

Genetic Testing Meets Big Data: Tort and Contract Law Issues

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I. INTRODUCTION

In 2014, a small hospital in Pennsylvania had to notify 1,800 patients that the security of their medical information, including their names, medical records numbers, lab tests and results, and visit dates were compromised

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because of an employee's mistake.¹ The hospital officials had discovered that a lab technician who was authorized to work with protected health information had accessed patient data through an unsecured USB device on his home network, instead of on the secured hospital system.² Similarly, administrators at the five-hospital St. Joseph Health System in Bryan, Texas, discovered that their organization had fallen victim to the biggest Health Insurance Portability and Accountability Act (HIPAA) security breach ever reported.³ The health system network was obligated to notify 405,000 individuals that their medical data, Social Security numbers, dates of birth, and addresses had been exposed after a three-day security attack.⁴ In another recent breach similar to the one in Pennsylvania, a computer at a research division of California health care provider Kaiser Permanente was found to be infected with malicious software.⁵ That computer contained the personal information of more than 5,000 patients who were participating in research studies.⁶ In that case, patients' names, birth dates, medical record numbers, and research-related lab results may have been compromised.⁷

The prevalence of these types of data breaches is why security experts have dubbed health data security the "Wild West."⁸ While major retailers such as Target and Neiman Marcus have reported extensive data breaches, a report by BitSight Technologies shows that health care companies are even more vulnerable to such hacking activity.⁹ BitSight, which evaluates companies' security effectiveness, used vast amounts of data on "[o]bserved security events and configurations, such as communication with a botnet, malware distribution," or spam propagation to analyze the security performance of companies in the S&P 500 stock index.¹⁰ It divided the firms into four industries: retail, finance, utilities and healthcare, and pharmaceuticals.¹¹ On a

¹ Erin McCann, *Staff Blunder Leads to HIPAA Breach*, HEALTHCARE IT NEWS (June 9, 2014), <http://www.healthcareitnews.com/news/staff-blunder-leads-hipaa-breach>, archived at <http://perma.cc/ALC4-TKRK>.

² *Id.*

³ Erin McCann, *Hacker Calls Health Security 'Wild West,'* HEALTHCARE IT NEWS (June 11, 2014), <http://www.healthcareitnews.com/news/hacker-calls-health-security-wild-west>, archived at <http://perma.cc/E9FX-6QY7>.

⁴ *Id.*

⁵ Erin McCann, *Fourth HIPAA Breach for Kaiser*, HEALTHCARE IT NEWS (Apr. 7, 2014), <http://www.healthcareitnews.com/news/fourth-hipaa-breach-kaiser-folks>, archived at <http://perma.cc/MYZ8-FKJC>.

⁶ *Id.*

⁷ *Id.*

⁸ See, e.g., McCann, *supra* note 3.

⁹ *Industry Analysis Reveals Healthcare and Pharmaceutical Industry Lags in Security Effectiveness*, BITSIGHT (May 28, 2014), <http://www.bitsighttech.com/news/press-releases/industry-analysis-reveals-healthcare-and-pharmaceutical-industry-lags-security>, archived at <http://perma.cc/P5FL-P6LX>.

¹⁰ *Id.*

¹¹ *Id.*

scale of 250 to 900—with higher ratings equating to better security performance—the healthcare sector scored a 660, the lowest of the four groups.¹² BitSight said the healthcare sector saw the largest percentage increase in the number of security incidents over the period studied (April 2013 to March 2014).¹³ These findings are consistent with the results of a study conducted by Ponemon Institute.¹⁴ In that study, 90% of healthcare organizations surveyed had experienced at least one data breach in the past two years.¹⁵ And 38% of those healthcare organizations said they had encountered more than five breaches.¹⁶

Given the demonstrated high likelihood that one's health or medical information may become compromised, one might wonder why anyone would choose to voluntarily engage in genetic testing which holds much promise for revealing even latent genetic defects. However, we cannot disclaim the utility of genetic testing. With James Watson and Francis Crick's discovery of the DNA molecule in 1953,¹⁷ it quickly became understood that encoded within our genes are reams of information as to propensity for future disease. As far back as the 1960s, the Black Panther party was organizing clinics in Oakland, California, where African-Americans were tested for the sickle cell gene,¹⁸ the cause of the debilitating sickle cell anemia. And since the 1980s, Jewish rabbis have been encouraging their temple congregations to be tested for the fatal Tay-Sachs gene prior to making marital commitments.¹⁹ More recently, the United States Supreme Court's decision in *Association for Molecular Pathology v. Myriad Genetics*,²⁰ which denies the constitutionality of human gene patents,²¹ has cleared the way for further development of genetic tests to test for even more types of genetic disease and should also lead to greater

¹² *Id.*

¹³ *Id.*

¹⁴ PONEMON INST. LLC, FOURTH ANNUAL BENCHMARK STUDY ON PATIENT PRIVACY & DATA SECURITY 2 (2014), available at <https://www.privacyrights.org/sites/privacyrights.org/files/ID%20Experts%204th%20Annual%20Patient%20Privacy%20&%20Data%20Security%20Report%20FINAL.pdf>.

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ See *Crick and Watson (1916–2004)*, BBC HISTORY, http://www.bbc.co.uk/history/historic_figures/crick_and_watson.shtml (last visited Oct. 8, 2014), archived at <http://perma.cc/6Y5W-3Q6X>; 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, 969 (2013).

¹⁸ ALONDRA NELSON, *BODY AND SOUL: THE BLACK PANTHER PARTY AND THE FIGHT AGAINST MEDICAL DISCRIMINATION* 115 (2011).

¹⁹ TROY DUSTER, *BACKDOOR TO EUGENICS* 46 (2d ed. 2003).

²⁰ *Ass'n for Molecular Pathology v. Myriad Genetics, Inc.*, 133 S. Ct. 2107, 2111 (2013) (challenging Myriad's patent, which was chiefly based on having found the precise location and genetic sequences of the BRCA1 and BRCA2 genetic mutations).

²¹ *Id.* (“[A] naturally occurring DNA segment is a product of nature and not patent eligible merely because it has been isolated.”).

affordability of genetic testing for the masses. However, while the information obtained from genetic testing represents the promise of greater agency to predict propensity for genetic disease, it also presents the peril of financial or emotional injury from the negligent handling of such information.²²

Consider the following hypothetical. Jack was adopted in a closed adoption and has been unable to locate his biological parents. Upon getting married and contemplating having children of his own, Jack decided to engage in direct-to-consumer (DTC) genetic testing, both for genealogical and health predictive reasons. He found a genetic testing company (GeneInfo4You) on the Internet and sent away for the “spit kit,” which he used to collect and send back his genetic materials in the form of a cheek swab. Jack was assigned a customer number and told to establish a password with which, he was promised, he could access his genetic information online. He was told that this information would be encrypted and that only he would have access to the genetic information. When Jack accessed his information, he discovered the following genealogical information: he was of mixed race parentage, as the report described it, 60–75% of his DNA came from Western Europe, 15–20% from Sub-Saharan Africa, and 5–10% from East Asia. His health report²³ informed him of the following: (1) he had a high risk—70% according to his health report—of developing Alzheimer’s disease; and (2) he was a carrier of the sickle cell gene.²⁴

²² See Ronald M. Green & A. Mathew Thomas, *DNA: Five Distinguishing Features for Policy Analysis*, 11 HARV. J.L. & TECH. 571, 572–73 (1998) (detailing the psychological and pecuniary risks, such as discrimination in employment, medical insurance, and life insurance).

²³ It is important to note that the Federal Drug Administration (FDA) has directed companies, such as 23andme, that provide direct-to-consumer health reports based on “spit kits,” to suspend this service. See Sarah Zhang, *23andMe Ordered to Halt Sales of DNA Tests*, NATURE (Nov. 25, 2013), <http://www.nature.com/news/23andme-ordered-to-halt-sales-of-dna-tests-1.14236>, archived at <http://perma.cc/E7G9-QTSE>. However, some have argued that the FDA cannot regulate genomic data, and that in fact any curtailment of such services would infringe upon First Amendment rights. See Robert C. Green & Nita A. Farahany, *Regulation: The FDA Is Overcautious on Consumer Genomics*, NATURE (Jan. 15, 2014), <http://www.nature.com/news/regulation-the-fda-is-overcautious-on-consumer-genomics-1.14527>, archived at <http://perma.cc/8SP5-NELE>.

²⁴ See *What Is Sickle Cell Disease?*, SICKLE CELL DISEASE ASS’N OF AM., <http://www.sicklecelldisease.org/index.cfm?page=about-scd> (last visited Oct. 8, 2014), archived at <http://perma.cc/AV6D-893E> (“Sickle cell disease is an inherited blood disorder that affects red blood cells.”). According to the National Heart, Blood and Lung Institute, “[s]ickle cell anemia is most common in people whose families come from Africa, South or Central America (especially Panama), Caribbean islands, Mediterranean countries (such as Turkey, Greece, and Italy), India, and Saudi Arabia.” See *Who Is at Risk for Sickle Cell Anemia?*, NAT’L HEART, LUNG, & BLOOD INST., <http://www.nhlbi.nih.gov/health/health-topics/topics/sca/atrisk.html> (last updated Sept. 28, 2012), archived at <http://perma.cc/H2C9-BZK3>. However, in America, having the sickle cell trait or sickle cell disease is almost solely associated with being of African descent. NELSON, *supra* note 18, at 116.

Jack was confused by some of the information. He had always identified as white and phenotypically could “pass” as white, and he wasn’t sure if this new information now meant that he could no longer be considered white.²⁵ He also started to worry about what passing on the sickle cell gene might mean to his children and what having the trait for Alzheimer’s disease would mean for his quality of life in his later years. He decided to not share any of this information (even with his wife) until he had the chance to do more research and consult with a doctor on what the results meant. Unfortunately, soon after Jack’s genetic information was posted, GeneInfo4You was the victim of a data breach. Hackers were able to access the company’s database and to link the genetic information contained therein to the names and billing addresses of clients.

Soon after the data breach, Jack started to regularly receive brochures at home related to new drugs for the treatment of sickle cell anemia and for Alzheimer’s disease.²⁶ He also received brochures advertising the tracing of African-American genealogy. His wife asked him about the brochures, and Jack told her about the genetic testing. Subsequently, Jack’s wife filed for divorce and told him it was because she was worried about having children with sickle cell disease and because she didn’t feel up to the difficult task of caring for a partner with Alzheimer’s disease who might become unable to recognize her. Jack is emotionally devastated.

Jack also received the same brochures at work. Jack works as an accountant for a multinational firm and is involved in managing large business

²⁵ “Passing” in American society refers to the practice of a person of African ancestry (no matter how minute) identifying publicly as white. Consider, for example, the case of Anatole Broyard. See BLISS BROYARD, *ONE DROP: MY FATHER’S HIDDEN LIFE STORY OF RACE AND FAMILY SECRETS* 17 (2007). In America, a person is considered black if they have *any* known African black ancestry. F. JAMES DAVIS, *WHO IS BLACK? ONE NATION’S DEFINITION* 5 (1991).

In the South it became known as the “one-drop rule,” meaning that a single drop of “black blood” makes a person a black. It is also known as the “one black ancestor rule,” some courts have called it the “traceable amount rule,” and anthropologists call it the “hypo-descent rule,” meaning that racially mixed persons are assigned the status of the subordinate group.

Id. at 5 (citation omitted).

²⁶ Personalized advertisements such as this have become commonplace. See, e.g., Charles Duhigg, *How Companies Learn Your Secrets*, N.Y. TIMES (Feb. 16, 2012), <http://www.nytimes.com/2012/02/19/magazine/shopping-habits.html?pagewanted=all>, archived at <http://perma.cc/88HN-FMKQ> (detailing how companies like Target use statistics coupled with other electronic information to send targeted advertising materials to shoppers). An anecdote in the article mentions how advertising materials for infant care products were sent to a teenage girl’s house before she had even told her parents she was pregnant. *Id.*; see also Kashmir Hill, *How Target Figured Out a Teen Girl Was Pregnant Before Her Father Did*, FORBES (Feb. 16, 2012, 11:02 AM), <http://www.forbes.com/sites/kashmirhill/2012/02/16/how-target-figured-out-a-teen-girl-was-pregnant-before-her-father-did>, archived at <http://perma.cc/5KK7-GGH6>.

clients with portfolios worth millions of dollars. Although Jack's salary is currently \$80,000 per year, he has high hopes of making manager within a year and then partner within a few years, at which time he would be making between \$400,000–500,000 per year. When the brochures arrived at Jack's work, they were not in envelopes and were visible to anyone who visited the mailroom at the workplace. Soon, Jack began to notice that his peers had begun to question his competence.²⁷ Also, he found that his supervisors now more rigorously scrutinized his work.²⁸ Jack was passed up for promotion, and during his review his supervisor mentioned that for managers, they need people who are going to “always be mentally sharp.” In the lunchroom, he overheard one of his supervisors (who had been on Jack's hiring committee) commenting to another that he did not realize Jack was black when he was hired.²⁹ Jack starts to believe that his treatment at work is a result of the

²⁷ There is strong stigma and fear surrounding Alzheimer's Disease. See Jon Hamilton, *Alzheimer's Blood Test Raises Ethical Questions*, NPR (Mar. 9, 2014, 2:04 PM), <http://www.npr.org/blogs/health/2014/03/09/286881513/alzheimers-blood-test-raises-ethical-questions>, archived at <http://perma.cc/P6N8-UREW> (“[T]he biggest concern about Alzheimer's testing probably has to do with questions of stigma and identity. . . . ‘How will other people interact with you if they learn that you have this information?’ . . . ‘And how will you think about your own brain and your . . . sense of self?’”).

