

**DIRECT-TO-CONSUMER GENETIC ANCESTRY TESTING: A MORALLY
OBJECTIONABLE PRACTICE**

By
Betty Cohn

A thesis submitted to Johns Hopkins University in conformity with the requirements for the
degree of Masters of Bioethics

Baltimore, Maryland
August 2020

© 2020 Betty Cohn
All Rights Reserved

Abstract

The popularity of direct-to-consumer (DTC) genetic ancestry testing has resulted in a surge of life-changing news for consumers and their families. DTC genetic ancestry testing companies and third-party websites have provided consumers with new ways to create family trees and connect with unknown relatives. However, these ways do not come without the potential harms of violating familial autonomy and privacy. This paper will examine the ethical implications of participating in DTC genetic ancestry testing, including violations of familial autonomy and privacy. These violations occur due to lack of familial consent, and inadequate database privacy measures. I argue that it is morally impermissible to submit DNA to DTC genetic ancestry testing companies because familial consent is morally required, but impossible – one should not submit one’s genetic data for ancestry testing *because* one is unable to fulfill her obligations to obtain unknown and possibly known family members’ consent. However, I appreciate that sending DNA to DTC genetic ancestry companies is not illegal, nor are these companies prohibited from conducting business in the United States (U.S.). Therefore, I offer recommendations for consumers and companies to decrease the harms that may occur by submitting DNA to DTC genetic ancestry companies. I discuss the uniqueness of DNA, familial autonomy and privacy implications, legal and psychological implications, and database privacy risks, all of which must be considered when weighing the benefits against the harms of genetic ancestry testing. I conclude by raising objections to my argument that individuals should not engage in DTC genetic ancestry testing and provide responses including the counterargument that individual action results in tangible consequences when it comes to genetic databases, and that the public, not just some individuals, should cease participation in DTC testing. Ultimately, if all consumers stop purchasing DTC genetic ancestry tests, future generations will not be

harmed by their ancestors' failing to respect familial autonomy and privacy due to DTC genetic ancestry companies and their databases.

Primary Reader: Gail Geller, Sc.D., M.H.S.

Secondary Reader: Debra Mathews, Ph.D., M.A.

Acknowledgements

I would like to thank my primary reader Dr. Gail Geller for her guidance, support, and enthusiasm throughout the process of writing my thesis. I would also like to thank my secondary reader Dr. Debra Mathews for helping me realize that the Master of Bioethics program at the Berman Institute of Bioethics was the perfect fit for me, and for helping shape my practicum experience, and all of her insights about DTC genetic testing. To the Agraphia group- Tiana Sepahpour, Isaac Wright, Stephanie Mou, Lauren Berninger, DO, Liz Ghandakly, JD, MPA, Dr. Casey Humbyrd, MD and David Myers, MD thank you for your constructive criticism, your invaluable feedback, and your late-night article submissions that always kept me thinking about my argument. I am also greatly appreciative to Dr. Travis Rieder for his unwavering support throughout this unprecedented year.

Lastly, I would like to thank my family for the financial and emotional support not just throughout this year, but throughout my entire life. To my mom, dad, sister, and grandmother thank you for always entertaining my questions and listening to my thesis ideas throughout the year.

Table of Contents

Abstract	ii
Acknowledgements	iv
Introduction	1
Uniqueness of DNA	4
Familial Autonomy and Privacy Implications	6
Legal and Psychological Implications	15
Database Privacy Risks	18
Weighing the Benefits Against the Harms of Genetic Ancestry Testing	21
Objections	24
Conclusion	26
References	28
Curriculum Vitae	32

Introduction

As we begin a new decade, controversy surrounding direct-to-consumer (DTC) genetic testing companies that offer ancestry testing, such as 23andMe and Ancestry.com, are frequent topics in the popular press. Daily, we hear from our colleagues or see news outlets' posts about finding unknown family members, half-siblings, or discrepancies regarding the identities of biological fathers, known as misattributed paternity. An unknown family member is someone who has not been identified by any relative as being included in the social definition of family. By contrast, known family members include any family member that the individual or an individual's relative has identified as being included in the social family. According to the National Institutes of Health (NIH), DTC genetic tests in general are tests that are "marketed directly to consumers. Consumers send the company a DNA sample and receive their results [online]."¹ In this paper, I will focus on DTC genetic tests that assess consumers' ancestry and genealogic data, and not those that also test for genetic variants for medical or health purposes. The ethical issues that surround DTC genetic ancestry testing companies are vast, and it is beyond the scope of this paper to discuss all of them. I will focus on familial repercussions of consumers' decisions to submit their DNA to DTC genetic ancestry testing companies, which exist as a result of similarities in DNA between family members, and inability for users' DNA to be kept private in DTC genetic ancestry company and third-party company databases.

