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The United States Should Take a Page Out of Canadian Law When It Comes to Privacy, Genetic and Otherwise

Ashley Rahaim*

Genetic information is intimate and telling data warranting privacy in public and private realms. The privacy protections offered in the United States and Canada vastly differ when it comes to genetic privacy. Search and seizure law mirrors the privacy gap in the countries, as well as their treatment of DNA database information.

This note explores the foreshadowing of the creation of genetic privacy laws and their varying levels of protection based on the way private information was treated by state actors through search and seizure caselaw, the creation of legal precedent, and the treatment of intimate personal data in the form of blood or DNA. The note will also address where the United States Genetic Information Non-Discrimination Act of 2008 fails to truly guard the American genetic information and the dangers that come with that gap.

* Editor-in-Chief, University of Miami Inter-American Law Review, Volume 54; J.D. Candidate 2023, University of Miami School of Law; B.S. 2020, Legal Studies with a Minor in Biomedical Sciences, University of Central Florida. This note is for the women who cannot get their genes tested for fear of insurance issues in the United States and represents my love of science, law, and the intersection they create. Thank you to the IALR board for your continued support and hard work in the editing process for my note and the rest of volume 54. To my advisors Professor Gabriel Scheffler and Professor Rosario Isasi, thank you for your invaluable advice and guidance. To my mom, thank you for the sacrifices that you made to get me to this point, the space to explore my interests when they changed, and the love and support that made me and this note what it is today.

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I. INTRODUCTION

Americans felt a sense of security in their information and homes due to the protections offered by the Fourth Amendment.¹ Canadians enjoy an almost mirror counterpart to the Fourth Amendment in the Canadian Charter of Rights and Freedoms, which enumerates the right to be free from “unreasonable search or seizure.”² These protections guard homes, belongings, and privacy.³ However, both countries’ respective privacy laws differ when it comes to the

¹ See U.S. CONST. amend. IV (“The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated . . .”).

² See Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, *being* Schedule B to the Canada Act 1982, s8 (Can).

³ See *id.*; U.S. CONST. amend. IV.

privacy of a citizen's genetic material.⁴ Both countries' privacy differences stem from the principles set forth in their respective caselaw from ranging from how to secure a warrant to when and in what instance DNA and blood samples can be collected.⁵ Criminal law has used DNA, fingerprints, and other identifiers to solve crimes for decades.⁶ However, the way that Canada keeps their DNA samples and the protections around them versus the United States highlights the disparity of protection present for American citizens which spans from the dawn of DNA's utilization.⁷ The United States continues to allow their state actors and private companies to utilize DNA in ways that Canada seeks to prohibit, which not only protects their citizens from discrimination, but also protects privacy as a whole.⁸

However, to understand why genetic information must be protected it is integral to understand what genetic testing is. Genetic testing provides patients, through the help of a healthcare provider, a way to determine what particular genes in their genome have mutations and how those mutations may affect their life in the future.⁹ Genetic testing has an interesting caveat: just because there is a mutation present in a person's genome, that does not mean that the mutation will manifest into a disease.¹⁰ Additionally, not all mutations have been linked to diseases, or are even found at this time.¹¹

⁴ *Compare* Genetic Non-Discrimination Act, S.C. 2017, c 3 (Can.) (offering protections for individuals' genetic results with the exception of certain healthcare situations); *with* Genetic Information Nondiscrimination Act, Pub. L. No. 110-233, 122 Stat. 881 (2008) (offering protections for individuals' genetic information in employment and the purchase of health insurance).

⁵ *See infra* Part II-III.

⁶ Michelle Hibbert, *DNA Databanks: Law Enforcement's Greatest Surveillance Tool?*, 34 WAKE FOREST L. REV. 767, 769 (1999).

⁷ *See id.*; *DNA Data Bank Legislation – Consultation Paper 2002*, GOV'T OF CAN. <https://www.justice.gc.ca/eng/cons/dna-adn/code.html> (last updated Sept. 7, 2021).

⁸ *See supra* note 6-7 and accompanying text.

⁹ *See Genetic Testing*, MAYO CLINIC, <https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827> (“Genetic testing involves examining your DNA, the chemical database that carries instructions for your body's functions.”).

¹⁰ *See id.*

¹¹ *Id.*

Genetic testing entered the consumer market in the early 2000s, while still operating in the healthcare industry; people gained the option to participate in direct-to-consumer genetic testing, which removed the need for a medical professional to learn about their genetic material.¹² For example, 23andMe kicked off their direct-to-consumer genetic testing company in December 2007; their business consists of collecting a DNA sample from their consumers and then turning around a genome panel with their DNA.¹³ Ancestry.com is another direct-to-consumer genetic testing company that provides traces of a consumer's ethnic backgrounds with their samples.¹⁴ When direct-to-consumer genetic testing began around the early 2000s, the testing was so expensive that it prevented certain individuals from taking part in the new technology.¹⁵ Now, as prices have dropped, there is greater accessibility of at home genetic testing.¹⁶ Because of that, people have been able to determine their risk for diseases like cancer and Alzheimer's.¹⁷ However, determining one's genetic risks can create unanticipated disadvantages for a consumer, such as increased costs of American life insurance.¹⁸ Genetic privacy is intimately linked to these discriminatory insurance practices because the United States has repeatedly sought to protect law enforcements collection of information from citizens while Canada seeks to protect private interests, thus leading to less stringent genetic privacy laws and allowing for this private sector discrimination.¹⁹ Canada circumvented this issue entirely through their genetic

¹² See Megan A. Allyse, PhD et al., *Direct-to-Consumer Testing 2.0: Emerging Models of Direct-to-Consumer Genetic Testing*, 93 SYMPOSIUM ON PRECISION MEDICINE 113, 113-14 (2018).

¹³ *Id.*

¹⁴ *Id.*

¹⁵ *Id.* at 114.

¹⁶ *Id.* At this point genetic testing had dropped from the price of around \$1,000 to \$100 in 2012 for 23andMe.

¹⁷ See Rob Stein, *Results of At-Home Genetic Tests For Health Can Be Hard To Interpret*, NPR (June 18, 2018, 4:58 AM), <https://www.npr.org/sections/health-shots/2018/06/18/609750963/results-of-at-home-genetic-tests-for-health-can-be-hard-to-interpret>.

¹⁸ See *Can the results of direct-to-consumer genetic testing affect my ability to get insurance?*, MEDLINEPLUS, <https://medlineplus.gov/genetics/understanding/dtcgenetictesting/dtcinsurancerisk/> (last updated June 23, 2022).

¹⁹ See *infra* Part VII.

privacy act and its continual rededication to the protection of their citizens' data.²⁰

This note will provide a side-by-side comparison of the American Genetic Information Nondiscrimination Act (GINA) and the Canadian Genetic Non-Discrimination Act under the historical context of privacy protections, with a focus on the Fourth Amendment of the United States Constitution and its Canadian counterpart within the Charter of Rights and Freedoms. Part II of this note will analyze what is protected, in terms of tangible and intangible evidence, under Fourth Amendment jurisprudence from the Supreme Court of the United States. Part III will analyze in what circumstances an individual is protected under the Supreme Court of Canada when it comes to search and seizure in similar contexts to that of the Part II cases. In Part IV, the cases from both the United States and Canada will be directly compared with a nod to DNA databanks and how their protections are related to the privacy ideals of their respective country. In Part V, will feature the creation and implementation of GINA in the United States, the Genetic Non-Discrimination Act in Canada, and will contrast the privacy protections offered to citizens' genetic material in the different Acts. Part VI will discuss search and seizure law, DNA databanks, and the resulting genetic privacy laws. Part VII will analyze the different problems imposed on American citizens as a result of the gaps in GINA and its failure to provide restrictions on the public sector. Part VIII will conclude the reasons that American lawmakers should look to Canadian law when it comes to genetic privacy and offer suggestions for the legislative change that must occur.

II. PRIVACY AND THE FOURTH AMENDMENT: WHAT IS THE U.S. PROTECTING?

The Fourth Amendment sets forth the right of people within the United States "to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures" instigated by government intervention.²¹ In effect, the Fourth Amendment

²⁰ See *infra* Part V B.