²⁸ WRITTEN IN BLACK & WHITE: EXPLORING CONFIRMATION BIAS IN RACIALIZED PERCEPTIONS OF WRITING SKILLS, NEXTIONS (2014), available at http://www.nextions.com/wp-content/files_mf/13972237592014040114WritteninBlackandWhiteYPS.pdf, archived at <http://perma.cc/5XQC-72D5>. In this research study, selected law firm partners were asked to evaluate a single research memo into which twenty-two different errors were deliberately inserted—seven spelling/grammar errors, six substantive writing errors, five errors in fact, and four analytic errors. *Id.* Half of the partner evaluators were told that the hypothetical associate author was African-American and half were told that the author was Caucasian. *Id.* On a five point scale, reviews for the exact same memo averaged a 3.2 for the “African-American” author and 4.1 for the “Caucasian” author. *Id.* More surprising were the findings of “objective” criteria such as spelling. See *id.* The partner evaluators found an average of 2.9 spelling and grammar errors for the “Caucasian” authors and 5.8 such errors for the “African-American” authors. *Id.* Overall the memo presumed to have been written by a “Caucasian” was “evaluated to be better in regards to the analysis of facts and had substantively fewer critical comments.” *Id.*

²⁹ See Angela Onwuachi-Willig & Mario L. Barnes, *By Any Other Name?: On Being “Regarded As” Black, and Why Title VII Should Apply Even if Lakisha and Jamal are White*, 2005 WIS. L. REV. 1283, 1283–84 (noting the very real discriminatory effects of a presumption of blackness even when the individual is not black); see also D. Wendy Greene, *Categorically Black, White, or Wrong: “Misperception Discrimination” and the State of Title VII Protection*, 47 U. MICH. J.L. REFORM 87, 88–89 (2013) (recognizing that there is a hole in anti-discrimination law when it comes to addressing discrimination suffered by individuals who are discriminated against based on a misperception of their race). Some scholars have also argued that based on the historical hierarchical organization of race in the United States and the marriage of racial categorization to economic and social status, “to be ascribed a stigmatized racial identity is to be subject to continuing harm[.] . . . [an] ‘ascriptive injury.’” Paul A. Gowder, Jr., *Racial Classification and Ascriptive Injury*, WASH. U. L. REV. (forthcoming 2014) (manuscript at 3), available at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2444184.

conclusions drawn from the brochures he received. Jack considers suing the advertising companies, but there are several of them. Mostly, however, Jack wants to sue the genetic testing company for not adequately protecting his genetic information.

This Article focuses on the issue of how to make whole consumers of DTC genetic testing³⁰ who, like Jack, have been harmed by the negligent disclosure of their genetic information.

This Article will proceed as follows: Part II details the risks associated with genetic testing, focusing particularly on the harms arising from the disclosure of genetic information. Part III discusses the availability of statutory and tort remedies for the wrongful disclosure of genetic information obtained from DTC genetic testing, and Part IV discusses solutions to the new problem of the wrongful or negligent disclosure of genetic information.

II. THE PERILS OF GENETIC TESTING

In this section, I argue that the peculiar technological and sociological characteristics of today have greatly increased the potential for novel harms arising from the disclosure of genetic information obtained from genetic testing. I note that these new perils include both genetic identity theft and genetic discrimination.

A. *The Genomic Age Meets the Digital Age*³¹

The confluence of the genomic age and the digital age has produced two factors that make the disclosure of genetic information more likely: first is the ubiquity³² and affordability³³ of opportunities to engage in genetic testing, and

³⁰ DTC, i.e., “direct-to-consumer” genetic testing refers to the industry of commercial companies that offer genetic testing for individuals, with or without medical need, usually through the Internet. See Stephanie Bair, *Direct-to-Consumer Genetic Testing: Learning from the Past and Looking Toward the Future*, 67 FOOD & DRUG L.J. 413, 413 (2012) (looking at the different kinds of genetic tests available and some regulations on the testing process).

³¹ I develop the arguments in this subsection in more detail in another Article. See Ifeoma Ajunwa, *Genetic Discrimination and Civil Rights: Why GINA Needs a Disparate Impact Clause* (unpublished manuscript) (on file with author).

³² See TIMATHIE LESLIE ET AL., MARKET TRENDS IN GENETIC SERVICES: IMPACTING CLINICAL CARE THROUGH BETTER PREDICTION, DETECTION, AND CARE SELECTION 1, 2–4 (2012), available at http://www.boozallen.com/media/file/GeneticTesting_VP.pdf; Abigail Lauren Perdue, *Justifying GINA*, 78 TENN. L. REV. 1051, 1067 (2011) (“A market for genetic tests has already developed. In June 2002, Myriad Genetics began marketing genetic tests for certain cancers to the general public, even though the tests were only appropriate for use by a very small portion of the population. In another case, a test for the APOE e4 allele, which is associated with late-onset Alzheimer’s disease, was sold directly to physicians before research was completed to determine how to interpret the connection between the existence of the allele and development of the condition. In 2003, a San

second is the proliferation of electronic medical information and the ease of access to that information that is allowed by the Internet.³⁴ Already, the number of genetic tests available has grown 72% between 2008 and 2012 (from 1,680 to 2,886 tests).³⁵ In 2011, the genetic testing market size amounted to \$5.9 billion.³⁶ A survey indicated that 81.5% of consumers would have their genome sequenced if they could afford it.³⁷ To declare that ours is a genomics age is to recognize that we live in a time in which DNA and genetic information in general has transformed all strata of society from the law to medicine.³⁸ Genetic information has come to permeate our daily lives, from

Francisco firm began selling genetic tests for cancer, cystic fibrosis, hemochromatosis, and other diseases to the public. Another company marketed a test for variations in a serotonin transporter gene linked to chronic depression, and a laboratory allegedly sold tests for genes linked to macular degeneration and glaucoma for \$99.95.”)

³³ See Phillip K. Vacchio & Joshua L. Wolinsky, Note, *Genetic Information Nondiscrimination Act of 2008: It's in Title VII's Genes*, 29 HOFSTRA LAB. & EMP. L.J. 229, 229 (2011) (“[I]ndividuals have become increasingly able to obtain new forms of personal information about themselves, most notably whether or not they possess genetic predispositions to certain diseases. Tests to acquire this type of information have become less costly and more accessible to the general public and therefore individuals are more likely to undergo such testing.”).

³⁴ See DEAN M. HARRIS, CONTEMPORARY ISSUES IN HEALTHCARE LAW AND ETHICS 102 (2d ed. 2003) (giving an overview of the context shaping the HIPAA law, i.e., the changing nature of information in the healthcare industry). Former U.S. Department of Health and Human Services Secretary Donna Shalala is reported as having said “[g]one are the days when our family doctor kept our records sealed away in an office file cabinet. Patient information is now accessed and exchanged quickly.” *Id.* (alteration in original); see also Kathryn McEnery, *The Usefulness of Non-Linear Thinking: Conceptual Analysis Tools and an Opportunity to Develop Electronic Health Information Privacy Law*, HEALTH LAW., Oct. 2010, at 18, 31 n.38 (“Today a patient's complete medical record can be retrieved virtually—and even multiple times in one day—without physically taking the file out of a file cabinet. Electronic files can be opened wherever the clinician (e.g., pharmacist, nurse, therapist, or doctor) is located. In constant motion, information in the complete file is also subject to frequent change, for example, whenever new data is added about test results. Finally, depending on the user's credentials, an individual may be granted virtual access to the complete file or just to a portion of it, a feature of the electronic file that is not available when accessing the physical copy.”).

³⁵ LESLIE ET AL., *supra* note 32, at 1.

³⁶ *Id.*

³⁷ *Id.* at 4.

³⁸ See generally GINA SMITH, THE GENOMICS AGE: HOW DNA TECHNOLOGY IS TRANSFORMING THE WAY WE LIVE AND WHO WE ARE 193–94 (2005); see also DOROTHY NELKIN & M. SUSAN LINDEE, THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON 204 (2004) (examining the connections between current social issues and ideas about genetic determinism).

As the science of genetics has moved from professional journals to mass culture, from the laboratory bench to the television screen, the gene has become an increasingly powerful actor in public life. . . . It is a source of human destiny and the key to human relationships and family cohesion. Instead of a string of purines and pyrimidines, it has become the locus of the human soul.

the use of DNA evidence as a tool to adjudicate culpability³⁹ or to exonerate,⁴⁰ to routine genetic testing now being employed for reproductive⁴¹ and other life-changing decisions.⁴² To observe that we inhabit a digital age is to take notice that the Internet is now the medium for much of human communication; it is also to accept that much of our personal information passes through “Big Data” digital networks and is highly vulnerable to third party capture.

Scholars have defined Big Data as “a cultural, technological, and scholarly phenomenon” that maximizes “computation power and algorithmic accuracy to gather, analyze, link, and compare large data sets.”⁴³ Big Data as a phenomenon draws from “large data sets to identify patterns in order to make economic, social, technical, and legal claims.”⁴⁴ The power of Big Data lies in “the widespread belief that large data sets offer a higher form of intelligence and knowledge that can generate insights that were previously impossible,” and that these insights are imbued “with the aura of truth, objectivity, and accuracy.”⁴⁵

The acquiescence to Big Data coupled with the proliferation of genetic testing raise a host of concerns, especially considering the predicted future pervasiveness of personal information on the Internet.⁴⁶ Despite what should be widespread knowledge about the insecurity of online information, a survey

Id.

³⁹ See Roma Khanna & Steve McVicker, *New DNA Test Casts Doubt on Man’s 1999 Rape Conviction*, HOUS. CHRON., (Mar. 10, 2003, 6:57 PM), <http://www.truthinjustice.org/sutton.htm>, archived at <http://perma.cc/66PM-UUDC> (discussing the case of Josiah Sutton, a man who was exonerated after DNA evidence proved he could not have committed a rape of which he had been convicted).

⁴⁰ See INNOCENCE PROJECT, <http://www.innocenceproject.org> (last visited July 19, 2014), archived at <http://perma.cc/8DY7-72RC> (“The Innocence Project is a national litigation and public policy organization dedicated to exonerating wrongfully convicted individuals through DNA testing and reforming the criminal justice system to prevent future injustice.”).

⁴¹ Currently, all fifty states and the District of Columbia mandate newborn testing for twenty-one or more core disorders. See Roni Caryn Rabin, *Screening for Rare Genetic Disorders Now Routine in Newborns*, N.Y. TIMES (Feb. 18, 2009), <http://www.nytimes.com/2009/02/19/health/18screening.html?ref=health>, archived at <http://perma.cc/6X4U-MSBJ>.

⁴² Based on the discovery via genetic testing that she carries BRCA1 (a breast cancer gene) and her doctor’s estimation that she has an 87% chance of having breast cancer, the actress Angelina Jolie chose to undergo a preventative double mastectomy. Angelina Jolie, Op-Ed., *My Medical Choice*, N.Y. TIMES (May 14, 2013), http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html?_r=0, archived at <http://perma.cc/VD3A-PZSP>.

⁴³ danah boyd & Kate Crawford, *Critical Questions for Big Data: Provocations for a Cultural, Technological, and Scholarly Phenomenon*, 15 INFO. COMM. & SOC’Y 662, 663 (2012).

