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## Privacy of Information and DNA Testing Kits

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# PRIVACY OF INFORMATION AND DNA TESTING KITS

Shanna Mason\*

The 2017 holiday season showed that more people than ever “gave the gift of spit.”<sup>1</sup> This popular gift—a direct to consumer DNA testing kit—requires a person to discharge their saliva, or provide a cheek swab to reveal information about a person’s ancestry, or predispositions to certain diseases.<sup>2</sup> In 2017, AncestryDNA sold roughly 1.5 million kits from Black Friday through Cyber Monday, triple the amount of sales from 2016.<sup>3</sup> “As more people learn about the role genetics play in healthcare and the cost of obtaining these at home DNA tests continue to decrease, the worldwide market of direct-to-consumer genetic tests could triple over the next five years.”<sup>4</sup> These kits are designed to give

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<sup>1</sup> Megan Molteni, *Ancestry’s Genetic Testing Kits Are Heading For Your Stocking This Year*, WIRED (Dec. 1, 2017, 7:00 AM), <https://www.wired.com/story/ancestrys-genetic-testing-kits-are-heading-for-your-stocking-this-year>.

<sup>2</sup> See U.S. NAT’L LIBRARY OF MED., *What is direct-to-consumer genetic testing*, GENETICS HOME REFERENCE (Mar. 13, 2018), <https://ghr.nlm.nih.gov/primer/testing/directtoconsumer> (describing direct-to-consumer genetic testing as bypassing the need for prior approval from doctors or insurance companies, because the kits are sold directly to consumers via television, print advertisements, and the internet).

<sup>3</sup> Melissa Anders, *DNA Ancestry Test Kits Are Hot Holiday Gifts Despite Privacy Concerns From Some*, FORBES (Dec. 6, 2017, 10:00 AM), <https://www.forbes.com/sites/melissaanders/2017/12/06/dna-ancestry-test-kits-are-hot-holiday-gifts-despite-privacy-concerns-from-some>.

<sup>4</sup> Mike Miliard, *Direct to consumer genetic testing set for big growth despite clinical and ethical challenges*, HEALTHCARE IT NEWS (Jan. 15, 2018, 3:16 PM), <http://www.healthcareitnews.com/news/direct-consumer-genetic-testing-set-big-growth-despite-clinical-and-ethical-challenges>; see also Kira Peikoff, *Fearing Punishment for Bad Genes*, N.Y. TIMES, Apr. 8, 2014, at D1 (describing the cost of at home genetic testing

consumers access to information that was previously only available through a doctor.<sup>5</sup> Now, consumers are looking for more control over their own health and healthcare, such as developing personalized treatment or ensuring precise medicine management.<sup>6</sup> This can be achieved with the information derived from affordable genetic testing.<sup>7</sup>

Affordable genetic testing raises issues that not many consumers have considered. That is, what type of privacy information is being given up when submitting to these tests? While there are some federal regulations that aim to protect individual's privacy rights with respect to their genetic information, more needs to be done.

First, this comment will discuss the popularity of direct-to-consumer DNA Testing Kits ("Testing Kit") and certain privacy risks that are likely unknown to the individual consumer. Next, this comment will discuss current federal regulations that are designed to protect individuals from being treated adversely based on their genetic markers. Then, this comment will address the shortcomings of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), as well as the Genetic Information Nondiscrimination Act of 2008 (GINA). Finally, this comment will conclude that GINA needs to be expanded to address legal matters outside of just the employment and health insurance spheres.

## I. BACKGROUND INFORMATION

### A. DNA Testing Kits

In an age where a person can swab their cheek at home and gain access to valuable information regarding their genealogy, ethnic roots and family ties, the popularity of direct-to-consumer DNA Testing Kits has skyrocketed.<sup>8</sup> In addition, people can discover if their genetic makeup reveals a predisposition

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decreasing substantially from ten years earlier).

<sup>5</sup> See U.S. NAT'L LIBRARY OF MED., *supra* note 2.

<sup>6</sup> Miliard, *supra* note 4; Consuelo Wilkins, *Putting The Person in Personalized Medicine*, HEALTHAFFAIRS (May 2018), <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2018.0359> (claiming personalized medicine "is expected to shift patients' involvement in their health care from passive to participatory. This high level of patient engagement is presumed to be a benefit of personalized medicine and has been touted as a way to empower patients to be more involved in their health.").

<sup>7</sup> Miliard, *supra* note 4; see also Annabel Action, *What You Need to Know About the Future of Healthcare*, FORBES (July 14, 2017, 10:11 AM), <https://www.forbes.com/sites/annabelacton/2017/07/14/the-future-of-health-its-in-your-hands/#5a18e01b2af2> (describing that individual consumers want to be in control and have options tailored specifically to them when it comes to healthcare).

<sup>8</sup> Antonio Regalado, *2017 was the year consumer DNA testing blew up*, MIT TECH. REV. (Feb. 12, 2018), <https://www.technologyreview.com/s/610233/2017-was-the-year-consumer-dna-testing-blew-up>; Ancestry, *Behind the Scenes: Courtney | Ancestry Stories | Ancestry*, YOUTUBE (May 2, 2018), [https://www.youtube.com/watch?time\\_continue=1&v=LWith5YzlXA](https://www.youtube.com/watch?time_continue=1&v=LWith5YzlXA) (telling the story of an AncestryDNA user who went to Ghana to learn more about the ethnic group she discovered she was most likely related to).

for various conditions and diseases.<sup>9</sup> This process can be done without having to leave the house.<sup>10</sup> The means of obtaining this information is similar amongst a variety of different brands on the market: a person answers a few personal questions, orders the kit, collects a sample, registers the kit, sends it back and waits for the results.<sup>11</sup> In order to collect a customer's DNA, direct-to-consumer DNA companies ("Companies") require either a swab of the cheek or a saliva sample. Generally, with a saliva sample, there is a fill line in the tube that is provided, that requires the consumer to produce enough saliva to reach that line.<sup>12</sup> In an individual sample the Company will find "cells from the inner lining of your cheeks, plus white blood cells that are naturally present in saliva."<sup>13</sup> Next, "the lab's processing steps will break these cells open, [and] separate their DNA from everything else" in order to analyze the information and determine what an individual's genetic makeup is.<sup>14</sup>

Companies emphasize the importance of registering the kit before shipping it back.<sup>15</sup> Failure to register the Testing Kit will prevent a person from accessing the results.<sup>16</sup> 23andMe, for example, provides "when you register your kit, you must use your real name. Once your kit has been registered, you may change your online profile name to any name you wish to use," this is included as an added layer of protection for an individual's information.<sup>17</sup> Companies use a barcode storing system to protect the individual's privacy by linking the sample and company-stored reports to a unique barcode.<sup>18</sup> Accordingly, the individual's name does not appear on the kits themselves.<sup>19</sup>

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<sup>9</sup> Lesley Fair, *DNA test kits: Consider the privacy implications*, FED. TRADE. COMM'N. (Dec. 12, 2017), <https://www.consumer.ftc.gov/blog/2017/12/dna-test-kits-consider-privacy-implications>.

<sup>10</sup> *Top Five Questions About Ancestry DNA*, ANCESTRYDNA, <https://www.ancestry.com/dna/> (last visited Sept. 8, 2018) (AncestryDNA "predicts genetic ethnicity and helps find new family connections" by providing consumers with a saliva test that they can take at home and then mail in to a lab); Fair, *supra* note 9.

<sup>11</sup> Molly K. McLaughlin, *The Best DNA Testing Kits of 2018*, PC MAG (Dec. 5, 2017, 3:17 PM), <https://www.pcmag.com/roundup/356975/the-best-dna-testing-kits>; *DNA Sample Collection Instructions*, EASYDNA, <https://www.easy-dna.com/resources/dna-testing-kit> (last visited Nov. 12, 2018) (describing the five-step process for DNA collection: 1. Remove the oral swabs from DNA test kit; 2. Fill out basic information in envelope, including consent form; 3. Rub the swabs firmly for about one minute against the entire inner cheek surface; 4. Allow the swabs to dry for an hour; 5. Return envelope with swab).

<sup>12</sup> See generally ANCESTRYDNA, <https://support.ancestry.com/s/article/US-Taking-a-DNA-Test> (last visited Oct. 29, 2018) (providing information regarding the consumer saliva sample).

<sup>13</sup> Beth Skwarecki, *How Mail-In DNA Testing Services Work*, VITALS (May 4, 2018, 9:00 AM), <https://vitals.lifehacker.com/how-dna-testing-services-work-182575929>.

<sup>14</sup> *Id.*

<sup>15</sup> McLaughlin, *supra* note 11; *Privacy Highlights*, 23ANDME.COM, <https://www.23andme.com/about/privacy> (last visited Sept. 8, 2018).

<sup>16</sup> McLaughlin, *supra* note 11.

<sup>17</sup> *Can I be Genotyped Anonymously?*, 23ANDME, <https://customercare.23andme.com/hc/en-us/articles/202907890-Can-I-be-genotyped-anonymously-> (last visited Nov. 17, 2018).

<sup>18</sup> McLaughlin, *supra* note 11.

<sup>19</sup> *Id.*; *AncestryDNA – Frequently Asked Questions*, ANCESTRY, [www.ancestry.com/dna](http://www.ancestry.com/dna) (last visited Nov. 8, 2018) (follow the "FAQ" link at bottom of page to access "Frequently Asked Questions").

While there are benefits to genetic Testing Kits, there are potential dangers in providing these Companies with an individual's unique genetic code.<sup>20</sup> An important concern is that when a person sends away their saliva sample, they also send their full genetic code.<sup>21</sup> Peter Pitts of the Center for Medicine in the Public Interest stated that your full genetic code is “the most valuable thing you own.”<sup>22</sup> The mutation pattern exclusive to your DNA is included in every cell in your body.<sup>23</sup> While this does not reveal all of what makes an individual unique, your genes could disclose information relating to health, personality traits, family history, and information about relatives, and when this information is placed in the wrong hands, it bears the risk of abuse.<sup>24</sup> Additionally, uneasy consumers worry about who actually gets this information when an individual submits to one of these types of genetic tests. Genetic testing companies promise not to sell or give this data away without consent.<sup>25</sup> Usually these agreements come with a broad scope of consent as part of their initial contract, which allows the companies to use the DNA sample however it wants.<sup>26</sup>

#### B. Terms and Conditions of AncestryDNA and 23andMe

When purchasing a genetic Testing Kit, the customers are presented with the company's terms and conditions and informed consent documents.<sup>27</sup> The terms

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<sup>20</sup> Ruth Saunders, *Legal Implications of Direct-to-Consumer Genetic Testing for Common Diseases*, 1 QUEEN MARY L.J. 70, 70-71 (2010) (describing benefits of enabling “a person to get a better understanding of themselves for those who believe their genetic make-up is a crucial component of their identity, or the psychosocial benefits of allowing an individual to make changes to their lifestyle or their surrounding environments by altering their diet or living conditions”); Gina Kolata, *Poking Holes in Genetic Privacy*, N.Y. TIMES (June 16, 2013), <https://www.nytimes.com/2013/06/18/science/poking-holes-in-the-privacy-of-dna.html> (advocating that consumers should acknowledge likely loss of privacy when providing genetic information).