²¹ U.S. CONST. amend. IV.

guarantees Americans the right to privacy in certain areas as interpreted by the decisions of the Supreme Court of the United States.²²

Katz v. United States is a landmark decision in American privacy rights related to search and seizures.²³ The Petitioner was allegedly making calls which communicated bets across state lines violating federal law.²⁴ Accordingly, the FBI wiretapped the photobooth where the Petitioner would make these calls, thus collecting evidence to convict him at both the trial court and court of appeals.²⁵ Granting *certiorari*, the Supreme Court of the United States took up the decision as to whether the public photobooth was protected under the Fourth Amendment, and therefore inadmissible to convict the Petitioner.²⁶ In Justice Harlan's concurrence, he created a two-fold test to determine if a "place" is protected under the Fourth Amendment since the Amendment offers protections to people instead of places.²⁷ The two prongs of the test are: (1) the person has a subjective "*expectation of privacy*" in the place in question, and (2) society as a whole would be able to accept that expectation as a "*reasonable*" one.²⁸ In light of the facts of the case, and following an analysis that would fall under Justice Harlan's test, the Court determined that when one person steps into a photo booth, shuts the door, and places a call, it is reasonable to assume that the person would hold an expectation of privacy.²⁹ This is because when the door is shut, it is not an area available to the public any longer.³⁰

Katz is important in this note to provide the background as to what is protected and how much in the United States.³¹ Genetic data is intimate information to a person, as it is the makeup for their entire being.³² While a phone call to a friend or family member regarding a dinner time could be publicly known with virtually no

²² *Id.*

²³ *See generally* *Katz v. United States*, 389 U.S. 347 (1967) (creating the two-part expectation of privacy test through Justice Harlan's concurrence).

²⁴ *Id.* at 348.

²⁵ *Id.* at 348-49.

²⁶ *Id.* at 349.

²⁷ *Id.* at 361 (Harlan, J., concurring).

²⁸ *Id.* at 361.

²⁹ *See Katz*, 389 U.S. at 352.

³⁰ *Id.*

³¹ *Id.* at 361 (Harlan, J., concurring).

³² *See Genetic Testing*, *supra* note 9.

consequences because there is no real monetary value in that information, the same cannot be said for genetic information.³³

Another central case in Fourth Amendment jurisprudence is *Chimel v. California*.³⁴ After an alleged burglary of a coin shop, police officers arrived at the Petitioner's home to arrest him and waited in the home for the Petitioner to return.³⁵ The officers had no search warrant, and even after the officers were denied consent to search the home, they proceeded under the guise that there was a lawful arrest of the Petitioner.³⁶ Through the search, the officers asked the Petitioner's wife to open drawers and shift the contents so they could find fruits of the burglary.³⁷ As a result of the search, officers located evidence of the crime, most notably the stolen coins that led to the Petitioner's conviction.³⁸ The Supreme Court of the United States granted *certiorari* to determine if there was a Fourth Amendment violation, meaning that the search conducted by the officers amounted to a search incident to lawful arrest.³⁹

The Court stated that searches incident to lawful arrest are to protect officers from an unknown weapon during the course of their arrest and here the scope of their search was far passed searching the Petitioner for a weapon.⁴⁰ Therefore, the search was an unlawful violation of the Fourth Amendment, and the officers needed a search warrant to conduct a search of that magnitude.⁴¹

Overall, the caselaw of the Supreme Court on the topic of the Fourth Amendment appears to offer more protection than people might anticipate.⁴² However, as will be shown in a latter case,

³³ See *Are My Genetic Results Private?*, KAILOS (June 8, 2021), <https://www.kailosgenetics.com/kailos-academy/are-my-genetic-results-private>.

³⁴ See generally *Chimel v. California*, 395 U.S. 752 (1969) (determining the boundaries of permissible searches incident to lawful arrest based on the robbery of a coin shop and a broad search performed by officers in the absence of a search warrant.).

³⁵ *Id.* at 753.

³⁶ *Id.* at 753-54.

³⁷ *Id.* at 754.

³⁸ *Id.*

³⁹ *Id.* at 755.

⁴⁰ *Chimel*, 395 U.S. at 764.

⁴¹ *Id.* at 768.

⁴² See generally *id.* (holding that without a warrant, a search of an arrestee's home was outside the scope of a permissible search incident to lawful arrest); *Katz v.*

Maryland v. King, other information, specifically a person's DNA profile does not need a warrant like was required to make the search valid in *Chimel*.⁴³ Similar to that of the automatic collection of DNA in *King* lies a driving under the influence ("DUI") case, *Mitchell v. Wisconsin*, that addressed what options police officers possess when there is a suspected DUI but the suspect cannot undergo a breathalyzer test.⁴⁴

In the case of *Mitchell v. Wisconsin*, an officer saw a seemingly intoxicated person, the Petitioner, enter his car and proceed to drive.⁴⁵ Accordingly, the officer conducted a routine DUI traffic stop, collected the Petitioner's Blood Alcohol Concentration ("BAC")—which was three times the legal limit at 0.24%—and proceeded to arrest the Petitioner.⁴⁶ Under the applicable procedures, a more accurate BAC level is required for DUI cases, and the Petitioner would undergo another BAC breathalyzer test upon arriving at the police station.⁴⁷ When they arrived, the Petitioner was unconscious and therefore unable to perform the breathalyzer test.⁴⁸ The officers then transported the Petitioner to the hospital where a blood BAC was collected and read at a 0.222%, which was still over double the legal limit in the State of Wisconsin.⁴⁹ The Petitioner was convicted at the trial court of DUI driving and at the court of appeals there were two certified questions sent the Supreme Court of Wisconsin who affirmed the conviction.⁵⁰ The Supreme Court of the United States then granted *certiorari* to ascertain whether blood BAC tests in the event of an unconscious suspect are warrantless searches under the Fourth Amendment.⁵¹

The Court determined that there was a "compelling need [which] justifies a warrantless search" because waiting on a warrant created an exigent circumstance under the exigency doctrine and the fact

United States, 389 U.S. 347 (1967) (holding that a telephone booth contained a reasonable expectation of privacy).

⁴³ See *Katz*, 389 U.S. at 347; *Maryland v. King*, 569 U.S. 435, 443 (2013).

⁴⁴ *King*, 569 U.S. at 443; *Mitchell v. Wisconsin*, 139 S. Ct. 2525, 2531 (2019).

⁴⁵ *Mitchell*, 139 S. Ct. at 2532.

⁴⁶ *Id.*

⁴⁷ *Id.*

⁴⁸ *Id.*

⁴⁹ *Id.*

⁵⁰ *Id.*

⁵¹ *Mitchell*, 139 S. Ct. at 2532.

that BAC naturally degrades in the human body rather quickly.⁵² Additionally, the Court stated that exigency was created to protect evidence and even getting telephonic warrants could have detrimental effects on the needs of safety and public health.⁵³ In sum, an officer may order a warrantless blood BAC test where the driver is not in the condition to undergo the alternative breathalyzer test and the blood BAC test will not be rendered a violation of the Fourth Amendment.⁵⁴ However, the Court did leave open the possibility that there could be a case where procuring a warrant for a blood BAC test would be consistent with public need and not get in the way of any additional duties.⁵⁵

Turning to *Mitchell*, the difference in needing a blood test of a potentially drunk driver to protect the public from a known and preventable danger and the genetic material of someone to change the insurance coverage offered to someone are not comparable.⁵⁶ The next case is much more closely related to the principles of genetic privacy.⁵⁷ In the case of *Maryland v. King*, a Maryland Act allowed collection of an arrestee's DNA if they had been charged for a series of different crimes, and the Supreme Court of the United States took the case to determine if the statute violated the Fourth Amendment.⁵⁸

The Appellant was arrested in 2009 “and charged with first- and second-degree assault for menacing a group of people with a shotgun.”⁵⁹ In turn, as part of the booking system implemented by the police department, the Appellant's cheek was swabbed with a “buccal swab” used to collect his DNA.⁶⁰ At the time of the DNA

⁵² *Id.* at 2537.

⁵³ *Id.* at 2538.

⁵⁴ *Id.* at 2539.

⁵⁵ *Id.*

⁵⁶ *Id.* at 2534; Michelle Andres, *Genetic Tests Can Hurt Your Chances of Getting Some Types of Insurance*, NPR (August 7, 2018, 9:00 AM), <https://www.npr.org/sections/health-shots/2018/08/07/636026264/genetic-tests-can-hurt-your-chances-of-getting-some-types-of-insurance>.

⁵⁷ *See generally* *Maryland v. King*, 569 U.S. 435 (2013) (upholding a Maryland statute allowing for the DNA collection of suspects who have been arraigned for certain crimes).

⁵⁸ *See generally id.*

⁵⁹ *Id.* at 439.

