup> In that era, strict liability typically applied to situations that were factually similar and shared the potential for serious harm.<sup>85</sup> These shared characteristics made it possible for strict liability to be narrowly applied.<sup>86</sup> For many years, the narrow use of strict liability prevented it from challenging the fault-based system's position as the "main determinant" of tort liability.<sup>87</sup>

### B. The Rise of Strict Liability

In the late nineteenth and early twentieth century, tort law began to change in fundamental ways.<sup>88</sup> The industrial revolution caused greater portions of the population to begin working in large factories, traveling further from their homes in pursuit of work, and interacting with unfamiliar people.<sup>89</sup> As a result of these developments, it became less likely that a person would be injured by the negligent conduct of a neighbor—at the same time, it became more likely

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80. LEVMORE & SHARKEY, *supra* note 70, at 249; Henderson, *supra* note 72, at 380.

81. *See, e.g.*, LEVMORE & SHARKEY, *supra* note 70, at 249.

82. *Id.* at 250.

83. *Id.*

84. *Id.* at 249; Henderson, *supra* note 72, at 384–85.

85. King, *supra* note 75, at 346–47.

86. *Id.*

87. *Id.* at 345–46; *see also* Smith, *supra* note 74, at 344. "Fault liability makes wrongful agency," which is defined as negligent behavior that does not comport with accepted standards, "the fundamental basis of responsibility for harm." *See* Keating, *supra* note 74, at 1286.

88. Goldberg, *supra* note 70, at 523.

89. *See* CORONA BREZINA, THE INDUSTRIAL REVOLUTION IN AMERICA: A PRIMARY SOURCE HISTORY OF AMERICA'S TRANSFORMATION INTO AN INDUSTRIAL SOCIETY 4 (2005).

that one would be injured by strangers, in workplace accidents, or by some other hazard created by industrialization.<sup>90</sup> Liability for these accidents was not merely a matter of shifting losses from one party to another, as called for under a fault-based theory.<sup>91</sup> Although the costs of accidents caused by fault might originally have been borne by the business enterprise causing the harm, they were eventually passed on to the public in the form of lower wages for employees, higher prices for consumers, and more.<sup>92</sup> This realization led to the expansion of strict liability.<sup>93</sup>

Toward the end of the nineteenth century, strict liability proponents began to call for the entities, such as automobile manufacturers and other product retailers, profiting from activities producing accident risk to bear the cost of such accidents “as a matter of first principle.”<sup>94</sup> Strict liability was thought to be better than fault-based

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90. See Robert I. Field, *The Malpractice Crisis Turns 175: What Lessons Does History Hold for Reform?*, 4 DREXEL L. REV. 7, 20 (2011) (noting the rise in workplace injuries that resulted from the American economy’s shift from an already dangerous agrarian base to an industrial base, which posed even more risks to workers). Courts and scholars began to realize that tort law was becoming primarily concerned with “injuries to person[s] or property by railroads, factories, and the like.” O.W. Holmes, Jr., Address, *The Path of the Law*, 10 HARV. L. REV. 457, 467 (1897). Tort complaints tended to concern “the failure of commercial enterprises to account adequately for the safety of employees, customers, and bystanders.” Goldberg, *supra* note 70, at 523.

91. See Holmes, *supra* note 90, at 467; Fleming James, Jr., *Accident Liability Reconsidered: The Impact of Liability Insurance*, 57 YALE L.J. 549, 551 (1948). This is so because “the person [or entity] nominally liable is often only a conduit through whom this process of distribution starts to flow.” *Id.* This recognition led courts to stop basing tort liability on localized morality. Geistfeld, *supra* note 9, at 389. In lieu of a tort analysis based on the mores of local communities, courts searched for a more objective standard to determine the norms of conduct by which tort liability was to be judged. Goldberg, *supra* note 70, at 523–24. In modern societies, business enterprises were initially assuming responsibility for “injuries to person[s] or property by railroads, factories, and the like,” but such liability is eventually spread out among the communities in which that enterprise exists. Holmes, *supra* note 90, at 467.

92. Holmes, *supra* note 90, at 467; Nolan & Ursin, *The Deacademification*, *supra* note 78, at 69.

93. Keating, *supra* note 74, at 1287.

94. Henderson, *supra* note 72, at 380; see also Keating, *supra* note 74, at 1301–02; Nolan & Ursin, *The Deacademification*, *supra* note 78, at 72. A particularly modern form of strict liability, known as “enterprise liability,” developed dur-

law at compensating injured parties by spreading the allocation of loss “across all those—owners, managers, customers, suppliers, employees—who benefit from the imposition of the enterprise’s characteristic risks.”<sup>95</sup> Additionally, strict liability was expected to achieve greater accident deterrence by placing liability for such accidents in the hands of the enterprises that are in the best position to understand the risks posed by their activities and take steps to prevent the accidents they cause.<sup>96</sup> By the late 1960s, as courts and legislatures across America began widely adopting strict liability, many expected strict liability principles to supplant the fault requirement in tort law.<sup>97</sup>

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ing this time. Keating, *supra* note 74, at 1287. “Whereas traditional strict liability expressed the maxim that those who act do so at their peril, enterprise liability expresses the maxim that those who profit from the imposition of risk should bear the costs of the accidents that are a price of their profits.” *Id.* In the name of clarity and economy, though, I will use the term strict liability throughout this Article to refer to “the maxim that those who profit from the imposition of risk should bear the costs of the accidents that are a price of their profits.” *Id.*

95. Keating, *supra* note 74, at 1295. The idea animating strict liability proponents was that the entities profiting from the risk they pose to workers and consumers should be responsible for the price of the accidents they cause. *Id.* at 1286. Thus, strict liability was thought to be the best theory by which the compensation-deterrence goals of tort law could be achieved. Nolan & Ursin, *The Deacademification*, *supra* note 78, at 64–65.

96. Nolan & Ursin, *The Deacademification*, *supra* note 78, at 64.

97. See G. Edward White, *The Unexpected Persistence of Negligence, 1980–2000*, 54 VAND. L. REV. 1337, 1343 n.18 (2001) (citing several cases and the *Restatement (Second) of Torts* indicating evidence that courts were beginning to develop doctrines based on strict liability during the late 1960s). Throughout the early nineteenth century, support for strict liability continued to gain steam. What began as a doctrine focused on workers’ compensation schemes began to expand into other areas of life. Strict liability began to seep into automobile accident disputes, food warranty cases, and more. Nolan & Ursin, *The Deacademification*, *supra* note 78, at 64–65; White, *supra* at 1342. By the late 1960s and early 1970s, many scholars and practitioners were convinced that strict liability achieved the aims of tort law better than negligence principles. Nolan & Ursin, *The Deacademification*, *supra* note 78, at 72. At that time, “[t]raditional tort theory, with its focus on doctrinal analysis and fault, appeared tired, passe, [and] obsolete.” *Id.* Many predicted that the coming years would see the replacement of fault principles with strict liability. White, *supra* at 1344.

Of course, strict liability did not replace tort law's fault-based principles, which are alive and well today.<sup>98</sup> A significant factor in strict liability's retrenchment is that, in the 1970s, courts, scholars,

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98. White, *supra* note 97, at 1344. Part of the reason for strict liability's diminished popularity is that some traditional theorists denounced the rise of strict liability as an objectionable form of social engineering that flirted too closely with socialism. See William L. Prosser, *The Assault Upon the Citadel (Strict Liability to the Consumer)*, 69 YALE L.J. 1099, 1120 (1960); White, *supra* note 97, at 1341 ("Americans, collectively if not universally, changed the direction of their thinking about government, free markets, and the role of risk and injury . . ."). Those agreeing with this position mounted stiff opposition to strict liability's expansion and looked to exploit weaknesses in the doctrine. One such weakness was the fragmentation of the strict liability movement during the late 1960s and early 1970s. Seeking to distinguish their ideas as novel improvements on strict liability, some scholars working in this space began referring to their proposals as "no-fault" schemes. Nolan & Ursin, *The Deacademification*, *supra* note 78, at 73–74 (noting that Jeffrey O'Connell did not mention "enterprise liability" in his 1973 book about compensation for automobile accidents). The long-term consequence of this fragmentation was to decouple compensation and insurance plans from the realm of tort law. *Id.* at 73. This was an important development because although strict-liability proponents had worked hard to establish the doctrine within tort theory during the nineteenth century, removing compensation and insurance plans from the sphere of tort law caused strict liability to eventually "be seen as an alternative to tort, not as a theory about the proper configuration of tort (personal injury) law." *Id.* at 74. As opposition to enterprise liability became more organized, its proponents allowed the movement to become splintered and, therefore, difficult to defend against sustained critiques. *Id.*

Another factor contributing to the decreased influence of strict liability was the desire of scholars and practitioners to work on cutting edge legal issues. *Id.* at 75. By the early 1970s, strict liability had been written about for decades. *Id.* When the economic efficiency and corrective justice analyses of tort law emerged as alternative methods for analyzing tort law, it is unsurprising that a significant amount of scholarly energy was diverted away from strict liability and funneled into these new directions. *Id.*

As strict liability theorists continued to splinter their ranks, economic critics of strict liability provided sophisticated critiques of enterprise liability that had a profound effect on tort scholarship and practice. See *id.* at 80–82. Several sources provide a more comprehensive discussion of the myriad of factors contributing to strict liability's waning influence. See generally Keating, *supra* note 74 (discussing the historical, political, and jurisprudential reasons for strict liability's waning influence); Nolan & Ursin, *The Deacademification*, *supra* note 78 (discussing the historical trends of negligence, enterprise liability, and corrective justice theories in tort law); White, *supra* note 97 (explaining why negligence law has persisted amidst challenges from strict liability, corrective justice, and other alternatives to negligence rules).

and members of the public began analyzing tort law through an economic-efficiency lens.<sup>99</sup> On the plane of economic analysis, defenders of fault-based principles succeeded in shifting enthusiasm away from strict liability.<sup>100</sup> A leader of the economic-efficiency critique of strict liability was Richard Posner.