<sup>21</sup> Maggie Fox, *What you're giving away with those home DNA tests*, NBC NEWS (Nov. 30, 2017, 7:01 AM), <https://www.nbcnews.com/health/health-news/what-you-re-giving-away-those-home-dna-tests-n824776>.

<sup>22</sup> *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> Kristen V. Brown, *What DNA Testing Companies' Terrifying Privacy Policies Actually Mean*, GIZMODO (Oct. 18, 2017, 10:10 AM), <https://gizmodo.com/what-dna-testing-companies-terrifying-privacy-policies-1819158337>; *DNA kits raise privacy concerns*, GAZETTE (Dec. 4, 2017), <https://www.thegazette.com/subject/news/business/dna-kits-raise-security-concerns-20171204>.

<sup>25</sup> Fox, *supra* note 21; *see also How secure and private is AncestryDNA?*, ANCESTRYDNA, <https://www.ancestry.com/dna/> (last visited Nov. 18, 2018) (stating genetic data is not shared without consent or as legally required); 23ANDME.COM, *supra* note 15; Michael Kan, *23andMe, Ancestry: DNA is Safe with Us*, PC MAG (Aug. 1, 2018, 8:02 PM), <https://www.pcmag.com/news/362873/23andme-ancestry-and-others-address-genetic-data-privacy?source=autosuggest> (agreeing to guidelines requiring consent of DNA owner to transfer genetic information).

<sup>26</sup> Brown, *supra* note 24.

<sup>27</sup> *What Happens to Your Genetic Data When you Take a Commercial DNA Ancestry Test?*, CITIGEN (Dec. 7, 2017), <http://www.citigen.org/2017/07/12/what-happens-to-your-genetic-data-when-you-take-a-commercial-dna-ancestry-test/>; *Informed Consent Guidelines & Templates*, U. MICH. RES. ETHICS & COMPLIANCE, <https://research-compliance.umich.edu/informed-consent-guidelines> (last visited Oct. 17, 2018) (defining

and conditions are presented to customers at the time of purchase and include a privacy statement.<sup>28</sup> Customers are required to consent to these general conditions in order to participate in the company's services.<sup>29</sup> The voluntary informed consent document relates to additional company-run research projects and is presented when individuals are registering their kit.<sup>30</sup>

AncestryDNA is a DNA testing company that utilizes DNA science combined with the world's largest online family history database resource to predict a person's genetic ethnicity and assist individuals with finding new family connections.<sup>31</sup> The results include information regarding the consumer's genetic ethnicity estimates, which are estimates of the consumer's historical origins of DNA, and identify potential DNA matches, linking an individual to others who have taken the AncestryDNA test.<sup>32</sup>

Another popular genetic testing company is 23andMe. 23andMe is a genetic testing company that offers two personal genetic services, Health + Ancestry and Ancestry.<sup>33</sup> Their Health + Ancestry service provides information on health risks, carrier status, traits, wellness, and ancestry, while their ancestry service provides information about where an individual's DNA comes from and their family history.<sup>34</sup> 23andMe was authorized by the U.S. Food and Drug Administration to market the first direct-to-consumer genetic tests.<sup>35</sup> 23andMe and AncestryDNA are the two most popular companies among consumers seeking genetic testing.<sup>36</sup>

AncestryDNA's terms and conditions state "the purpose of the DNA Services is to provide genetic and genealogy results and related reports for your informational, recreational, educational, and research use."<sup>37</sup> Additionally, there is a clause that states:

by submitting User Provided Content through any of the Services, you grant Ancestry a sublicensable, worldwide, royalty-free license to host,

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informed consent documents as providing subjects with the information they need to make a decision to volunteer for a research study).

<sup>28</sup> CITIGEN, *supra* note 27.

<sup>29</sup> *Id.*

<sup>30</sup> *Id.* (describing the Ancestry Human Diversity Project and 23andMe Research as being each company's research projects).

<sup>31</sup> ANCESTRY, *supra* note 19; *see also* Ken Chahine, *DNA and the Masses: The Science and Technology Behind Discovering Who You Really Are*, WIRED, <https://www.wired.com/insights/2014/03/dna-masses-science-technology-behind-discovering-really/> (last visited Nov. 9, 2018) (explaining how ancestry companies distinguish different ethnicities using DNA).

<sup>32</sup> ANCESTRY, *supra* note 19.

<sup>33</sup> *What Services do you provide?*, 23ANDME.COM, <https://www.23andme.com> (last visited Nov. 8, 2018); *see FDA allows marketing of first direct-to-consumer tests that provide genetic risk information for certain conditions*, U.S. FOOD & DRUG ADMIN. (Apr. 6, 2017), <https://www.fda.gov/newsevents/newsroom/Pressannouncements/ucm551185.htm> (stating that the 23andMe GHR test was the first direct-to-consumer test approved by the FDA).

<sup>34</sup> 23ANDME.COM, *supra* note 33.

<sup>35</sup> *What is the history of the company?*, 23ANDME.COM, <https://www.23andme.com> (last visited Nov. 10, 2018); *see* Molteni, *supra* note 1 (stating that the Food and Drug Administration regulated consumer DNA tests that relate to health).

<sup>36</sup> Regalado, *supra* note 8.

<sup>37</sup> *Ancestry Terms and Conditions*, ANCESTRY (June 5, 2018), <http://www.ancestry.com/cs/legal/termsandconditions>.

store, copy, publish, distribute, provide access to, create derivative works of, and otherwise use such User Provided Content to the extent and in the form or context we deem appropriate on or through any media or medium and with any technology or devices now known or hereafter developed or discovered.<sup>38</sup>

This language may be of some concern for potential consumers since it is granting a broad licensing right in the user's genetic results.

23andMe has similar language in its terms and conditions stating, "unless you make a request for us to delete your account or delete certain Personal Information (i.e. User Content, etc.), we will store your Personal Information as long as your account is open."<sup>39</sup> It also states that some of your privacy rights "may be limited by local laws. Further, your right to access and deletion is not absolute and may not be available if . . . [it will] cause interference with execution and enforcement of the law and legal private rights."<sup>40</sup> Both 23andMe and AncestryDNA provide and emphasize that individuals who use their service continue to have ownership of their genetic information that was used to complete the tests.<sup>41</sup> However, reading the other clauses in their respective privacy agreements together, suggests that an individual does not have complete control over their sensitive information.

Nonetheless, these companies obtain consent from customers to share their identifiable data, but according to Peter Pitts "genetic testing firms sell the results of their tests to pharmacological companies and third-party laboratories."<sup>42</sup> Anonymizing DNA is a challenging task because it requires the data to be stripped of all identifying information, with no possibility that it can be reversed.<sup>43</sup> Researchers have easily traced back an individual based on DNA that was posted anonymously on the Internet.<sup>44</sup> Yaniv Erlich, of the Whitehead Institute for Biomedical Research, stated "we could actually identify all the other people in the family, basically by looking at public websites, public records of

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<sup>38</sup> *Id.*

<sup>39</sup> *Consent to the use of Sensitive Information*, 23ANDME (July 17, 2018), <https://www.23andme.com/about/privacy>.

<sup>40</sup> *Id.*

<sup>41</sup> ANCESTRY, *supra* note 37 (stating "AncestryDNA does not claim any ownership rights in the DNA that is submitted for testing. Any Genetic Information (your DNA and any information derived from it) belongs to the person who provided the DNA sample, subject only to the rights granted to AncestryDNA in this Agreement"); *see also Terms of Service*, 23ANDME, <https://www.23andme.com/about/tos/> (last visited Nov. 10, 2018) (stating "[a]ny Genetic Information derived from your saliva remains your information, subject to rights we retain as set forth in these TOS").

<sup>42</sup> *See* Stephanie Pappas, *Could Genetic Testing Companies Violate Your Privacy?*, LIVESCIENCE (Dec. 1, 2017, 3:13 PM), <https://www.livescience.com/61079-why-dna-privacy-matters.html>.

<sup>43</sup> *Id.*; *see also Anonymized versus Pseudonymized Data and Your Genetic Privacy*, DNAEXPLAINED (May 31, 2018), <https://dna-explained.com/2018/05/31/concepts-anonymized-versus-pseudonymized-data-and-your-genetic-privacy/> (describing that "[a]nonymized data must be entirely stripped of any identifiable information, making it impossible to derive insights on a discreet individual, even by the person or entity who performed the anonymization.").

<sup>44</sup> Veronique Lacapra, *Anonymity in Genetic Research Can Be Fleeting*, NPR (Jan. 17, 2013, 3:47 PM), <https://www.npr.org/sections/health-shots/2013/01/17/169609144/anonymity-in-genetic-research-can-be-fleeting>.

these people, and Facebook and other websites.”<sup>45</sup> This brings new concerns to people who submit to these genetic tests, because not only are they exposing themselves to the risk of their genetic information getting into the wrong hands, but are also exposing information about shared familial risk.<sup>46</sup> Genetic discrimination is a serious concern for those considering genetic testing due to potential ways in which the findings could be used against consumers.<sup>47</sup>

### C. Genetic Discrimination

Genetic discrimination occurs when employers or insurance companies treat people differently “because they have a gene mutation that causes or increases the risk of an inherited disorder.”<sup>48</sup> For example, a healthy 36-year-old woman’s application for life insurance was denied because her genetic testing came back as positive for the BRCA 1 gene, the gene that is associated with an increased risk of breast and ovarian cancer.<sup>49</sup> However, many of these genetic tests do not reveal whether an individual will develop a disease or disorder, instead it will only tell an individual if they have a predisposition with an increased chance of developing a particular disease or disorder.<sup>50</sup> Due to several other factors that go into the development of a condition, many individuals who test positive for genetic mutations never actually develop the condition.<sup>51</sup> Testing positive alone is usually not enough to determine whether an individual will get the predisposed

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<sup>45</sup> *Id.*; see also Ifeoma Ajunwa, *There’s No Guarantee of Anonymity*, N.Y. TIMES (Mar. 4, 2015, 7:22 PM), <https://www.nytimes.com/roomfordebate/2015/03/02/23andme-and-the-promise-of-anonymous-genetic-testing-10/theres-no-guarantee-of-anonymity>.

<sup>46</sup> See Pappas, *supra* note 42 (explaining that disclosure of one person’s genetic information could potentially expose information about shared familial risks).