⁶⁰ *Id.*

collection, there was an Act in effect in Maryland that allowed for the automatic collection of DNA of any individual who had been charged with an attempt or commission of a violent crime or burglary.⁶¹ The DNA of the individual, under the Act, could not however be put into the criminal DNA database until after their arraignment or upon their consent.⁶² As a result of the Appellant's buccal swab, he was identified as the suspect in a rape case from 2003 and convicted against his assertions that the DNA sample collected at his initial booking violated his Fourth Amendment rights.⁶³

The Supreme Court of the United States upheld that the Maryland Act was in fact Constitutional for the following reasons.⁶⁴ The Act serves a "legitimate government interest" to allow law enforcement to have "a safe and accurate way to process and identify the persons and possessions they must take into custody."⁶⁵ DNA identification of those charged with crimes are vital to not only identify the individual in question, but determine their history of criminal activity, protect the staff of the facility in which the individual would be detained, plan for the future prosecution of the individual, consider their criminal history in the lens of bail determinations, and potentially exonerate the wrongfully accused.⁶⁶ Additionally, the intrusion into the individual's expectation of privacy is minimal in comparison to the "substantial government interest."⁶⁷

III. PRIVACY AND THE CANADIAN CHARTER OF RIGHTS AND FREEDOMS: WHAT IS CANADA PROTECTING?

Canada has Section 8 of the Canadian Charter of Rights and Freedoms which contains the Canadian equivalent of the Fourth Amendment.⁶⁸ The Canadian Charter of Rights and Freedoms substantially mirrors the wording of the Fourth Amendment:

⁶¹ *Id.* at 443.

⁶² *Id.* at 443.

⁶³ *Maryland*, 569 U.S. at 441.

⁶⁴ *Id.* at 449, 450-55, 461.

⁶⁵ *Id.* at 449.

⁶⁶ *Id.* at 450-55.

⁶⁷ *Id.* at 461.

⁶⁸ *See* U.S. CONST. amend. IV; *see also* Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, *being* Schedule B to the Canada Act 1982, s8 (Can.).

“[e]veryone has the right to be secure against unreasonable search and seizure.”⁶⁹ While these provisions have virtually the same wording, the way that they are implemented proves quite different.⁷⁰ Like in the previous section of this note, this section will follow that structure: summarizing Canadian caselaw from the Supreme Court of Canada. The first case in this section will be *Canada (Combines Investigation Acts, Director of Investigation and Research) v. Southam Inc.* (“Combines”) from 1984.⁷¹

In *Combines*, the Edmonton Journal, which was covered under Southam, Inc. was under investigation for violating the *Combines Investigation Act*.⁷² There was a certification that came from the Director of Investigation and Research for the *Combines Investigation Act* that said all of the information necessary to their investigation was going to be collected and that they had the authority to enter the premises; meanwhile Section 8 of the Canadian Charter of Rights and Freedoms was valid law for two days at that point.⁷³ Accordingly, in the course of the case the dispute as to whether a warrant was needed to collect these papers ended up being a decision for the Supreme Court of Canada.⁷⁴

The Supreme Court of Canada through this inquiry created some of the standout rules of search and seizure law in Canada.⁷⁵ The case opinion in particular offered the outermost guideline of what is necessary for a valid warrant; a neutral arbiter who has the ability to properly balance both state and private interests in the Section 8 context.⁷⁶ This case, like *Katz*, is offered to introduce the search and seizure scheme for each country as the analysis narrows in scope towards privacy law and how its origins seem to have affected United States genetic privacy law as opposed to its Canadian counterpart.⁷⁷

⁶⁹ See *supra* notes 21, 68 and accompanying text.

⁷⁰ See discussion *infra* Section IV.

⁷¹ See *Canada (Combines Investigation Acts, Director of Investigation and Research) v. Southam Inc.*, [1984] 2 S.C.R. 145 (Can.).

⁷² *Id.*

⁷³ *Id.*

⁷⁴ *Id.*

⁷⁵ See *id.*

⁷⁶ *Id.*

⁷⁷ See *Canada (Combines Investigation Acts, Director of Investigation and Research) v. Southam Inc.*, [1984] 2 S.C.R. 145 (Can.); *Katz v. United States*, 389

As a parallel to the search incident to lawful arrest case, *Chimel v. California*, *R. v. Caslake*, is a Canadian Supreme Court decision that clarified the limits of searches incident to lawful arrest in Canada.⁷⁸ An officer saw the appellant seemingly hunting, but the Appellant stated that he was using the bathroom.⁷⁹ Nevertheless, when the Appellant left, the officer went back to the pseudo-bathroom area and found a trash bag of nine pounds of marijuana.⁸⁰ The officer then arrested the Appellant for possessing narcotics.⁸¹ The Appellant's car was impounded as a result of the arrest and the officer—who took the Appellant into custody—searched the impounded vehicle as was their routine practice.⁸² As a result of the search, over a thousand dollars in cash and about ½ a gram of cocaine was found.⁸³ “The appellant was convicted of possession of marijuana for the purposes of trafficking, and possession of cocaine.”⁸⁴ The Appellant attempted to suppress the evidence on the grounds that it was a violation of the “unreasonable search and seizure” clause of Section 8 of the Canadian Charter of Rights and Freedoms.⁸⁵

The Supreme Court of Canada determined that the search was in fact a violation of Section 8 for the following reasons.⁸⁶ The Court first brought in the *Combines* test which states that “only protected an individual's reasonable expectation of privacy, and that reasonableness is to be evaluated by balancing that privacy interest against the state's interest in law enforcement.”⁸⁷ Next, citing the decision in *R. v. Collins*, the Court stated that “a search must be authorized by law, the law itself must be reasonable, and the search must be

U.S. 347 (1967) (holding that a telephone booth contained a reasonable expectation of privacy).

⁷⁸ See generally *Chimel v. California*, 395 U.S. 752 (1969) (determining the boundaries of permissible searches incident to lawful arrest); *R. v. Caslake*, [1998] 1 S.C.R. 51 (Can.) (stating that the inventory search present in the case was not a permissible search incident to lawful arrest due to the large time gap between the arrest and the search).

⁷⁹ *R. v. Caslake*, [1998] 1 S.C.R. 51, para. 2 (Can.).

⁸⁰ *Id.*

⁸¹ *Id.* at para 3.

⁸² *Id.*

⁸³ *Id.*

⁸⁴ *Id.* at para. 4.

⁸⁵ *R. v. Caslake*, [1998] 1 S.C.R. 51, para. 4 (Can.).

⁸⁶ *Id.* at para. 10-1.

⁸⁷ *Id.* at para. 10.

carried out in a reasonable manner.”⁸⁸ As with American jurisprudence, searches incident to lawful arrest are meant to protect civilians and officers, and here the Court determined that those goals were not present.⁸⁹ The Court did not employ a bright line rule for the time frame in which a search incident to lawful arrest may occur but did note that it must be within a reasonable time frame and should be without “substantial delay.”⁹⁰ Therefore, since the time frame was so vast in this case and done as an inventory search as opposed to a search incident to lawful arrest, Section 8 was in fact violated.⁹¹ However, due to other caselaw present in Canada, the breach was dismissed on appeal and the evidence was still admitted.⁹²

Caslake gave a car, within the custody of police, the inability to be searched without a warrant for the purpose of an inventory search.⁹³ The decision present in *Caslake* allowed Canadian citizens to have an expectation in their property when it is in police custody, while still giving officers the right to protect themselves and other people through the grant of searches incident to lawful arrest.⁹⁴ This is the exact opposite holding in the case of *Colorado v. Bertine*.⁹⁵ In that United States case, the holding was that the Defendant was lawfully arrested and his car proceeding the arrest was impounded by the police, where there was an inventory search done on the car.⁹⁶ Since the inventory search was done in the regular course of police activity, it was lawful, and any evidence found was to protect the property of the Defendant.⁹⁷ Hence, it is not a violation of the Fourth Amendment.⁹⁸ Canada seems to not only provide better protections

⁸⁸ *Id.*

⁸⁹ *Id.* at para. 19.

⁹⁰ *Id.* at para. 24.

⁹¹ *R. v. Caslake*, [1998] 1 S.C.R. 51, para. 30 (Can.).

⁹² *Id.* at 36; *see also* *Colorado v. Bertine*, 479 U.S. 367, 369, 372 (1987) (describing an inventory search as a cataloging procedure in which police officers will determine the contents of a car protect the owner from theft and police from the risk of danger).

⁹³ *See* *R. v. Caslake*, [1998] 1 S.C.R. 51, para. 30 (Can.).