*C. Economic Efficiency's Rise, the Pruning of Strict Liability, and Fault's Return*

For Posner, who began writing on strict liability in the early 1970s and later became a judge on the U.S. Court of Appeals for the Seventh Circuit, fault-based tort principles are preferable to strict liability because the former achieves the greatest—and most efficient—deterrence of risky behavior.<sup>101</sup> He argued that fault-based tort law requires injury-causing actors to bear their acts' cost up to the point that doing so will encourage them to take greater precautions.<sup>102</sup> As then-Judge Posner wrote in 1987, if the burden of taking precaution "is less than the magnitude of the accident . . . the precaution should be taken."<sup>103</sup> If it is not, however, liability will not be imposed on people who fail to take a precaution that imposes a greater burden than the cost of a potential accident.<sup>104</sup> According to this view, an entity that is liable under a strict liability regime has no incentive to take steps to prevent an accident if the cost of doing so is greater than the potential price the entity would have to pay in the event of an accident.<sup>105</sup> In such a scenario, an enterprise might simply choose to pay

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99. White, *supra* note 97, at 1345. To be sure, some economic efficiency theorists, such as Guido Calabresi, supported the continued expansion of strict liability. Guido Calabresi sought to develop a tort theory that was "less concerned with the risk spreading" justifications for strict liability. Guido Calabresi, *Some Thoughts on Risk Distribution and the Law of Torts*, 70 YALE L.J. 499, 501–02 (1961) [hereinafter Calabresi, *Some Thoughts*]. In lieu of risk spreading justifications for strict liability, Calabresi suggested a more general argument for strict liability based on the theory of efficient resource allocation. *Id.*

100. See Nolan & Ursin, *The Deacademification*, *supra* note 78, at 63.

101. *Id.*

102. See Goldberg, *supra* note 70, at 545.

103. *McCarty v. Pheasant Run, Inc.*, 826 F.2d 1554, 1556 (7th Cir. 1987).

104. Richard A. Posner, *Strict Liability: A Comment*, 2 J. LEGAL STUD. 205, 206 (1973).

105. *Id.* at 207 n.6.

the price of the accident instead of taking the more costly steps to avoid the activity creating a risk of injury.<sup>106</sup> Posner argued that if entities do not have a greater incentive to take precautions and deter accidents under a strict liability regime than they do under a fault-based system, there is no reason to prefer a strict liability regime.<sup>107</sup>

In the mid-1970s and beyond, Posner's forceful challenge to strict liability produced a wave of scholarship focused on defending fault-based tort law on economic-efficiency grounds.<sup>108</sup> Partly due to the shift in tort theory inspired by Posner and partly due to factors that are beyond the scope of this Article,<sup>109</sup> fault-based principles regained their prominence by the late 1970s.<sup>110</sup> Fault is now—and has been for the last several decades—the dominant principle in American tort law.<sup>111</sup> This shift away from strict liability created doctrinal barriers that stand between injured persons and compensation for the harms they suffer. The next section will illustrate these doctrinal barriers in greater detail and describe how they have a negative effect on genetic privacy violations' victims.

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106. *Id.*

107. *Id.* at 220–21. As he put it, “[t]he question whether a general substitution of strict for [fault] liability would improve efficiency seems at this stage hopelessly conjectural; the question is at bottom empirical and the empirical work has not been done.” *Id.* at 211–12.

108. Nolan & Ursin, *The Deacademification*, *supra* note 78, at 62–63.

109. *See supra* note 98 and accompanying text.

110. *See* Henderson, *supra* note 72, at 404; Nolan & Ursin, *Enterprise Liability*, *supra* note 13, at 836–37.

111. *See, e.g.*, CHRISTOPHER M. ERNST, BALDWIN'S OHIO PRACTICE, OHIO TORT L. § 10:5 (2d ed. 2010 & Supp. 2018) (observing that fault-based principles of tort law have become the “dominant cause of action for accidental injury in this nation today”) (footnote omitted); PETER NASH SWISHER ET AL., VIRGINIA PRACTICE SERIES: TORT AND PERSONAL INJURY LAW § 3:1 (2018–2019 ed.) (observing that fault-based actions “represent the vast majority of tort actions alleged, presented, settled, or tried in American courts today”) (footnote omitted); Henderson, *supra* note 72, at 380.

## IV. DOCTRINAL BARRIERS IMPEDE ACCESS TO TORT REMEDIES

Several tort claims are available to victims of genetic privacy violations.<sup>112</sup> As Ifeoma Ajunwa notes, however, three are most ap-

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112. See, e.g., Ajunwa, *supra* note 8, at 1243, 1245–54 (commenting on the possibility of raising the following tort claims: unreasonable publicity of private facts, negligent and intentional infliction of emotional distress, and breach of fiduciary duty); Gerald Carr, *Protecting Intangible Cultural Resources: Alternatives to Intellectual Property Law*, 18 MICH. J. RACE & L. 363, 381–82 (2013) (discussing several claims—including fraud and misrepresentation, negligent and intentional infliction of emotional distress, breach of fiduciary duty, and unreasonable disclosure of private facts—that could be appropriate in the genetic data context); Susan M. Denbo, *What Your Genes Know Affects Them: Should Patient Confidentiality Prevent Disclosure of Genetic Test Results to a Patient's Biological Relatives?*, 43 AM. BUS. L.J. 561, 574 (2006) (discussing the possibility of a tort claim for an invasion of privacy in the genetic privacy context); Drabiak-Syed, *supra* note 5, at 185–98 (discussing *Tilousi v. Arizona State Univ. Bd. of Regents*, No. 04-CV-1290-PCT-FJM, 2005 WL 6199562, at \*1 (D. Ariz. Mar. 3, 2005), which was a case alleging the following counts for the misuse of genetic material: “(1) breach of fiduciary duty and lack of informed consent; (2) fraud, misrepresentation, and fraudulent concealment; (3) intentional and negligent infliction of emotional distress; (4) conversion; (5) violation of civil rights; (6) negligence, gross negligence, and negligence per se; (7) unreasonable disclosure of private facts; and (8) intentional intrusion upon seclusion”); Ken M. Gatter, *Genetic Information and the Importance of Context: Implications for the Social Meaning of Genetic Information and Individual Identity*, 47 ST. LOUIS U. L.J. 423, 450–61 (2003) (discussing the tort of misappropriation of identity as being appropriate in the genetic data context); Madison Jennings, *Protected Genetics: A Case for Property and Privacy Interests in One's Own Genetic Material*, 23 RICH. J.L. & TECH. 10, 28 (2017) (discussing the torts of breach of informed consent, breach of fiduciary duty, and conversion in the genetic data context); Makdisi, *supra* note 8, at 982–91 (discussing intrusion on seclusion, unwanted disclosure of private facts, false light, and appropriation of name or likeness as privacy tort remedies for the misuse of genetic data); Natalie Ram, *Assigning Rights and Protecting Interests: Constructing Ethical and Efficient Legal Rights in Human Tissue Research*, 23 HARV. J.L. & TECH. 119, 158–61 (2009) (discussing violation of privacy and conversion as possible tort remedies for the misuse of genetic data); Mark A. Rothstein, *Genetic Stalking and Voyeurism: A New Challenge to Privacy*, 57 U. KAN. L. REV. 539, 547–57 (2009) (listing intrusion on seclusion, public disclosure of private facts, false light, and appropriation of name or likeness as possible remedies for the misuse of genetic data); Pilar N. Ossorio, *Product Liability for Predictive Genetic Tests*, 41 JURIMETRICS J. 239, 239 (2001) (making a case for the applicability of negligence liability and products liability for genetic testing services); David F. Partlett, *Misuse of Genetic Information: The Common Law and Professionals' Liability*, 42 WASHBURN L.J. 489, 496–99 (2003) (mentioning the tort of privacy as a possible



appropriate: unreasonable publicity of private facts; infliction of emotional harm; and breach of fiduciary duty.<sup>113</sup> Although these claims are available in theory, the reality is that doctrinal barriers erected by fault-based tort principles prevent those who suffer genetic privacy violations from succeeding on these claims.

*A. Publicity from the Unwanted Disclosure of Sensitive Personal Information*

According to the *Restatement (Second) of Torts*, a person's right to privacy is invaded when there has been an unreasonable publicity of a person's private life.<sup>114</sup> To see how a claim for unreasonable publicity might arise, consider *Balzac v. Stamford Hospital*.<sup>115</sup> The plaintiff in that case was a patient who Stamford Hospital in Connecticut tested for HIV.<sup>116</sup> After the test, the plaintiff waited for the results in the hospital's waiting room.<sup>117</sup> Eventually, an agent of the hospital returned and loudly announced the test results to the plaintiff and several other people present in the waiting room.<sup>118</sup> The plaintiff argued that the hospital agent's statements in the waiting room had violated the *Restatement's* prohibition against giving "unreasonable publicity" to a person's "private life."<sup>119</sup> But according to the *Restatement*, publicity does not exist when intimate facts are made

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method for addressing the misuse of genetic information); Pike et al., *supra* note 8, at 816–18 (commenting on the availability of breach of fiduciary duty and negligence as tort remedies in the genetic data context); Anita Silvers & Michael Ashley Stein, *An Equality Paradigm for Preventing Genetic Discrimination*, 55 VAND. L. REV. 1341, 1352–55 (2002) (discussing the torts of appropriation and unwanted disclosure of private facts in the genetic data context).

113. Ajunwa, *supra* note 8, at 1245–52. Although Ajunwa identifies these three claims as most appropriate for the genetic data context, they are among a selection of several tort claims commonly discussed in the literature on this subject. See *supra* note 112 and accompanying text.

114. See *Nelson v. Me. Times*, 373 A.2d 1221, 1225 (Me. 1977) (discussing RESTATEMENT (SECOND) OF TORTS § 652D (AM. LAW INST. 1977)).

115. *Balzac v. Stamford Hosp.*, No. CV 950143645S, 1996 WL 222406 (Conn. Super. Ct. Apr. 2, 1996).

116. *Id.* at \*1.

117. *Id.* at \*2.

118. *Id.*

119. *Id.* at \*2–3.

known to only “a small group of persons.”<sup>120</sup> Consequently, the *Balzac* court held that the plaintiff’s cause of action could not succeed because a group of people in a waiting room was not large enough to satisfy the level of publicity specified by the *Restatement*.<sup>121</sup>

Like the plaintiff in *Balzac*, Deborah, the hypothetical plaintiff described earlier, could attempt to establish a claim for an unreasonable publication of one’s private life, but it is unclear whether Deborah could succeed on an unwanted publicity cause of action. Deborah’s neighbors could be a group that is too small to meet the *Restatement*’s standard for “publicity.” Granted, a court might find that the hackers are included among the group that the genetic data is disclosed to and that those added individuals satisfy the publicity threshold. Nevertheless, the uncertainty regarding the *Restatement*’s numerosity requirement creates a barrier that Deborah would have to overcome before she can succeed on this privacy claim.<sup>122</sup> Hence, an unwanted publicity cause of action is unlikely to provide redress for a victim of a genetic privacy violation.