<sup>47</sup> See Christina Farr, *If You Want Life Insurance, Think Twice Before Getting A Genetic Test*, FAST COMPANY (Feb. 17, 2016), <https://www.fastcompany.com/3055710/if-you-want-life-insurance-think-twice-before-getting-genetic-testing> (describing an instance where a woman was denied life insurance because her genetic test revealed that she had the BRCA 1 gene and an increased risk of breast and ovarian cancer); see U.S. NAT’L LIBRARY OF MED., *What is genetic discrimination?*, GENETICS HOME REFERENCE (Aug. 21, 2018), <https://ghr.nlm.nih.gov/primer/testing/discrimination> (explaining that although regulations exist to stop genetic discrimination in the workplace and in providing health insurance, they do not protect against discrimination regarding life, disability, or long-term care insurance).

<sup>48</sup> U.S. NAT’L LIBRARY OF MED., *supra* note 47; accord, Ifeoma Ajunwa, *Genetic Testing Meets Big Data: Tort and Contract Law Issues*, 75 OHIO STATE L. J. 1225, 1235 (2014) (advocating that genetic discrimination is 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 . . . genetic composition.”).

<sup>49</sup> Farr, *supra* note 47.

<sup>50</sup> *Genetic Discrimination in the Workplace Factsheet*, ACLU, <https://www.aclu.org/other/genetic-discrimination-workplace-factsheet> (last visited Aug. 17, 2018) (referring to genetic testing for conditions such as breast cancer, a test which “cannot predict whether a person will actually develop the disease [or] . . . if they have a genetic predisposition and a greater likelihood of developing cancer.”); e.g., Samantha Masunaga, *What the new, FDA-approved 23andMe genetic health risk reports can, and can’t, tell you*, L.A. TIMES (Apr. 14, 2017, 8:40 AM), <http://www.latimes.com/business/la-fi-23andme-reports-20170414-htmistory.html> (“the mere instance of a variant does not mean an individual has a disease or is certain to develop it. Likewise, the absence of a variant doesn’t guarantee that someone won’t ever get that disease . . . intended to provide genetic risk information to consumers”).

<sup>51</sup> *Genetic Discrimination in the Workplace Factsheet*, *supra* note 50 (explaining that not all genetic tests can accurately determine if an individual will develop a certain disease).



condition.<sup>52</sup> Nonetheless, employers and insurance companies may want to use this information against individuals in determining whether to offer them health insurance benefits, or when hiring or terminating employees.<sup>53</sup>

#### D. Health Insurance Portability and Accountability Act of 1996 (HIPAA)

HIPAA is the most prominent American law regulating privacy and security of health information.<sup>54</sup> HIPAA's Privacy Rule governs the use and disclosure of protected health information (PHI) by covered entities and business associates.<sup>55</sup> PHI is information that identifies or provides a reasonable basis to identify an individual.<sup>56</sup> PHI can include demographic data relating to the individual's "past, present or future physical or mental health condition . . . the provisions of health care to [the] individual . . . or [any] payment for the provision of health care" to the individual."<sup>57</sup> HIPAA regulates "covered entities", which are health plans, health clearinghouse, and healthcare provider that transmits PHI electronically.<sup>58</sup> Covered entities also include business associates, defined as a "person or organization, other than a member of a covered entity's workforce, that performs certain functions or activities on behalf of, or provides certain services to, a covered entity that involve the use or disclosure of individually identifiable health information."<sup>59</sup> The privacy rule under HIPAA generally prohibits a covered entity from using or disclosing PHI unless approved by patients, except where this prohibition would result in an interference of treatment or efficient payment for health care services.<sup>60</sup>

In 2013, the HIPAA Omnibus Rule amended HIPAA regulations to include genetic information in the definition of protected health information, thereby specifically applying HIPAA's privacy protections to individuals' genetic information.<sup>61</sup>

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

<sup>53</sup> See generally Farr, *supra* note 47 (describing a woman who was denied insurance coverage after testing positive for the BRCA gene, which is associated with an increased risk of breast and ovarian cancer).

<sup>54</sup> Health Insurance Accountability and Portability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of 42 U.S.C.); see Joanna Belbey, *Privacy and Security: Learn From Best Practices for HIPAA Compliance*, FORBES (Dec. 19, 2015, 8:41 PM), <https://www.forbes.com/sites/joannabelbey/2015/12/19/privacy-and-security-learn-from-best-practices-for-hipaa-compliance/#3611367b71b4> (stating that HIPAA was one for the first Acts to regulate the privacy and security of client information).

<sup>55</sup> 45 C.F.R. § 160.103 (2014).

<sup>56</sup> *Id.*

<sup>57</sup> *Id.*; see also U.S. DEP'T OF HEALTH AND HUMAN SERVS., SUMMARY OF THE HIPAA PRIVACY RULE (July 26, 2013), <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>.

<sup>58</sup> U.S. DEP'T OF HEALTH AND HUMAN SERVS., *supra* note 57.

<sup>59</sup> *Id.*

<sup>60</sup> 45 C.F.R. § 164.506; see also U.S. DEP'T OF HEALTH AND HUMAN SERVS., USES AND DISCLOSURES FOR TREATMENT, PAYMENT, AND HEALTH CARE OPERATIONS (2013), <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/disclosures-treatment-payment-health-care-operations/index.html> (detailing circumstances under which private health information may or may not be disclosed).

<sup>61</sup> See 45 C.F.R. § 160.103 (defining protected health information); *HIPAA: Impacts and Actions by States*, NAT'L CONFERENCE OF STATE LEGISLATURES (May 2018)

#### E. The Genetic Information Nondiscrimination Act of 2008 (GINA)

In the 13 year battle to pass GINA, the American population raised concerns that “they should not be penalized because they happened to be born at a higher risk for a given disease.”<sup>62</sup> In 2008, Congress passed GINA “to prohibit discrimination on the basis of genetic information with respect to health insurance and employment.”<sup>63</sup> GINA protects “genetic information”: an individual’s genetic tests, the genetic tests of a family member, or the manifestation of a disease or disorder in a family member.<sup>64</sup> The manifestation of a disease or disorder in a family member can be used to predict an individual’s own genetic predisposition to certain diseases.<sup>65</sup> This definition does not include the sex or age of an individual.<sup>66</sup> The statute defines ‘genetic test’ as an “analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes.”<sup>67</sup> However, GINA excludes analysis of “proteins or metabolites that do not detect genotypes, mutations, or chromosomal changes” or inquiries that “are directly related to a manifested disease that could be reasonably detected by a health care professional.”<sup>68</sup>

There are two parts to GINA: Title I of GINA applies to health insurance and Title II applies to employment-related matters. Title I prohibits group and individual health insurers from using a person’s genetic information to determine their eligibility and premiums.<sup>69</sup> Additionally, Title I prevents insurers from requesting or requiring a person undergo a genetic test.<sup>70</sup> Title II excludes employers from hiring, firing, or otherwise changing terms of an employee’s employment based on genetic information.<sup>71</sup> Employers may not require, purchase or request from employees or their family members any genetic information.<sup>72</sup> While GINA is a step forward in the protection of

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<http://www.ncsl.org/research/health/hipaa-a-state-related-overview.aspx>.

<sup>62</sup> Amy Harmon, *Congress Passes Bill to Bar Bias Based on Genes*, N.Y. TIMES (May 2, 2008), <https://www.nytimes.com/2008/05/02/health/policy/02gene.html>.

<sup>63</sup> Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881, 881 (2008).

<sup>64</sup> *Id.* at 906.

<sup>65</sup> Perry W. Payne, Jr. et al., *Health Insurance and the Genetic Information Nondiscrimination Act of 2009: Implications for Public Health Policy and Practice*, 124 PUB. HEALTH REP. 328, 328 (2009); 42 U.S.C. § 2000ff(4).

<sup>66</sup> 42 U.S.C. § 2000ff(4)(C); U.S. DEP’T OF HEALTH AND HUMAN SERVS., “GINA” *The Genetic Information Nondiscrimination Act of 2008: Information for Researchers and Health Care Providers*, at 2 (Apr. 6, 2009), <https://www.genome.gov/pages/policyethics/geneticdiscrimination/ginainfodoc.pdf>.

<sup>67</sup> 42 U.S.C. § 2000ff(7)(A); *Ortiz v. City of San Antonio Fire Dep’t*, 806 F.3d 822, 826 (5th Cir. 2015) (holding that “genetic tests” do not include other medical tests).

<sup>68</sup> 42 U.S.C. § 2000ff(7)(B).

<sup>69</sup> Genetic Information Nondiscrimination Act of 2008, § 101(3)(a).

<sup>70</sup> *Id.* at 888-89, 893-94; *see also* Kathy L. Hudson et al., *Keeping Pace with the Times – The Genetic Information Nondiscrimination Act of 2008*, 358 NEW ENG. J. MED. 2661, 2662 (2008) (quoting Senator Edward Kennedy, who cosponsored the bill, stating “[d]iscrimination in health insurance and the fear of potential discrimination threaten both society’s ability to use new genetic technologies to improve human health and the ability to conduct the very research we need to understand, treat, and prevent genetic disease”).

<sup>71</sup> Genetic Information Nondiscrimination Act of 2008, § 202(a); *see also* Hudson, *supra* note 70.

<sup>72</sup> Genetic Information Nondiscrimination Act of 2008, § 202(b); *see also* Hudson, *supra* note 70.

individuals' genetic information, there are significant pitfalls to its regulation, specifically in the lack of coverage in areas outside of the employment and health insurance context.

#### F. Relationship between HIPAA and GINA

GINA and HIPAA each provide privacy protections for individuals, specifically relating to genetic information. Before GINA there was no federal regulation relating to genetic information.<sup>73</sup> By early 2008, 32 states had enacted legislation providing varying levels of protection from genetic discrimination.<sup>74</sup> However, no minimum standard of protections existed besides the limited protections offered in HIPAA, which only applied to employer-based and commercially issued health insurance.<sup>75</sup> Congress determined that HIPAA did not sufficiently protect individuals from potential genetic discrimination.<sup>76</sup> For instance, an insurer was prohibited from "charging one individual in a group a higher premium than the rest of the group based on genetic information," but the insurer could authorize "premiums for the entire group based on genetic information of one individual."<sup>77</sup> Congress also criticized HIPAA for limiting its application to only insurance companies writing group health policies, and exempting those writing policies only for individuals.<sup>78</sup>

The enactment of GINA filled in some of the gaps in the HIPAA privacy rule. Prior to the enactment of GINA, HIPAA did not provide sufficient privacy protection to an individual's genetic information. The enactment of GINA required HIPAA's original privacy rule to be modified and expanded.<sup>79</sup> For instance, prior to GINA there was no prohibition preventing health care plans from using or disclosing genetic information for underwriting purposes.<sup>80</sup> While the HIPAA rules did not define what qualified as underwriting purposes, GINA defined the term with respect to health plans and the final rule adopted the GINA definition.<sup>81</sup> Additionally, the final rule adopts GINA's proposed rule adding

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<sup>73</sup> See *Legislative History of GINA*, NAT'L HUM. GENOME RES. INST. (Apr. 17, 2017), <https://www.genome.gov/27568535/legislative-history-of-gina> (explaining that the first piece of legislation banning genetic discrimination was introduced thirteen years prior to GINA, but efforts to implement that law failed).