⁹⁴ *See id.*

⁹⁵ *See generally Bertine*, 479 U.S. at 374 (holding that the Fourth Amendment is not violated by inventory searches of vehicles in normal police procedure).

⁹⁶ *Id.* at 369

⁹⁷ *Id.* at 373.

⁹⁸ *See id.* at 369, 371-372 (1987).

regarding search and seizures, but also, as the later sections of the note will establish, the county's genetic privacy laws seem to provide heightened privacy protections than the United States.⁹⁹

The next case, *R. v. S.A.B.*, addresses bodily autonomy in the form of a DNA sample of the appellant and whether the sample was lawful when analyzed under the rights retained under Section 8 of the Charter of Canadian Rights and Freedoms.¹⁰⁰ Analyses of how courts approach bodily autonomy, as opposed to searches of homes, provide a greater understanding of what protections are offered or expected in cases regarding genetic freedoms.¹⁰¹ This case provides a Canadian parallel to the United States cases of *Mitchell v. Wisconsin* and *Maryland v. King*, which addressed protections of blood and DNA samples in Part II.¹⁰²

In *R. v. S.A.B.*, the Supreme Court of Canada had to determine if DNA warrants violated an individual's expectation of privacy present in Section 8.¹⁰³ In the case, there was a 14-year-old girl who suffered a sexual assault which resulted in a pregnancy.¹⁰⁴ After undergoing an abortion, fetal tissue was collected by the police.¹⁰⁵ Utilizing an *ex parte* warrant, "the police seized a blood sample from the appellant and conducted DNA analysis."¹⁰⁶ Two of the five blood samples collected from the appellant led to unusable results, but "five of the seven DNA samples . . . appellant were conclusive and established the probability that S.A.B. was not the father of the fetus to be 1 in 10 million."¹⁰⁷ The appellant was convicted, and the Supreme Court of Canada then had to determine if the warrant

⁹⁹ See *id.*; *R. v. Caslake*, [1998] 1 S.C.R. 51, para. 24, 30 (Can.). Later in this note the differences between the United States GINA Law and the Canadian Genetic Non-Discrimination Act will be evaluated on what they protect and what they fail to protect in terms of genetic privacy. See *infra* Part V A-C.

¹⁰⁰ See *R. v. S.A.B.*, [2003] S.C.J. No. 61., para. 1, 36 (Can.).

¹⁰¹ See *infra* Part IV-VI.

¹⁰² *Id.* See generally *Mitchell v. Wisconsin*, 139 S. Ct. 2525, 2531 (2019); *Maryland v. King*, 569 U.S. 435 (2013).

¹⁰³ *R. v. S.A.B.*, [2003] S.C.J. No. 61., para. 1 (Can.).

¹⁰⁴ *Id.* at para. 22.

¹⁰⁵ *Id.*

¹⁰⁶ *Id.* at para. 23.

¹⁰⁷ *Id.* at para. 24.

provisions for DNA in the Criminal Code were a violation of the constitution.¹⁰⁸

Section 8 protects an individual's reasonable expectation of privacy and to ensure that right is not violated, the court is tasked with determining whether "the public's interest in being left alone must give way to the government's interest in advancing its goals, notably law enforcement."¹⁰⁹ DNA evidence has the benefit of serving two purposes, it can find the culprit of a crime, but it can also exonerate the innocent.¹¹⁰ DNA evidence collection also comes with strict safeguards for the accused, "only non-coding DNA" is collected and it is only tested against specific samples.¹¹¹ Also, DNA misuse is strictly prohibited.¹¹² Accordingly, the Supreme Court of Canada determined that "[t]he DNA provisions contain procedural safeguards that protect adequately the multiple interests of the suspected offender."¹¹³

Looking at the conclusion in *R. v. S.A.B.*, it is important to look back at the reason for this note, the protection of genetic information.¹¹⁴ This case, which exemplified the Canadian safeguards to prevent an individual's DNA from being entered into a database without justification, was decided before the inception of the Canadian Genetic Non-Discrimination Act, and there were safeguards to prevent an individual's DNA from just entering into a database to be used in perpetuity unjustly.¹¹⁵ In the United States, the CODIS database has over two million DNA profiles, some of which should

¹⁰⁸ *Id.* at para. 27.

¹⁰⁹ *R. v. S.A.B.*, [2003] S.C.J. No. 61., para. 38 (Can.) (citing *Canada (Combines Investigation Act, Director of Investigation and Research) v. Southam Inc.*, [1984] 2 S.C.R. 145 (Can.)).

¹¹⁰ *Id.* at para. 54.

¹¹¹ *Id.* at para. 49; Shurgo K. Sen, *Non-Coding DNA*, NAT'L HUM. GENOME RSCH. INST., <https://www.genome.gov/genetics-glossary/Non-Coding-DNA> (last updated Apr. 18, 2023) ("Non-coding DNA corresponds to the portions of an organism's genome that do not code for amino acids, the building blocks of proteins.").

¹¹² *R. v. S.A.B.*, [2003] S.C.J. No. 61., para. 50 (Can.)

¹¹³ *Id.* at para 61.

¹¹⁴ *See id.*

¹¹⁵ *See id.* It is also important to note that the DNA Identification Act was enacted in 1998. See DNA Identification Act, SC 1998, c 37, Enactment Clause (Can.). At the time of its enactment, the statute only allowed for the collection of DNA samples from individuals who had been convicted of certain crimes. See *id.* at c 37 s 5.

be destroyed because the individual in question was not convicted, exonerated, or never charged for the crime they were arrested in connection with.¹¹⁶ One thing that is not widely known about CODIS—and the profiles that should no longer be within the system—is that the removal process of these profiles is arduous at times, especially for low income individuals.¹¹⁷ The way that these materials are treated exemplifies the lack of regard given to the DNA material of Americans, thus allowing the private sector to run amok with genetic information even after the implementation of federal genetic privacy laws.

IV. HOW SEARCH AND SEIZURE LAW FORESHADOWED THE LATER GAP IN THE U.S.'S AND CANADA'S GENETIC PRIVACY LAWS

The Bill of Rights was signed on December 15, 1791, and with it came the Fourth Amendment, the right to be free from “unreasonable searches and seizures.”¹¹⁸ Then in Canada on April 17, 1982, The Canadian Charter of Rights and Freedoms’ Section 8 took effect.¹¹⁹ It had virtually the same language of the United States’ Fourth Amendment.¹²⁰ Yet, even with over 190 years to develop search and seizure jurisprudence, Canada has surpassed the United States in its protections of its citizens through the use of this vital right.¹²¹ Through each of the cases analyzed in Parts II and III, the cases decided similar issues and led to different outcomes as to how the case would be handled and the rule that was created.¹²² Additionally, the creation and use of DNA databanks shows that the protection offered to intimate personal data, even when it should no

¹¹⁶ Elizabeth E. Joh, Essay, *The Myth of Arrestee DNA Expungement*, 164 UNIV. OF PA. L. REV. ONLINE 51, 51 (2015).

¹¹⁷ *Id.* at 53-4.

¹¹⁸ History.com Editors, *Bill of Rights is Finally Ratified*, HISTORY, <https://www.history.com/this-day-in-history/bill-of-rights-is-finally-ratified> (last updated Dec. 14, 2020); U.S. CONST. amend. IV.

¹¹⁹ Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, *being* Schedule B to the Canada Act 1982, s8 (Can).

¹²⁰ *See infra* notes 124-48 and accompanying text.

¹²¹ *See supra* Part II-III.

¹²² *See id.*

longer be held by the United States, falls short yet again to that of the Canadian counterparts.¹²³

Starting with the cases that helped to first define the boundaries of the search and seizure protections, *Katz* and *Combines*, *Katz* created, through its concurrence, the scheme that in order for there to be a place to be searched there must be a reasonable expectation of privacy held by someone and it must be recognizably reasonable.¹²⁴ *Combines* instead places the power to determine what would be a reasonable expectation of privacy to some degree in the hands of the arbiter.¹²⁵ Simply put, the arbiter is tasked to determine whose interest is better served in that factual instance of the issuance of a warrant.¹²⁶ In the United States warrants are issued upon probable cause, however in *Combines*, the Canadian Supreme Court adds a level of analysis that seems to be beneficial to their citizens in the foregoing caselaw.¹²⁷

In the second line of cases, the idea of a search incident to lawful arrest is explored.¹²⁸ In *Chimel*, the court concluded that the scope of the officer's search in that instance was too broad, but did allow for a search of the grabbing area to protect the safety of civilians and officers.¹²⁹ In *Caslake*, a similar rule was applied—after a lawful arrest officers are permitted to search an individual where there is “some reasonable basis for doing what the police officer did.”¹³⁰ However, the case itself made inventory searches effectively a violation of Section 8.¹³¹ In the United States, inventory searches are a common practice of law enforcement agencies since they were allowed by the case, *Colorado v. Bertine*, holding that since inventory searches are done in the regular course of police activity, they do not violate an individual's Fourth Amendment rights.¹³² Looking between the three cases, that is a large gap between what is lawful in

¹²³ See *supra* note 114-17 and accompanying text.