#### *B. Emotional Distress from the Unwanted Disclosure of Genetic Data*

According to the *Restatement (Third) of Torts*, “[a]n actor whose negligent conduct causes serious emotional harm to another is subject to liability to the other if the conduct . . . occurs in the course of specified categories of activities, undertakings, or relationships in which negligent conduct is especially likely to cause serious emotional harm.”<sup>123</sup> The misuse of a person’s genetic information can cause a very serious emotional injury regardless of whether physical harm occurs.<sup>124</sup> As mentioned above, genetic privacy violations diminish au-

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120. RESTATEMENT (SECOND) OF TORTS § 652D cmt. a (AM. LAW INST. 1977).

121. *Balzac*, 1996 WL 222406, at \*3.

122. See, e.g., *C.L.D. v. Wal-Mart Stores, Inc.*, 79 F. Supp. 2d 1080, 1084 (D. Minn. 1999) (citing several cases in support of the claim that “the majority of state and federal courts to consider this issue have held that communication to a few people is not sufficient publicity to state a cause of action under this tort”).

123. RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL & EMOTIONAL HARM § 47 (AM. LAW INST. 2012).

124. See Zhansheng Chen et al., *When Hurt Will Not Heal: Exploring the Capacity to Relive Social and Physiological Pain*, 19 PSYCHOL. SCI. 789, 793–94

tonomy by inhibiting others' ability to make their own choices, failing to respect the choices people make, and providing inadequate conditions in which to make free choices.<sup>125</sup> Studies indicate that subjective social harms—like those resulting from diminished autonomy—are traumatic experiences that can result in more severe and longer-lasting effects than some types of physical injuries.<sup>126</sup> As case law on this matter demonstrates, though, plaintiffs face an uphill battle when attempting to receive redress for the emotional harms they suffer.

For example, in *St. Anthony's Medical Center v. H.S.H.*, St. Anthony's Hospital turned the plaintiff's medical records over to his wife's divorce attorney.<sup>127</sup> The plaintiff acknowledged that part of the records were properly disclosed to the wife's lawyer pursuant to a court order to turn over medical information concerning chemical dependency.<sup>128</sup> But St. Anthony's Hospital responded to the wife's attorney's request by including both chemical dependency records and also those pertaining to psychiatric and psychological care—the latter records were not within the scope of the court order.<sup>129</sup> Then, when the wife's attorney refused to return the inappropriately disclosed records, the plaintiff sued St. Anthony's Hospital for both intentional and negligent infliction of emotional distress.<sup>130</sup> On the question of intentional infliction of emotional distress, the court noted that Missouri law required the defendant's conduct to be "extreme and outrageous" for the plaintiff to succeed on this claim.<sup>131</sup> Because the inappropriately disclosed psychological records included references to the possibility of chemical abuse, and the hospital could have reasonably in-

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(2008) (discussing studies that suggest "reliving social pain triggers higher levels of pain than reliving physical pain").

125. See Brownsword, *supra* note 64, at 416 (providing a nice overview of discussions concerning human dignity and autonomy in the genetic data context); see also M. Ryan Calo, *The Boundaries of Privacy Harm*, 86 IND. L.J. 1131, 1144 (2011).

126. Chen et al., *supra* note 124, at 793–94; see also Calo, *supra* note 125, at 1144–47 (discussing the adverse effects of subjective—as opposed to objective—privacy violations).

127. *St. Anthony's Med. Ctr. v. H.S.H.*, 974 S.W.2d 606, 608 (Mo. Ct. App. 1998).

128. *Id.*

129. *Id.* at 608, 611.

130. *Id.* at 608–09.

131. *Id.* at 611.

terpreted that information to fall under the release authorization, the court found that St. Anthony's Hospital had not acted in an outrageous or extreme manner.<sup>132</sup> On the question of negligent infliction of emotional distress, the court found that there was insufficient evidence to conclude that St. Anthony's Hospital should have known that disclosing the psychiatric records to the wife's attorney would cause the plaintiff to experience emotional distress.<sup>133</sup> For this reason, the court ruled against the plaintiff's negligent infliction of emotional distress claim.<sup>134</sup>

The decision in *St. Anthony's* militates toward concluding that Deborah would be unlikely to succeed in securing damages for an emotional distress claim. In the first place, like St. Anthony's Hospital, the DTC company Deborah used likely did not act in an "extreme" or "outrageous" manner when it lost control over some of its customers' genetic information due to a hack.<sup>135</sup> Deborah's DTC company could have implemented state-of-the-art cyber protections, and a very sophisticated cyber-attack could still have breached these protections. Second, based on the standard established in *St. Anthony's*, the DTC provider might be able to claim that it could not have reasonably known Deborah would suffer emotional distress from the disclosure of her genetic information. After all, because she turned her information over to be analyzed, the DTC company could infer that she did not mind too much if third parties became aware of sensitive genetic facts about her. These doctrinal barriers represent an unacceptable limitation on the ability of people like Deborah to receive redress for the injuries they suffer from violations of their genetic privacy. Thus, as Ajunwa notes, the emotional distress claim is an inadequate means of protecting the interest people have in their genetic information.<sup>136</sup>

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132. *Id.*

133. *Id.* at 613.

134. *Id.*

135. *See* Ajunwa, *supra* note 8, at 1244–45.

136. *See id.* at 1245, 1254 (stating that even a breach of fiduciary duty claim, which may be the strongest for a plaintiff in a similar scenario, would "not offer a sufficient remedy").

*C. Fiduciary Violations from the Unwanted Disclosure of Genetic Data*

Ajunwa and others—such as Elizabeth Pike—recognize that a breach of fiduciary duty claim is perhaps the best chance a victim of a genetic privacy violation has in succeeding on a tort cause of action.<sup>137</sup> Pike and Ajunwa draw on the influential work of Thomas Hafemeister, who has been widely cited because of the convincing case he makes in support of applying the breach of fiduciary duty cause of action in a variety of novel circumstances.<sup>138</sup> In fiduciary duty cases, the success of a plaintiff's claim depends on the existence of a fiduciary relationship between the parties.<sup>139</sup> “Fiduciary” has been interpreted to mean not only monetary relationships but also other sorts of obligations particular parties owe each other.<sup>140</sup> Hafemeister observes that these obligations play an important role in protecting “and maintain[ing] important societal relationships that the ‘morals of the market place’ would put in jeopardy.”<sup>141</sup> A doctor-patient relationship is typically considered sufficient to establish a fiduciary relationship,<sup>142</sup> and it seems appropriate to find a similar set of duties existing between customers and DTC companies. Indeed, “[a] hallmark of fiduciary law is its flexibility to accommodate new situations as they arise,” and to redress situations “where the ordinary

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137. See Ajunwa, *supra* note 8, at 1249–52 (discussing the scholarship of Thomas Hafemeister and Joshua Hinckley Porter on the topic of fiduciary duties (citing Thomas L. Hafemeister & Joshua Hinckley Porter, *Don't Let Go of the Rope: Reducing Readmissions by Recognizing Hospitals' Fiduciary Duties to Their Discharged Patients*, 62 AM. U. L. REV. 513, 544–46 (2013)); Pike et al., *supra* note 8, at 817–18 (citing work by Thomas Hafemeister and Selina Spinos on the subject of fiduciary duties, Thomas L. Hafemeister & Selina Spinos, *Lean on Me: A Physician's Fiduciary Duty to Disclose and Emergent Medical Risk to the Patient*, 86 WASH. U. L. REV. 1167, 1186–87 (2009))).

138. See *supra* note 137 and accompanying text.

139. See Ajunwa, *supra* note 8, at 1249 (stating when “an agreement [involves] the entrustment of genetic material in exchange for diagnostic services, [a plaintiff] could argue that a fiduciary duty [is] created” that is breached when the information is hacked).

140. See *id.* at 1250 (observing that courts and scholars have recognized the important role fiduciary duties play in promoting trust and communication between parties in specific types of relationships, such as doctor-patient and attorney-client).

141. Hafemeister & Porter, *supra* note 137, at 544.

142. See Ajunwa, *supra* note 8, at 1250.

laws of contract, tort and unjust enrichment are silent or insufficient.”<sup>143</sup> Despite the relative strength of this claim, it too is unlikely to succeed in the genetic data context. To see why this is so, consider the well-known case of *Greenberg v. Miami Children’s Hospital Research Institute, Inc.*<sup>144</sup>

In *Greenberg*, the plaintiffs were a group of individuals and organizations with an interest in discovering genes responsible for Canavan disease.<sup>145</sup> The plaintiffs entered into an agreement with the defendant, who was a physician conducting research on Canavan disease.<sup>146</sup> Pursuant to the agreement, the plaintiffs provided blood and tissue samples for the defendant to use in his research.<sup>147</sup> The plaintiffs thought any research breakthroughs would remain publicly available and accessible to communities afflicted with Canavan.<sup>148</sup> Contrary to this understanding, after the defendant made a research breakthrough, he applied for and received a patent that allowed him to restrict public access to the Canavan breakthrough and charge royalty fees for the fruits of the research.<sup>149</sup> In response, the plaintiffs filed a breach of fiduciary duty claim.<sup>150</sup> The complaint alleged that the defendant failed to disclose “all material information relating to the Canavan disease research . . . including any economic interests of the [defendant] relating to that research.”<sup>151</sup> Despite the plaintiffs’ claim, the *Greenberg* court found that a fiduciary relationship is not automatically created when a medical researcher accepts medical donations.<sup>152</sup> Put slightly differently, although the plaintiffs might have assumed that the defendant accepted certain duties to the plaintiffs by receiving medical donations, the court concluded that no such duties exist unless the defendant expressly “recognized and accepted” the duties the plaintiffs allege.<sup>153</sup>

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143. See *id.* at 1250 (alteration in original).

144. 264 F. Supp. 2d 1064 (S.D. Fla. 2003).