⁴⁴ *Id.*

⁴⁵ *Id.*

⁴⁶ See generally ERIC SCHMIDT & JARED COHEN, *THE NEW DIGITAL AGE: RESHAPING THE FUTURE OF PEOPLE, NATIONS AND BUSINESS* (2013).

of twenty-two genetic testing companies, which provide the results of genetic testing online revealed something surprising: all of the companies' agreements neglect to include a provision regarding the redress of inadvertent disclosures of the information entrusted to them.⁴⁷ Thus, the DTC genetic testing client is left uninformed about the probability of the inadvertent disclosure of genetic information and about the harms that might stem from that disclosure.⁴⁸

B. Genetic Discrimination

The wrongful disclosure of genetic information, much of which is about propensity for disease or other physical attributes such as race, renders an individual vulnerable to discrimination. The National Institute of Health has defined "genetic discrimination" as "when people are treated differently by their employer or insurance company because they have a gene mutation that

⁴⁷ See, e.g., *Privacy Highlights*, 23ANDME, <https://www.23andme.com/about/privacy/> (last visited Sept. 17, 2013), *archived at* <http://perma.cc/NQA8-TX32> (providing privacy information on testing for adoption, deep ancestry, ethnicity, and genealogy). The disclaimer statement disclaims liability for any consequences that result from information that the customers themselves share with third parties. *Id.* There is no reference to inadvertent disclosures from the testing company. *Id.* A customer's information may be shared with third-party contractors and other researchers, but the company will do this pursuant to a signed Consent Form or if the law requires disclosure. *Id.*; see also, e.g., *Privacy Policy*, DNA CONSULTANTS, <http://dnaconsultants.com/privacy> (last updated Sept. 20, 2009), *archived at* <http://perma.cc/NQA8-TX32> (providing privacy information on testing for deep ancestry and ethnicity). This policy does not mention inadvertent disclosures but disclaims liability for disclosures made by third parties. *Id.* The disclaimer reads: "DNA Consultants is not responsible for the information collection or privacy practices or the content of any such third party websites or applications. DNA Consultants urges users to familiarize themselves with the applicable terms of use and/or privacy policies provided by any such third parties." *Id.*; see also, e.g., *Legal Issues—Privacy Policy and Terms of Service*, FAMILY TREE DNA, <http://www.familytreedna.com/privacy-policy.aspx> (last visited Sept. 17, 2013), *archived at* <http://www.perma.cc/4CMH-BJM3> (providing privacy information on testing for adoption, deep ancestry, full mtDNA sequencing, genealogy, identity, and relationship). There is no mention of inadvertent disclosures, but the company enumerates limited circumstances under which they may disclose consumer information to third parties. *Id.* The policy also states that "[w]hile we cannot guarantee that loss, misuse or alteration of data will not occur, we use commercially reasonable efforts to prevent this." *Id.*; see also, e.g., *Terms and Conditions*, GENE BY GENE, <https://www.genebygene.com/pages/terms> (last visited Oct. 9, 2014), *archived at* <http://perma.cc/C9JQ-Q9SV> (providing information on genetic testing). This company does not specifically reference a privacy policy, nor does it state anything about inadvertent disclosures. *Id.* It disclaims all liability for any damages resulting from the gene tests, and it further requires that the customer indemnify the company with respect to any damage suffered. *Id.* It also caps its liability at the amount the consumer pays for genetic testing. *Id.*

⁴⁸ I take up the particular issue of new regulations that would allow genetic testing companies to better protect their consumers in another article. See Ifeoma Ajunwa, *Protecting Consumers of Online Genetic Testing* (unpublished manuscript) (on file with author).

causes or increases the risk of an inherited disorder.”⁴⁹ I advocate for both a broader and more precise definition of genetic discrimination. Genetic discrimination should be defined as when an individual is subjected to negative treatment, not as a result of the individual’s physical manifestation of disease or disability, but solely because of the individual’s genetic composition. This definition is more precise because it makes clear that the difference in treatment that constitutes genetic discrimination is detrimental to the individual. Also, this definition takes into account personalized medicine, wherein doctors do, in a beneficial manner,⁵⁰ treat patients differently based on their genetic markers for disease.⁵¹ This definition is broader because it recognizes that other entities, besides an employer or insurance company, may discriminate against an individual on the basis of her genetic makeup.⁵²

At the beginning of the genomic age, with more people starting to eagerly partake in genetic testing, prescient legal scholars accurately identified the growing need to protect workers and seekers of health insurance from genetic discrimination.⁵³ With this Article, I seek to expand the scholarly conversation to other ills arising from genetic testing that occur beyond the workplace and the health insurance context. In particular, I focus on the financial and

⁴⁹ *What Is Genetic Discrimination?*, GENETICS HOME REFERENCE (Aug. 12, 2014), <http://ghr.nlm.nih.gov/handbook/testing/discrimination>, archived at <http://perma.cc/S8CH-ZCXR>.

⁵⁰ I recognize that the benefits of some personalized medicine practices are contested. For example, BiDil, a heart disease medicine, received FDA approval to be marketed to only African-Americans. See Tara Bannow, *Race-Related Controversy Causes Drug Flop: BiDil Was Approved by the FDA in 2005 to Treat Heart Failure*, MINN. DAILY (Mar. 9, 2010), <http://www.mndaily.com/2010/03/09/race-related-controversy-causes-drug-flop>, archived at <http://perma.cc/WRQ4-RK94>. Noted health scholar Professor Dorothy Roberts explained:

All of a sudden, a trial involving only African-Americans could only prove it works in blacks[.] . . . By approving BiDil for use only on blacks, the FDA emphasized the supposed distinctive—some might say substandard—quality in blacks. The message is black people can’t represent all of humanity the way that white people can.

Id. (internal quotation marks omitted).

⁵¹ See generally Margaret A. Hamburg & Francis S. Collins, *The Path to Personalized Medicine*, 363 NEW ENG. J. MED. 301, 301 (2010). Consider also the growth of pharmacogenomics—drugs that are developed for specific genetic markers. See also *Genomics*, U.S. FOOD & DRUG ADMIN., <http://www.fda.gov/Drugs/ScienceResearch/ResearchAreas/pharmacogenetics/> (last visited Sept. 15, 2014), archived at <http://perma.cc/D7NF-NXCM>.

⁵² I am cognizant that under my proposed definition for genetic discrimination, not all perpetrators of genetic discrimination would be liable; for example, an individual who has experienced genetic discrimination from a romantic prospect would not have a recognizable legal claim for redress against the romantic prospect.

⁵³ See Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 109 (1991).

emotional ills arising from the wrongful disclosure of genetic information.⁵⁴ Defining genetic discrimination as extending to more than just the employment or health insurance context opens doors for consumers of DTC genetic testing to obtain legal redress when they have been harmed by the wrongful disclosure of their genetic testing. Recent articles have noted the high potential for genetic discrimination.⁵⁵ One problem that lies in the way of reducing the instances of genetic discrimination is that the law, as it currently stands, generally employs a rather narrow definition of genetic discrimination, such that only workers or those seeking health insurance are recognized as victims.⁵⁶ This myopic focus overlooks other important issues associated with genetic testing.

C. Gene Theft and Genetic Identity Theft

The unauthorized disclosure of genetic information obtained via genetic testing is linked to other harms such as gene theft and genetic identity theft. Gene theft or “gene-napping” is recognized as the practice of surreptitiously or clandestinely collecting an individual’s genetic materials and testing that material without the individual’s knowledge or consent.⁵⁷ While the United Kingdom has a blanket ban on such practices,⁵⁸ there is no federal law against this practice in the United States.⁵⁹ Although some legal scholars have advocated for the recognition of DNA theft as a distinct criminal offense,⁶⁰ only a few states have instituted laws that address the practice; Alaska, Florida, New Jersey, New York, and Oregon impose fines or jail sentences for individuals caught taking samples of DNA.⁶¹ Minnesota, New Hampshire, and New Mexico allow civil lawsuits by the individual whose genetic material was

⁵⁴ See *supra* Part I.

⁵⁵ See Elizabeth Collins, Note, *Do You Know Where Your DNA Is? The Need for DNA Legislation in Ohio*, 26 J.L. & HEALTH 349, 358 (2013) (arguing that without DNA theft laws (i.e., to protect against unlawful DNA collections), the potential for genetic discrimination is high because the private information inevitably becomes public).

⁵⁶ See *supra* Part II.B.; see also Jacob M. Appel, ‘Gene-Nappers,’ like Identity Thieves, *New Threat of Digital Age*, NEW HAVEN REG. (Nov. 5, 2009, 12:00 AM), <http://www.nhregister.com/general-news/20091105/gene-nappers-like-identity-thieves-new-threat-of-digital-age>, archived at <http://perma.cc/JJ2A-H3SL>.

⁵⁷ Elizabeth E. Joh, *DNA Theft: Recognizing the Crime of Nonconsensual Genetic Collection and Testing*, 91 B.U. L. REV. 665, 669–70 (2011).

⁵⁸ “As a result of recommendations of its Human Genetics Commission, the British government implemented the Human Tissue Act in 2006, criminalizing genetic testing on human residue without the subject’s consent. Offenders risk up to three years in prison.” Appel, *supra* note 56; see also Peter N. Furness, *The Human Tissue Act: Reassurance for Relatives, at a Price*, 333 BRIT. MED. J. 512, 512 (2006).

⁵⁹ See Appel, *supra* note 56.

⁶⁰ See Joh, *supra* note 57, at 666.

⁶¹ Appel, *supra* note 56. Law enforcement officials are usually exempt from these laws.

taken.⁶² And in most states, a Fourth Amendment exception to the seizure of genetic information by law enforcement is widely recognized.⁶³

It is important to make the distinction between when law enforcement collects genetic information and when genetic material is collected by individuals who are not law enforcement and who do not have the consent to do so.⁶⁴ I do not propose that the actions of law enforcement, which surreptitiously collect the DNA samples of a suspect, should be considered gene theft particularly when that collection is tailored to solving the crime. The legality of this practice by law enforcement, however, still remains in question.⁶⁵

Of importance to this Article is that gene theft involves the theft of more than merely genetic materials; it allows the thief to gain access to an individual's genetic information and endows the thief with the power to disclose that information in a manner that is harmful to the victim.⁶⁶ Some might consider the practice of gene theft to be fairly benign; after all, the individual is not being physically harmed to obtain the genetic materials, and, in contested paternity cases, it might mean that a child now has legal recourse to receive financial support.⁶⁷ However, allowing gene theft to exist as a legally gray practice encourages the disclosure of genetic information in ways

⁶² *Id.*

⁶³ *E.g.*, *Commonwealth v. Bly*, 862 N.E.2d 341, 356–57 (Mass. 2007) (concluding that defendant had no expectation of privacy in a water bottle and cigarette butts from which DNA was taken); *State v. Athan*, 158 P.3d 27, 37 (Wash. 2007) (en banc) (finding no Fourth Amendment violation regarding DNA taken from suspect's used envelope); *State v. Wickline*, 440 N.W.2d 249, 253 (Neb. 1989) (rejecting argument for Fourth Amendment protection of DNA taken from cigarette butts).

⁶⁴ For example, in the Grim Sleeper serial killer case in Los Angeles County, police were able to identify the serial killer after “[a]n undercover officer pretending to be a waiter in Los Angeles collected tableware, napkins, glasses, and pizza crust at a restaurant where the suspect ate, allowing detectives to obtain a DNA match.” *LA ‘Grim Sleeper’ Probe to Check Unsolved Killings*, THEGRIO (July 9, 2010, 3:53 PM), <http://thegrio.com/2010/07/09/la-grim-sleeper-probe-to-check-unsolved-killings/>, archived at <http://perma.cc/P5TY-CB45>.

⁶⁵ *See, e.g.*, Amy Harmon, *Defense Lawyers Fight DNA Samples Gained on Sly*, N.Y. TIMES (Apr. 3, 2008), <http://www.nytimes.com/2008/04/03/science/03dna.html?pagewanted=all>, archived at <http://perma.cc/B2FN-T3MP>; Natalie Ram, *Fortuity and Forensic Familial Identification*, 63 STAN. L. REV. 751, 755 (2011); *see also* Elizabeth Joh, Op-Ed., *A ‘Familial’ Net: We Mustn’t Ignore the Perils of Genetic Data Mining*, L.A. TIMES, July 10, 2010, at A27.

⁶⁶ Robbie Gonzalez, *Your Biggest Genetic Secrets Can Now be Hacked, Stolen, and Used for Target Marketing*, IO9 (Jan. 17, 2013, 12:38 PM), <http://io9.com/5976845/your-biggest-genetic-secrets-can-now-be-hacked-stolen-and-used-for-target-marketing>, archived at <http://perma.cc/GHH6-PGJG>.

⁶⁷ *See* Dorothy Nelkin, *Paternity Palaver in the Media: Selling Identity Tests, in GENETIC TIES AND THE FAMILY: THE IMPACT OF PATERNITY TESTING ON PARENTS AND CHILDREN* 3, 5, 8 (Mark A. Rothstein et al. eds., 2005).

that erode privacy.⁶⁸ The American Bar Association Journal has also documented how DNA labs prefer to remain agnostic about the provenance of the DNA submitted to them, thus making the labs a helpful resource for individuals who steal DNA to gain genetic information.⁶⁹

The practice of gene theft, besides being considered an invasion of privacy⁷⁰ and a theft of what some jurisdictions have now recognized as property,⁷¹ opens the door to the negligent disclosure of an individual's private and potentially damaging genetic information, and leaves the individual vulnerable to the menace of genetic identity theft. Yaniv Erlich, a researcher who demonstrated how the identities of individuals whose genomes had been posted online could be uncovered, has this to say:

“We are living in a brave new world . . . a world where more information than ever is readily available online.” What happens to this information depends on who's making use of it. In the hands of a scientist, it can be used to study, treat and cure diseases. In the hands of Facebook, it can be used to

⁶⁸ Professors Robert Green and George Annas make note of how the genetic privacy of presidential candidates might be lost when the legality of using “abandoned” DNA is left undefined. Robert C. Green & George J. Annas, *The Genetic Privacy of Presidential Candidates*, 359 NEW ENG. J. MED. 2192, 2192 (2008).

During future campaigns, presidential candidates could release information about parts of their own genomes in order to highlight what might be considered a favorable ethnic background or, if they have already had a disease such as cancer, to highlight the absence of genes that confer a risk of recurrence. But in a climate of negative personal and political messages, it is more likely that persons or groups opposing a candidate will release such information, hoping to harm his or her chances for election or reelection.

Id.

⁶⁹ See Eriq Gardner, *Gene Swipe: Few DNA Labs Know Whether Chromosomes Are Yours or if You Stole Them*, ABA J. (Aug. 1, 2011, 8:40 AM), http://www.abajournal.com/magazine/article/gene_swipe_few_dna_labs_know_whether_chromosomes_are_yours_or_if_you_stole/, archived at <http://perma.cc/92DQ-MYU5>.

⁷⁰ See *infra* Part III.B.1.