¹²⁴ *Katz v. United States*, 389 U.S. 347, 361 (1967) (Harlan, J., concurring).

¹²⁵ *Canada (Combines Investigation Acts, Director of Investigation and Research) v. Southam Inc.*, [1984] 2 S.C.R. 145 (Can.)

¹²⁶ *Id.*

¹²⁷ *Id.*; U.S. CONST. amend. IV.

¹²⁸ See *supra* notes 34-41, 78-99 and accompanying text.

¹²⁹ *Chimel v. California*, 395 U.S. 768 (1969).

¹³⁰ *R. v. Caslake*, [1998] 1 S.C.R. 51, para. 20 (Can.).

¹³¹ *Id.* at para. 30.

¹³² *Colorado v. Bertine*, 479 U.S. 367, 742 (1987).

the United States versus that of Canada when it comes to inventory searches.¹³³ This gap shows that the U.S. interest in allowing more freedom to law enforcement under the guise of *normal police activity* outweighs the interest in allowing people to be secure in their property and belongings—completely contrary to the Canadian approach.¹³⁴

The next cases to compare are *Mitchell* and *R. v. S.A.B.*; in each case, blood samples are collected from the Appellants, *Mitchell* for BAC and *S.A.B.* for a DNA comparison.¹³⁵ In *Mitchell*, there was absolutely no warrant gathered, and the decision was based on the exigency doctrine and the fact that BAC depletes over time.¹³⁶ However, in *S.A.B.*, not only was the warrant specific to DNA collection, but it also laid out exactly how the DNA was to be used and even what type of DNA was to be collected, only non-coding.¹³⁷

Finally, the last two cases to compare are *S.A.B.* and *King*.¹³⁸ In *King*, the Supreme Court allowed for DNA samples to be collected via buccal swab for an individual who has been charged with committing or attempting to commit a violent crime.¹³⁹ While the DNA sample cannot be put into a database without the individual's arraignment and the sample must be destroyed if the person is not convicted—the fact that there is no warrant required is a complete departure from that of the Canadian jurisprudence.¹⁴⁰ In *S.A.B.*, there was a warrant in place and the warrant itself had to comport with Section 8.¹⁴¹ In addition to that aspect, the *S.A.B.* warrant provided that the sample was only to be tested against the evidence—fetal tissue—in that specific case; the sample was explicitly not to be kept in perpetuity like the United States.¹⁴²

¹³³ See *supra* notes 129-33 and accompanying text.

¹³⁴ See *id.*

¹³⁵ See *Mitchell v. Wisconsin*, 139 S. Ct. 2525, 2532 (2019); *R. v. S.A.B.*, [2003] S.C.J. No. 61., para. 23 (Can.).

¹³⁶ *Mitchell*, 139 S. Ct. at 2532, 2537.

¹³⁷ *R. v. S.A.B.*, [2003] S.C.J. No. 61., para. 49 (Can.).

¹³⁸ See *supra* notes 58-67, 100, 102-15 and accompanying text.

¹³⁹ *King*, 569 U.S. at 443.

¹⁴⁰ *Id.* at 443-44; Joh, *supra* note 116, at 53 (stating that even though the DNA samples that no possess grounds to be held by law enforcement agencies often do not have individual friendly guidelines and are not regulated by federal law).

¹⁴¹ *R. v. S.A.B.*, [2003] S.C.J. No. 61., para. 49-51 (Can.).

¹⁴² *Id.* at para. 49.

The collection of DNA materials in *S.A.B.* and *King* have serious implications within their own countries' laws.¹⁴³ In Canada, under their DNA Databank Legislation and specifically in their DNA Identification Act, the law establishes different DNA databanks of "convicted offenders index," a "victims index," "a missing persons index, a relatives of missing persons index[,] a human remains index, and "a voluntary donors index."¹⁴⁴ However, as evident in the holding in *King*, the United States is apt to hold DNA of arrestees, and while it would be assumed that if someone is not convicted or even exonerated their DNA would be erased automatically, that is not always the case.¹⁴⁵ In particular some states require that you send in a request to remove your DNA in order for that profile to be expunged.¹⁴⁶ Meanwhile in Canada, one of the principles of the databank within the DNA Identification Act is "to protect the privacy of individuals with respect to personal information about themselves," and lists the safeguards that must be put in place for this principle to be fulfilled.¹⁴⁷ The fact that these safeguards are so vastly different, and that in order for a DNA collection in Canada there must be a conviction, only lends to the idea that DNA protections have and continue to be better in Canada due to their consistency in putting the privacy of their citizens over the aim of law enforcement principles.¹⁴⁸

V. PROTECTIONS TO GENETIC MAKEUP AND HOW THEY WERE IMPLEMENTED

a. *United States: GINA*

States began to protect genetic information beginning in the 1970s, but the federal government got involved by passing their first

¹⁴³ See *infra* notes 144-48 and accompanying text.

¹⁴⁴ DNA Identification Act, SC 1998, c 37, s 5 (Can.).

¹⁴⁵ *King*, 569 U.S. at 443; Sarah B. Berson, *Debating DNA Collection*, NAT'L INST. OF JUST. (Oct. 28, 2009), <https://nij.ojp.gov/topics/articles/debating-dna-collection#:~:text=All%20states%20with%20laws%20allowing,that%20their%20profile%20be%20expunged.>

¹⁴⁶ Berson, *supra* note 145.

¹⁴⁷ DNA Identification Act, SC 1998, c 37, s 4(c) (Can.).

¹⁴⁸ See *supra* notes 118-47 and accompanying text.

federal law regarding genetic information in 2008.¹⁴⁹ The United States passed the Genetic Information Non-Discrimination Act on May 21, 2008.¹⁵⁰ The Act was passed to prevent genetic discrimination of individuals in two specific situations: employment discrimination and discrimination when obtaining health insurance.¹⁵¹ Section 2 of the Act lays out findings Congress made when drafting the act: (1) advancements in genetic technology and the prevalence of genetic testing; (2) former State sterilization laws targeting people shown (or thought) to have genetic “defects”; (3) genetic discrimination based on the presence of certain genes in certain minority groups; (4) a history of “genetic discrimination in the workplace,” as shown in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1269 (9th Cir. 1998); and (5) the need for a “national and uniform basic standard . . . to fully protect the public from discrimination” in the face of multiple State laws that varied widely.¹⁵²

Title 1 of the Genetic Information Non-Discrimination Act’s establishes genetics law regarding health insurance.¹⁵³ Section 101 amends the Employee Retirement Income Security Act of 1974 by stating that when an insurance provider is providing a group health insurance plan, the insurance provider cannot raise the premiums in that plan after learning the genetic makeup of those insured.¹⁵⁴ Section 101(a) also states that an insurance company lacks the power to raise a group’s healthcare premium price simply because one person in the group manifests a disorder or disease; this manifestation also cannot be used to determine the health of other members under the plan and thus “further increase the premium for the employer.”¹⁵⁵

Later in this section, the Act explicitly forbids a health care insurance company from asking or requiring someone under a group

¹⁴⁹ Ellen Wright Clayton, et. al., *The Law of Genetic Privacy: Applications, Implications, and Limitations*, J. OF L. BIOSCIENCES NAT’L (May 14, 2019) at 1,7, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6813935/>.

¹⁵⁰ *Genetic Information*, U.S. DEP’T OF HEALTH & HUM. SERV., <https://www.hhs.gov/hipaa/for-professionals/special-topics/genetic-information/index.html> (last updated June 16, 2017).

¹⁵¹ *Id.*

¹⁵² *Id.*

¹⁵³ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, Tit. I, § 101-106, 122 Stat. 881, 882.

¹⁵⁴ § 101(a)(3)(A).