145. *Id.* at 1066.

146. *Id.* at 1066–67.

147. *Id.* at 1067.

148. *Id.*

149. *Id.*

150. *Id.* at 1068, 1071.

151. *Id.* at 1071.

152. *Id.* at 1072.

153. *Id.* at 1071–72.

Like the plaintiffs in *Greenberg*, it could be a challenge for individuals using genetic-testing services to prove a fiduciary relationship between themselves and any DTC genetic-testing service they use.<sup>154</sup> DTC companies like 23andMe expressly include in their terms of service a provision authorizing them to sell customers' genetic data to third parties.<sup>155</sup> For this reason, it is unlikely that DTC companies will be found to have "recognized and accepted" fiduciary duties to customers. Further, although genetic testing concerns intimate information, it is usually done remotely over the Internet<sup>156</sup> and, therefore, is not the sort of face-to-face interaction occurring in doctor-patient relationships, which have come to be seen as textbook examples of fiduciary relationships.<sup>157</sup> Granted, the disclosure of genetic information to a private company could be analogized to the more general types of fiduciary relationships, which "tend to be those in which one party, . . . the fiduciary, . . . is expected to loyally employ specialized knowledge, skills, and power over some aspect of the beneficiary's affairs to further the beneficiary's interests."<sup>158</sup> Customers are certainly relying on DTC companies' special knowledge and skills to analyze the genetic samples provided to the company. Nevertheless, it is doubtful that courts will find the remote interaction between a DTC company and a client to amount to a fiduciary relationship.<sup>159</sup> This is

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154. Ajunwa, *supra* note 8, at 1250–52.

155. *Privacy Highlights*, 23ANDME, <https://www.23andme.com/about/privacy/> (last updated July 17, 2018) (stating if a customer "choose[s] to consent to participate in 23andMe Research, 23andMe researchers can include [the customer's] de-identified Genetic Information and Self-Reported Information in a large pool of customer data for analyses aimed at making scientific discoveries"). It is also common for DTC companies' terms and conditions to explain that data breaches are an assumed risk of using 23andMe's services—such breaches may result in the data being associated with customers' identity and the use of customers' data against their interests. *Id.*

156. Ajunwa, *supra* note 8, at 1251.

157. See Thomas L. Hafemeister & Richard M. Gulbrandsen, Jr., *The Fiduciary Obligation of Physicians to "Just Say No" if an "Informed" Patient Demands Services that Are Not Medically Indicated*, 39 SETON HALL L. REV. 335, 369–71 (2009).

158. See Hafemeister & Porter, *supra* note 137, at 545–46.

159. See Ajunwa, *supra* note 8, at 1251–52.

especially true given the waiver included in the terms of service used by 23andMe and other DTC companies.<sup>160</sup>

Even if courts were to recognize a fiduciary relationship between DTC genetic testing services and their clients, the doctrinal barriers discussed earlier<sup>161</sup> remain a serious obstacle for plaintiffs seeking compensation for violations of their genetic privacy in cases where the party with the fiduciary duty is not responsible for a privacy breach. DTC companies could exercise due care and install state-of-the-art encryption software to protect the genetic data they collected from clients. But enterprising hackers could still find a way to obtain this protected genetic data and use it for purposes that are averse to the interests of the clients who provided it. Plaintiffs would have the burden of overcoming one doctrinal barrier or another before they could recover damages for the harm they incurred as a result of their genetic privacy being violated. For instance, plaintiffs might have to prove negligence on the part of the DTC companies. Alternatively, if clients bring an emotional distress claim, they will be required to show that their genetic data were disclosed to a sufficiently wide audience. The following subsection will illustrate how these doctrinal barriers stand between victims of genetic privacy violations and compensation for their injuries.

*D. The Effect of Doctrinal Barriers: Uncompensated Genetic Privacy Harms*

The foregoing discussion suggests that traditional tort claims like unreasonable publicity, emotional distress, and breach of fiduciary duty are incapable of addressing genetic privacy violations. Influenced by fault-based tort principles, all these claims focus too narrowly on achieving deterrence and, as a result, impose the doctrinal barriers mentioned above on plaintiffs. These doctrinal barriers permit victims to recover damages for their injuries only when they experience harms resulting from “faultily caused accidents.”<sup>162</sup> Since

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160. See Schulson, *supra* note 7 (discussing the consent forms DTC customers are required to sign when providing their genetic data to DTC companies).

161. See *supra* Sections IV.A, IV.B.

162. Guido Calabresi, *The Decision for Accidents: An Approach to Nonfault Allocation of Costs*, 78 HARV. L. REV. 713, 720 (1965) [hereinafter Calabresi, *The Decision*].



the late 1970s, proponents of fault-based principles have argued that imposing liability for accidents that are not the result of fault is not efficient.<sup>163</sup> Efficiency, on this view, is achieved at the expense of those who are injured by no-fault accidents but are denied compensation for their injuries because imposing liability in such scenarios does not achieve either greater deterrence or some other benefit.<sup>164</sup> This unfortunate reality is illustrated by Deborah's hypothetical, where agents seeking to obtain genetic information and sell it for profit hacked Deborah's DTC company. If Deborah's DTC company installed the most sophisticated and well-guarded system to protect the genetic data of its customers, the company would still be vulnerable to attack as hackers continue becoming more sophisticated through technological developments. Further, the hackers who engaged in the behavior that caused the unwanted disclosure of genetic information are not deterred if they are not caught and punished.<sup>165</sup>

To be sure, privacy torts are partially intended to impose penalties "to deter . . . irreparable injury . . . without imposing undue hardship on" various activities (e.g., commerce, research, and more) that are beneficial to society.<sup>166</sup> Although deterrence is one goal of tort law, it is not the doctrine's only goal. Another primary goal of tort law is to ensure that victims of privacy violations receive compensation.<sup>167</sup> Compensation is important because it provides these individuals with an acknowledgement of their injury.<sup>168</sup> The preceding

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163. Goldberg, *supra* note 70, at 545.

164. In the genetic data context, "some other benefit" might be the fruit of research conducted with the genetic data of DTC customers. The economic efficiency principles championed by Posner and others suggest that if the cost of imposing liability on DTC and pharmaceutical companies does not outweigh the benefit created by the research these companies produce, then liability should not be imposed. Putting this point slightly differently, the fault-based theory of economic efficiency places the interests of society in the aggregate over the interests of individuals. See John Rawls, *Themes in Kant's Moral Philosophy*, in *KANT & POLITICAL PHILOSOPHY: THE CONTEMPORARY LEGACY* 291, 302–306 (Ronald Beiner & William James Booth eds., 1993).

165. Calabresi, *The Decision*, *supra* note 162, at 718–19 (explaining that in some instances, risky behavior goes undeterred under an efficient liability regime).

166. Geistfeld, *supra* note 9, at 415.

167. Margaret Jane Radin, *Compensation and Commensurability*, 43 *DUKE L.J.* 56, 57, 73 (1993).

168. *Id.* at 73.

discussion suggests that the fault-based model of tort law is insufficient for providing compensation to genetic privacy victims. Hence, strict liability is needed because it deters risky behavior and also provides compensation to acknowledge the wrong visited upon victims of genetic privacy violations.<sup>169</sup> Part V will explain how a strict liability regime avoids the doctrinal barriers mentioned above while achieving the compensatory and deterrent goals of tort law.

#### V. TOWARD A STRICT LIABILITY REGIME FOR GENETIC PRIVACY VIOLATIONS

Posner was not the only theorist analyzing tort law on economic-efficiency grounds during the 1970s. Some economic-efficiency theorists, such as Guido Calabresi, supported the continued expansion of strict liability.<sup>170</sup> Calabresi suggested that strict liability is economically efficient because it places responsibility for injuries with the agent who is best positioned to conduct an analysis regarding the cost of those accidents.<sup>171</sup> The entity creating a risk can pass the cost of any harm that might result from its activities among all those participating in—or benefiting from—the sort of activity causing harm.<sup>172</sup> Calabresi argued that the most efficient distribution of resources occurs when the party causing injuries is responsible—regardless of fault—for the cost of that accident, providing compensation to those

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169. See Ajunwa, *supra* note 8, at 1260–62.

170. In fact, Calabresi was one of the first theorists to present an economic-efficiency approach to avoiding accidents. Yuval Sinai & Benjamin Shmueli, *Calabresi's and Maimonides's Tort Law Theories—A Comparative Analysis and a Preliminary Sketch of a Modern Model of Differential Pluralistic Tort Liability Based on the Two Theories*, 26 YALE J.L. & HUMAN. 59, 64, 66–67 (2014).

171. Guido Calabresi & Jon T. Hirschoff, *Toward A Test for Strict Liability in Torts*, 81 YALE L.J. 1055, 1060 (1972). If an enterprise is “forced to bear all accident costs [it] will have an incentive to find the optimal accident level for [its] product.” Marc A. Franklin, *Tort Liability for Hepatitis: An Analysis and a Proposal*, 24 STAN. L. REV. 439, 462 (1972).

172. Keating, *supra* note 74, at 1286–87. Strict liability is concerned with promoting distributive justice by spreading “the burdens and benefits of risky, but beneficial, activities fairly.” *Id.* at 1330.

injured by an accident and passing those costs on to customers, employees, and more.<sup>173</sup>

Calabresi's theory can be applied in the genetic data context. Law enforcement agencies collecting genetic data can raise taxes on the citizens they serve to cover the cost of a potential misuse of genetic data.<sup>174</sup> Additionally, DTC companies could charge Deborah and other customers like her a little more for their services in anticipation of the potential costs associated with either negligent conduct or cyber-attacks.<sup>175</sup> Doing so will ensure that "the cost of injuries [are] borne by the activities which caused them, whether or not fault is involved, because, either way, the injury is [the] real cost of those activities."<sup>176</sup> This approach to tort law ensures that tort burdens are distributed in a way that is commensurate with the creation of risk and

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173. Calabresi & Hirschoff, *supra* note 171, at 1084. This was so, Calabresi argued, because that party is in the best position to predict the risk of injury and take steps to prevent harmful accidents. *Id.* This approach was thought to achieve the greatest level of accident deterrence because requiring the entities to bear the cost of injuries caused by their presence in the marketplace, regardless of whether fault occurred, will make activities that are prone to causing accidents more expensive. Guido Calabresi, *Fault, Accidents and the Wonderful World of Blum and Kalven*, 75 YALE L.J. 216, 223 (1965) [hereinafter Calabresi, *Fault*].