⁷¹ A Canadian court found in June 2014 that human tissue removed from the body for diagnostic medical tests is “personal property” that belongs to the hospital where the procedure was performed. Richard Warnica, *Human Tissue Removed for Medical Tests Is ‘Personal Property’ of Institution, Not Person It Came from: Ruling*, NAT’L POST (June 5, 2014, 7:00 PM) <http://news.nationalpost.com/2014/06/05/human-tissue-removed-for-medical-tests-is-personal-property-of-institution-not-person-it-came-from-ruling/>, archived at <http://perma.cc/N9GQ-LCWT>; cf. Moore v. Regents of the Univ. of Cal., 793 P.2d 479, 480 (Cal. 1990) (en banc) (denying plaintiff’s conversion claim and rejecting the notion that an individual has property interests in his cells or other bodily products). *But see* Wash. Univ. v. Catalona, 490 F.3d 667, 676–77 (8th Cir. 2007) (relying on property law to hold that plaintiffs who had provided bio-specimens for genetic cancer research did so as *inter vivos* gifts, resulting in a completed donative transfer which could not be revoked).

create powerful new search engines In the hands of a criminal, it can be used to commit identity theft.⁷²

An example of genetic identity theft is when one individual is able to impersonate another through the use of genetic materials such as blood or hair, a scenario that is of particular concern to law enforcement.⁷³ As genomic identity anonymity is rapidly lost, the potential for harm arising from the improper use of an individual's genetic information increases.⁷⁴

Although this Article constrains its focus to individuals who have willingly relinquished their genetic material, it is important to note that those individuals are no less vulnerable to both gene theft and genetic identity theft.⁷⁵

III. THE AVAILABILITY OF STATUTORY AND TORT REMEDIES

In this section, I discuss what statutory and tort remedies are available to consumers of genetic testing, such as Jack, who willingly share their genetic material and who then suffer harm due to the negligent disclosure of genetic information. First, I examine the provisions of The Genetic Information Nondiscrimination Act (GINA), which is the only federal statute that directly addresses the use of genetic information.⁷⁶ I also discuss some tort remedies available to a would-be plaintiff seeking redress of the wrongful disclosure of genetic information. I explain why both GINA and extant tort remedies are insufficient to make whole all individuals who have been harmed by the negligent disclosure of their genetic information.

A. *The Genetic Information Nondiscrimination Act*

Signed into law in 2008, GINA focuses on genetic discrimination by employers and health insurance companies; it is silent on the issue of wrongful disclosure of genetic information by genetic testing companies.⁷⁷ The impetus

⁷² Gonzalez, *supra* note 6.

⁷³ In 2009, scientists in Israel demonstrated that it is possible to fabricate DNA evidence for a crime scene. Andrew Pollack, *DNA Evidence Can Be Fabricated, Scientists Show*, N.Y. TIMES (Aug. 17, 2009), <http://www.nytimes.com/2009/08/18/science/18dna.html>, archived at <http://perma.cc/CS7L-ZHGJ> (“The scientists fabricated blood and saliva samples containing DNA from a person other than the donor of the blood and saliva.”).

⁷⁴ *See id.*

⁷⁵ Scientists in Israel revealed that “if they had access to a DNA profile in a database, they could construct a sample of DNA to match that profile without obtaining any tissue from that person.” *Id.*

⁷⁶ *See generally* Louise Slaughter, *Genetic Information Non-Discrimination Act*, 50 HARV. J. ON LEGIS. 41, 66 (2013).

⁷⁷ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified in scattered sections of 26, 29, and 42 U.S.C.).

for GINA was the progress of the Human Genome Project.⁷⁸ As the U.S. government began to see advancements in the research of the human genome,⁷⁹ it also began to be concerned about issues arising from genetic discrimination.⁸⁰ GINA⁸¹ was promulgated to protect workers from being discriminated against on the basis of their genetic information both in employment and for obtaining health insurance.⁸² And it is true that employers would select healthy workers to the detriment of unhealthy or even *potentially* unhealthy ones.⁸³

⁷⁸ See *About the Human Genome Project*, HUMAN GENOME PROJECT INFO. ARCHIVE 1990–2003, http://web.ornl.gov/sci/techresources/Human_Genome/project/index.shtml (last modified July 23, 2013), archived at <http://perma.cc/MML7-J9V4>.

⁷⁹ “Begun formally in 1990, the U.S. Human Genome Project was a 13-year effort coordinated by the U.S. Department of Energy (DOE) and the National Institutes of Health (NIH). The project originally was planned to last 15 years, but rapid technological advances accelerated the completion date to 2003.” *Id.* Some project goals were to “*identify* all the approximately 20,000–25,000 genes in human DNA, *determine* the sequences of the 3 billion chemical base pairs that make up human DNA, [and] *store* this information in databases.” *Id.* (emphasis in original).

⁸⁰ See Jared A. Feldman & Richard J. Katz, Note, *Genetic Testing & Discrimination in Employment: Recommending a Uniform Statutory Approach*, 19 HOFSTRA LAB. & EMP. L.J. 389, 389 (2002). It is often difficult to recognize—much less prove—that discrimination has occurred, yet “[p]ublic concerns about the possible misuse of their genetic information by insurers or employers have been documented.” *The Threat of Genetic Discrimination to the Promise of Personalized Medicine: Testimony Before the Subcomm. on Health of the H. Comm. on Ways and Means*, 110th Cong. 4 (2007) (statement of Francis Collins, Director, Nat’l Human Genome Research Inst.), available at <http://waysandmeans.house.gov/Media/pdf/110/3-14-07/CollinsTestimony.pdf>.

⁸¹ Genetic Information Nondiscrimination Act § 1. On May 21, 2008, President George W. Bush signed GINA into law. See *President Bush Signs the Genetic Information Nondiscrimination Act of 2008*, NAT’L HUMAN GENOME RES. INST. (May 21, 2008), <http://www.genome.gov/27026050>, archived at <http://perma.cc/T87M-3WP9>.

⁸² See Genetic Information Nondiscrimination Act § 2(1). As rationale for the need for GINA, Congress noted: “New knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment.” *Id.*

⁸³ See *Perdue*, *supra* note 32, at 1101.

[E]mployers want to ensure that employees are fit to perform the essential functions of their jobs. “If a worker will become ill, and if the employer will be responsible for the medical costs as well as the output costs of the worker’s absence, then the predicted illness is nothing but a future dollar cost that the employer must consider and discount.” Unhealthy employees pose huge costs to employers in the form of above-average absenteeism, decreased productivity, overtime payments to hire workers to cover absent employees’ shifts, higher job turnover, administrative costs inherent in hiring, recruiting, and training replacements, and higher workers’ compensation insurance premiums that result when an employee makes a claim for benefits.

Title I of GINA contains provisions related to health insurance.⁸⁴ “[T]ogether with already existing nondiscrimination provisions of the Health Insurance Portability and Accountability Act,” Title I of GINA “generally prohibits health insurers or health plan administrators from requesting or requiring genetic information of an individual or the individual’s family members, or using it for decisions regarding coverage, rates, or preexisting conditions.”⁸⁵ Title II of GINA covers genetic discrimination by employers.⁸⁶ That part of GINA “prohibits most employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment.”⁸⁷

It is important to understand that GINA is not primarily designed for the use of the individual citizen; rather, governmental agencies such as the Equal Employment Opportunity Commission (EEOC) are its first line of defense.⁸⁸ Thus, the Department of Labor, the Department of the Treasury, and the Department of Health and Human Services are charged with enforcing the provisions of Title I of GINA; that is, they are responsible for bringing suits against insurance companies that use genetic information in ways prohibited by GINA.⁸⁹ The EEOC enforces Title II of GINA by suing employers who use genetic information to discriminate in employment.⁹⁰

Before an individual could bring a suit on the basis of GINA’s prohibitions, that individual must first satisfy Title II’s provision for the exhaustion of administrative remedies.⁹¹

Id. (citing Gostin, *supra* note 3, at 133); *see also* Jia Lynn Yang, *AOL Chief Cuts 401(k) Benefits, Blames Obamacare and Two “Distressed Babies,”* WASH. POST (Feb. 7, 2014), <http://www.washingtonpost.com/blogs/wonkblog/wp/2014/02/06/aol-chief-cuts-401k-benefits-blames-obamacare/>, archived at <http://perma.cc/B23A-Q6LT> (AOL chief executive Tim Armstrong said, “[w]e had two AOL-ers that had distressed babies that were born that we paid a million dollars each to make sure those babies were OK in general . . . [a]nd those are the things that add up into our benefits cost. So when we had the final decision about what benefits to cut because of the increased healthcare costs, we made the decision, and I made the decision, to basically change the 401(k) plan.”) (internal quotation marks omitted)).

⁸⁴ *See* Genetic Information Nondiscrimination Act, tit. I, §§ 101–06.

⁸⁵ DEP’T OF HEALTH & HUMAN SERVS., “GINA”: THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 INFORMATION FOR RESEARCHERS AND HEALTH CARE PROFESSIONALS 2 (2009), available at <http://www.genome.gov/pages/policyethics/geneticdiscrimination/ginainfodoc.pdf>; *see* Genetic Information Nondiscrimination Act, tit. I, §§ 101–06.

⁸⁶ *See* Genetic Information Nondiscrimination Act §§ 202–03.

⁸⁷ DEP’T OF HEALTH & HUMAN SERVS., *supra* note 85, at 2; *see also* Genetic Information Nondiscrimination Act §§ 202–03.

⁸⁸ *See* Genetic Information Nondiscrimination Act § 207; *see also* *Laws Enforced by the EEOC*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION, <http://www.eeoc.gov/laws/statutes/index.cfm> (last visited Oct. 8, 2014), archived at <http://perma.cc/M644-VMU8>.

⁸⁹ DEP’T OF HEALTH & HUMAN SERVS., *supra* note 85, at 2.

⁹⁰ *Id.*

⁹¹ *See* *Macon v. Cedarcroft Health Servs., Inc.*, No. 4:12–CV–1481 CAS, 2013 WL 1283865, at *6 (E.D. Mo. Mar. 27, 2013). The requirement to exhaust administrative

[This] requires that the complainant file a timely charge with the EEOC, thereby allowing the agency time to investigate the charge. Only after the charge is filed, and either the EEOC's attempts at conciliation have failed or the EEOC determines that there is no reasonable cause to believe discrimination occurred, may the plaintiff file suit in federal court.⁹²

The EEOC reports that between 2010 and 2013, 1,059 charges were filed under GINA.⁹³ In contrast, the EEOC filed its first two lawsuits for GINA violations in 2013.⁹⁴ Thus, GINA's protections are mostly left to the discretion of the EEOC to enforce and are not meant to be wielded by the individual consumer as a tool for redress of harm suffered from the disclosure of genetic testing. Thus, in the hypothetical, GINA might be useful for Jack if he wants to sue for genetic discrimination by his employer, but GINA is of no help to Jack in seeking damages from the genetic testing company.

B. *Tort Remedies*

As GINA is primarily designated to be an administrative tool for government agencies to combat genetic discrimination in employment and insurance, and as individuals must first exhaust administrative remedies before they employ GINA for a law suit, tort litigation is somewhat better suited to consumers of DTC genetic testing. Legal scholars have recognized that “[a]n injury to health information privacy can be established using principles of contract or tort law.”⁹⁵ Such “an injury occurs when a person obligated to

remedies is codified at 29 C.F.R. § 1635.10 (2014), which incorporates by reference the administrative remedy requirement from other discrimination statutes. *Id.* at *7.

⁹² *Id.* (citations omitted). In *Macon*, the court dismissed the plaintiff's GINA claim based on new regulations that require a plaintiff to exhaust administrative remedies prior to bringing a suit in court. *Id.*

⁹³ *Genetic Information Non-Discrimination Act Charges FY 2010-2013*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION, <http://www.eeoc.gov/eeoc/statistics/enforcement/genetic.cfm> (last visited Aug. 8, 2014), *archived at* <http://perma.cc/M644-VMU8>.

⁹⁴ See Joint Motion for Entry of Agreed Consent Decree, *EEOC v. Fabricut, Inc.*, No. 13-CV-248-CVE-PJC (N.D. Okla. May 7, 2013); Press Release, EEOC, Fabricut to Pay \$50,000 to Settle EEOC Disability and Genetic Information Discrimination Lawsuit (May 7, 2013), *available at* <http://www.eeoc.gov/eeoc/newsroom/release/5-7-13b.cfm>; see also Complaint and Jury Demand, *EEOC v. Founders Pavilion, Inc.*, No. 13-cv-06250-CJS (W.D.N.Y. May 16, 2013).

⁹⁵ *McEnery*, *supra* note 34, at 23; see Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 207 (1890) (explaining that while some theorists find privacy to be a form of property right, some courts have found a privacy right as a function of contract law). Warren and Brandeis write that, “in some instances where protection has been afforded against wrongful publication, the jurisdiction has been asserted, not on the ground of property, or at least not wholly on that ground, but upon the ground of an alleged breach of an implied contract or of a trust or confidence.” *Id.* The authors further explain:

maintain confidentiality of personal health information breaches that duty, or when one is embarrassed as a result of some unauthorized disclosure of information.”⁹⁶ Tort claims may thus provide a more feasible way than legislative remedies such as GINA for individuals who have been harmed from disclosure of their genetic testing to be made whole again.