<sup>74</sup> *HIPAA: Impacts and Actions by States*, *supra* note 61.

<sup>75</sup> Alicia A. Parkman et al., *Public Awareness of Genetic Nondiscrimination Laws in Four States and Perceived Importance of Life Insurance Protections*, 24 J. OF GENETIC COUNSELING 512, 512-13 (2015).

<sup>76</sup> See S. Rep. No. 110-48, at 10-15 (2007); Morse Hyun-Myung Tan, *Advancing Civil Rights, the Next Generation: The Genetic Information Nondiscrimination Act of 2008 and Beyond*, 19 HEALTH MATRIX: J. OF LAW- MED. 63, 96 (2009) (explaining "GINA compensates for HIPAA's deficiencies.").

<sup>77</sup> S. REP. NO. 110-48, at 9-10.

<sup>78</sup> S. REP. NO. 110-48, at 10 (noting that if a health insurance company does both group and individual policies then they would still be subject to HIPAA).

<sup>79</sup> GEO. WASH. U. DEP'T OF HEALTH POL'Y, A SIDE-BY-SIDE TABLE COMPARING THE ADMINISTRATIVE SIMPLIFICATION REGULATIONS TO THE CHANGES IN THE PROPOSED INTERIM FINAL AND FINAL OMNIBUS RULES IMPLEMENTING HITECH, GINA, AND PSQIA, <http://www.healthinfolaw.org/sites/default/files/article-files/HIPAA%20Side-by-Side%20Table.pdf>.

<sup>80</sup> *HIPAA: Impacts and Actions by States*, *supra* note 61.

<sup>81</sup> See GEORGE WASHINGTON UNIVERSITY DEPARTMENT OF HEALTH POLICY, *supra* note

reference to the underwriting prohibition such that “group health plans and issuers may not disclose genetic information that is protected health information for underwriting purposes” when disclosing summary health information to a plan sponsor.<sup>82</sup> While the implementation of GINA improved the privacy protections of HIPAA, more needs to be done to further expand GINA.

## II. ANALYSIS

### A. Employers Using Genetic Information to Discriminate

Employers desire genetic information about current and prospective employees for various reasons, such as “to protect employee safety and health, to save money by avoiding high risk employees, and to protect themselves against future liability for the possible adverse health consequences that exposure to hazardous workplace chemicals might have on employees genetically predisposed for certain health conditions.”<sup>83</sup> Additionally, employers may seek to ensure that employees can perform the necessary functions of a specified job.<sup>84</sup> Accordingly, “[i]f 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.”<sup>85</sup> There are financial benefits in only hiring healthy workers.<sup>86</sup> Hiring an unhealthy worker can add to potential

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79, at 5 (proposing the GINA rule to define underwriting purposes with respect to health plan as: (i) rules governing benefit determinations/eligibility for benefits, or the determination of benefits/eligibility for benefits (including enrollment, continued eligibility, and changes in deductibles or other cost-sharing mechanisms in return for activities such as completing a health risk assessment or participating in a wellness program); (ii) premium or contribution calculations (including discounts, rebates, payments in kind, or other premium differential mechanisms in return for activities such as completing a health risk assessment or participating in wellness programs); (iii) the application of any preexisting condition exclusion; and (iv) other activities related to the creation, renewal, or replacement of a contract of health insurance or health benefits); Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules Under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act; Other Modifications to the HIPAA Rules, 78 Fed. Reg. 5566, 5665 (Jan. 25, 2013); 45 C.F.R. § 164.502(a)(5)(i) (2013).

<sup>82</sup> GEORGE WASHINGTON UNIVERSITY DEPARTMENT OF HEALTH POLICY, *supra* note 79, at 7.

<sup>83</sup> Abigail Lauren Perdue, *Justifying GINA*, 78 TENN. L. REV. 1051, 1100 (2011); *see also* Program Report, NAT’L HUM. GENOME RES. INST.: GENETIC INFO. AND THE WORKPLACE (Jan. 20, 1998) <https://www.genome.gov/10001732/genetic-information-and-the-workplace-report/> (explaining employers may “avoid hiring workers who they believe are likely to take sick leave, resign, or retire early for health reasons (creating extra costs in recruiting and training new staff), file for workers’ compensation, or use health care benefits excessively”).

<sup>84</sup> *See generally* Paula Reece, *The benefits of healthy employees*, THE BUS. TIMES (Mar. 30, 2012), <http://thebusiness-times.com/the-benefits-of-healthy-employees/>.

<sup>85</sup> Perdue, *supra* note 83, at 1101 (quoting Lance Liebman, *Too Much Information: Predictions of Employee Disease and the Fringe Benefit System*, 1988 U. CHI. LEGAL F. 57, 82 (1988)).

<sup>86</sup> Reece, *supra* note 84 (describing how fit employees are “less likely to get sick” and have “more energy”, as well as how health care expenditures are reduced); *see* Ben Greenfield, *Unhealthy Employees Are Killing Your Bottom Line*, HUFFPOST (May 3, 2013, 4:12 PM), <https://www.huffingtonpost.com/ben-greenfield/employee->

expenses such as “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.”<sup>87</sup>

Consumer protection concerns arise if all employers could discriminate against those predisposed to incurring additional expenses on a company and require employees and prospective employees to disclose genetic testing.<sup>88</sup>

Title II of GINA protects these consumers from these issues by “prohibiting most employers from using genetic information for hiring, firing, or promotion decisions, and for any decision regarding terms of employment.”<sup>89</sup> This imposed additional deterrents on employers. GINA requires employers in “possess[ion] [of] genetic information about an employee or member” to “maintain[] [such information] on separate forms and in separate medical files and . . . [treat] as a confidential medical record of the employee or member.”<sup>90</sup> Unless the genetic information falls under an enumerated exception under GINA, an employer has a duty to refrain from disclosing such information.<sup>91</sup> Accordingly, this requires employers to have additional safeguards to protect confidential employee medical information. The legislative comments accompanying GINA address this matter, stating, “[T]he covered entity must tell the health care professional not to collect genetic information as part of medical examinations intended to determine the ability to perform a job, and must take additional reasonable measures within its control if it learns that genetic information is being requested

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wellness\_b\_3101223.html (describing how unhealthy employees who are “sick, overtired, or distracted by stress at home” causes an employer to lose “at least 115 productive hours each year due to chronic conditions like stress.”); Tatiana Spears, *How Unhealthy Employees Are Killing Your Bottom Line*, CAREATC (Sept. 8, 2017), <https://www.careatc.com/ehs/unhealthy-employees-killing-your-bottom-line> (stating how a University of Michigan study found that “the average health care cost for a healthy employee was roughly \$3,000, and roughly \$10,000 for an employee with at least one medical condition.”).

<sup>87</sup> Perdue, *supra* note 83, at 1101; see Alicia Ciccone, *Unhealthy Employees Cost Businesses \$153 Billion in Lost Productivity*, HUFFPOST (Oct. 18, 2011, 12:47 AM), [https://www.huffingtonpost.com/2011/10/17/unhealthy-employees-cost-153-billion\\_n\\_1016568.html](https://www.huffingtonpost.com/2011/10/17/unhealthy-employees-cost-153-billion_n_1016568.html) (stating that a recent poll “estimates that unhealthy workers cost businesses \$153 billion a year in lost productivity”).

<sup>88</sup> See U.S. EQUAL EMP’T OPPORTUNITY COMM’N, GENETIC INFORMATION DISCRIMINATION (stating how “it is illegal to discriminate against employees or applicants because of genetic information” and that the Equal Employment Opportunity Commission under the Federal Trade Commission enforces such consumer protections).

<sup>89</sup> DEP’T OF HEALTH & HUM. SERVS., “GINA”: THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 INFORMATION FOR RESEARCHERS AND HEALTH CARE PROFESSIONALS 2 (2009).

<sup>90</sup> 42 U.S.C. § 2000ff-5(a) (2008).

<sup>91</sup> See 42 U.S.C. § 2000ff-5(b) (2008) (“An employer . . . shall not disclose genetic information concerning an employee . . . except - (1) to the employee . . . at the written request of the employee; (2) to a . . . health researcher if the research is conducted in compliance with . . . Federal Regulations; (3) in response to an order of a court . . .; (4) to government officials investigating compliance with this chapter if the information is relevant to the investigation; (5) to the extent that such disclosure is made in connection with the employee’s compliance with . . . family and medical leave laws; or (6) to a Federal, State, or local public health agency . . . concerned with a contagious disease that presents an imminent hazard of death or life-threatening illness.”).

or required.”<sup>92</sup> These reasonable steps could include “no longer using the services of a health care professional who continues to request or require genetic information during medical examinations after being informed not to do so.”<sup>93</sup> Ultimately, employers must be proactive when it comes to preventing access to this protected information under GINA.

Employee wellness programs give rise to new issues with employer implementation. While these programs are usually voluntary, many employees choose to participate. “Wellness programs” generally refer to “health promotion and disease prevention programs and activities offered to employees.”<sup>94</sup> Workplace wellness programs have two main goals: improving employee’s health and lowering their employer’s health care costs.<sup>95</sup> Many of these programs require employees to answer questions on health risk assessment and/or undergo biometric screenings for risk factors.<sup>96</sup> Some wellness programs “involve the exchange of health information between employees and their employers,” and are relevant to “the enforcement of GINA in cases where wellness programs request genetic information from employees.”<sup>97</sup>

The Equal Employment Opportunity Commission (EEOC) has issued guidance regarding wellness programs and its relationship with GINA.<sup>98</sup> The final rule issued by the EEOC states, “employers may provide limited financial or other inducements (also called incentives) in exchange for an employee’s spouse providing information about his or her current, or past health status as part of a wellness program, whether or not the program is part of the group health plan.”<sup>99</sup> The final rule does not allow employers to induce children to participate in a wellness program if it would be “in exchange for information about their current health status or genetic information.”<sup>100</sup> This decision was based in part on the concern that an employer, with access to employee’s children’s health information, including genetic information, may use it to discriminate against employees.<sup>101</sup> This is compared to the disclosure of the health information of the employee’s spouse, where the final rule recognizes “there is minimal, if any, chance of determining information about an employee’s genetic make-up or predisposition to disease from health information about the employee’s

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<sup>92</sup> Regulations Under the Genetic Nondiscrimination Act of 2008, 75 Fed. Reg. 68912, 68926 (Nov. 9, 2010).