174. This is not to say that the legislative achievement necessary for such a tax increase would not face difficulties. As James Henderson, Jr. claims, even if the superiority of strict liability is assumed, the doctrine still faces several fiscal and administrative challenges. *See, e.g.,* Henderson, *supra* note 72, at 391–93; *see also* Fleming James, Jr., *The Columbia Study of Compensation for Automobile Accidents: An Unanswered Challenge*, 59 COLUM. L. REV. 408, 423–24 n.83 (1959) (discussing the individual-rights-based opposition of some practitioners and scholars to the compensation scheme required to pay for the expansion of liability); Christopher Ingraham, *Congressional Gridlock Has Doubled Since the 1950s*, WASH. POST (May 28, 2014), [https://www.washingtonpost.com/news/wonk/wp/2014/05/28/congressional-gridlock-has-doubled-since-the-1950s/?utm\\_term=.a202230481dc](https://www.washingtonpost.com/news/wonk/wp/2014/05/28/congressional-gridlock-has-doubled-since-the-1950s/?utm_term=.a202230481dc) (observing how the partisan gridlock affecting legislatures across the nation makes legislative achievements, like those needed to raise taxes, difficult). Although Henderson and others raise legitimate concerns, such challenges are best taken up in a separate piece providing a more detailed account of how strict liability can achieve tort law's fundamental objectives by overcoming the fiscal and administrative challenges present in the American legal system. For now, I note that claiming it will be difficult to achieve a proposed goal is often not sufficient for concluding that the aim isn't achievable and should not still be pursued.

175. *See supra* note 172 and accompanying text.

176. Calabresi, *Some Thoughts*, *supra* note 99, at 505.

the overall benefit agents pose to the societies they perform their activities in.<sup>177</sup>

Of course, this is not to say that the sole aim of strict liability is to spread the cost of risk among various members of society. If that were the case, “by far the most effective and efficient method of accomplishing it would be through a system of general social insurance.”<sup>178</sup> Such an insurance scheme would simply externalize accident costs while failing to deter risky behavior.<sup>179</sup> Indeed, as Posner would argue, entities whose activities create accident risks will not take on precautionary burdens if the costs of compensating victims for injuries caused by their actions are less than the profits they make without taking adequate precautions to prevent certain harms.<sup>180</sup> Such entities might conduct a cost-benefit analysis and determine that paying the cost of an accident is lower than the burden of taking greater precautions to prevent the harms caused by their activities.<sup>181</sup>

Applying this line of reasoning to the genetic data context, suppose Deborah’s DTC company can purchase insurance to guard against the risk posed by the sort of hack occurring in that hypothetical, but the cost of this insurance is lower than taking adequate protections against the risk of a hack like the one revealing Deborah’s genetic data. Based on these facts, her DTC company might rationally choose to pay insurance costs because doing so is cheaper than purchasing the adequate precautions. For these reasons, critics of strict liability can argue that strict liability does not provide agents with incentives to take any greater precautions than those taken under the fault-based theory.<sup>182</sup>

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177. *Id.* at 505. Calabresi believes the goal of tort law should be “less concerned with the risk spreading potential of enterprise liability than with whether another, more general, justification exists for the ‘should’ in the phrase ‘an enterprise should bear its costs.’” *Id.* at 501.

178. Calabresi, *The Decision*, *supra* note 162, at 744.

179. *Id.*

180. Posner, *supra* note 104, at 206.

181. *Id.* at 207 n.6.

182. *Id.* at 211–12. Posner contends that Calabresi’s “question whether a general substitution of strict for negligence liability would improve efficiency seems at this stage hopelessly conjectural; the question is at bottom empirical and the empirical work has not been done.” *Id.* Although, he acknowledges that enough empirical data could tip the scales in favor of one or the other, he thinks that “we do not have any.” *Id.* at 221.

In response, it is important to note that strict liability aims to not only compensate victims of no-fault injuries but also deter risky behavior by making risky activities more expensive and, as a result, making safer alternatives more desirable.<sup>183</sup> Prior to Calabresi's commentary on this subject, proponents of strict liability generally focused on making the case that placing liability in the hands of risk-creating enterprises was the best way to distribute the costs of accidents.<sup>184</sup> Calabresi broadened the focus of strict liability beyond loss spreading and toward the additional goal of achieving efficient deterrence of accidents.<sup>185</sup> Ensuring that the cost of any injury is placed with the agent—such as DTC companies, law enforcement agencies, or medical researchers—in the best position to understand the risks and benefits associated with a particular activity achieves deterrence.<sup>186</sup> If entities are responsible for the cost of accidents caused by their activities, they will be incentivized to take the optimal amount of precaution for the service or product they offer.<sup>187</sup> This approach achieves the greatest level of accident deterrence because it makes accident-prone activities more expensive.<sup>188</sup> As a consequence of accident-prone activities being more expensive, alternatives to risky behavior will be substituted by safer—and less expensive—alternatives.<sup>189</sup>

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183. Calabresi, *Fault*, *supra* note 173, at 223 (stating strict liability “seeks to diminish accident costs not by directly attacking specific occasions of danger, but (like workmen’s compensation) by making more expensive those activities which are accident prone and thereby making more attractive their safer” alternatives); *see also* Calabresi, *The Decision*, *supra* note 162, at 744–45 (commenting on the compensatory and deterrent goals of tort law and noting that if compensation were the only goal of tort law, social insurance would be the most efficient means of accomplishing that goal).

184. Geistfeld, *supra* note 9, at 412; Nolan & Ursin, *The Deacademification*, *supra* note 78, at 69.

185. Nolan & Ursin, *The Deacademification*, *supra* note 78, at 76.

186. Calabresi & Hirschhoff, *supra* note 171, at 1060 (“[T]he strict liability test would simply require a decision as to whether the injurer or the victim was in the better position both to judge whether avoidance costs would exceed foreseeable accident costs . . .”).

187. Franklin, *supra* note 171, at 462.

188. Calabresi, *Fault*, *supra* note 173, at 223.

189. *Id.*

Even if strict liability fails to discourage more risky behavior than a fault-based regime, the former increases the amount of compensation available to those harmed in two ways. First, avoiding the doctrinal barriers imposed by fault-based tort law improves the ability of genetic privacy violations' victims to receive remedies for their injuries without having to overcome onerous hurdles. Further, requiring agents to account for the possibility of injuries caused by their actions ensures that at least some form of compensation—fiscal or otherwise—is available to victims like Deborah. Indeed, “no one would claim that [efficient deterrence theory] also gives the ‘promising blend of efficient compensation and economical administration’ that [strict liability] provides in addition to effective accident prevention.”<sup>190</sup> This compensation is important because it provides these individuals with an acknowledgement of the wrong they have suffered.<sup>191</sup>

Granted, an award of damages does not completely restore genetic privacy victims to the state they were in prior to the misuse of their genetic data. But despite the fact that money cannot fully account for the harm, it can serve as an apology or acknowledgement for the wrong that occurred.<sup>192</sup> The payment of damages could go a long way toward making victims feel that they are valued members of society and that their community acknowledges a wrong that has been done to them.<sup>193</sup> Tort law's compensatory goals are partially directed at ensuring that a message of justice has been sent to those who have been harmed.<sup>194</sup> By awarding damages for genetic privacy violations,

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190. See Nolan & Ursin, *Enterprise Liability*, *supra* note 13, at 854 (footnote omitted).

191. See Radin, *supra* note 167, at 73 (stating compensation helps make the victim feel valued).

192. Louis L. Jaffe, *Damages for Personal Injury: The Impact of Insurance*, 18 L. & CONTEMP. PROBS. 219, 224 (1953).

193. Radin, *supra* note 167, at 73–74.

194. See, e.g., Pamela Hieronymi, *Articulating an Uncompromising Forgiveness*, in 62 PHILOSOPHY AND PHENOMENOLOGICAL RESEARCH 529, 546 (Ernest Sosa et al. eds., 2001) (suggesting that an uncompensated injury stands without apology or anything to “recognize it as a wrong”); Gregory C. Keating, *Distributive and Corrective Justice in the Tort Law of Accidents*, 74 S. CAL. L. REV. 193, 204 (2000) (contending that when those creating a risk that harmed a victim are not required to provide compensation for an accident, a dignitary harm is inflicted on the victim).

the justice system aims to correct the message that was sent by the wrong visited upon such victims. As Pamela Hieronymi put it, “a past wrong against you, standing in your history without apology, atonement, retribution, punishment, restitution, condemnation, or anything else that might recognize it as a *wrong*, makes a claim. It says, in effect, that you can be treated in this way, and that such treatment is acceptable” because doing so creates a benefit to society as a whole.<sup>195</sup>

For all these reasons, strict liability will deter risky behavior while also providing compensation to acknowledge the wrong visited upon victims of genetic privacy violations. To be sure, the popularity of strict liability waned in the years following the 1970s, after which fault-based principles became the prevailing theory regarding tort law’s appropriate scope.<sup>196</sup> Despite the retrenchment of strict liability over the last several decades,<sup>197</sup> this Article endorses the expanded version of strict liability that was first envisioned by economic-efficiency theorists in the 1970s. Whereas strict liability was traditionally applied only to exceptionally dangerous activities, the doctrine evolved in the middle of the nineteenth century to express the maxim that entities profiting from the imposition of risk should bear the cost of that risk “as a matter of first principle.”<sup>198</sup> Hence, I do not suggest that DTC genetic testing needs to be fit into one of the traditional strict liability categories—such as exceptionally hazardous activities—to be liable for the harms resulting from its presence in the market. Rather, as entities generating accident risks, DTC companies should be held responsible for the cost of those risks. This approach achieves the greatest level of accident deterrence because requiring the entities to bear the cost of injuries caused by their presence in the marketplace, regardless of whether fault occurred, will make accident-prone activities more expensive;<sup>199</sup> consequently, safer and

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195. Hieronymi, *supra* note 194, at 546. Deterring future tortious acts is a fundamental aspect of tort law. In addition, though, tort law has a reparative function.

196. Nolan & Ursin, *The Deacademification*, *supra* note 78, at 81.

197. Again, a full discussion of the variety of reasons that contributed to strict liability’s reduced influence over the years is outside the scope of this Article. See *supra* note 99 and accompanying text.