Although HIPAA does not provide a private tort cause of action,⁹⁷ two particular cases have become canonical for establishing private tort causes of action for suits brought in state court regarding the disclosure of electronic medical information.⁹⁸

In *Acosta v. Byrum*,⁹⁹ the plaintiff, a patient, sued her psychiatrist, among other defendants, for negligent infliction of emotional distress.¹⁰⁰ The patient alleged that the doctor wrongfully allowed an office manager to access her medical records using his medical record access number, and that she suffered severe emotional distress, humiliation, and anguish when the office manager then disclosed her medical records to other parties.¹⁰¹ In her complaint, the plaintiff asserted that when the psychiatrist provided his medical access code to the office manager, the doctor violated the rules and regulations established

This process of implying a term in a contract, or of implying a trust (particularly where the contract is written, and where there is no established usage or custom), is nothing more nor less than a judicial declaration that public morality, private justice, and general convenience demand the recognition of such a rule, and that the publication under similar circumstances would be considered an intolerable abuse. So long as these circumstances happen to present a contract upon which such a term can be engrafted by the judicial mind, or to supply relations upon which a trust or confidence can be erected, there may be no objection to working out the desired protection through the doctrines of contract or of trust.

Id. at 210.

⁹⁶ McEnery, *supra* note 34, at 23.

⁹⁷ See generally Jack Brill, Note, *Giving HIPAA Enforcement Room to Grow: Why There Should Not (Yet) Be a Private Cause of Action*, 83 NOTRE DAME L. REV. 2105, 2124–39 (2008) (recommending that no cause of action be added to HIPAA at this time); see also Daniel J. Oates, Comment, *HIPAA Hypocrisy and the Case for Enforcing Federal Privacy Standards Under State Law*, 30 SEATTLE U. L. REV. 745, 775–76 (2007) (concluding that the HIPAA Privacy Rule is too narrow and recommending increased use of the tort of intrusion upon seclusion).

⁹⁸ See McEnery, *supra* note 34, at 18 (describing trends in privacy litigation, including state cases such as *Acosta* and *Herman*); see also Tresa Baldas, *Hospitals Fear Claims over Medical Records*, NAT’L L. J., May 28, 2007, at 4.

⁹⁹ *Acosta v. Byrum*, 638 S.E.2d 246, 250–52, 254 (N.C. Ct. App. 2006) (holding that a patient could establish a sufficient claim for negligent infliction of emotional distress against her physician for an incident in which he gave his computer security code to his office manager, who then accessed the patient’s confidential healthcare records and disclosed the information to other parties and that the plaintiff was allowed to derive a “standard of care” from HIPAA rules, defining the physician’s duty to protect the confidentiality of the patient’s records).

¹⁰⁰ *Id.* at 249.

¹⁰¹ *Id.*

by HIPAA.¹⁰² Although she did not assert a HIPAA claim, the plaintiff cited to HIPAA as establishing the appropriate standard of care in her case.¹⁰³ The case was dismissed on the grounds that HIPAA does not grant an individual a private cause of action, but on appeal, the court reversed and agreed with the plaintiff that HIPAA's provisions may be referred to for the appropriate standard of care in the case, albeit that this was a suit based on a negligence cause of action and no HIPAA violation was being alleged in the case.¹⁰⁴

Similar to *Acosta*, *Herman v. Kratche* also involved the unauthorized disclosure of sensitive medical information.¹⁰⁵ In *Herman*, a patient brought suit against a medical clinic and the physician for the clinic after the clinic inadvertently sent medical records from a physical—a mammogram screening, and a diagnostic mammogram—the physician had conducted at the clinic to her employer.¹⁰⁶ She asserted claims of unauthorized disclosure, invasion of privacy, and intentional infliction of emotional distress.¹⁰⁷ The trial court granted the defendants summary judgment on the claims and the plaintiff appealed.¹⁰⁸ The appeals court found both that the clinic had a fiduciary duty to avoid unauthorized disclosure of the patient's medical records, and that it had breached that duty.¹⁰⁹ Further, the court also found that the state of Ohio recognizes the tort of the negligent invasion of privacy and that the plaintiff's claims were strong enough to create a question of fact and withstand summary judgment.¹¹⁰ As to the claim for intentional infliction of emotional distress, the court upheld the summary judgment ruling, noting that the plaintiff had not provided expert testimony as to the severity of her distress.¹¹¹

The *Herman* and *Acosta* cases bolster the notion that state tort law may be employed by a plaintiff who has suffered harm due to the unauthorized disclosure of her genetic information, which in many cases doubles as medical information.¹¹² The facts of the hypothetical make Jack's case akin to *both Herman* and *Acosta* as both involved negligent disclosures of information.

¹⁰² *Id.* at 253.

¹⁰³ *Id.*

¹⁰⁴ *Id.* at 253–54.

¹⁰⁵ See *Herman v. Kratche*, No. 86697, 2006 WL 3240680, at *6 (Ohio Ct. App. Nov. 9, 2006) (holding that a tort of negligent invasion of the right of privacy existed when the plaintiff's medical information was inadvertently sent to her employer rather than her health insurance company). “Ohio recognizes the tort of negligent invasion of the right of privacy. . . . We have already determined that the Clinic made an unauthorized disclosure of plaintiff's personal health information to Nestle. When it mistakenly mailed plaintiff's information to Nestle, the Clinic wrongfully intruded into plaintiff's private life.” *Id.*

¹⁰⁶ *Id.* at *1.

¹⁰⁷ *Id.*

¹⁰⁸ *Id.*

¹⁰⁹ *Id.* at *3.

¹¹⁰ *Id.* at *6.

¹¹¹ *Herman*, 2006 WL 3240670, at *7.

¹¹² See *Macon v. Cedarcroft Health Servs., Inc.*, No. 4:12-CV-1481 CAS, 2013 WL 1283865, at *1–2 (E.D. Mo. Mar. 27, 2013).

Therefore, in seeking to bring suit against the genetic company which did not intentionally release his information, Jack may allege tort claims similar to those found in the two cases. Below, I analyze the three tort actions that are most appropriate given the facts of Jack's case. I discuss why, although a claim of breach of fiduciary duty is ultimately Jack's strongest tort claim, it still does not offer a sufficient remedy.

1. *Negligent Invasion of Privacy*

Jack could bring a claim for negligent invasion of privacy¹¹³ based on the public disclosure of private facts, in this case his genetic information. Although some scholars have argued for greater transparency for medical records and other health information as a public good,¹¹⁴ it is generally understood that, absent some exceptions for public health and safety,¹¹⁵ there

¹¹³ There has been legal debate over whether genetic information should be considered as falling under privacy or property rights. See Mary J. Hildebrand et al., *Toward a Unified Approach to Protection of Genetic Information*, 22 BIOTECH. L. REV. 602, 602 (2003) (discussing whether genetic information falls under privacy or property interests); cf. Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737, 746, 763 (2004) (proposing that genetic information should be regarded as a privacy right rather than a property interest because the former observes a holistic view of the individual). Some scholars have asserted the belief that property rights would afford greater protections. See Gabrielle Kohlmeier, *The Risky Business of Lifestyle Genetic Testing: Protecting Against Harmful Disclosure of Genetic Information*, 11 UCLA J.L. & TECH. 1, 21 n.66 (2007) (citing Hildebrand et al., *supra*, at 604) ("Conceivably, through property rights, an individual could be provided with a series of rights regarding the control, possession, and transferability of his genetic information that are unavailable through privacy legislation."). In *Moore v. Regents of the University of California*, however, the court rejected the property interest approach and denied the plaintiff's claim to profits made from his tissue. See 793 P.2d 479, 497 (Cal. 1990); see also Art Caplan, *NIH Finally Makes Good with Henrietta Lacks' Family—and It's About Time, Ethicist Says*, NBC NEWS (Aug. 7, 2013), <http://www.nbcnews.com/health/health-news/nih-finally-makes-good-henrietta-lacks-family-its-about-time-f6C1086794>, archived at <http://perma.cc/WZ57-NDL9>.

¹¹⁴ See Barry R. Furrow, *Data Mining and Substandard Medical Practice: The Difference Between Privacy, Secrets and Hidden Defects*, 51 VILL. L. REV. 803, 806 (2006) ("Is there any good reason to let people have property rights in secret information about themselves that will discredit them if revealed? In the abstract, the answer is clearly no. In the medical environment, the guiding principle should be discovery of 'secrets' and harvesting of data regarding defects in the system. Ultimately, concealment in medicine can do greater harm to patients."). But see Daniel J. Solove, *"I've Got Nothing to Hide" and Other Misunderstandings of Privacy*, 44 SAN DIEGO L. REV. 745, 772 (2007) (asserting that there is a right to privacy that exists beyond governmental concerns).

¹¹⁵ See *Whalen v. Roe*, 429 U.S. 589, 598 (1977) (holding that for purposes of combating drug abuse, a state may enact legislation that requires the names of individuals prescribed Schedule II narcotics (opium, methadone, cocaine, etc.) to be reported to the state department of health). In *Whalen*, the Court found:

may be a right to privacy that exists for one's medical and health information.¹¹⁶ Justice Louis Brandeis and Samuel Warren write that we have come to an understanding of the privacy right where "now the right to life [arising from common law] has come to mean the right to enjoy life,—the right to be let alone."¹¹⁷ The legal scholar Erwin Chemerinsky has noted that areas influenced by electronic technology (in this case, the disclosure of genetic information) represent "the unfinished legacy of Warren and Brandeis, and now, more than ever, it needs to be realized."¹¹⁸ Beyond just protecting individual consumers like Jack, there are important public policy reasons for finding a privacy right in genetic information. For one, it enables research in genetic information.¹¹⁹ The absence of privacy protections for genetic information would have a chilling effect on would-be volunteers.¹²⁰

To establish an invasion of privacy claim, Jack would look to the *Restatement (Second) of Torts* which states:

[D]isclosures of private medical information to doctors, to hospital personnel, to insurance companies, and to public health agencies are often an essential part of modern medical practice even when the disclosure may reflect unfavorably on the character of the patient. Requiring such disclosures to representatives of the State having responsibility for the health of the community, does not automatically amount to an impermissible invasion of privacy.

Id. at 602; *see also* *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 348 (Cal. 1976) (holding that a therapist has a duty to report to police a threat that a psychiatric patient has made against a third party and to warn the subject of that threat); HARRIS, *supra* note 34, at 102. Harris explains the exceptions to medical and health information privacy:

Despite the importance of protecting medical privacy, some situations occur in which the public interest requires that information be disclosed, even without the consent of the individual patient. To prevent epidemics, for example, we want physicians to report communicable diseases to public health authorities. We also want healthcare providers to report gunshot wounds and suspected cases of child abuse to designated agencies, despite the consequent breach of confidentiality. In addition, the use and disclosure of medical records may be necessary to provide appropriate treatment and to conduct important medical and pharmaceutical research. Therefore, the issue of public policy is not merely a question of how we can provide the maximum protection for individual privacy. Rather, it is a question of how we can provide sufficient protection for individual privacy without interfering too much with other public needs such as public safety, communicable disease control, medical treatment, and healthcare research.

Id. at 103.

¹¹⁶ *See e.g.*, Warren & Brandeis, *supra* note 5, at 193.

¹¹⁷ *Id.* at 193.

¹¹⁸ Erwin Chemerinsky, *Rediscovering Brandeis's Right to Privacy*, 45 BRANDEIS L.J. 643, 656–57 (2007) (acknowledging that the further development of information privacy law is timely).

¹¹⁹ Josef A. Mejido, Note, *Personalized Genomics: A Need for a Fiduciary Duty Remains*, 37 RUTGERS COMPUTER & TECH. L.J. 281, 300 (2011).

¹²⁰ *Id.*

- (1) One who invades the right of privacy of another is subject to liability for the resulting harm to the interests of the other.
- (2) The right of privacy is invaded by
 - (a) unreasonable intrusion upon the seclusion of another, as stated in § 652B; or
 - (b) appropriation of the other's name or likeness, as stated in § 652C; or
 - (c) *unreasonable publicity given to the other's private life*, as stated in § 652D; or
 - (d) publicity that unreasonably places the other in a false light before the public, as stated in § 652E.¹²¹

From the hypothetical, Jack could argue that the way his genetic information was publicized was unreasonable. He would note that his genetic information, particularly relating to medical information about future disease, is private information, which he had not even shared with his wife, and that it was unreasonable to have that information publicized to his co-workers and supervisors.

In Ohio, however, Jack would be met with a higher burden in establishing an invasion of privacy claim.¹²² He must show “a wrongful intrusion into one’s private activities in a manner that outrages or causes mental suffering, shame, or humiliation to a person of ordinary sensibilities.”¹²³ Specifically, the “intrusion must be ‘*highly offensive*’ to a reasonable person.”¹²⁴ Jack “must be able to demonstrate that the area intruded into was private and that the intrusion itself was unwarranted and offensive or objectionable to a reasonable person.”¹²⁵ The wording “highly offensive” creates a higher standard than “unreasonable.” It seems that in Ohio, it is not enough for Jack to prove that the intrusion into his private affairs was unreasonable; he must show that a reasonable person would find the intrusion to be highly offensive, which is a higher degree of offense.¹²⁶ Some facts in the hypothetical would be useful to Jack in meeting this standard. For one, the disclosure of genetic information resulted in Jack receiving brochures regarding diseases at his place of work. Further, one of the diseases in question was a cognitive disease—i.e., Alzheimer’s disease. Jack suffered shame and humiliation at work, as his co-workers and supervisors, who suspected him of having Alzheimer’s disease, began to question his competence. These experiences would seem highly offensive to a reasonable person.

There is the argument, however, that Jack’s case is distinguishable from *Herman* based on the fact that there was no actual disclosure of his medical records. In *Herman*, the results of a patient’s physical exam and mammogram

¹²¹ RESTATEMENT (SECOND) OF TORTS § 652A (1977) (emphasis added).