<sup>93</sup> *Id.*; see also 29 C.F.R. § 1635.8 (mandating employers to tell healthcare providers they must not collect genetic information as part of an examination intended to evaluate if an employee can perform their job).

<sup>94</sup> U.S. EQUAL EMP’T OPPORTUNITY COMM’N, EEOC’S FINAL RULE ON EMPLOYER WELLNESS PROGRAMS AND THE GENETIC INFORMATION NONDISCRIMINATION ACT 1 (May 17, 2016).

<sup>95</sup> Rebecca Greenfield, *Workplace Wellness Programs Don’t Work*, BLOOMBERG (Jan. 26, 2018, 6:00 AM), <https://www.bloomberg.com/news/articles/2018-01-26/workplace-wellness-programs-really-don-t-work>.

<sup>96</sup> U.S. EQUAL EMP’T OPPORTUNITY COMM’N, *supra* note 94.

<sup>97</sup> *GINA and Employee Wellness Programs*, NAT’L HUM. GENOME RES. INST. (Apr. 17, 2017), <https://www.genome.gov/27568501/gina-and-employee-wellness/>.

<sup>98</sup> Genetic Information Nondiscrimination Act, 81 Fed. Reg. 31143, 31143 (May 17, 2016); see generally U.S. EQUAL EMP’T OPPORTUNITY COMM’N, *supra* note 94.

<sup>99</sup> *Id.*

<sup>100</sup> *Id.*

<sup>101</sup> *Id.*

spouse.”<sup>102</sup> This ruling changed the way wellness programs were treated under GINA, however, it does not change the fundamental prohibition of employment discrimination based upon genetic information.<sup>103</sup>

This new rule was brought into question in *AARP v. EEOC*, where AARP filed a motion for a preliminary injunction to prevent these new regulations promulgated by the EEOC from becoming applicable on January 1, 2017.<sup>104</sup> Ultimately, the district court concluded the commission had failed to adequately justify its conclusion that incentives and penalties of up to 30 percent of the cost of an employee’s health insurance coverage does not render plan participation ‘involuntary.’<sup>105</sup> The court, however, is not concluding the EEOC has shown a substantial likelihood of success.<sup>106</sup> This case raises important questions regarding the complex interaction of the ADA, GINA, the ACA, and HIPAA that implicate the public interest on all sides, and the court will have the opportunity to consider these questions carefully once the administrative record has been produced and further briefing ensues.<sup>107</sup> The holding leaves the new rule in place and merely requires the EEOC to come up with justification for the specific shortcomings that the court found. Currently, the “EEOC wellness program regulations will remain effective through 2018, but will become null and void beginning on January 1, 2019.”<sup>108</sup> The impending end of regulation creates uncertainty for employers regarding wellness program compliance under GINA beginning in 2019.<sup>109</sup>

## B. Insurance Companies Using Genetic Information to Discriminate

Title I of GINA prohibits health insurers from using genetic information to determine coverage, eligibility, or premiums; from requesting or requiring genetic tests for genetic information; and from obtaining genetic information for underwriting purposes.<sup>110</sup> It also prohibits “individual insurers and issuers of

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<sup>102</sup> *Id.*; Genetic Information Nondiscrimination Act, 81 Fed. Reg. 31143, 31147 (May 17, 2016); see 29 CFR § 1635.8(b)(2)(A)(iii) (2018).

<sup>103</sup> *GINA and Employee Wellness Programs*, NAT’L HUM. GENOME RES. INST. (Apr. 17, 2017), <https://www.genome.gov/27568501/gina-and-employee-wellness>; see 29 CFR § 1635.4; 42 U.S.C. § 2000ff-1(a).

<sup>104</sup> *A.A.R.P. v. United States Equal Emp’t Opportunity Comm’n*, 226 F.Supp.3d 7, 10-11 (D.D.C. 2016).

<sup>105</sup> *Id.*

<sup>106</sup> *Id.*

<sup>107</sup> *Id.*; see Jonathan H. Adler, *Federal court rejects EEOC wellness program rule*, WASH. POST (Aug. 25, 2017), [https://www.washingtonpost.com/news/volokh-conspiracy/wp/2017/08/25/federal-court-rejects-eeoc-wellness-program-rule/?noredirect=on&utm\\_term=.1b23688921c4](https://www.washingtonpost.com/news/volokh-conspiracy/wp/2017/08/25/federal-court-rejects-eeoc-wellness-program-rule/?noredirect=on&utm_term=.1b23688921c4) (highlighting the public interest in GINA from different lobbying groups).

<sup>108</sup> Thomas Sullivan, *AARP v. EEOC: Motion to Vacate Granted*, POLICY MED. (May 4, 2018), <http://www.policymed.com/2018/01/aarp-v-eeoc-motion-to-vacate-granted.html>.

<sup>109</sup> *Id.*; John L. Barlament & Averi A. Niemuth, *Employer-Sponsored Wellness Programs in Limbo After 2018*, QUARLES & BRADY LLP (Jan. 18, 2018), <https://www.quarles.com/publications/employer-sponsored-wellness-programs-in-limbo-after-2018>.

<sup>110</sup> Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 451 (2010); Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 §§ 101-106 (2008).

supplemental Medicare coverage [from using] genetic information as a preexisting condition.”<sup>111</sup> However, unless the health insurance companies do not receive this information on their own, the provision preventing insurance companies from acquiring this information is ineffective.<sup>112</sup> For instance, even if a person does not directly reveal “information about their genetic tests or family history in an insurance application,” insurance companies can still have access if it is included in medical records requests, causing a loophole and eliminating the protection.<sup>113</sup> This is known as an “incidental collection” provision and “notes that if a health insurance company inadvertently acquires genetic information while gathering other information about the individual, there will be no violation of GINA.”<sup>114</sup>

The final rule addressed the reality of health insurance companies inadvertently receiving this information.<sup>115</sup> It explains “if it is reasonable for an insurance company to expect that genetic information will be gathered as part of a request for medical records and information, the collection request must explicitly state that genetic information should not be provided.”<sup>116</sup> If the healthcare professionals “do not comply with the notice and still include this information” it would “fall under the incidental collection provision, but the insurance companies still cannot use this information to discriminate against an individual.”<sup>117</sup> Health insurance companies are not permitted to use this information for discrimination purposes and must do their due diligence to confirm that “medical underwriters are not taking any genetic information into account in any decision-making.”<sup>118</sup> Insurance companies struggle with determining premiums and risk factors because they can no longer use genetic information in the underwriting process.

### C. Areas Where GINA Falls Short

#### 1. Long Term Care, Disability and Life Insurance

GINA falls short in regulating long-term care, disability, and life insurance coverage. GINA applies only to employment and health insurance policies, thus leaving companies that sell long-term care, disability and life insurance in the clear when it comes to using individual’s genetics as a means of denying coverage.<sup>119</sup> Robert Green, a researcher in the Genetics Department at Harvard

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<sup>111</sup> Roberts, *supra* note 110, at 451; Genetic Information Nondiscrimination Act of 2008, 122 Stat. 881 § 2753(c-d) (2008).

<sup>112</sup> Anya Prince, *Genetic Information and Medical Records – A Cautionary Tale for Patients, Healthcare Professionals, and Insurance Companies*, 24 HEALTH L. 29, 29 (2012); Mark A. Rothstein & Laura Rothstein, *The Use of Genetic Information in Real Property Transactions*, 31 PROB. & PROP. MAG. 1, at 3 (2017).

<sup>113</sup> Prince, *supra* note 112, at 29; Rothstein, *supra* note 112, at 2.

<sup>114</sup> Prince, *supra* note 112, at 29; Rothstein, *supra* note 112, at 3; 42 U.S.C. § 300gg-53(e)(3).

<sup>115</sup> Prince, *supra* note 112, at 30.

<sup>116</sup> *Id.* at 30.

<sup>117</sup> *Id.*

<sup>118</sup> *Id.* at 31.

<sup>119</sup> Emily Holbrook, *Life Insurance and the Genetic Information Nondiscrimination Act*, GENETIC LITERACY PROJECT (Sept. 4, 2014),



Medical School, conducted a study examining how people react after they learn they have the gene associated with Alzheimer's.<sup>120</sup> The study revealed "people who discover they have the gene are five times more likely than the average person to go out and buy long term care insurance."<sup>121</sup> However, these individuals may be unable to acquire long-term insurance because "there's nothing stopping the insurance companies from demanding to see the results of their genetic tests."<sup>122</sup> Moreover, "a long-term-care company could legally require someone to take a genetic test before selling [them] a policy."<sup>123</sup> This statement confuses many since these long term care policies cover the cost of nursing homes, assisted living facilities, home health aides and other things that people with these types of disease often need to use, but is not protected under GINA.<sup>124</sup>

Many of the patients who seek long-term care insurance are troubled with the possibility that they may be denied insurance coverage, or risk paying higher premiums due to a pre-existing DNA mutation.<sup>125</sup> Specifically, Northwestern Mutual Life Insurance Company asked potential Massachusetts customers about genetic testing, stipulating that refusal "to share results could lead to a declined application or an extra premium."<sup>126</sup>

Insurance companies are concerned that their business model would collapse if they are forced to accept higher-risk applicants.<sup>127</sup> Life insurance companies use an underwriting process to assess an applicant's risk.<sup>128</sup> Based on the assigned risk class, an insurance company determines what premiums an individual will pay, or whether they will even grant coverage.<sup>129</sup> Genetic information plays a significant role in the underwriting process of life insurance companies.<sup>130</sup> Courts consider the life insurance underwriting process to be a method of "fair discrimination," therefore excluding genetic information from

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<https://geneticliteracyproject.org/2013/09/04/the-tricky-landscape-between-life-insurers-science-and-consumers>.

<sup>120</sup> David Schultz, *It's Legal For Some Insurers To Discriminate Based on Genes*, NPR (Jan. 17, 2013, 6:04 PM), <https://www.npr.org/sections/health-shots/2013/01/17/169634045/some-types-of-insurance-can-discriminate-based-on-genes>.

<sup>121</sup> *Id.*; see Gina Kolata, *New Gene Tests Pose a Threat to Insurers*, N.Y. TIMES (May 13, 2017), <https://www.nytimes.com/2017/05/12/health/new-gene-tests-pose-a-threat-to-insurers.html> (describing a man who had the genetic mutation that increases the risk of developing Alzheimer's disease who applied for long-term care insurance without telling the insurance company about the genetic test which revealed he had the gene).

<sup>122</sup> Schultz, *supra* note 120.