198. Henderson, *supra* note 72, at 380.

199. Calabresi, *Fault*, *supra* note 173, at 223.

cheaper alternatives will replace risky behavior.<sup>200</sup> In addition to optimizing deterrence, strict liability accomplishes tort law's compensatory goal because requiring that injury-causing entities bear the cost of those accidents makes compensation available to injured parties even for injuries that are not the result of fault.<sup>201</sup>

At this point, it is important to address some objections to strict liability other than those concerning economic efficiency. The following section will identify and respond to a few challenges that have yet to be taken up.

## VI. RESPONDING TO CRITICS

Critics of the approach endorsed by this Article could raise a few objections; some of these criticisms, though, can be relatively easily disposed of. For example, some scholars have suggested using property-like rights—in lieu of tort law—to protect genetic data.<sup>202</sup> The privacy versus property debate is extensive,<sup>203</sup> and the literature on the subject does not need to be reproduced here. This is so because property-like rights have the significant drawback of requiring beneficial research that was conducted without a donor's consent to be destroyed.<sup>204</sup> Indeed, it is a well-established property law principle that a property owner may do whatever she pleases with her property, “including destroying it.”<sup>205</sup> In the genetic data context, the right to destroy results in the loss of “all diagnostic, epidemiologic, and envi-

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200. *Id.*

201. Calabresi & Hirschoff, *supra* note 171, at 1059.

202. *See, e.g.*, Contreras, *supra* note 8, at 8–9, 20–39 (discussing several scholars and cases that have applied property-like analyses to disputes over genetic data); Colin McFerrin, *DNA, Genetic Material, and a Look at Property Rights: Why You May Be Your Brother's Keeper*, 19 TEX. WESLEYAN L. REV. 967, 967 (2013) (discussing legislative efforts to apply property rights in the genetic data context); Kelli Rockandel, *A Myriad of Reasons to Celebrate: Why the Invalidation of Isolated DNA Patents Is a Victory for Personal Property Rights*, 38 VT. L. REV. 225, 234–48 (2013) (same).

203. *See supra* note 202 and accompanying text.

204. *See* Contreras, *supra* note 8, at 23–24, 35.

205. *Id.* at 23–24.



ronmental data contained in those samples.”<sup>206</sup> Strict liability is preferable to property-like rights because the former provides compensation to victims of genetic privacy violations while not requiring beneficial data to “be destroyed or removed from data sets, and [allowing] permissible research using that data [to] continue.”<sup>207</sup>

Another objection critics might raise is that anti-discrimination law—based on the Civil Rights Act of 1964—is the most appropriate way to address threats posed in the genetic data context.<sup>208</sup> Title VII of that law supports the notion “that sex, race, religion, and national origin are not relevant to the selection, evaluation, or compensation of employees.”<sup>209</sup> Pauline Kim notes that an anti-discrimination fix to the contemporary challenges surrounding the security of genetic information is unlikely to be achieved for two main reasons.<sup>210</sup> First, plaintiffs still face significant doctrinal barriers—like those afflicting tort law—when bringing an anti-discrimination claim.<sup>211</sup> Establishing

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206. *Id.* at 24 (citing *Beleno v. Lakey*, 306 F. Supp. 3d 930 (W.D. Tex. 2009)). In *Beleno*, following a settlement concerning the misuse of blood samples, 5.3 million blood samples were destroyed. *Id.*

207. *Id.* at 39.

208. *See, e.g.*, Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109 (1991) (advocating for the revision of the Americans with Disabilities Act to better protect individuals against genetic discrimination).

209. *Price Waterhouse v. Hopkins*, 490 U.S. 228, 239 (1989) (Brennan, J., plurality opinion). These anti-discrimination-based arguments were largely codified in law when Congress passed the Genetic Information Nondiscrimination Act of 2008 (“GINA”). *See* Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-223, 122 Stat. 881 (2008) (prohibiting employers from discriminating against prospective or current employees on the basis of genetic characteristics); *see also* Health Insurance Portability and Accountability Act of 1996, 42 U.S.C. § 201 (2012) (establishing national standards for the appropriate use of genetic information and other health information); Privacy Act of 1974, 5 U.S.C. § 552a (2012) (imposing guidelines on the use of personal information existing in databases maintained by the federal government); Louise Slaughter, *Genetic Information Non-Discrimination Act*, 50 HARV. J. ON LEGIS. 41, 47 (2013) (explaining that by the time GINA was passed by Congress in 2008, over 40 states had passed anti-discrimination laws relating to genetic information).

210. *See* Pauline T. Kim, *Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace*, 96 NW. U. L. REV. 1497, 1500–01 (2002) (discussing the doctrinal burdens and application restrictions associated with using anti-discrimination law to address the misuse of genetic data).

211. *See id.* at 1513.

a violation of Title VII's prohibition against disparate treatment of a protected class in the genetic data context requires proof that "the genetic criterion was a pretext for intentional discrimination against the affected group."<sup>212</sup> Intent, unfortunately, is often difficult to prove.<sup>213</sup> Second, because Title VII claims are typically confined to the em-

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212. *Id.*; see also *Griggs v. Duke Power Co.*, 401 U.S. 424, 432 (1971) (explaining that "Congress directed the thrust of [the Civil Rights Act] to the consequences of employment practices, not simply the motivation") (emphasis added). Put slightly differently, successful disparate treatment claims require the plaintiff to demonstrate that others "intentionally discriminated against" an individual because of that individual's association with a protected class. *Tex. Dep't. of Cmty. Affairs v. Burdine*, 450 U.S. 248, 253 (1981); *St. Mary's Honor Ctr. v. Hicks*, 509 U.S. 502, 511 (1993).

213. Kim, *supra* note 210, at 1525. Recognizing this difficulty, the Supreme Court attempted to make it easier for plaintiffs to succeed on a disparate treatment claim by providing a framework for establishing intent when only circumstantial evidence is available. See *Furnco Constr. Corp. v. Waters*, 438 U.S. 567, 577 (1978) (describing a framework for shifting evidentiary burdens for establishing proof in disparate treatment cases). Despite these efforts by the courts, unconscious biases may underlie some forms of discrimination, and it can be difficult to collect enough evidence to satisfy even a circumstantial evidence bar. See Charles R. Lawrence III, *The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism*, 39 STAN. L. REV. 317 (1987).

In lieu of disparate treatment, victims of genetic discrimination could seek relief under Title VII's adverse impact doctrine. Successful adverse impact claims, unlike disparate treatment, do not require intent to be proven. Kim, *supra* note 210, at 1526. According to this doctrine, the plaintiff must demonstrate that a particular "use of the [genetic] test had a statistically significant impact on . . . a protected class." *Id.* at 1513. However, although this doctrine is available in theory, courts have been cutting back on adverse impact claims for the past few decades. Nikole Hannah-Jones, *Supreme Court's Latest Race Case: Housing Discrimination*, PROPUBLICA (Jan. 21, 2015, 12:18 PM), <https://www.propublica.org/article/supreme-courts-latest-race-case-housing-discrimination>. In fact, recent cases indicate that courts will take a dim view of creating any new causes of action on the grounds of adverse impact, including claims based on genetic discrimination. See, e.g., Garrett Epps, *The U.S. Supreme Court Barely Saves the Fair Housing Act*, THE ATLANTIC (June 25, 2015), <https://www.theatlantic.com/politics/archive/2015/06/the-supreme-court-barely-saves-the-fair-housing-act/396902/> (discussing the history of the adverse impact doctrine and explaining that recent cases affirming the legitimacy of the doctrine are more warnings that the theory might be abandoned than ringing endorsements of adverse impact).

ployment context, anti-discrimination law is too limited in scope.<sup>214</sup> Hence, the anti-discrimination model is an inadequate vehicle for addressing the misuse of genetic information.

Despite the lack of force carried by the foregoing objections, two challenges to the application of strict liability in the genetic data context present more pressing concerns. The first is whether concerns about genetic privacy offenses are premature, and the second is whether damages under this strict liability approach are too speculative. Because these two challenges deserve a bit more attention, the following subsections will consider these challenges and respond in turn.

#### *A. Worries About Genetic Privacy Violations Are Not Premature*

Until recently, scholars working in this space have felt a bit like Cassandra of Troy, who is a famous character in Greek mythology.<sup>215</sup> She possessed the ability to predict future tragedies, but she was also burdened with the curse that nobody would believe her warnings.<sup>216</sup> Like Cassandra's doubters, skeptics of genetic privacy risks have downplayed the concerns of scholars working on the topic of genetic privacy.<sup>217</sup> Critics might point to the lack of genetic privacy violations as evidence that efforts to address this issue are either

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214. 42 U.S.C. § 2000e-2(k)(1)(A)(i) (2012).

215. GIOVANNI BOCCACCIO, *FAMOUS WOMEN* 137, 139 (Virginia Brown ed., trans. 2001). According to Greek mythology, Cassandra "was loved by Apollo who sought to sleep with her. Cassandra is said to have agreed on the condition that he would first give her the art of knowing the future. But once she had received the gift, she reneged on her promise." *Id.* at 137. After Cassandra abjured her promise, "Apollo, unable to take back what he had bestowed, added to the gift the proviso that no one would believe what Cassandra said. And so it happened that, whenever she spoke, everyone regarded her words as silly." *Id.* As a result, her warnings about the Greeks inside the Trojan horse were dismissed, and Agamemnon's army destroyed Troy in the Trojan War. *Id.* at 137, 139.

216. *Id.*

217. Anya E. R. Prince & Myra I. Roche, *Genetic Information, Non-Discrimination, and Privacy Protections in Genetic Counseling Practice*, 23 J. GENETIC COUNSELING 891, 891–92 (2014) ("Ironically, as genetic testing becomes an increasingly powerful diagnostic and prognostic tool, health care providers and their patients remain wary of the potential of genetic testing to trigger discrimination.").

premature or unnecessary. Two responses to these critics are available.