¹²² *Stefanski v. W.W. Grainger, Inc.*, No. 1:02 CV 1163, 2003 WL 25719641, at *3 (N.D. Ohio Sept. 23, 2003).

¹²³ *Id.*

¹²⁴ *Id.* (emphasis added).

¹²⁵ *Id.*

¹²⁶ *Id.*

screenings were disclosed to her employer.¹²⁷ In Jack's case, all that his co-workers and supervisors saw were brochures, not his actual medical information. However, Jack could still argue that these brochures enabled his co-workers to deduce personal medical information about Jack, including that he is a carrier for the gene for Alzheimer's and for the sickle cell trait. Further, he would argue that even if his status as a genetic carrier of disease is not deemed to be medical information, it was still information that he meant to remain private. The level of privacy he attached to the information is noted in the fact that he kept from his own wife. Therefore, whether or not Jack's case involved the same medical information as in *Herman*, it did involve private information, and he may argue that his privacy was invaded when this information was revealed.

2. Negligent Infliction of Emotional Distress

The private, personal, and sensitive nature of genetic information heightens the potential for emotional harm arising from its public disclosure.¹²⁸ Therefore, Jack could assert a claim for negligent infliction of emotional distress based on the release of his medical information. The *Restatement (Third) of Torts* states that “[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.”¹²⁹ The most significant part of this rule for determining liability for the negligent infliction of emotional distress is that there is no physical harm¹³⁰ or “zone of danger”¹³¹ requirement. The disclosure of genetic information generally does not cause physical harm, but this in no way diminishes the acuteness of the injury done to the individual.¹³²

¹²⁷ See *Herman v. Kratche*, No. 86697, 2006 WL 3240680, at *1 (Ohio Ct. App. Nov. 9, 2006).

¹²⁸ See Philip R. Reilly et al., *Ethical Issues in Genetic Research: Disclosure and Informed Consent*, 15 NATURE GENETICS 16, 16 (1997) (noting the emotionally fraught nature of genetic information). Genetic testing also has the potential to reveal non-paternity, which can come as an unpleasant emotional surprise to test-takers. See, e.g., Daniel Engber, *Who's Your Daddy? The Perils of Personal Genomics*, SLATE (May 21, 2013, 5:45 AM), http://www.slate.com/articles/health_and_science/science/2013/05/paternity_testing_personal_genomics_companies_will_reveal_dna_secrets.html, archived at <http://perma.cc/4FWD-VDPR>.

¹²⁹ RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL & EMOTIONAL HARM § 47 (2012).

¹³⁰ Cf. RESTATEMENT (THIRD) OF TORTS: PHYSICAL & EMOTIONAL HARM §§ 5–6, 20–23 (2010).

¹³¹ See RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL & EMOTIONAL HARM § 47(a) (2012).

¹³² Zhansheng Chen et al., *When Hurt Will Not Heal: Exploring the Capacity to Relieve Social and Physiological Pain*, 19 PSYCHOL. SCI. 789, 793 (2008) (finding that subjects

Thus, although Jack was not physically harmed by the disclosure of his genetic information, that disclosure did cause him emotional distress.

In Jack's case, he could argue that he experienced "mental suffering" as a result of the brochures, as they caused his wife to learn about and draw damaging assumptions from Jack's genetic test results, leading to their divorce. As a result of the brochures being delivered to his office, Jack would also argue that he experienced shame and embarrassment as well as the stigmatization arising from the assumption that he is suffering from a cognitive disease such as Alzheimer's.

3. Breach of Fiduciary Duty

Ultimately, a claim for breach of fiduciary duty is Jack's strongest tort claim. Jack will note that, as a client, he is in privity with the genetic testing company and that the unauthorized disclosure of his genetic information is a breach of the genetic testing company's fiduciary duty. For Justice Brandeis and Samuel Warren, injuries to privacy could be considered under contract law when the disclosure of information violated an implicit agreement between two individuals.¹³³ This is illustrated in *Herman*, where the court found that there was a breach of implied contractual terms: a breach of fiduciary duty.¹³⁴

In Jack's case, there was a contractual relationship established when Jack entered into an agreement with the genetic testing company for the provision of genetic information.¹³⁵ Because this was an agreement that involved the entrustment of genetic material in exchange for diagnostic services, Jack could argue that a fiduciary duty was created and that this fiduciary duty was breached when his information was hacked.

The Supreme Court of Ohio has found that the "claim of breach of a fiduciary duty is basically a claim of negligence, albeit involving a higher standard of care."¹³⁶ An Ohio court of appeals has further affirmed that it is undisputed that a medical provider holds a fiduciary position over patients and thus has a duty to keep patients' information confidential.¹³⁷ Thus, in order to prevail on this claim, Jack must: (1) establish that a fiduciary duty existed between him and the genetic testing company and (2) prove that the breach of that duty resulted in his damages.

reported higher levels of pain upon reliving a socially painful event versus one of physical pain).

¹³³ See Warren & Brandeis, *supra* note 95, at 210.

¹³⁴ *Herman v. Kratche*, No. 86697, 2006 WL 3240680, at *2-3 (Ohio Ct. App. Nov. 9, 2006) (holding that an unauthorized disclosure of information violates a breach of confidence and fiduciary duty).

¹³⁵ See *infra* Part I.

¹³⁶ *Strock v. Pressnell*, 527 N.E.2d 1235, 1243 (Ohio 1988).

¹³⁷ *Herman*, 2006 WL 3240680, at *3.

A breach of fiduciary duty claim will prevail only if the plaintiff can first show the existence of a fiduciary relationship between the parties.¹³⁸ The Court of Appeals of Ohio defines “fiduciary relationship” as “one in which special confidence and trust is reposed in the integrity and fidelity of another”¹³⁹ That court also held that a fiduciary relationship involves “a resulting position of superiority or influence, acquired by virtue of [a] special trust.”¹⁴⁰

The court also noted that “the law has recognized a public interest in fostering certain professional relationships, such as the doctor–patient and attorney–client relationships,” but not the insurance agent–client relationship.¹⁴¹ Other legal scholars have found that the aim of fiduciary law is “to protect and maintain important societal relationships that the ‘morals of the market place’ would place in jeopardy.”¹⁴² The aim of fiduciary doctrine is to demand “special obligations” for those who are in relationships “deemed critical for an ordered and humane society.”¹⁴³ Finding a fiduciary relationship for the relatively new industry of DTC genetic testing seems particularly appropriate when we consider that “[a] hallmark of fiduciary law is its flexibility to accommodate new situations as they arise,” and to redress situations “where the ordinary laws of contract, tort and unjust enrichment are silent or insufficient.”¹⁴⁴

Arguably, the relationship between the provider of genetic testing services and its clients is more similar to that of doctor–patient than insurance agent and other unrecognized relationships because the information being obtained pertains directly to the health of the consumer. Further, “[r]elationships recognized as fiduciary in nature tend to be those in which one party, the beneficiary, is especially vulnerable and dependent upon another party, the fiduciary, who is expected to loyally employ specialized knowledge, skills, and power over some aspect of the beneficiary’s affairs to further the beneficiary’s interests.”¹⁴⁵ With these considerations in mind, other scholars have argued explicitly for the recognition of a fiduciary duty when it comes to genomics research.¹⁴⁶

¹³⁸ See *Tornado Techs., Inc. v. Quality Control Inspection, Inc.*, 977 N.E.2d 122, 127 (Ohio Ct. App. 2012).

¹³⁹ *Id.* at 126 (citations omitted) (internal quotation marks omitted).

¹⁴⁰ *Id.*

¹⁴¹ *Id.* at 127.

¹⁴² 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 (2013).

¹⁴³ *Id.* at 545.

¹⁴⁴ *Id.* (footnotes omitted).

¹⁴⁵ *Id.* at 545–46.

¹⁴⁶ Josef Mejido argues that the use of genomic research in personalized medicine demands a fiduciary duty interpretation because “[a] fiduciary relationship is one founded on trust or confidence reposed by one person in the integrity and fidelity of another.” Mejido, *supra* note 9, at 304 (internal quotation marks omitted).

It is true that courts have not recognized mere transmittance of money as establishing a fiduciary relationship.¹⁴⁷ Jack's case, however, goes beyond the mere entrustment of finances. When Jack entered into a contract with the genetic testing company, he entrusted his genetic material to the company as trustee and established himself as the sole beneficiary of the genetic information to be obtained from the genetic testing. This genetic material was much more personal than money and left Jack vulnerable to whatever information it revealed. Just as the court found in *Herman*, when an unauthorized disclosure of medical information breached a fiduciary duty, the genetic testing company owed a duty to protect Jack's information and not allow it to be used in a manner that would bring harm to him.¹⁴⁸

The advantage that a breach of fiduciary duty has above other tort claims is that it carries a stricter standard of behavior than a negligence claim.¹⁴⁹ In Jack's scenario, it can be argued that a fiduciary relationship exists wherein the trustee is the genetic testing company and Jack is the sole beneficiary. Further, what is being entrusted here is not money or financial information; rather, it is genetic information, which arguably is even more important than a pecuniary good because it goes to the very core of how an individual is perceived by society. Although Jack's case involved hacking by third parties and no intentional disclosure, the stricter standard of care applied for fiduciary relationship demands that the genetic testing company should have been more vigilant about the maintenance of the genetic information. If hackers were able to gain access to Jack's information, it is because the genetic testing company's Internet security protocols were not sufficiently stringent.

While the claim of a breach of fiduciary duty could potentially offer many advantages for Jack to bring a lawsuit, its great disadvantage is that Jack must first prove that there was a fiduciary relationship between the genetic testing company and Jack. As outlined above, a fiduciary relationship has typically been recognized in doctor-patient relationships but not in merely commercial transactions where no special relationship exists.¹⁵⁰ Although Jack could make a case that he is entrusting his genetic information to the genetic testing company and therefore creating a relationship based on trust and the handling of sensitive information, the business of DTC consumer testing, much of which is conducted over the Internet, is unlike the traditional doctor-patient relationship that is conducted face-to-face.¹⁵¹ Some might argue that engaging in DTC consumer testing is not the same as consulting a known and trusted

¹⁴⁷ For example, an Ohio court found that a bank that receives confidential information about a customer does not necessarily have a fiduciary duty to that customer. *Groob v. KeyBank*, 843 N.E.2d 1170, 1175 (Ohio 2006).

¹⁴⁸ See *Herman v. Kratche*, No. 86697, 2006 WL 3240680, at *3 (Ohio Ct. App. Nov. 9, 2006).

¹⁴⁹ A fiduciary relationship requires that the fiduciary acts in its entrusted party's best interest, even to its own detriment. *Groob*, 843 N.E.2d at 1175.

¹⁵⁰ *Id.*

¹⁵¹ See *Bair*, *supra* note 30, at 413.

doctor with whom a patient has developed a special relationship and that if no special relationship exists, a fiduciary duty should not be implied. Thus, the conclusion would be that Jack might be challenged to sustain a breach of a fiduciary duty claim.

C. Why Existing Remedies Are Insufficient

In the previous subsections, I have detailed some potential statutory and tort remedies to redress the disclosure of genetic information.¹⁵² In this subsection, I provide reasons why currently available legal tools are ultimately inadequate to address the type of damages that genetic testing consumers, such as Jack, suffer when their genetic information is wrongfully disclosed.

1. GINA's Limitations

GINA's major limitation is that it only protects an individual from genetic discrimination by health insurers and employers.¹⁵³ Even then, GINA does not offer protections when it comes to life insurance, long-term care insurance, and disability insurance.¹⁵⁴ This means that the results of genetic testing may still be used in those fields, even to the detriment of the testing subject. In addition, although GINA does not require "deliberate acquisition" of the genetic information,¹⁵⁵ it explicitly disallows disparate impact claims.¹⁵⁶ Thus, for an individual to sue an employer or prospective employer for genetic discrimination, that individual would be required to show actual intent to discriminate on the basis of genetic status.¹⁵⁷ As historically seen from other

¹⁵² See *supra* Part III.A–B.

¹⁵³ See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified in scattered sections of 26, 29, and 42 U.S.C.).

¹⁵⁴ See *Genetic Discrimination*, NAT'L HUM. GENOME RES. INST., <http://www.genome.gov/10002077> (last updated July 31, 2014), *archived at* <http://perma.cc/VV5T-B4Q6>.

¹⁵⁵ See Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912, 68,913 (Nov. 9, 2010) (codified at 29 C.F.R. pt. 1635).

¹⁵⁶ See Genetic Information Nondiscrimination Act § 208; Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. at 68,918. *But see* Ifeoma Ajunwa, *Genetic Discrimination and Civil Rights: Why GINA Needs a Disparate Impact Clause* (unpublished manuscript) (on file with author) (providing legal arguments for why a disparate impact cause of action should be added to the Genetic Information Non-Discrimination Act provisions).

¹⁵⁷ This is typically how disparate treatment has been construed under traditional anti-discrimination laws. *See, e.g.*, *Tex. Dep't of Cmty. Affairs v. Burdine*, 450 U.S. 248, 256 (1981) (involving Title VII claims); *Raytheon Co. v. Hernandez*, 540 U.S. 44, 52 (2003) (involving ADA claims).

discrimination cases, it is notoriously difficult to prove intent to discriminate.¹⁵⁸

The limitations detailed above would make it difficult for an individual to prove genetic discrimination by an employer or insurance company when the individual's genetic information has been compromised. But of more significance to our hypothetical, GINA has no provisions that would aid consumers of genetic testing like Jack who would seek to sue the genetic company for the negligent handling of genetic information resulting in employment discrimination and other harms.¹⁵⁹ When GINA was signed into law in 2008, it was hailed as a brave new anti-discrimination law.¹⁶⁰ And while GINA does have some protections in the employment and health insurance arena, it is woefully inadequate in addressing the privacy issues associated with the handling and disclosure of genetic information by genetic testing companies.¹⁶¹

2. *The Difficulties of Tort Litigation*

In addition to the fact that GINA offers no help for the DTC genetic testing litigant, a plaintiff seeking to bring a tort action suit for the unauthorized disclosure of genetic information faces some difficult hurdles. Mostly, these hurdles are present when it comes to proving the elements of a negligence case, notably, causation and damages.