<sup>123</sup> *Id.*

<sup>124</sup> See generally Education & Outreach, *Understanding Long-Term Care Insurance*, AARP (May 2016), <https://www.aarp.org/health/health-insurance/info-06-2012/understanding-long-term-care-insurance.html> (summarizing the coverage of long-term care insurance coverage and exceptions).

<sup>125</sup> Peikoff, *supra* note 4, at D1.

<sup>126</sup> *Id.*

<sup>127</sup> Farr, *supra* note 47.

<sup>128</sup> KAROL K. SPARKS, INSURANCE ACTIVITIES OF BANKS § 16.02[A][3] (2nd ed. Supp. 2018).

<sup>129</sup> *Id.*

<sup>130</sup> Brianna E. Kostecka, *GINA Will Protect You, Just Not From Death: The Genetic Information Nondiscrimination Act and its Failure to Include Life Insurance within its Protections*, 34 SETON HALL LEGIS. J. 93, 109 (2009).

this process might have a negative impact on life insurance companies.<sup>131</sup> “Fair Discrimination” in the life insurance industry is not an issue “because the unequal treatment of people with unequal risks is a necessary and accepted characteristic of life insurance.”<sup>132</sup> But, if these insurance companies no longer have access to genetic information in underwriting, adverse selection can occur.<sup>133</sup> Adverse selection is the “process by which consumers make insurance decisions based on risk characteristics that are known to them but not revealed to the insurer.”<sup>134</sup> This could enable “consumers to obtain insurance at cheaper rates than they would otherwise qualify for.”<sup>135</sup>

Adverse selection raises concerns “of the possibility of industry dissolution . . . [causing p]rices for policies to drastically increase, leading to a decreased number of purchased policies and ‘potential insolvency for insurers.’”<sup>136</sup> These competing concerns need to be addressed by lawmakers. Congress should prioritize individuals’ protection from discrimination in obtaining health and life insurance by expanding GINA.

## 2. Education

GINA also falls short in the education arena. Since GINA only applies to employers and health insurance, it excludes the potential for genetic discrimination in the school setting. In *Chadam v. Palo Alto Unified School District*, the parents of a sixth grade boy allege that the parents of a sixth grade boy alleged that a school district violated his son’s rights by forcing him to transfer schools based off his genetic information.<sup>137</sup> As soon as their son was born, he underwent emergency surgery to correct a health defect, and during this process his DNA was analyzed.<sup>138</sup> The DNA test revealed the son had the genetic markers linked with cystic fibrosis, and he has been monitored ever since with no development of the condition.<sup>139</sup> The school district learned of the boy’s

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<sup>131</sup> *Id.*

<sup>132</sup> Kostecka, *supra* note 130, at 109; *but see* Telles v. Comm’r of Ins., 574 N.E.2d 359, 361-62 (Mass. 1991) (explaining that under Massachusetts law, “unfair discrimination” in life insurance occurs when individuals of the same class and equal expectation of life are treated differently).

<sup>133</sup> Kostecka, *supra* note 130.

<sup>134</sup> Knowledge@Wharton, *Genetic Testing’s Uneasy Relationship with Life Insurance* (Mar. 1, 2000), <http://knowledge.wharton.upenn.edu/article/genetic-testings-uneasy-relationship-with-life-insurance>.

<sup>135</sup> *Id.*

<sup>136</sup> Kostecka, *supra* note 130, at 110.

<sup>137</sup> *Chadam v. Palo Alto Unified Sch. Dist.*, 666 F. App’x. 615, 616 (9th Cir. 2016).

<sup>138</sup> Stephanie M. Lee, *This Boy Was Thrown Out of School Because of His DNA*, *Parents Say*, BUZZFEED NEWS (Feb. 5, 2016, 3:02 PM), [https://www.buzzfeed.com/stephaniemlee/this-boy-was-thrown-out-of-school-because-of-his-dna-parents?utm\\_term=.wiaqdOAR#.csQA1WEJ](https://www.buzzfeed.com/stephaniemlee/this-boy-was-thrown-out-of-school-because-of-his-dna-parents?utm_term=.wiaqdOAR#.csQA1WEJ).

<sup>139</sup> *Id.*; *See* Jennifer K. Wagner, *Genetic Discrimination Case Against School District is Appealed to Ninth Circuit*, THE PRIVACY REPORT (Feb. 2, 2016), <https://www.genomicslawreport.com/index.php/2016/02/02/genetic-discrimination-case-against-school-district-is-appealed-to-ninth-circuit> (explaining that cystic fibrosis is not contagious, however individuals with the disease can spread germs to each other and pose a “cross infection” risk to another with cystic fibrosis. If an individual just carries the genes but does not develop the disease this cross infection is not a risk the individual poses to others with the condition).

genetic information relating to cystic fibrosis after a teacher improperly disclosed that the boy had the disease to two other parents, whose children did have cystic fibrosis.<sup>140</sup> After learning this, “the boy was regarded as disabled by the school district, and [] on the basis of the perceived disability, the school district decided to transfer the boy to another school to protect two other students at the school who have cystic fibrosis.”<sup>141</sup>

Unfortunately, this case does not implicate GINA due to the lack of GINA protections in education context. The Chadams claimed that the school negligently violated Title II of the Americans with Disability Act of 1990 (ADA), Section 504 of the Rehabilitation act of 1973, and the First Amendment by transferring their child to a different school.<sup>142</sup> The case was dismissed by the district court but ultimately reversed in part by the Ninth Circuit with regards to the ADA and Section 504 claim.<sup>143</sup> Both the ADA and Section 504 require public education and federally funded programs, respectively, to be free from discrimination.<sup>144</sup> Both provisions mandate “individuals cannot be excluded from participating in or enjoying the benefits of education because of a disability.”<sup>145</sup> They offer protections to individuals who fall in one of three classes: “[1] a person who has a physical or mental impairment that substantially limits one or more major life activities, [2] a person who has a history or record of such impairment, or [3] a person who is perceived by others as having such impairment.”<sup>146</sup> The issue is whether genetic information can be classified as a “perceived disability” in order to offer individuals who are discriminated against based on their genetic information a cause of action. However, “most individuals with hereditary predispositions to [a disease] do not have disease effects which rise to the level of disability” and unless they are classified as disabled they cannot use the ADA as a means for relief.<sup>147</sup>

This case could have been brought under California’s broader GINA statute, CalGINA, but, when asked, the attorney for the Chadams stated “[a] lawsuit under California law would, even if it would prevail, affect only California . . . This [federal suit] would affect other states, it would have a much broader application.”<sup>148</sup> This illustrates the potential relief for similarly situated persons in contexts outside of employment and health insurance. Expanding GINA to include protections in education would address the issue of individuals who do

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<sup>140</sup> *Id.*

<sup>141</sup> *Id.*

<sup>142</sup> *Chadam*, 666 F. App’x at 616.

<sup>143</sup> *Id.* at 617.

<sup>144</sup> OFFICE FOR CIVIL RIGHTS, *Protecting Students With Disabilities F.A.Q.*, U.S. DEP’T OF EDUC., <https://www2.ed.gov/about/offices/list/ocr/504faq.html> (last visited Sept. 12, 2018); Wagner, *supra* note 141.

<sup>145</sup> *Id.*

<sup>146</sup> CIVIL RIGHTS DIV., *A Guide to Disability Rights Laws*, U.S. DEP’T OF JUSTICE (July 2009), <https://www.ada.gov/cguide.htm#anchor62335>.

<sup>147</sup> Amanda Gammon & Deborah W. Neklason, *Confidentiality & the Risk of Genetic Discrimination: What Surgeons Need to Know*, *SURGICAL ONCOLOGY CLINIC N. AM.* 24(4):667, 669 (2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4568442>.

<sup>148</sup> Jon Brooks, *Alleged Genetic Discrimination at California School Strikes a Nerve, Raises More Questions*, *KQED SCIENCE* (Feb. 10, 2016), <https://www2.kqed.org/futureofyou/2016/02/10/alleged-genetic-discrimination-at-california-school-strikes-a-nerve-and-raises-more-questions>.

not rise to level of disability required by the ADA.

### 3. Real Property Transactions

Real property may also pose a risk of genetic discrimination. Entities that have “an economic interest in the future health status of individuals may be tempted to use predictive genetic information to [determine] the health risk of individuals who are parties to real property transactions.”<sup>149</sup> For example, “mortgage lenders, mortgage insurers, real estate sellers, senior living centers, retirement communities, and other entities involved in residential property might begin requiring genetic information as part of the application process.”<sup>150</sup> Individuals with predispositions to certain health risks could expect their healthcare costs to increase if they do develop a disease or disorder which may ultimately affect their ability to pay a mortgage.<sup>151</sup> For example, the “mortgage application of a woman who has tested positive for the BRCA gene may be denied on the grounds of her predicted shortened life span and subsequent inability to pay the loan in full.”<sup>152</sup>

Mortgage companies have an interest in knowing “that the borrower currently has and will continue to have the financial means to make payments” on their mortgage which typically require payments for 20 to 30 years.<sup>153</sup> If an individual’s genetic test reveals that they are predisposed to certain high cost diseases which may develop within that 20 to 30 year repayment period, mortgage companies have an interest in knowing this information.

The Equal Credit Opportunity Act prohibits credit discrimination on the basis of race, color, religion, national origin, sex, marital status, age, or because an individual receives public assistance.<sup>154</sup> Genetic information is not included under the Act. Once an individual develops a disability they may be covered under the Fair Housing Act, but individuals who are predisposed to conditions that could lead to a disability are left without protections.<sup>155</sup> In *Texas Department of Housing & Community Affairs v. Inclusive Communities Project, Inc.*, a case involving the Texas Department of Housing and Community Affairs’ allocation of low income housing tax credits that was allegedly resulting in a disparate impact on African-American residents, the Supreme Court held that “disparate-impact claims are cognizable under the Fair Housing Act.”<sup>156</sup>

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<sup>149</sup> Rothstein, *supra* note 112, at 13.

<sup>150</sup> *Id.*

<sup>151</sup> *Id.* at 14.

<sup>152</sup> Olivia Nash, *DNA Discrimination: Fixing the Fears of Genetic Testing*, BROWN POL. REV. (Dec. 13, 2017), <http://www.brownpoliticalreview.org/2017/12/dna-discrimination-fixing-fears-genetic-testing>; see *BRCA: The Breast Cancer Gene*, NAT. BREAST CANCER FOUND., <http://www.nationalbreastcancer.org/what-is-brca> (last visited Sept. 16, 2018) (explaining that BRCA stands for “breast cancer gene” and refers to BRCA1 and BRCA2 which are two genes that have been found to impact an individual’s chances of developing breast cancer).

<sup>153</sup> Rothstein, *supra* note 112, at 15.

<sup>154</sup> 15 U.S.C. § 1691 (2018).