First, there is a growing consensus among policymakers and the general public that the security of genetic data is at risk. Genetic information “‘is never 100% safe,’” says Peter Pitts, president of the Center for Medicine in the Public Interest.<sup>218</sup> As mentioned above, over 1,000 cyber-attacks have targeted large dossiers of sensitive health-care information in the last few years.<sup>219</sup> Genetic privacy is threatened in a number of different ways by the increasingly common use of genetic data in medical research, commercial enterprises, law enforcement efforts, and more. These threats are likely to increase dramatically now that the Food and Drug Administration has decided to allow DTC companies to provide consumers with information about their propensity for very serious health conditions, including cancer.<sup>220</sup> Because consumers are keen to detect such health risks, they are willing to pay DTC companies for their services. Pharmaceutical companies interested in obtaining large amounts of genetic data are also willing to pay DTC companies for the right to analyze the samples provided by consumers. For example, GSK—a large pharmaceutical company—announced that it was paying 23andMe \$300 million for the right to use the DTC company’s consumer data for genetic research.<sup>221</sup> Because the value of genetic data to research institutions is so great,<sup>222</sup> transactions like the one between 23andMe and GSK are likely to become more common. Even the most effective safety mechanisms and deterrence schemes will be unable to completely protect the interests people have in keeping their sensitive genetic information private. “‘The risk is magnified when one organ-

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218. Ducharme, *supra* note 5.

219. See Ornstein, *supra* note 5.

220. See Carolyn Y. Johnson, *23andMe Gets FDA Approval to Report Breast Cancer Risk Without a Doctor*, WASH. POST: WONKBLOG (Mar. 6, 2018), [https://www.washingtonpost.com/news/wonk/wp/2018/03/06/23andme-gets-fda-approval-to-report-breast-cancer-risk-without-a-doctor/?utm\\_term=.50feb0830d95](https://www.washingtonpost.com/news/wonk/wp/2018/03/06/23andme-gets-fda-approval-to-report-breast-cancer-risk-without-a-doctor/?utm_term=.50feb0830d95).

221. Zhang, *supra* note 27. GSK was careful to note that it would only receive anonymized data from 23andMe’s customers. See *GSK and 23andMe*, *supra* note 27.

222. See Murphy, *supra* note 33. “‘The long game’” for DTC companies “‘is not to make money selling [genetic testing] kits . . . . Once you have the data, the [genetic testing company] does actually become the Google of personalized health care.’” *Id.*

ization shares it with a second organization. When information moves from one place to another, [there is] always a chance for it to be intercepted by unintended third parties.”<sup>223</sup> Faced with this reality, it is difficult to effectively argue that efforts to improve the control people have over their genetic data are unnecessary.

Second, the argument that efforts to protect genetic privacy are premature fails to appreciate the opportunity to prevent genetic discrimination before it starts.<sup>224</sup> Historically, laws to address injustices have been “Janus-like,” with one eye toward past wrongs and the other looking forward with an aim to prevent such wrongs in the future.<sup>225</sup> Despite this history, adopting a strict liability regime in the genetic privacy context presents a unique opportunity to put measures in place to address—and perhaps even prevent—the harms resulting from genetic privacy violations before they occur. Further, adopting the approach recommended by this Article does not require much effort. This is so because applying strict liability in the genetic data context requires only utilizing an analytical framework and does not necessitate formal changes to federal or state law.<sup>226</sup> For these reasons, strict liability should be endorsed as the analytic lens through which to view genetic privacy violations.

#### *B. Damages for Genetic Privacy Violations Can Be Predictable*

A second worry is that even if a strict liability regime is adopted, awarding damages for genetic privacy violations might impose unpredictable and crushing liability on DTC companies and medical researchers. Determining the appropriate amount of damages for non-

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223. Ducharme, *supra* note 5.

224. See Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 441 (2010).

225. *Id.* at 440.

226. Of course, some states have enacted legislation to address privacy concerns associated with the genetic information’s use in research. See, e.g., Kayte Spector-Bagdady et al., *Analysis of State Laws on Informed Consent for Clinical Genetic Testing in the Era of Genomic Sequencing*, 178 AM. J. MED. GENETICS 81 (2018) (discussing several state laws enacted to address the misuse of genetic data in research projects). Such efforts could supplement the strict liability regime proposed by this Article.

economic, pain and suffering torts is a difficult task.<sup>227</sup> Moreover, practitioners and academics hold a variety of views on the topic of whether harms like emotional distress are properly considered within the same damages category as those for purely economic damages, like medical bills.<sup>228</sup> Despite the divergence of opinion on this topic, though, it is now widely accepted “that non-economic damages are real” and that victims of these injuries can be compensated.<sup>229</sup> An important challenge associated with the acceptance of pain and suffering is precisely how to measure the severity of these injuries and award an appropriate level of damages. An influential answer to this question was proposed in a 1989 Article that “has become one of the most important pieces concerning pain-and-suffering damages in the legal literature.”<sup>230</sup>

In *Valuing Life and Limb in Tort: Scheduling “Pain and Suffering,”* Randall R. Bovbjerg, Frank A. Sloan, and James F. Blumstein argued that a scale should be used to differentiate between different degrees of pain-and-suffering.<sup>231</sup> The authors suggested that degrees could be distinguished by the severity of injury experienced by a plaintiff.<sup>232</sup> Severity of injury was used to differentiate between degrees of pain-and-suffering because research indicated the “best available single predictor [of] award amount is the severity of injury.”<sup>233</sup> Bovbjerg et al., as well as many other academics, “used The National Association of Insurance Commissioner’s (“NAIC”) nine-point severity-of-injury scale to categorize seriousness of injuries and

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227. See, e.g., Randall R. Bovbjerg et al., *Valuing Life and Limb in Tort: Scheduling “Pain and Suffering,”* 83 NW. U. L. REV. 908, 910 n.12 (1989) (citing several cases where judges comment on the difficulty of determining a fixed compensation measure for pain and suffering).

228. See *id.* at 919.

229. *Id.*

230. Ronen Avraham, *Putting a Price on Pain-and-Suffering Damages: A Critique of the Current Approaches and a Preliminary Proposal for Change*, 100 NW. U. L. REV. 87, 87 (2006).

231. Bovbjerg et al., *supra* note 227, at 919–20.

232. *Id.* at 920.

233. *Id.*

facilitate commensuration of the pain-and-suffering of dissimilar injuries.”<sup>234</sup> Table 1 reproduces the sort of scale used by the NAIC.<sup>235</sup>

TABLE 1  
SEVERITY OF INJURY SCALE

Severity of Injury	Examples
1. Emotional only	Fright, no physical damage.
2. Temporary insignificant	Lacerations, contusions, minor scars, rash. No delay.
3. Temporary minor	Infections, mis-set fracture, fall in hospital. Recovery delayed.
4. Temporary major	Burns, surgical material left, drug side-effect, brain damage. Recovery delayed.
5. Permanent minor	Loss of fingers, loss or damage to organs. Include non-disabling injuries.
6. Permanent significant	Deafness, loss of limb, loss of eye, loss of one kidney or lung.
7. Permanent major	Paraplegia, blindness, loss of two limbs, brain damage.
8. Permanent grave	Quadriplegia, severe brain damage, lifelong care or fatal prognosis.
9. Death	

Granted, the question of how to appropriately calculate pain-and-suffering damages is a topic that lawyers, courts, and academics continue to struggle with. Nevertheless, many influential commentators have endorsed Bovbjerg et al.’s proposal as a reliable way of navigating such difficult issues.<sup>236</sup> For these reasons, Bovbjerg et al.’s seminal article “is as relevant today as it was” when it was first published.<sup>237</sup>

To mitigate speculative damage awards, I suggest that like the table established by the NAIC, a matrix can be developed for genetic privacy violations. These categories can each be given a value amount, with the level of damages increasing in relation to the severity of injury.<sup>238</sup> The category of the genetic privacy violation experi-

234. Avraham, *supra* note 230, at 94; see NAT’L ASS’N OF INS. COMM’RS, MALPRACTICE CLAIMS: FINAL COMPILATION 10 (M. Patricia Sowka ed., 1980) (providing a scale to determine the severity of injuries and the corresponding amount of damages owed).

235. *Id.*

236. Avraham, *supra* note 230, at 93 (noting a “stream of research,” which includes Bovbjerg et al.’s work, that rejects the notion that pain-and-suffering awards are too random).

237. *Id.* at 87.

238. See Bovbjerg et al., *supra* note 227, at 939–41.

enced by Deborah would depend on the number of people her genetic information was disclosed to and her subjective aversion to that exposure.<sup>239</sup> An additional benefit of this matrix is that it can address the asymmetrical genetic privacy harms experienced by marginalized communities. Genetic privacy violations affect everyone, but they affect historically marginalized communities more than non-marginalized groups.<sup>240</sup> Consider the following example of the sort of

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239. A person's subjective aversion to the unwanted disclosure of private facts could be affected by a number of factors, including cultural values or religious beliefs. *See, e.g., infra* note 240 and accompanying text.

240. For example, consider the case of *Havasupai Tribe v. Arizona Board of Regents*. *Havasupai Tribe v. Ariz. Bd. of Regents*, 204 P.3d 1063, 1066 (Ariz. Ct. App. 2008). The Havasupai Tribe, which is a group of Native Americans who have called the Grand Canyon home for centuries, sought assistance from Arizona State University ("ASU") in the early 2000s to determine the cause of an abnormally high percentage of diabetes among the Havasupai people. *Id.* After studying blood samples provided by the Tribe, ASU researchers concluded that the Havasupai people possessed no genetic predisposition to develop diabetes. *Id.* at 1067. Once the study was complete, the ASU team kept the samples—against the wishes of the Havasupai people—and continued examining them for other genetic links to different conditions, such as schizophrenia. *Id.* Certainly, this use of genetic samples for unauthorized research about conditions containing social stigmas is likely troubling to just about anybody. *See, e.g., Contreras, supra* note 8, at 22 (noting that the Tribe members objected to the subsequent use of their genetic information partly because the research could have yielded "stigmatizing revelations"). It is important to note, though, that blood represents a very special aspect of the Havasupai people's closely-held spiritual beliefs about connections with their ancestors. Drabiak-Syed, *supra* note 5, at 213. According to Havasupai beliefs, blood contains "an interconnected web of meaning, . . . [such that] mishandling one person's blood causes significant damages and disrupts the community, the family, and that person's spiritual welfare." *Id.* at 214 (footnote omitted). In response to the Tribe's claims that the misuse of their blood samples was especially harmful given their spiritual beliefs, the court and the attorney for ASU expressed a "sentiment that the tribe's claims and request for damages merely represented an extreme irrational or anti-science sentiment, rather than a genuine attempt to signify the harm they incurred." *Id.* at 196. This example demonstrates that the Havasupai people's status as a marginalized community, possessing unique spiritual beliefs, affected the level of harm they suffered by the misuse of their genetic data. To be sure, Native Americans are not the only communities that are particularly vulnerable to these types of injuries. *See, e.g., Ari N. Schulman, What Is the Body Worth?*, NEW ATLANTIS, Spring 2012, at 99, 104–07. Examples of asymmetrically affected communities abound, but one prominent illustration is the fact that African Americans were viewed by doctors in the 1940s as research subjects first and patients second. *Id.* This reality caused African



modified matrix, inspired by Table 1, which could be used to calculate damages for all victims—including members of historically marginalized communities—of genetic privacy damages.