The case of *Acosta* has established the standard for determining causation in unauthorized disclosure of medical information cases. To show proximate cause the question is “whether the risk of injury, not necessarily in the precise form in which it actually occurs, is within the reasonable foresight of the defendant.”¹⁶² Further, the *Acosta* court noted that “[q]uestions of proximate cause and foreseeability are questions of fact to be decided by the jury,” such that causation should not be the fatal flaw that derails a case at summary

¹⁵⁸ *McCleskey v. Kemp*, 481 U.S. 279, 298–99 (1987) (holding that the “racially disproportionate impact” in Georgia death penalty imposition indicated by a comprehensive scientific study was not enough to overturn the guilty verdict without the plaintiff showing a “racially discriminatory purpose”).

¹⁵⁹ See *supra* Part III.A.

¹⁶⁰ See Slaughter, *supra* note 76, at 66 (“When GINA passed in 2008, the late Senator Kennedy (D-Mass.) declared it the ‘first civil rights bill of the new century.’”).

¹⁶¹ See Brandon Keim, *Genetic Protections Skimp on Privacy, Says Gene Tester*, WIRED (May 23, 2008, 8:13 AM), <http://www.wired.com/2008/05/genetic-protect/>, archived at <http://perma.cc/9ZKR-AMTH> (quoting Tera Eerkes, founder of personal genetic testing company Qtrait after GINA was passed by Congress as having said, “[I]astly, [GINA] is likely to lead to a surge in demand for personal genetic testing. What has not been addressed, by this or any other measure that I know of, is the possible institutional misuse of genetic information. For example, some personal genetic testing companies include contractual clauses that lets them use and sell their clients genetic information to outside parties”).

¹⁶² *Acosta v. Byrum*, 638 S.E.2d 246, 251 (N.C. Ct. App. 2006).

judgment.¹⁶³ In Jack's case, he will need to convince the jury that, given the pervasiveness of online data breaches, it should have been foreseeable to the genetic testing company that its online system was vulnerable to hackers, and furthermore, given the prevalence of marketing using personal data, it should have been foreseeable to the genetic company that Jack's information would have been used for marketing purposes, thus resulting in his emotional and pecuniary injuries. The issue is that it is not always foreseeable what hackers will do with information they obtain. The genetic company might argue that it is unreasonable for it to be held responsible for all ills flowing from a hacker's actions.

Establishing damages also represents another stumbling point for victims of wrongful disclosure of genetic information who are seeking a tort remedy. A looming issue is how to deal with damages that are non-pecuniary in nature. As we see in Jack's case, not all the damages from the negligent disclosure of genetic information are monetary. In Jack's case he lost his wife and he experienced the loss of confidence and the stigma associated with having a cognitive disease. Courts, however, have been reluctant to redress such genre of damages.¹⁶⁴ Although one speculation as to the reason for this is that "lawmakers may fear chilling truthful speech," scholars have argued that the courts should more readily redress reputational injuries since "the Internet creates a permanent, searchable record of embarrassing personal facts."¹⁶⁵

Besides bearing the burden of proving its damages, the plaintiff must also show that those damages are certain, that is, the damages are not merely speculative.¹⁶⁶ Furthermore, a plaintiff asserting a claim for diminution of future earnings must show evidence demonstrating the difference between what the plaintiff is now able to earn and what the plaintiff could have earned if she had not been injured.¹⁶⁷

¹⁶³ *Id.* (citing *Rouse v. Jones*, 119 S.E.2d 628, 632 (N.C. 1961)).

¹⁶⁴ "Reputational harm and shame are among the most commonly cited privacy harms. The information age has undeniably increased the availability of reputation-damaging content. . . . Privacy scholars are puzzled that shame and reputational harms are only reluctantly, if ever, vindicated by U.S. courts." Jane Yakowitz Bambauer, *The New Intrusion*, 88 NOTRE DAME L. REV. 205, 258-59 (2012) (footnotes omitted); *see also Doe v. Cent. Iowa Health Sys.*, 766 N.W.2d 787, 795 (Iowa 2009).

¹⁶⁵ Bambauer, *supra* note 164, at 259.

¹⁶⁶ *See, e.g., Timmons v. Mass. Bay Transp. Auth.*, 591 N.E.2d 667, 671 (Mass. 1992); *Jamison v. Knosby*, 423 N.W.2d 2, 6 (Iowa 1988) ("Under general damage principles, overly speculative damages cannot be recovered."); *Novak & Co. v. Facilities Dev. Corp.*, 498 N.Y.S.2d 492, 494 (N.Y. App. Div. 1986) (holding that damages based on bid estimate were improper due to inherent unreliability of bid); *Brown v. Critchfield*, 161 Cal. Rptr. 342, 350 (Cal. Ct. App. 1980); *DMI, Inc. v. Country Mut. Ins. Co.*, 402 N.E.2d 805, 807 (Ill. App. Ct. 1980); *Rosini v. Cunanan*, 503 N.Y.S.2d 969, 972 (N.Y. Sup. Ct. 1986) (holding loss of possible children due to sterilization too speculative to be compensable); *Goldner v. Doknovitch*, 388 N.Y.S.2d 504, 507 (N.Y. Sup. Ct. 1976).

¹⁶⁷ *See, e.g., Timmons*, 591 N.E.2d at 669; *Kaylor v. Amerada Hess Corp.*, 528 N.Y.S.2d 845, 846 (N.Y. App. Div. 1988).

In Jack's case, the claim for damages, which the genetic testing company might attack as speculative, is Jack's loss of future earnings as a partner. For one, it is not certain that Jack would have still been made a partner if he had not been injured. Further, with fluctuations in the market, it is also not certain what Jack's earnings would have been once he had become a partner. Courts have found that there is no one standard by which damages can be measured and that each case must stand on its own facts.¹⁶⁸ Courts have held that "when elements of damages for personal injuries cannot be precisely calculated, the exact amount of a damages award is left to the discretion of the trier of fact within the framework of allowable elements under the law."¹⁶⁹ This means that Jack's damages, which would be determined by a jury, could vary widely.

IV. ENGENDERING NEW SOLUTIONS

Given the deficiencies of the available remedies detailed in the previous section, in this section, I discuss new solutions to redress damages resulting from the wrongful disclosure of genetic information.

A. *An Issue of (Un)informed Consent?*

Correcting the information asymmetry between consumers and genetic testing companies by mandating informed consent may represent one way to tackle the ill of unauthorized genetic information disclosures. In 2012, the Presidential Commission for the Study of Bioethics released a report in which it found that while there is some protection afforded to individuals who engage in whole genome sequencing "carried out by clinicians—who are subject to the Health Insurance Portability and Accountability Act"—there is "inadequate protection of genetic privacy in commercial and research arenas, which are so far only subject to Common Rule or Institutional Review Boards."¹⁷⁰ Legal scholars have noted that "[t]he roots of informed consent doctrine lie in privacy theory, in three pertinent areas: the right to informational privacy, the right to bodily integrity, and the right to informed decision making."¹⁷¹ As it stands, genetic testing consumers who have not

¹⁶⁸ See, e.g., *Moore v. Thornwell Warehouse Ass'n*, 524 So. 2d 828, 831 (La. Ct. App. 1988); *Body Rustproofing, Inc. v. Mich. Bell Tel. Co.*, 385 N.W.2d 797, 800 (Mich. Ct. App. 1986); *Gonzales v. Sw. Bell Tel. Co.*, 555 S.W.2d 219, 223 (Tex. Civ. App. 1977).

¹⁶⁹ *Neyer v. United States*, 845 F.2d 641, 644 (6th Cir. 1988); see also *Timmons*, 591 N.E.2d at 669.

¹⁷⁰ Beth Marie Mole, *Preventing Genetic Identity Theft*, SCIENTIST (Oct. 11, 2012), www.the-scientist.com/?articles.view/articleNo/32796/title/Preventing-Genetic-Identity-Theft/, archived at <http://perma.cc/4JEQ-6ENH>.

¹⁷¹ Elizabeth B. Cooper, *Testing for Genetic Traits: The Need for a New Legal Doctrine of Informed Consent*, 58 MD. L. REV. 346, 370 (1999) (footnotes omitted) (examining the existing legal doctrine of informed consent, the existing state of pre-test counseling for HIV/AIDS tests, and suggesting a model statute to address informed consent in relation to genetic testing).

been advised as to all the potential risks associated with genetic testing—including the risk of genetic discrimination by employers, insurance companies, and others—cannot be said to be providing their informed consent.

Indeed, there exists a lack of awareness about the reach and limits of legal protection of genetic information, both on the part of the public and also of health care providers. Although GINA was signed into law in 2008, a national survey in 2011 revealed that less than one in five Americans (16%) were aware of GINA's existence.¹⁷² “[E]ven among physicians, a staggering eighty-one percent are not familiar with GINA protections.”¹⁷³ If many *doctors* are unaware of GINA's protections, and therefore, its limitations, similarly, there should be a concern that direct-to-consumer genetic testing companies and their consumers may be equally as ignorant.

Informed consent has been established as a *sine qua non* of medical practice.¹⁷⁴ Doctors are obliged to carefully spell out the risks and benefits of a medical procedure before a patient may consent to them.¹⁷⁵ The direct-to-consumer genetic testing industry could benefit from such a standard. As it stands, consumers are lulled into a false sense of security by genetic testing companies that promise privacy in the handling of genetic testing results over the Internet.¹⁷⁶ Meanwhile, Internet and other database breaches continue to occur which reveal such encryption protections as tenuous. Although people may willingly undertake genetic testing, legal scholars have noted that voluntary consent is not the same as informed consent.¹⁷⁷

At the very least, the purveyors of consumer genetic testing should be required to prominently carry a disclaimer alerting potential consumers that there is a high potential that their genetic information may be intercepted by third parties on the Internet and that this information may be used for a variety of nefarious purposes including both genetic discrimination and genetic

¹⁷² Slaughter, *supra* note 76, at 62.

¹⁷³ *Id.* at 63.

¹⁷⁴ See *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir. 1972).

¹⁷⁵ *Id.*

¹⁷⁶ See, e.g., *Privacy Policy*, AFRICAN ANCESTRY, <http://africanancestry.com/privacy/> (last visited Sept. 17, 2014), *archived at* <http://perma.cc/W5XN-TSHY> (providing testing for deep ancestry). There is no provision for inadvertent disclosures. See *id.* The company states that it “make[s] every effort to preserve user privacy” and that it may disclose information only where they are legally obligated to do so. *Id.*; see also, e.g., *Privacy Policy*, AFRICAN DNA, <http://www.africandna.com/privacy.aspx> (last visited Sept. 17, 2014), *archived at* <http://perma.cc/J6E7-F2RC> (providing testing for deep ancestry, ethnicity, and genealogy). The company does not mention inadvertent disclosures, but states that “African DNA accepts the responsibility to keep your specific data private.” *Id.*

¹⁷⁷ Merryn Ekberg, *Governing the Risks Emerging From the Non-Medical Uses of Genetic Testing*, 3 AUSTL. J. EMERGING TECHS. & SOC'Y 1, 10 (2005) (“They may give their consent voluntarily, but without understanding the immediate and long term health, social and psychological consequences of the test result, this voluntary consent is not informed consent.”).

identity theft.¹⁷⁸ Other scholars have also argued that there should be statutory requirements in place for obtaining informed consent prior to genetic testing, adapted largely from HIV-related counseling that already exists.¹⁷⁹ The current system of informed consent is ill equipped to adequately protect the interests of genetic testing subjects because “even the more appropriate ‘reasonable patient’ standard frequently is filtered through the physician’s perceptions of what risks a reasonable person in the patient’s position would want to know.”¹⁸⁰ This means that in practice, doctors are really only concerned about acquiring informed consent “in the context of significantly invasive procedures, because this doctrine was developed to warn of medical risks, not social risks; and mere nondisclosure of a nonoccurring risk without ensuing harm is not actionable.”¹⁸¹ Ensuring that consumers of genetic testing provide informed consent is not a task that should be ignored given the history of malicious or callous healthcare practices in the United States.¹⁸²

B. *A Hybrid Law: The Tort of Genetic Information Disclosure*

Yet, even informed consent cannot prevent data breaches and the wrongful disclosure of genetic information. Only through tort law, can a consumer of genetic testing who has suffered harm from the disclosure of her genetic information be made whole. Ultimately, the unique social position of genetic information necessitates the promulgation of a new type of tort: the tort of genetic information disclosure. Some legal scholars have argued that the tort of intrusion upon seclusion holds much potential to address privacy harms created by advances in technological information.¹⁸³ One limitation of that approach is that the tort of intrusion upon seclusion requires a deliberate act—the example that one scholar gives is the hyper-surveillance of Ralph Nader by GM operatives once they learned of Nader’s plan to serve as a whistleblower.¹⁸⁴ Therefore, that tort claim would not be applicable to genetic testing companies who negligently allow genetic information within their control to be intercepted by third parties. Also, genetic information is distinct

¹⁷⁸ See Reilly, *supra* note 128, at 16–20 (advocating for a broader approach to informed consent).