¹⁵⁵ § 101(a)(3)(B)(A).

health plan, or any of their family members, to get genetic testing or have their family member do the same; the health care provider also cannot require an individual to undergo a genetic test.¹⁵⁶ A group health plan provider under Section 101(b) may only request the results from a genetic test of a group member where: (1) it follows state and federal regulations; (2) the insured person participates in genetic testing results willingly; and (3) if the insured person chooses to refuse disclosure of their results such refusal would not affect their premium, “contribution amount,” or status of enrollment.¹⁵⁷ In terms of collecting genetic information, insurance companies cannot ask for, require, or buy genetic information of someone for the purpose of underwriting insurance plans, nor can a company do so before someone enrolls in one of their health insurance plans.¹⁵⁸ However, if the insurance provider gains information about an insured person’s genetic testing results due to “incidental collection,” that provider has not violated GINA.¹⁵⁹ Incidental Collection occurs as a result of “requesting, requiring, or purchasing of other information concerning any individual.”¹⁶⁰ GINA also protects embryos legally held by an individual through assisted reproductive technology and unborn fetuses being carried by a pregnant individual to the same degree as any living individual.¹⁶¹

Under Section 101(e), GINA amends the Employment Retirement Income Security Act (ERISA) of 1974 by giving the Secretary of Health and Human Services the power to penalize any entity that sponsors a group health plan or offers group health insurance coverage if that entity violates the genetic protections within the Act.¹⁶² The penalties for violation of the modified ERISA are noted as fines that range from \$100 to \$500,000 or 10% of the total amount paid by an employer for the previous taxable year on the group health plans depending on the circumstances, extent, and duration of the violation of this section of the Act.¹⁶³ Depending on the reason for

¹⁵⁶ § 101(b)(c)(1).

¹⁵⁷ § 101(b)(c)(4).

¹⁵⁸ § 101(b)(d)(1)-(2).

¹⁵⁹ § 101(b)(d)(3).

¹⁶⁰ *Id.*

¹⁶¹ § 101(c)(f).

¹⁶² § 101(e)(9)(A).

¹⁶³ § 101(e).

the violation, including whether it was willful or not, the Secretary maintains power to waive monetary penalties if the penalty is greater in severity than the committed violation.¹⁶⁴

Section 102 amends the Public Health Service Act.¹⁶⁵ For example, one amendment states there should be no genetic discrimination taking place among group health plans or increases in the premiums employers pay for group health plans because of a health condition of a person who is covered under the plan.¹⁶⁶ The section also protects persons under group health plans against requests for genetic testing, the use of genetic test results to determine the price of a health plan premium, and the use of genetic test results to inform insurance underwriting.¹⁶⁷ There is an exception enumerated in the section for the conditions under which an insurance company can *ask* a person under a group health plan to get genetic testing; however, the insurance company cannot *require* the person to get genetic testing.¹⁶⁸ The repercussions for the amendments to the Public Health Service Act range from fines of \$100 to \$500,000, or 10% of the total paid by the employer for the prior taxable year on the group health plans.¹⁶⁹ The fines are dependent on the violations by the insurance company and their nature.¹⁷⁰ Much like ERISA in Section 101 of the Act, there is the potential for the Secretary to change the fine paid by the insurance company if certain conditions are present.¹⁷¹ Additionally, where genetic information is found unintentionally, or the violation could not have been found by using a reasonable degree of diligence, there is no violation of GINA's provisions.¹⁷² In terms of the individual market, instead of group health plans, the amendments to the Public Health Service Act make virtually the same prohibitions for the individual health insurance market as they did for the group insurance provided by employers.¹⁷³ Insurance companies giving individual insurance plans, like group rates,

¹⁶⁴ § 101(e)(9)(E).

¹⁶⁵ § 102.

¹⁶⁶ *See* § 102(b)(1)(B)(b)(2).

¹⁶⁷ § 102(a)(2)(c)(1).

¹⁶⁸ § 102(a)(2)(c)(4).

¹⁶⁹ § 102(a)(5).

¹⁷⁰ *Id.*

¹⁷¹ § 102(a)(5)(3)(E).

¹⁷² § 101(a)(2)(c)(d)(3).

¹⁷³ *See* §§ 101, 102(b).

cannot ask or make mandatory genetic testing or use genetic test results in order to calculate premium rates for plans.¹⁷⁴

Section 103 amends the Internal Revenue Code to prevent people from facing discrimination in the form of heightened premiums as a result of one person under a group plan having a health condition for a reason similar to those in the amendments made through Sections 101 and 102.¹⁷⁵ Similar to Section 102, these amendments prevent insurance companies from asking for or making mandatory genetic tests and from gathering insured persons' genetic information.¹⁷⁶

Section 104 amends the Social Security Act in relation to Medigap, by penalizing genetic discrimination in the drafting of health insurance policy and providing rules regarding the treatment of fetuses and embryos.¹⁷⁷ Section 105 of GINA then adds a section to the Social Security Act which applies the regulations of HIPAA to genetic information.¹⁷⁸ Section 106 states the process in which Health and Human Services and the Department of Treasury shall communicate in order to create coordinated enforcement and uniform regulation.¹⁷⁹

Title II of GINA focuses on the effects of GINA regarding genetic discrimination in the realm of United States employment.¹⁸⁰ Section 201 lays out the definitions that will be used throughout Title II of GINA.¹⁸¹ The next section, 202, enumerates what employers cannot do based on the genetic discrimination protections offered in GINA.¹⁸² Under Section 202, employers cannot "fail or refuse to hire, or [] discharge" anyone based on their genetic makeup or, if the individual is hired, "request, require, or purchase genetic information" for any employee with the company or family member of an employee.¹⁸³ Section 202 allows for some exceptions to the rule

¹⁷⁴ § 101(b)(1)(B)(b)(1).

¹⁷⁵ § 103(a)(3).

¹⁷⁶ § 103(b).

¹⁷⁷ § 104(a)(E).

¹⁷⁸ § 105(a).

¹⁷⁹ § 106.

¹⁸⁰ Tit. II, § 201-213.

¹⁸¹ § 201.

¹⁸² § 202.

¹⁸³ § 202(a)-(b).

on collecting employee or family member genetic information as well as identifies when a violation has occurred.¹⁸⁴

Beyond employers, the protections in GINA apply to employment agencies through Section 203.¹⁸⁵ Under Section 203, similar genetic discrimination prohibitions imposed on employers, employment agencies may not “fail or refuse to refer for employment, or otherwise [] discriminate against” any individual for any reason that would prevent the individual from gaining employment opportunities due to their genetic makeup.¹⁸⁶ Additionally, an employment agency may not “request, require, or purchase genetic information” of any person, with some exceptions, or the agency risks violating GINA.¹⁸⁷

Section 204 governs the restrictions on Labor Organizations; under the section, they cannot prevent someone from joining the organization based on their genetic makeup or ask for, make necessary, or buy someone’s genetic information.¹⁸⁸ Section 204 creates exceptions regarding when genetic information may be known or collected without constituting a violation of the Act.¹⁸⁹

In the context of training programs, Section 205 provides that a violation occurs when “any employer, labor organization, or joint labor-management committee” that has control over any processes regarding training, discriminates against employees or applicants based on their genetic makeup in different listed situations.¹⁹⁰ The following section, 206, controls the confidentiality of genetic information.¹⁹¹ It states, “[i]f an employer, employment agency, labor organization or joint labor-management committee” has the genetic information of their “employee or member” then that information must be treated in the same manner in which other confidential medical information is treated.¹⁹² Additionally, when employers hold the genetic information of their employees, there are certain rules that must be followed in the storage and disclosure of that

¹⁸⁴ § 202(b)–(c).

¹⁸⁵ § 203.

¹⁸⁶ § 203(a)(1)–(2).

¹⁸⁷ § 203(b).

¹⁸⁸ § 204(a)–(b).

¹⁸⁹ § 204(b).

¹⁹⁰ § 205(a).

¹⁹¹ § 206.