TABLE 2  
DAMAGES MATRIX FOR THE SEVERITY OF GENETIC PRIVACY VIOLATIONS

Severity of Injury	Example
1. Fleeting Minor	Fleeting stress—producing no physical symptoms—connected to an embarrassing misuse of sensitive genetic information not connected to any systemic discrimination against a marginalized group.
2. Fleeting Major	Fleeting stress—producing no physical symptoms—connected to an embarrassing misuse of sensitive genetic information that is connected to systemic discrimination directed against a marginalized group.
3. Temporary Critical	Temporary significant anxiety—producing physical symptoms—connected to an embarrassing misuse of sensitive genetic information that is not connected to systemic discrimination directed against a marginalized group.
4. Temporary Grave	Temporary significant anxiety—producing physical symptoms—connected to an embarrassing misuse of sensitive genetic information that is connected to systemic discrimination directed against a marginalized group.
4. Persistent Minor	Persistent stress—producing no physical symptoms—connected to an embarrassing misuse of sensitive genetic information not connected to any systemic discrimination against a marginalized group.
5. Persistent Major	Persistent significant anxiety—producing no physical symptoms—connected to an embarrassing misuse of sensitive genetic information that is connected to systemic discrimination directed against a marginalized group.
6. Persistent Critical	Persistent significant anxiety—producing physical symptoms—connected to an embarrassing misuse of sensitive genetic information that is not connected to systemic discrimination directed against a marginalized group.
7. Persistent Grave	Persistent significant anxiety—producing physical symptoms—connected to an embarrassing misuse of sensitive genetic information that is connected to systemic discrimination directed against a marginalized group.

The severity of injury can be measured by one's aversion to the type of genetic privacy violation one is exposed to. Aversion can be understood to mean the degree to which a person feels uneasy, or downright traumatized, by unauthorized parties observing their ge-

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Americans to feel unable to reject certain medical procedures—including the unauthorized use of their genetic information—for fear that doctors would simply refuse to treat them. *Id.*

conomic information.<sup>241</sup> Importantly, this observation “admits of degrees” and is not binary.<sup>242</sup> We might have only a slight (if any) aversion to some privacy violations<sup>243</sup> while being very troubled by other types<sup>244</sup> of privacy violations. The difference in our reactions to various forms of observation can be reflections of cultural, racial, and socioeconomic realities.<sup>245</sup> To be sure, the amount of damages awarded

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241. Ruth Gavison, *Privacy and the Limits of Law*, 89 YALE L.J. 421, 447 (1980) (noting that even a “casual observation” can have the “inhibitive effect on most individuals that makes them [feel] more formal and uneasy”). Many scholars have noted the importance of having a reprieve from perceived or actual observation in our daily lives. DANIEL J. SOLOVE, UNDERSTANDING PRIVACY 2–4 (2008) (identifying the important role privacy plays in people’s daily lives); Lior Jacob Strahilevitz, *Reputation Nation: Law in an Era of Ubiquitous Personal Information*, 102 NW. U. L. REV. 1667, 1736 (2008) (“Privacy theorists have long argued that protecting privacy is essential so that individuals can relax, experiment with different personalities to figure out who they truly are, or develop the insights that will make them more productive citizens.”).

242. See Calo, *supra* note 125, at 1144.

243. See Jeffrey Rosen, *Nude Awakening*, NEW REPUBLIC (Jan. 28, 2010), <https://newrepublic.com/article/72843/nude-awakening> (explaining that the public is largely supportive of full-body scanners at airports, especially after revelations concerning the Christmas Day Bomber were made public).

244. See SOLOVE, *supra* note 241, at 118–20 (discussing the uniquely sacred respect privacy has been given in the law).

245. See, e.g., Glenn Negley, *Philosophical Views on the Value of Privacy*, 31 L. & CONTEMP. PROBS. 319 (1966). Negley observed that traditional British–American thinking has understood the judgments of private citizens to be the source of legitimacy for individual rights. *Id.* at 321. According to this paradigm, privacy is a right because members of a given society demand it. This model has been largely inherited from Greek philosophy, which developed amid a low degree of “geographic, ethnic, religious, [and] moral” diversity. *Id.* at 322. The Athenian-style community, which has been appropriately described by Peter Laslett as a “face-to-face society,” is distinguished by a high degree of mutuality and homogeneity. *Id.* (citing PETER LASLETT, *The Face to Face Society*, in PHILOSOPHY, POLITICS AND SOCIETY 157–84 (Oxford: Blackwell 1956)). As the world became more industrialized in the eighteenth and nineteenth centuries, various intellectuals began to recognize that this analytical framework would not be appropriate for an increasingly institutional and centralized society. For example, in contrast to the individual-dependent understanding of moral status typified by British–American thinking on the subject, Hegelian thought has approached the topic of privacy by identifying the interests that are relevant within the context of a society. *Id.* at 322. According to Hegel, privacy rights—understood as an expression of free will—do not exist in isolation. Marco De Boni & Martyn Prigmore, *A Hegelian Basis for Information*

at one end of the scale could be enormous compared to the other end.<sup>246</sup> Arguably, this variation would be an appropriate reflection of the varied circumstances unique to each claimant.<sup>247</sup> This seems to make good sense in terms of vertical equity, which describes “the fairness between separate categories of injury,” but it fares less well in terms of horizontal equity between individuals or groups in the same damages category.<sup>248</sup> This concern about horizontal equity can likely be addressed over time as more and more cases use the matrix and provide additional examples for courts and practitioners to compare a given situation to.<sup>249</sup>

A further point about the proposed matrix is that each category would set a range of damages. Ranges would be supplemented by hypothetical scenarios that would help courts and practitioners award the appropriate compensation based on the facts before them.<sup>250</sup> The proposed boundaries could be established legislatively, by judicial conferences, or by individual courts as they adopt and implement the matrix.<sup>251</sup> Although these guidelines would serve as benchmarks, they need not be binding.<sup>252</sup> Indeed, there may be outlier categories at either end of the spectrum that warrant novel awards.<sup>253</sup> Despite the existence of occasional outliers, though, this matrix would bring an

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*Privacy as an Economic Right*, 3 CONTEMP. POL. THEORY 168, 180–81 (2004). Instead, they exist in the relation between the free will of various individuals. *Id.*

246. Bovbjerg et al., *supra* note 227, at 921–23.

247. *Id.* at 923.

248. *Id.* at 924.

249. See M. Gregg Bloche, *The Invention of Health Law*, 91 CAL. L. REV. 247, 254–56, 321 (2003) (explaining that when courts adopt a new legal model, coherence in legal reasoning and court decisions can be achieved over time as courts and practitioners in different doctrinal settings communicate with each other and align their judgments).

250. Bovbjerg et al., *supra* note 227, at 953.

251. See *id.* at 923; see also Bloche, *supra* note 249, at 256, 321.

252. Bovbjerg et al., *supra* note 227, at 938.

253. I should note here that there remains significant debate over whether strict liability and damages scales like the one proposed here impose the possibility of astronomically high awards and are thus inappropriate because of the cost they could impose on taxpayers. This debate is beyond the scope of this Article. I simply suggest including considerations about marginalized communities into the ongoing debate on this matter.

overall level of predictability to the calculation of damages for genetic privacy violations.<sup>254</sup>

Because the aforementioned matrix can provide a reliable benchmark by which to calculate damages for genetic privacy violations, concerns about a strict liability regime imposing unpredictable and crushing liability on DTC companies are misplaced. The sort of matrix discussed above can bring predictability to the calculation of damages for genetic privacy victims, and this predictability can help ensure they receive compensation for their injuries.

## VII. CONCLUSION

Genetic data are becoming an increasingly valuable commodity.<sup>255</sup> Genetic data are being used in research, law enforcement efforts, commercial endeavors, etc. The growing use of genetic data could yield many benefits, but it is also increasing the chances that nefarious or negligent actors will misuse genetic data. The risk of misuse is particularly alarming because extant law provides woefully inadequate protections against the harms resulting from genetic privacy violations.

I contend that applying strict liability in the genetic data context has the benefit of placing the risk assessment burden of any harm resulting from the genetic data's misuse in the hands of the entities routinely handling that data.<sup>256</sup> These entities—such as genetic researchers, DTC genetic testing companies, law enforcement agencies, and more—are able to pass the costs of compensating victims of genetic privacy violations onto those benefitting from these entities' activities.<sup>257</sup> In the case of genetic researchers, these costs could be passed on through higher drug prices. Likewise, DTC genetic testing companies could simply charge more for the services they provide. Those in the enterprise of handling genetic information also possess better knowledge regarding the possible misuse and harms that could

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254. See Bloche, *supra* note 249, at 256, 321.

255. See *supra* Part II.

256. See Ajunwa, *supra* note 8, at 1260.

257. See Keith N. Hylton, *The Law and Economics of Products Liability*, 88 NOTRE DAME L. REV. 2457, 2465–66 (2013).

result from the unwanted disclosure of genetic information.<sup>258</sup> In addition to improving the ability of genetic privacy victims to receive compensation for violations of their genetic privacy, strict liability also provides more respect for these victims' autonomy. This is so because strict liability does not place the interests of those harmed by non-negligent activities below the collective interest of society. For all these reasons, strict liability is the most appropriate legal mechanism for protecting the interest people have in ensuring their genetic data remains private.

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258. See Ajunwa, *supra* note 8, at 1260. Most individuals "lack all the information to understand the emotional, social, and economic risks associated with genetic testing." *Id.*