Public motivations for genetic ancestry testing vary. According to a 2013 study, consumers pursue ancestry testing for three general reasons: (1) identity-seeking, (2) disease risk-testing that complements health care, and (3) curiosity-driven testing/searching for a better lifestyle.² However, these reasons are not mutually exclusive, as some consumers' motivations consist of two or more of these motivations. Some individuals submit their DNA to DTC genetic

ancestry testing companies for solely recreational purposes, which could belong to the third reason for pursuing testing, like that of the relative of the Golden State Killer.³ However, others seek out ancestry testing to ascertain information about their health history through their ancestral roots or paternity, as in the second reason for pursuing testing.² According to a more recent study, consumers are also purchasing genetic ancestry testing kits to find genetic relationships and create contact with newly found relatives.⁴ However, the most up-to-date and most comprehensive study indicates that the main reason (nearly 85% of study respondents) for taking a genetic ancestry test was for genealogical research.⁵ Within each motivation, there are likely people who are concerned with the potential violation of familial autonomy or the privacy implications of doing so, but there are also many who do not know or care about such concerns. A 2019 study reported that almost all of the study participants were not worried about the negative implications of submitting their DNA to a DTC genetic ancestry testing company, and that many didn't believe that their personal or genetic information was being shared.⁶ This paper is primarily focused on the group of consumers that pursues genetic ancestry testing but is unaware of, unconcerned with, or believes that the benefits of receiving genealogical information outweigh the familial implications of submitting genetic information. I do not consider here those who choose not to undergo genetic testing precisely because of their interest in protecting familial autonomy and privacy. Nor am I concerned with those who self-select to engage with DTC genetic ancestry testing companies with the full support of their families.

There are two levels of consumer self-selection. Level one includes people who submit their DNA to DTC genetic ancestry testing companies. Level two is a subset of Level one that includes people who opt in for more privacy protections within their chosen DTC genetic ancestry testing service. For example, if one submits her DNA (Level one) and opts in to contact

from genetic relatives, she can see other relatives added to her family tree if those individuals also consent to be seen, but it is also possible that she decides that she does not want to be seen or contacted by those to whom she may be related (Level two).⁷ The more privacy settings an individual selects, the less severe the potential for a privacy violation, which ultimately has implications for their genetic and social relatives.

Since DTC testing has familial implications, each family member's autonomy and privacy must be considered and respected. Due to the practical impossibility of respecting familial autonomy and privacy while participating in DTC genetic testing, I argue that it is morally impermissible to submit genetic material to DTC genetic ancestry testing companies. I am not arguing that it is illegal to provide DNA samples to DTC genetic ancestry companies, or that the companies themselves should be banned. Rather, acknowledging that such testing will continue, I offer guidance for individuals and companies aimed at mitigating what I see as a morally reprehensible action and reducing the severity of harmful consequences.

In this paper, I first describe the uniqueness of DNA in order to emphasize why there must be specific ethical guidance for DTC genetic ancestry testing companies, third party sites (e.g., GEDMatch), and for those who choose to submit their information to these companies. Second, I outline how submission of an individual's genetic information has familial autonomy and privacy implications and why this is significant. Third, I note legal and psychological implications of engaging in testing for individuals and their families. These additional implications affect familial autonomy and privacy and thus provide further evidence of how familial autonomy and privacy can negatively be affected. Fourth, I specifically note database privacy risks due to the nature of company biobanking technology. These risks each have familial privacy implications. Fifth, I weigh the benefits against the harms of partaking in DTC

genetic ancestry testing for the individual, and for one's family members, through a utilitarian lens.⁸ Finally, I respond to objections to the significance of individual action by arguing that individual action results in nonnegligible consequences due to the shared nature of genetic information and how genetic ancestry companies connect individuals to their family members.

Uniqueness of DNA

At the outset, I would like to define the term “genetic exceptionalism,” as it provides the underpinnings for my argument. Genetic exceptionalism, coined by Thomas Murray, is “the claim that genetic information is sufficiently different from other kinds of health-related information that it deserves special protection or other exceptional measures.”⁹ Throughout the past 20 years, the idea that genetic information is unique has been disputed, however the original purpose of the term was to focus on the moral, legal, and policy issues that arise from the advent of new genetic technologies, and our increasing understanding of the human genome. Recently, after much discourse, the term, “genetic contextualism” has been introduced in order to concede that genetic information does contain similarities to other medical tests, however, what matters is the context in which we place the genetic information.¹⁰ Murray argues that perhaps the term “genetic exceptionalism” should be discontinued, however, the idea still stands: genetic information should be treated with caution.¹⁰ I do not wish to take a stance on whether the term should be used in and of itself, but rather note that my argument is predicated on the idea that genetic ancestry information poses different privacy concerns from other medical and health information, and in specific contexts, the publication of this information can have profound implications beyond the individual from whom the information is derived. Thus, my argument is grounded on the uniqueness of genetic information, and the importance of preserving the

autonomy and privacy of individuals who seek and those who do not seek genetic ancestry testing for various purposes.