¹⁹² § 206(a).

information.¹⁹³ Section 207 states the remedies afforded to parties whose genetic privacy rights are violated based on the law implicated by the employer's actions in concert with GINA.¹⁹⁴

Section 208 then provides the information needed regarding Disparate Impact; essentially stating that there is no cause of action under GINA because of the failure to follow the guidelines set forth in the Act regarding genetic information.¹⁹⁵ Section 208 also creates a commission that will be called the Genetic Nondiscrimination Study Commission, which will "review the developing science of genetics and [] make recommendations to Congress regarding whether to provide a disparate impact cause of action under [GINA]."¹⁹⁶ Section 209 then establishes that the Act should not be seen as constraining individuals' rights as limited under this title, or that an individual cannot bring an action against a party for a violation of this Act.¹⁹⁷

Section 210 states that GINA is not violated by "an employer, employment agency, labor organization, or joint labor-management committee" by "us[ing], acqu[iring], or disclos[ing] [] medical information that is not genetic information" about the manifested condition of a member or employee, even if the condition has a genetic basis.¹⁹⁸

Section 211 states that the regulations required to carry out the Act must be enacted no later than one year after the Title's enactment.¹⁹⁹ The next section, 212, authorizes the use of appropriations to carry out the provisions set forth in the Act.²⁰⁰

Title III includes other miscellaneous provisions that were drafted into GINA.²⁰¹ The severability section of GINA, Section 301, states that if one section of the Act is found to be unconstitutional, the lawful sections of GINA will remain in effect.²⁰² The last miscellaneous section of GINA is Section 302; this section amends the Fair Labor Standards Act and created penalties for violations of

¹⁹³ § 206(b).

¹⁹⁴ § 207(a).

¹⁹⁵ § 208(a).

¹⁹⁶ § 208(b).

¹⁹⁷ § 209(a)(1)-(2)(A).

¹⁹⁸ § 210.

¹⁹⁹ § 211.

²⁰⁰ § 212.

²⁰¹ Tit. III, § 301-302, 122 Stat. at 920.

²⁰² § 301.

child labor provisions.²⁰³ While GINA seemed to be the answer to protect what people hold nearest and dearest, it came with its own host of problems and gaps.²⁰⁴

b. Canada: Genetic Non-Discrimination Act

The Genetic Non-Discrimination Act prohibits any person from making genetic testing “a condition of” activities such as: (1) supplying someone with a good or service, (2) contracting with a person or upholding a preexisting contract with a person, “or [(3)] offering or continuing specific terms or conditions in a contract or agreement with that individual.”²⁰⁵ Any person that refuses the activities listed in the act on the grounds that such person has refused genetic testing is prohibited under the law.²⁰⁶ However, for a person who has already undergone genetic testing, Section 4 of the law prohibits required disclosures in order to perform any of the activities listed in Section 3 of the act or the refusal to perform any of the aforementioned acts because a person declines to divulge genetic test results.²⁰⁷ Section 5 prohibits any person engaging in any of the activities listed in Section 3 from “use[ing] or disclose[ing] the results of a genetic test of the individual without the individual’s written consent.”²⁰⁸ A person can release the genetic test results of another under if the situation fits within one of two exceptions: when “(a) a physician, a pharmacist, or any other health care practitioner in respect of an individual to whom they are providing health services; or (b) a person who is conducting medical, pharmaceutical or scientific research” for a person that is a subject of the research.²⁰⁹ The penalties for violating any of the prohibitions in the Act make a person, who is found guilty and therefore deemed liable on an indictment and charged a fine up to \$1,000,000, a prison sentence lasting longer than 5 years, or both.²¹⁰

²⁰³ § 302(a).

²⁰⁴ See Sarah Zhang, *The Loopholes in the Law Prohibiting Genetic Discrimination*, ATL. (Mar. 13, 2017), <https://www.theatlantic.com/health/archive/2017/03/genetic-discrimination-law-gina/519216/>.

²⁰⁵ Genetic Non-Discrimination Act, S.C. 2017, c 3 s 3 (Can.).

²⁰⁶ *Id.*

²⁰⁷ *Id.* at c 3 s 4.

²⁰⁸ *Id.* at c 3 s 5.

²⁰⁹ *Id.* at c 3 s 6.

²¹⁰ *Id.* at c 3 s 7.

c. How GINA and the Canadian Genetic Non-Discrimination Act Differ

While the United States' GINA law is much lengthier than that of the Canadian Genetic Non-Discrimination Act, the protections offered in the law fall short.²¹¹ There are only two instances in which genetic material is protected in the United States—employment and the purchase of health insurance—and while these are important protections, they are not as extensive as they should be.²¹² In turn, there are gaps present in the United States because of GINA that are just not present in Canada after the enactment of the Genetic Non-Discrimination Act.²¹³ Individuals are left open to discrimination when attempting to purchase “life, long-term care, and disability” insurance.²¹⁴ In Canada, genetic data is virtually fully protected besides the specific exceptions listed in the Non-Discrimination Act that are primarily for the health of the individual who had or will have a genetic test.²¹⁵

VI. FROM SEARCH AND SEIZURE TO DNA DATABANKS: HOW PRIVACY IN THOSE AREAS LED TO GINA AND ITS PITFALLS IN THE UNITED STATES

While search and seizure law and the law surrounding the privacy of someone's genetics may not seem to be related, the way that DNA is treated in the criminal context based on search and seizure law and the interpretation of the Fourth Amendment foreshadowed the use and protections of DNA in the public and private sections at the inception of GINA. The Canadian privacy laws from how warrants are to be obtained, to the illegality of inventory searches, and finally the heavily regulated collection of DNA samples in criminal

²¹¹ See *supra* Part V (describing the provisions of GINA in Part V, A and the provisions of the Canadian Genetic Non-Discrimination Act in Part V, B).

²¹² See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881.

²¹³ See *Precision Medicine: Genetic Discrimination*, AMA, <https://www.ama-assn.org/delivering-care/precision-medicine/genetic-discrimination> (last visited Apr. 20, 2023); see also Genetic Non-Discrimination Act, S.C. 2017, c 3, s 3 (Can.).

²¹⁴ *Precision Medicine: Genetic Discrimination*, *supra* note 213.

²¹⁵ See Genetic Non-Discrimination Act, S.C. 2017, c 3, s 6 (Can.).

cases, demonstrates how the Canadian government has repeatedly gone out of its way to protect individual privacy.²¹⁶ On the American side, the United States has virtually the same constitutional search and seizure provision, but continues to fall short in areas where there could—and should—be more protections for its citizens.²¹⁷ Therefore, as DNA was more widely used in criminal arenas, the law already present was the standard to create the next line of laws surrounding DNA databanks—the United States had less restrictive means than that of Canada and it has continued to show.²¹⁸ The creation, utilization, and regulation of DNA databanks only further foreshadow this issue.²¹⁹

Additionally, while search and seizure law does not apply to private companies, the Canadian Non-Discrimination Act avoids this problem by including private actors within the scope of their legislature.²²⁰ Another area that provides a clearer picture for how the United States and Canada protected genetic material before the boom in genetic testing services is the regulation of DNA Databanks. For instance, one of the United States DNA Databases—CODIS—contains DNA profiles that should have been long deleted.²²¹ In the alternative, Canada's genetic databases are reserved for the DNA samples of individuals who were convicted of certain crimes, not just arrested.²²² Canada is the prime example that there are ways to further criminal justice, but also prevent the scheme of *solving crime* from giving law enforcement free reign over such telling information.²²³ So this leads to the question yet again, why is it that there are more protections present in the United States for the shirts in your dresser drawer than your DNA information? This question causes even greater concern when someone who has undergone a genetic test attempts to purchase various types of insurance.²²⁴

²¹⁶ See *supra* Part IV.

²¹⁷ See *id.*

²¹⁸ See *id.*

²¹⁹ See *supra* notes 143-48 and accompanying text.

²²⁰ Genetic Non-Discrimination Act, SC 2017, c 3, s 3 (Can.).

²²¹ Joh, *supra* note 116, at 53.

²²² See DNA Identification Act, SC 1998, c 37, s 5 (Can.).

²²³ See *id.*

²²⁴ See Zhang, *supra* note 204.

VII. THE EFFECT OF GENETIC TESTING ON LIVES IN THE UNITED STATES AS OPPOSED TO CANADA IN THE PRIVATE SECTOR

The gap this note seeks to shed light on between Canadian and American genetic privacy protections is the danger genetic testing presents to those who have received abnormal test results.²²⁵ GINA does prevent certain parties—employers and health insurance companies—from requesting or discriminating against people based on their genetic material; it does not protect from discrimination by other entities like insurance companies, businesses, or even everyday people.²²⁶ The GINA drafters prioritized employment and health insurance discrimination because, according to Jeremy Gruber, “the arguments were strongest and the support was strongest” for protections in those areas.²²⁷ In theory, the thought process follows everyday logic because the purchase of life insurance is far less prevalent.²²⁸ Therefore, citizens that are looking to buy “life insurance, long-term care insurance, and disability insurance” have a lack of protection that can lead to problems securing coverage for these types of policies, having to pay too much for these policies, or even purchasing policies that lack the extent of coverage they desire.²²⁹ For example if someone tests positive for something like *BRCA1* which is known as the breast cancer gene they can be completely denied coverage for life insurance.²³⁰

There are concerns on the part of insurance companies about their underwriting processes—assuring their profitability by assessing the risk of the individuals they insure and charging them accordingly.²³¹ These insurance companies perform actuarial research

²²⁵ See Meredith Knight, *Life Insurance Companies Deny Coverage to Those with Cancer Genes like BRCA*, GENETIC LITERACY PROJECT (May 9, 2016), <https://geneticliteracyproject.org/2016/05/09/life-insurance-companies-deny-coverage-cancer-genes-like-brca/>.