¹⁷⁹ “As the HIV epidemic showed, it is not wise to allow hospital committees and doctors’ offices to blunder into a ‘standard of care’ regarding genetic pre-test counseling.” Cooper, *supra* note 171, at 403.

¹⁸⁰ *Id.* at 421.

¹⁸¹ *Id.*

¹⁸² See, e.g., *U.S. Public Health Service Syphilis Study at Tuskegee*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/tuskegee/timeline.htm> (last updated Sept. 24, 2013), archived at <http://perma.cc/8HEN-5T3S>; see also REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* 212–17 (2010) (telling the story of Henrietta Lacks, a poor Black woman who died of cervical cancer and whose cancerous cells, taken without her consent, were used for research and development of the polio vaccine).

¹⁸³ Bambauer, *supra* note 164, at 206–07.

¹⁸⁴ See *id.*

from other types of electronic information and thus demands special legal attention.¹⁸⁵ Some scholars view the notion that genetic information requires its own distinct legal jurisprudence as asserting “genetic exceptionalism.”¹⁸⁶ While some argue that genetic information is not exceptional and therefore should not be awarded any special legal concessions,¹⁸⁷ others argue that the diagnostic and predictive nature of genetic information puts it in a genre all by itself when it comes to personal information.¹⁸⁸ The exceptional nature of genetic information is underscored by the fact that in almost every American jurisdiction there are new laws prohibiting discriminatory practices by insurance companies based on genetic information, and a majority of states have established the same prohibitions in the employment context.¹⁸⁹ As unauthorized genetic information disclosure cases may be described as falling beneath the penumbra of property law, privacy law, and contract law, a new tort that adequately addresses this issue would be a hybrid law that borrows from the above listed fields of law.

First, in establishing its elements, the new tort could be a negligence claim that borrows from statutory laws such as HIPAA. The elements of the tort

¹⁸⁵ Social scientists have taken note of the special position that genetic information occupies in society. Instead of a piece of hereditary information, genetic information has become the “key to human relationships and family cohesion.” NELKIN & LINDEE, *supra* note 38, at 204.

¹⁸⁶ Thomas Murray is attributed with the first use of the term “genetic exceptionalism.” See, e.g., Thomas H. Murray, *Genetic Exceptionalism and “Future Diaries”: Is Genetic Information Different from Other Medical Information?*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 60, 61 (Mark A. Rothstein ed., 1997) (describing the use of the term “genetic exceptionalism” by the Task Force on Genetic Information and Insurance of the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of the Human Genome Project).

¹⁸⁷ See, e.g., NIH-DOE TASK FORCE ON GENETIC INFO. & INS., GENETIC INFORMATION AND HEALTH INSURANCE I (1993), available at <https://www.genome.gov/Pages/ELSI/TaskForceReportGeneticInfo1993.pdf> (recommending against special treatment of genetic information); Michael J. Green & Jeffrey R. Botkin, “Genetic Exceptionalism” in *Medicine: Clarifying the Differences Between Genetic and Nongenetic Tests*, 138 ANNALS INTERNAL MED. 571, 573 (2003) (suggesting that there are few clear distinctions between genetic and nongenetic tests that justify genetic exceptionalism); Mark A. Rothstein, *Genetic Exceptionalism and Legislative Pragmatism*, 35 J.L. MED. & ETHICS 59, 59 (Supp. 2007) (arguing that “genetic exceptionalism represents poor public policy”); Pamela Sankar, *Genetic Privacy*, 54 ANN. REV. MED. 393, 394–95 (2003) (comparing similarities and differences between genetic and other kinds of medical information and concluding that genetic information is not a distinct category); Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L. Q. 669, 671 (2001) (contending that genetic information is not unique and raises longstanding concerns about privacy and discrimination).

¹⁸⁸ *United States v. Kincade*, 379 F.3d 813, 842 n.3 (9th Cir. 2004) (Gould, J., concurring) (“Like DNA, a fingerprint identifies a person, but unlike DNA, a fingerprint says nothing about the person’s health, propensity for particular disease, race and gender characteristics, and perhaps even propensity for certain conduct.”).

¹⁸⁹ Rothstein, *supra* note 188, at 59.

would be the negligent disclosure of genetic information resulting from the breach of a duty to safeguard said information. This duty would be owed by anyone or any entity to which an individual entrusts her genetic information. Under this version of the tort, an option is to utilize HIPAA to determine what standard of care should apply for the new tort. In addition to the “reasonable person” standard, HIPAA has been used to establish a standard of care with which to judge a defendant’s actions in cases of unauthorized disclosure of medical information.¹⁹⁰ A West Virginia court found “that a HIPAA violation may be used either as the basis for a claim of negligence *per se*, or that HIPAA may be used to supply the standard of care for other tort claims.”¹⁹¹

However, the nature of genetic information and the manner in which it is procured really demands a higher level of responsibility than either the traditional negligence reasonable person standard or the standard implied under the provisions of HIPAA. When “it was founded in 2006, 23andMe maintained that its DNA tests provided general information rather than a medical service.”¹⁹² “[In 2012], however, the company reversed that stance, submitting paperwork for FDA clearance on its genetic tests.”¹⁹³ In keeping with this new development, I argue that tort actions involving DTC genetic testing should be treated the same as products liability cases, which carry a strict liability standard, much like a tort action involving a medical device would.

There are three recognized types of product liability claims: (1) manufacturing defect, (2) design defect, and (3) a failure to warn (also known as marketing defects).¹⁹⁴ The lack of comprehensive disclaimers about the foreseeable social and economic risks associated with genetic testing is a failure to warn. This failure to warn of the foreseeable risks arising from genetic testing constitutes a marketing defect pursuant to the strict liability doctrine.¹⁹⁵

¹⁹⁰ See *I.S. v. Wash. Univ.*, No. 4:11CV235SNLJ, 2011 WL 2433585, at *1–2 (E.D. Mo. June 14, 2011) (asserting that while no private action exists under HIPAA, HIPAA could still be used to establish a standard of care with which to judge defendant’s actions).

¹⁹¹ *R.K. v. St. Mary’s Med. Ctr.*, 735 S.E.2d 715, 7234 (W. Va. 2012), *cert. denied*, 133 S. Ct. 1738 (2013).

¹⁹² See Zhang, *supra* note 23.

¹⁹³ *Id.*

¹⁹⁴ See *Feldman v. Lederle Labs.*, 479 A.2d 374, 385 (N.J. 1984) (citing *O’Brien v. Muskin Corp.*, 463 A.2d 298, 304 (N.J. 1983) (noting three types of defects); W. Page Keeton, *The Meaning of Defect in Products Liability Law—A Review of Basic Principles*, 45 MO. L. REV. 579, 585–88 (1980) (describing, in some detail, three types of defects); John W. Wade, *On the Nature of Strict Tort Liability for Products*, 44 MISS. L.J. 825, 830–31 (1973) (describing the defect requirement and three types of defects).

¹⁹⁵ See *Payne v. Soft Sheen Prods. Inc.*, 486 A.2d 712, 725 (D.C. 1985) (stating that defect may result from failure to attach adequate warnings if product may in certain circumstances cause injury); see also M. Stuart Madden, *The Duty to Warn in Products Liability: Contours and Criticism*, 89 W. VA. L. REV. 221, 222 (1987) (describing the failure to warn as defect). Although a product is of proper design and manufacture, it may,

Proponents of strict liability assert that it is preferable to place the economic costs of any harm arising from the product on the manufacturer because it can better absorb them and pass them on to other consumers.¹⁹⁶ The manufacturer thus becomes a de facto insurer of its own products with premiums built into the product's price.¹⁹⁷ Strict liability also seeks to diminish the impact of information asymmetry between manufacturers and consumers.¹⁹⁸ Manufacturers have better knowledge of their own products' dangers than do consumers. Therefore, manufacturers should be charged with finding, correcting, and warning consumers of those dangers. The existence of an informational asymmetry between consumers of genetic testing and genetic testing companies is precisely why strict liability is appropriate for cases of genetic disclosure. As it stands, most consumers lack all the information to understand the emotional, social, and economic risks associated with genetic testing.¹⁹⁹ Most consumers are not even equipped with the proper analytical skills to fully understand what the genetic profile reports they receive from genetic testing companies mean.²⁰⁰ Also, strict liability reduces litigation costs, because a plaintiff need only prove causation, and not also negligent acts on the part of the purveyor of the product.²⁰¹ This lessened burden of proof is particularly advantageous for a victim of wrongful disclosure like Jack who would find it extremely difficult to track exactly how his information ended up in the possession of the advertising companies.

Strict liability is not without its critics. Opponents of strict liability have argued that it creates a "moral hazard," wherein consumers are not likely to mitigate risk because they know that the consequences will be borne by another party.²⁰² The risk of moral hazard would be rather low in cases of

nevertheless, be defective because of the manufacturer's failure to warn of dangers inherent in the use of the product. *Jarrell v. Monsanto Co.*, 528 N.E.2d 1158, 1166 (Ind. Ct. App. 1988).

¹⁹⁶ See Keith N. Hylton, *The Law and Economics of Products Liability*, 88 NOTRE DAME L. REV. 2457, 2465–66 (2013); Ellen Wertheimer, *The Biter Bit: Unknowable Dangers, the Third Restatement, and the Reinstatement of Liability Without Fault*, 70 BROOK. L. REV. 889, 890 (2005).

¹⁹⁷ James R. Garven, *Moral Hazard, Adverse Selection, and Tort Liability*, 28 J. INS. ISSUES 1, 6 (2005).

¹⁹⁸ Legal scholars have argued that "the manufacturer has greater access to expertise, information, and resources" and that "[i]mposing strict liability relieves plaintiff of the burden of proving fault." John F. Vargo, *The Emperor's New Clothes: The American Law Institute Adorns a "New Cloth" for Section 402A Products Liability Design Defects—A Survey of the States Reveals a Different Weave*, 26 U. MEM. L. REV. 493, 508 (1996) (citation omitted).

¹⁹⁹ See Sophie Novack, *It's Really Easy to Get Your Genetic Results. But Good Luck Making Sense of Them*, NATIONAL JOURNAL (Nov. 8, 2013), <http://www.nationaljournal.com/innovation-works/it-s-really-easy-to-get-your-genetic-results-but-good-luck-making-sense-of-them-20131108>, archived at <http://perma.cc/XV7S-WNE8>.

²⁰⁰ *Id.*

²⁰¹ See e.g., *Escola v. Coca-Cola Bottling Co.*, 150 P.2d 436, 440–41 (1944).

²⁰² Garven, *supra* note 198, at 4.

genetic testing. It is the rare individual who would willingly disclose or negligently handle her own genetic profile, resting on the knowledge that the genetic testing company would indemnify any resulting embarrassment, heartbreak, or loss of economic opportunity.

V. CONCLUSION

The law is saddled with the onerous task of reconciling the tension between privacy and public health concerns. Legal scholars have previously noted that there is a trade-off between personal privacy and public health concerns when it comes to medical information.²⁰³ However, public health concerns do not always outweigh the privacy rights vested in individuals' protection of their genetic information. In her groundbreaking article, Professor Julie Cohen makes the argument that strong data privacy protection is good public policy.²⁰⁴ She notes that such policy advances the goals of "protection of individual dignity, promotion of personal autonomy, and development of the capacity for meaningful participation in the social and political life of the community."²⁰⁵ The human need to protect one's genetic information and the public right to certain pertinent health information, such as the diagnosis of HIV infection and other communicable diseases, need not be seen as a choice between Scylla and Charybdis. Rather, the law must distinguish between instances when there is a public right to know versus those instances when there has been an unnecessary and wrongful intrusion into the private life of an individual resulting in mental anguish and lost economic opportunity. In our current society, the genetic profile of an individual is perceived, in a reductionist sense, as the complete sum of that individual. Thus, it is common for some to draw inferences about an individual's fitness for work or suitability for reproduction based on genetic tests that offer merely probabilistic predictions. The law must remain ever vigilant to the ways in which these inferences may be employed for discriminatory purposes. The Genetic Information Nondiscrimination Act as an anti-discrimination law is inadequate to deal with all instances of genetic discrimination. The government should ensure that consumers of genetic testing are fully informed of the privacy risks associated with genetic testing and the potential for discrimination arising from the genetic information

²⁰³ See Furrow, *supra* note 114, at 806 ("The advent of computer-based patient records, inexorable pressures to adopt linked computer systems with access to patient treatment information, and the use of the Internet to easily share information have all increased our worries about how to protect data leakage or theft. . . . A standardized database of patient information has the potential to promote efficiency, further competition and allow providers to better track patient outcomes, so long as patient privacy interests are properly respected.") (footnotes omitted).

²⁰⁴ See Julie E. Cohen, *Examined Lives: Informational Privacy and the Subject as Object*, 52 STAN. L. REV. 1373, 1386-87 (2000).

²⁰⁵ *Id.*

obtained. Tort law represents an avenue for an individual, who has been harmed by the negligent disclosure of genetic information, to be made whole. But the existing tort law is inadequate to accurately redress the novel injuries originating from the confluence of the genomic and digital age; this necessitates the promulgation of a new tort that would more appropriately address the wrongful disclosure of genetic information.