<sup>155</sup> See 42 U.S.C. § 3604 (2018) (prohibiting discrimination in the sale or rental of housing on the basis of race, color, religion, national origin, sex, disability or familial status).

<sup>156</sup> *Texas Dep’t. of Hous. and Cmty. Affairs v. Inclusive Cmty. Project, Inc.*, 135 S. Ct.

Disparate impact claims could be a form of redress for individuals who are subject to policies requiring mortgage applicants to submit genetic information. These policies “could be viewed as having a disparate impact on individuals with disabilities.”<sup>157</sup> Alternatively, to prevent this type of discrimination, lawmakers should broaden GINA to include additional titles, and outline the prohibition of genetic information used for purposes of determining mortgages and other real property transactions.

This same argument could be made in the case of private student loans. Currently, there are no reported cases of genetic information being used as a screening tool for the approval or denial of private student loans. However, in the future, it could be an issue as the price of higher education continues to increase.<sup>158</sup> Lawmakers should be proactive and consider this type of discrimination in the reform of GINA.

#### 4. *Military, Federal Employees, and Indian Health Services*

GINA does not include specific protections for individuals who receive healthcare through the U.S. Military or Veteran’s Administration.<sup>159</sup> The United States military currently uses and collects genetic information by requiring all service members to provide a “DNA sample to be used for the identification of remains.”<sup>160</sup> The military may use this genetic information as a screening tool for potential members.<sup>161</sup> This could be a benefit by helping “ensur[e] troop readiness, optimizing performance and in some cases reducing morbidity and mortality.”<sup>162</sup> However, it would need to be weighed against the risk of “adversely impacting a [service] member’s career” by “identifying a deleterious genetic variant to reduce risk and enhance mission effectiveness.”<sup>163</sup>

Although GINA does not cover military members, changes to military laws provide some protections. Since the passage of GINA, the military has incorporated “service members are entitled to compensation and benefits so long as there is no clear and unmistakable evidence that they had a hereditary or congenital disease at the time of enlistment, or if the disease was aggravated by their service.”<sup>164</sup> It further states a “variant found in genetic testing cannot result in any action unless that individual suffers symptoms during their time of service

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2507, 2525 (2015).

<sup>157</sup> Rothstein, *supra* note 112, at 4.

<sup>158</sup> See generally Jeffrey J. Selingo, *Why the price tag of a college degree continues to rise*, WASH. POST, (Jan. 22, 2016), [https://www.washingtonpost.com/news/grade-point/wp/2016/01/22/why-the-price-tag-of-a-college-degree-continues-to-rise/?utm\\_term=.7f7a1af8875c](https://www.washingtonpost.com/news/grade-point/wp/2016/01/22/why-the-price-tag-of-a-college-degree-continues-to-rise/?utm_term=.7f7a1af8875c).

<sup>159</sup> *The Genetic Information Nondiscrimination Act*, NAT’L HUM. GENOME RES. INST. (Apr. 17, 2017), <https://www.genome.gov/27568492/the-genetic-information-nondiscrimination-act-of-2008> (stating GINA does not extend to TRICARE, which is the US Military healthcare for military members, retirees, and their families).

<sup>160</sup> Mauricio De Castro et al., *Genomic Medicine in the Military*, GENOMIC MED. 1, 1 (Jan. 16, 2016), <https://www.nature.com/articles/npjgenmed20158.pdf>.

<sup>161</sup> *Id.* at 2.

<sup>162</sup> *Id.*

<sup>163</sup> *Id.*

<sup>164</sup> *Id.* at 2-3.

and those symptoms limit the member's ability to carry out their duties."<sup>165</sup> The military is a special context in its "legitimate interest in obtaining information about [service member's] physical and mental abilities[.]"<sup>166</sup> Using genetic information in the military context should be weighed against the privacy risks to the individuals whose genetic information could be exploited.

Native Americans who are covered under Indian Health Services are also not given GINA protections.<sup>167</sup> This is because "Title I of GINA amends laws that do not have jurisdiction over these groups."<sup>168</sup>

Federal government employees are also not included in GINA's protections. However, President Clinton signed Executive Order 13145 in February 2000 "to prohibit discrimination in federal employment based on genetic information."<sup>169</sup> While Federal employees have been protected from genetic discrimination since early 2000, a uniform set of protections covering all of these groups would be beneficial in the reformation of GINA.

#### D. Obstacles with Bringing a Claim Under GINA

Plaintiffs are faced with a substantial burden to file a claim under GINA. Congress borrowed heavily from other federal employment laws in writing the remedies and enforcement provisions in GINA.<sup>170</sup> Similar to cases filed under Title VII and the ADA, plaintiffs wishing to bring a suit under GINA are first required to exhaust all administrative remedies.<sup>171</sup> Plaintiffs who wish to bring their claim under Title I of GINA would first be "advised to go to [their] state health insurance commissioner for assistance . . . [and] HHS will enforce GINA protections when states fail to provide equally strong protections."<sup>172</sup> To bring a claim under Title II of GINA, plaintiffs must file a charge with the EEOC, who regulates this provision in the legislation.<sup>173</sup> Plaintiffs "would need to obtain what is known as a 'right to sue' letter from the EEOC in order to move forward with a lawsuit against an employer."<sup>174</sup> They would need to obtain the letter "within 90 days of the alleged discriminatory employment action or they forfeit

<sup>165</sup> *Id.* at 3.

<sup>166</sup> *Id.*

<sup>167</sup> Mary Beth Steck & Julia A. Eggert, *The Need to Be Ware and Beware of the Genetic Information Nondiscrimination*, 15 CLINICAL J. OF ONCOLOGY NURSING, E34, E38 (2011).

<sup>168</sup> NAT'L HUM. GENOME RES. INST., *supra* note 159.

<sup>169</sup> Exec. Order 13,145, 65 Fed. Reg. 6877 (2000); *President Clinton's Comments on the Signing of Executive Order 13145*, NAT'L HUM. RES. INST. (Feb. 8, 2000), <https://www.genome.gov/10002346/executive-order-13145-clintons-comments> (explaining that with all the technological advances, the need to protect privacy will allow for more people to get genetic testing without fear of their results being used against them).

<sup>170</sup> See 42 U.S.C. § 2000ff-6(a)-(e) (citing to previous employment laws that shall apply in specific instances for genetic nondiscrimination).

<sup>171</sup> See Joanne Barken, *Judging GINA: Does the Genetic Information Nondiscrimination Act of 2008 Offer Adequate Protection?*, 75 BROOK. L. REV. 545, 575 (2009).

<sup>172</sup> Susannah Baruch & Kathy Hudson, *Civilian and Military Genetics: Nondiscrimination Policy in a Post-GINA World*, 83 AM. J. HUM. GENETICS 435, 439 (2008) (stating that different government agencies will enforce GINA, depending on the type of insurance and particular claims brought by a plaintiff).

<sup>173</sup> U.S. EQUAL EMP'T OPPORTUNITY COMM'N, BACKGROUND INFORMATION FOR EEOC FINAL RULE ON TITLE II OF THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008, <https://www.eeoc.gov/laws/regulations/gina-background.cfm> (last visited Sept. 16, 2018).

<sup>174</sup> Baruch, *supra* note 172, at 439.

their right to bring a claim.”<sup>175</sup> Since many Title VII and ADA claims are dismissed based on the failure to exhaust administrative remedies, the same problem will likely arise with cases brought under GINA because plaintiffs are unfamiliar with the rigid deadlines involved.<sup>176</sup>

GINA fails to contain a cause of action for disparate impact.<sup>177</sup> As such, evidence of an employer’s actions resulting in a disparate impact on employees is insufficient to bring a cause of action under GINA.<sup>178</sup> Thus, requiring plaintiffs to allege “specific instances where the employer intentionally discriminated against him or her on the basis of his or her genetic information.”<sup>179</sup> As seen in other discrimination cases, it is famously difficult to prove intent to discriminate, hence creating an additional obstacle for plaintiffs to overcome when bringing a claim.<sup>180</sup>

Despite the difficulties in bringing a GINA claim, some cases have succeeded under the law. The first GINA related case to be resolved in court was *Lowe v. Atlas Logistics Group Retail Services*.<sup>181</sup> This case arose out of an incident when a grocery warehouse company discovered an employee had been “habitually defecating in one of its warehouses.”<sup>182</sup> To resolve the mystery, “Atlas requested some of its employees, including Jack Lowe and Dennis Reynolds, to submit to a cheek swab.”<sup>183</sup> The samples “were then sent to a lab where a technician compared the cheek cell DNA to DNA from the offending fecal matter.”<sup>184</sup> The two suspected employees were not a match and ultimately filed suit under GINA.<sup>185</sup>

The Court ruled in favor of Mr. Lowe and Mr. Reynolds, stating that “the plain language of the statute provides that employers may not ‘request . . .

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<sup>175</sup> Barken, *supra* note 171, at 575.

<sup>176</sup> See MARIA L. ONTIVEROS ET AL., EMPLOYMENT DISCRIMINATION LAW: CASES AND MATERIALS ON EQUALITY IN THE WORKPLACE 24 (9th ed. 2016) (describing in Title VII and ADA claims that “[a]n individual must satisfy two statutory requirements in order to bring a civil action: (1) timely file a charge with the EEOC, and (2) timely file a complaint in federal court within 90 days of receipt of the right-to-sue notice from the EEOC”).

<sup>177</sup> 42 U.S.C. § 2000ff-7(a) (2008).

<sup>178</sup> Phillip K. Vacchio & Joshua L. Wolinsky, *Genetic Information Nondiscrimination Act of 2008: It’s in Title VII’s Genes*, 29 HOFSTRA LAB. & EMP. L.J. 229, 236 (2011); see 42 U.S.C. § 2000ff-7(a).

<sup>179</sup> Vacchio, *supra* note 178, at 236.

<sup>180</sup> See generally *McCleskey v. Kemp*, 48 U.S. 279, 298-99 (1987) (holding that the “racially disproportionate impact” in Georgia’s 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”).

<sup>181</sup> Natasha Gilbert, *Why the ‘devious defecator’ case is landmark for US genetic-privacy law*, NATURE (June 25, 2015), <https://www.nature.com/news/why-the-devious-defecator-case-is-a-landmark-for-us-genetic-privacy-law-1.17857>.

<sup>182</sup> *Lowe v. Atlas Logistics Group Retail Services, LLC*, 102 F.Supp.3d 1360, 1361 (N.D. Ga. 2015).

<sup>183</sup> Philip Miles, *\$2.25 Million GINA Verdict in the “Case of the Devious Defecator,”* LEXISNEXIS LEGAL NEWSROOM (June 25, 2015, 5:20 PM), <https://www.lexisnexis.com/legalnewsroom/labor-employment/b/labor-employment-top-blogs/archive/2015/06/25/2-25-million-gina-verdict-in-the-quot-case-of-the-devious-defecator-quot.aspx>; *Lowe*, 102 F.Supp.3d at 1361.