²²⁶ See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881.

²²⁷ See Zhang, *supra* note 204. Jeremy Gruber was the previous Council for Responsible Genetics President.

²²⁸ *Id.*

²²⁹ *Id.*

²³⁰ Knight, *supra* note 225.

²³¹ Michael S. Blackwell, Comment, *Insurance, Employment, and the Genetic Information Discrimination Act of 2008*, 55 LOY. L. REV. 125, 133-35 (2009).

to properly group insureds based on their risk categories.²³² Insurance companies as a result of the greater use of genetic testing have voiced their concerns that without genetic information, they will not be able to perform their functions properly, but this is not completely true.²³³ A mutation does not mean that a person will absolutely manifest a disease, it is simply an indication of an irregularity in someone's genetic code.²³⁴ Therefore, while the argument of the insurance companies seems to have merit on its face, the science offers evidence that their need to put someone in a high-risk category based on a pathogenic mutation, which may never affect them, medically is illogical.²³⁵

Another variable that is not always known by consumers, and that further helps to refute the argument of insurance companies' actuarial data, is that DTC genetic testing is largely unreliable in certain cases.²³⁶ In fact, the way that certain DTC genetic testing is done—by checking for single nucleotide polymorphisms (“SNPs”)—has a false positive rate of 40%.²³⁷ While a false positive may not seem to be a large issue, it can potentially lead to large decisions in preventative care that are not necessary.²³⁸ So, revisiting the idea that BRCA1 is found in a woman's genetic test, a positive test could encourage a woman to undergo surgery to avoid the higher risk of cancer; and, if that surgery were based on false positive DTC results, a woman has just largely changed her body and has gone through immense pain for virtually no reason.²³⁹ This false result also comes with a less medically dangerous result; there are companies in the life insurance industry that will reject applications based

²³² *Id.*

²³³ *See id.*

²³⁴ *Genetic Disorders*, CLEVELAND CLINIC (Aug. 20, 2021), <https://my.clevelandclinic.org/health/diseases/21751-genetic-disorders>.

²³⁵ *See id.*; see also Blackwell, *supra* note 231 at 133-35.

²³⁶ Amanda Ewart Toland, Ph.D., *New Study Shows the Inaccuracy of At-Home Genetic Tests*, 43 ONCOLOGY TIMES 14, 15 (July 20, 2021).

²³⁷ *Id.*

²³⁸ *See id.*

²³⁹ *See id.*

on finding a positive BRCA1 result and in this example it would be on no reasonable grounds.²⁴⁰

Canada passed their Genetic Non-Discrimination Act in 2017, in order to protect their citizens' from genetic discrimination based on genetic test results when they choose to or are encouraged to undergo a genetic test.²⁴¹ "The Act prohibits all people and businesses from requiring the results of genetic tests when providing services or goods, entering contractual agreements, or offering specific terms or conditions in a contract."²⁴² There are parties that qualify as exceptions; some parties not affected by the Act include "physicians, pharmacists, or other health practitioners who are providing health services," as well as "pharmaceutical or scientific researchers acting in the course of their studies."²⁴³ Even with those exceptions, Canadian citizens can test their genetic material without fear of discrimination or disclosure in every area of their life; and they gain the benefit of healthcare providers offering the proper care due to their knowledge of their genome's material.²⁴⁴

The Canadian Genetic Non-Discrimination Act allows for people to access genetic testing without fear of being discriminated against—in the private or public sector—due to their genetic makeup when obtaining different insurance such as life or disability.²⁴⁵ Meanwhile in the United States, the private sector faces no repercussions from genetic discrimination and the only protections are present in employment situations and the purchase of health insurance.²⁴⁶ Effectively, Canada continues to do better in terms of

²⁴⁰ See *id.*; Christina Farr, *If You Want Life Insurance, Think Twice Before Getting a Genetic Test*, FAST CO. (Feb. 17, 2016), <https://www.fastcompany.com/3055710/if-you-want-life-insurance-think-twice-before-getting-genetic-testing>.

²⁴¹ Bernice Karn & Gordon Goodman, *Genetic Non-Discrimination Act Upheld by the Supreme Court: Implications for Insurers*, CASSELS (Aug. 25, 2020), <https://cassels.com/insights/genetic-non-discrimination-act-upheld-by-the-supreme-court-implications-for-insurers/#:~:text=Conclusion,as%20a%20condition%20of%20coverage>.

²⁴² Guest Author, *The Genetic Non-Discrimination Act: An Overview*, CANADIAN C. L. ASS'N (Apr. 11, 2018), <https://ccla.org/get-informed/talk-rights/the-genetic-non-discrimination-act-an-overview/>.

²⁴³ *Id.*

²⁴⁴ See *id.*; Genetic Information Nondiscrimination Act, Pub. L. No. 110-233 (2008).

²⁴⁵ Guest Author, *supra* note 242.

²⁴⁶ See Zhang, *supra* note 204.

what they choose to protect in both aspects of the right to privacy and the United States should be taking a page out of their book to protect citizens who are still facing discrimination in other facets because of their genetic material. Specifically, the United States should be adjusting their legislation, whether it be GINA or the implementation of a new law, to protect the genetic information of citizens from discrimination in areas that are not specifically enumerated in the current version of GINA. The United States' insurance market should not take precedent to the medical care and inquiry that genetic testing can provide or in the alternative prevent people from obtaining coverage they need based on results that could be completely incorrect.

VIII. CONCLUSION

While genetic privacy does not seem linked to the idea of search and seizure law, that disregards the idea that the first of all privacy law and how it was implemented was the guide for the remainder of privacy protections. At least in the United States, the right to privacy law started with the idea that people wanted to be secure in their persons, belongings, and lives behind the closed doors of their homes in the colonies. As technology has developed over time, what we find to be private versus public has greatly changed. However, the difference present between Canada and the United States in the way that they handle genetic privacy does start with how they treat the rest of their privacy as a whole. Canada has made it a point of protecting the privacy of their citizens to a greater extent than that of the United States while often citing to our jurisprudence in their decisions under “search and seizure.”

Then as DNA databanks gained popularity and use, Canada continued to surpass that of the United States. The United States allowed for lackadaisical DNA collection for criminal activity that had virtually no confirmation other than the presence of a probable cause arrest in some areas. Meanwhile, Canada provided that only those convicted of a series of crimes could be subjected to this large intrusion of privacy. Not to mention that once the United States placed this DNA profile in CODIS—even wrongfully—the odds of getting that profile expunged are slim at best. The lack of regulatory scheme to allow people to protect and remove their data from

CODIS, exemplifies the lack of deference to the privacy of an individual and their information.

The culmination of these precedents when it came to the individual data of United States citizens then led to the creation of GINA which only allowed for two specific instances of genetic protection. GINA left open abuses from private companies that are just not present in Canadian law. Canada created and continues to create laws that put the privacy of the individual at a higher priority than that of law enforcement and their goals, as well as private interests. The United States fought for independence to prevent abuses from the government, the English monarchy, but yet now continues to allow for the abuse of its citizens for the bottom line of insurance companies and law enforcement practices.

The United States as a whole needs to change the way that their legislature protects the genetic information of its citizens. Legislation in the United States should focus on the protection of the citizen as opposed to the private actor seeking to learn about their consumer by enforcing the genetic privacy standards on every entity in the United States save for the actual medical professionals seeking to do research or provide medical care. As for DNA databases, if the United States changes the genetic privacy standards to where they need to be, the next step is to also provide those with information wrongfully in CODIS proper channels to remove that data. The current system wrongfully forces people to essentially litigate for the removal of their data when it should not be present in the database at all. Those are the only ways to combat the privacy deficits present in the nation whose search and seizure provision is over 190 years older than that of the Canadian counterpart. In order to accomplish that goal, lawmakers must look to the example set by their neighbors to the North and give greater deference to individual privacy.