<sup>184</sup> Miles, *supra* note 183; *Lowe*, 102 F.Supp.3d at 1361.

<sup>185</sup> *Lowe*, 102 F.Supp.3d at 1361; see Gilbert, *supra* note 181.

genetic information with respect to an employee.”<sup>186</sup> Additionally the court held that GINA broadly defines the term ‘genetic information’ “to include information about an individual’s ‘genetic test,’ such as the [test] of Lowe’s and Reynold’s DNA here,” and ultimately concluded that this was a violation of GINA.<sup>187</sup> This application was a broad interpretation of GINA and thus increases the scope of what the law covers.<sup>188</sup> Jessica L. Roberts, director of the Health Law and Policy Institute at the University of Houston Law Center stated that “even if an employer, as in this case, did not seek an employee’s DNA to look for medical conditions, it was getting a trove a data that it arguably should not have.”<sup>189</sup> Additionally, Ms. Roberts recognized that this raises the main concern for individuals that once an employer “gained access to [DNA], it could have theoretically tested for all kinds of other things, including issues relating to health, and used that information to discriminate.”<sup>190</sup>

This case shows that there are successful outcomes for plaintiffs when it comes to the few areas that GINA is designed to protect and expanding GINA into other spheres should allow individuals with similar problems in areas outside of employment and health insurance context to be able to seek justice when their genetic information is improperly utilized.

#### E. Proposed Improvements to GINA

When GINA was passed it was seen as “the first civil rights bill of the new century.”<sup>191</sup> Unlike many before it, it was forward-looking by applying to a new form of discrimination that was not yet common. Expanding GINA would provide protections for individuals who are treated adversely because of their genetic information in a variety of settings.<sup>192</sup> As genetic testing is becoming more frequent and available, especially in the direct-to-consumer testing market, problems arise for individuals outside of the employment and health insurance contexts. GINA needs to catch up with the technology to provide individuals with adequate protection of their genetic information.

HIPAA and GINA only set a national floor for protections against genetic discrimination in employment and health insurance contexts and do not preempt more restrictive state laws.<sup>193</sup> Accordingly, many states have created more stringent guidelines when it comes to protecting individual’s genetic information from being used as a means to discriminate.<sup>194</sup> These more stringent state laws

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<sup>186</sup> Lowe, 102 F.Supp.3d at 1370.

<sup>187</sup> *Id.*

<sup>188</sup> *Id.*

<sup>189</sup> See Gina Kolata, *Strange Violation of a Genetics Law*, N.Y. TIMES, June 2, 2015, at D6.

<sup>190</sup> *Id.*

<sup>191</sup> GENETIC FAIRNESS, *President Bush Signed GINA Into Law!*, <http://www.geneticfairness.org/act.html> (last visited Sept. 18, 2018).

<sup>192</sup> Sarah Zang, *The Loopholes in the Law Preventing Genetic Discrimination*, THE ATLANTIC (Mar. 13, 2017), <https://www.theatlantic.com/health/archive/2017/03/genetic-discrimination-law-gina/519216/> (stating the national limits of GINA and that some states have expanded GINA to protect citizens in additional settings).

<sup>193</sup> NAT’L HUMAN GENOME RES. INST., *Genetic Discrimination and Other Laws* (Apr. 17, 2017), <https://www.genome.gov/27568503/genetic-discrimination-and-other-laws>.

<sup>194</sup> *Id.* (stating that 17 states have additional laws restricting the use of genetic



that include a higher level of protection than offered in GINA are micro examples of what GINA could be if it was broadened.

California is progressive when it comes to genetic discrimination, evidenced by its expansive anti-discrimination law, known as CalGINA.<sup>195</sup> CalGINA expands GINA by including protection to additional areas including: “housing, provision of emergency services, education, mortgage lending and elections.”<sup>196</sup> Additionally, it extends the prohibition on genetic discrimination to employers, who have five or more employees. Whereas, GINA only applies to employers who employ fifteen or more people.<sup>197</sup>

Connecticut law is broader than California’s law and applies “to employers with three or more employees.”<sup>198</sup> A reform to GINA needs to allow coverage of entities that collect genetic information. Alternatively, a reform could “apply protections to the data itself, rather than making them dependent on who has the data.”<sup>199</sup> Additionally, Connecticut uses a broader definition of genetic information: “information about genes, gene products or inherited characteristics that may derive from an individual or family member.”<sup>200</sup> In *Burns v. Department of Public Safety*, the court held that specific intent is not an element requisite to the Connecticut Fair Employment Practices Act prohibiting an employer from requesting or requiring genetic information from an employee.<sup>201</sup> GINA should adopt this approach to overcome the burden of proving specific intent when bringing a claims. If GINA were amended to exempt the showing of specific intent for cases involving an employer or insurance company, more individuals would likely be successful in bringing claims regarding the protection of their genetic information. An amended GINA could dissuade employers and insurance companies from getting their hands on this information in the first place.

Michigan requires “healthcare providers to obtain written informed consent from an individual prior to pre-symptomatic or predictive genetic testing” making it more expansive than GINA.<sup>202</sup> Requiring the express written consent of the patient prior to genetic testing equips the individual with more knowledge about what they are doing, and what information they are potentially sharing. The Michigan Department of Health and Human Services satisfies the state’s written informed consent laws by providing sample booklets to individuals obtaining genetic testing.<sup>203</sup> This booklet provides definitions for common

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information in determining coverage for life insurance).

<sup>195</sup> S.B. 559, 2011 Leg., Reg. Sess. (Cal. 2011).

<sup>196</sup> ELECTRONIC FRONTIER FOUND., *Genetic Information privacy*, <https://www.eff.org/issues/genetic-information-privacy> (last visited Nov.18, 2018).

<sup>197</sup> Hunton & Williams LLP, *California Passes Law Prohibiting Discrimination Based on Genetic Information*, HUNTON EMPLOY. & LAB. PERSPECTIVE (Oct. 21, 2011), <https://www.huntonlaborblog.com/2011/10/articles/employee-privacy/california-passes-law-prohibiting-discrimination-based-on-genetic-information>.

<sup>198</sup> Parkman, *supra* note 75, at 515.

<sup>199</sup> ELECTRONIC FRONTIER FOUND., *supra* note 196.

<sup>200</sup> Conn. Gen. Stat. § 46a-60(a)(11) (2017).

<sup>201</sup> *Burns v. Dep’t of Public Safety*, 973 F.Supp.2d 141, 157-58 (D. Conn. 2013) (quoting *Evening Sentinel v. Nat’l Org. for Women*, 168 Conn. 26, 33 (1975)).

<sup>202</sup> Parkman, *supra* note 75, at 514; MICH. COMP. LAWS § 333.17020(6) (2000).

<sup>203</sup> MICH. DEPT. OF HEALTH & HUMAN SERVS., *Informed Consent for Genetic Testing*:

genetic testing and other medical terms.<sup>204</sup> Additionally, the booklet includes a frequently asked questions section, a discussion addressing the benefits and risks of genetic testing and includes a model form for physician use.<sup>205</sup> On this form it explicitly states, “I have discussed the benefits and risks of this genetic test with my physician and . . . understand some genetic tests can involve possible medical, psychological or insurance issues for my family and me.”<sup>206</sup> This type of comprehensive informational booklet and waiver is what should be required under GINA to provide individuals access to this information and to help them understand the benefits, and most importantly, the risks of submitting to genetic testing.

Oregon also surpasses GINA by “requiring individual consent before a covered entity can obtain, retain, or disclose individually identifiable genetic information, and allowing an individual to inspect, request correction of, and obtain their genetic records.”<sup>207</sup> It also requires “patient notification and the opportunity to opt-out of possible anonymous or coded use of genetic information by the covered entity or a third party.”<sup>208</sup> Oregon gives “patients the right to refuse to have their information or biological samples used for research”, and can include a “blood sample, urine sample, or other materials collected from the body.”<sup>209</sup> Therefore, health care providers in Oregon “must notify their patients that any specimens or health information collected will be available for . . . research unless the ‘patient opts’” out by completing a written form and submitting it to their health care providers.<sup>210</sup> This severely limits the types of research that can be done without first obtaining a patients informed consent.<sup>211</sup> Knowledge is essential to reaching autonomy between the person receiving genetic testing and the company performing the tests. GINA would be more effective in protecting an individual’s genetic information if it were to include strict informed consent laws, similar to Oregon and Michigan.

While it would be easier for Congress to leave it up to the states to provide for additional protections for genetic based discrimination, it raises additional issues, particularly regarding the inconsistencies in these laws from state to state. Some states protect individuals based on the type of policy they have, while other states do not offer protections beyond the minimum federal requirements. Additionally, “since hereditary [] predispositions are by nature a family affair – the [individual] initially seeking genetic testing could live in a state with strong legislative protections while their potentially at-risk relatives could reside in states with no protections.” GINA addressed this problem in a narrow context,

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*Patient Education Information for Use with the Michigan Model Consent Form for Genetic Testing* (2015), [http://www.michigan.gov/documents/InformedConsent\\_69182\\_7.pdf](http://www.michigan.gov/documents/InformedConsent_69182_7.pdf).

<sup>204</sup> *Id.*

<sup>205</sup> *Id.*

<sup>206</sup> *Id.*

<sup>207</sup> Parkman, *supra* note 75, at 515; OR. REV. STAT. § 192.531-192.549 (2017); OR. REV. STAT. § 746.135(1) (2017).

<sup>208</sup> Parkman, *supra* note 75, at 515; OR. REV. STAT. § 192.537.

<sup>209</sup> OR. HEALTH & SCI. UNIV., *Genetic Privacy*, <http://www.ohsu.edu/xd/about/services/information-technology/information-privacy-security-ips/state-federal-regulations/Genetic-Privacy.cfm> (last visited Nov. 16, 2018).

<sup>210</sup> *Id.*

<sup>211</sup> *Id.*

by creating a national floor of protections; however, a revamped GINA could provide additional protections to everyone in the United States and not rely on state legislatures to take actions on their own.

### III. CONCLUSION

GINA was a major progressive measure for legislatures when it came to protecting genetic information. However, there are still certain subject areas that require further protection. GINA should be modified using states with stricter laws as guidelines for the appropriate use of genetic information, such as Oregon. The first step to more comprehensive protections of individual's rights is increasing the knowledge and information that consumers receive before consenting to any genetic testing. This could be done by requiring DNA testing providers to provide potential consumers with information that illustrate the potential benefits and disadvantages of the testing. Another option would be to require individuals to take an online course explaining the benefits and disadvantages before they are permitted to participate in genetic testing. Secondly, as technology continues to develop and evolve over time, GINA needs to do the same and evolve its protections to apply anywhere discrimination may take place.