Similar to Murray's original claim, genealogists also emphasize the uniqueness of genetic information compared to traditional document-based evidence. According to the 2019 Genealogy Standards, the official manual for genealogists written by the Board of Certification for Genealogists, genetic information contains similarities and differences from document-based information. Genetic information is similar to other types of genealogical information in that it is only significant in the context of other information and analysis.¹¹ For example, if an individual submits her genetic information to a DTC genetic ancestry testing company, she will only learn about other relatives, with a moderate degree of certainty, who are six generations or degrees of separation (or less) from her and who also sent their DNA to said company.⁴ Therefore, if one relative never sends in his information, the company itself will not be able to connect her to this relative. This falls under Level two self-selection, which serves to mitigate breaches of autonomy and privacy. However, the individual can utilize other publicly sourced databases and social media websites to find family members who are connected to the one relative who *did* submit a sample for testing, which is common practice among many searching for their genealogical roots. For example, in Dani Shapiro's experience, her biological father did not submit his DNA to Ancestry.com, but her biological cousin did, making him her biological father's nephew. The information that Ancestry.com provided her, in conjunction with information from Facebook, enabled her to discover the identity of her father, without him ever engaging with Ancestry.com.¹² The last main difference between DNA and documentary evidence that genealogists note is that DNA is often from living individuals, whereas documentary evidence tends to be gathered regarding the deceased.¹¹

Broadly speaking, all humans share 99.9% of our DNA.¹³ Specifically, the average amount of DNA shared between identical twins is 100%, between parent and child and siblings is ~50%, between grandchild and grandparents, half-siblings and aunt/niece and uncle/nephew is ~25%, first cousins is 12.5%, and as one gets farther removed the percent similarity decreases.¹⁴ DTC genetic ancestry testing companies note that their probability of detecting even farther relationships is fairly high (e.g., first cousins are detected ~100% of the time, second cousins ~99%, third cousin ~90%, fourth cousin ~45%, and fifth cousin ~15%).⁷ Thus, DTC genetic ancestry companies, in conjunction with personal and genealogist research, can connect individuals to their relatives by cross-referencing multiple company databases, demographic data, other public records, and social media websites, and can do so with fairly high detection rates.¹⁵

Familial Autonomy and Privacy Implications

In Beauchamp and Childress's *Principles of Biomedical Ethics* (2019), respect for autonomy is one of the four principles of biomedical ethics. The purpose of upholding respect for autonomy is to protect individual rights and respect one's ability to self-govern and make fully informed voluntary choices without controlling influences.¹⁶ However, autonomy is not only an individualistic principle. At times, due to our social relationships with others and the impact we have on them, respect for autonomy can also be a communitarian ethical requirement.³ In addition to self-determination, respecting autonomy includes the preservation of individual privacy. Breaches of privacy directly conflict with the goal of self-determination, as one is no longer able to control what happens to the information exposed in the breach (e.g., genetic data).

Furthermore, a 2004 research study emphasizes familial implications of genetic testing. Evidence suggests that people are aware of and sometimes motivated by the familial implications of genetic testing.¹⁶ This is because consumers' choices can be influenced by family members due to their social and trusting relationships. For example, a 2018 study notes that it is common for females who wish to learn about their paternal lineage to ask relatives to participate in DTC genetic ancestry testing to learn more about their family tree.⁵ The same study notes that approximately 3% of their survey respondents pursued genetic testing upon request from a relative.⁵ Thus, the decision-making process must be inclusive of these family members.¹⁷ However, to reinforce the notion of self-selection as described above, people who do not wish to learn about their ancestral roots or any other information that DTC genetic ancestry testing companies provide, such as paternity, would not engage in genetic ancestry testing (Level one self-selection). This results in a skewed sample of individuals who may not be concerned with familial autonomy and privacy implications accessing DTC testing. Although there are some privacy measures put in place on DTC genetic ancestry testing company websites, they are not enough to preserve individual and familial genetic privacy, as evidenced by individuals publicly sharing their stories of finding relatives through DTC genetic ancestry testing companies websites who were not listed on the website.^{18,19} This, in conjunction with researchers' and hackers' ability to access private genetic information from DTC genetic ancestry testing company websites and third party websites makes the few privacy measures inadequate to maintain users' and their families' genetic privacy.

Therefore, I argue that due to the familial implications of genetic ancestry testing, consent is needed from consumers, and their known and unknown family members. But this is unrealistic in practice. Even the feasibility of gaining consent from known family members is

questionable. Are consumers obligated to get consent from every family member? This seems arduous and supererogatory, and impossible for family members who are too young or otherwise not competent to give consent. However, getting informed consent from all family members is necessary due to the shared nature of genetic information and the lack of adequate privacy protections for genetic information that is in DTC genetic ancestry companies' databases. How privacy protections are insufficient is outlined below and includes the inability to deidentify genetic information and the ability for legal authorities to access genetic databases. Furthermore, as Witt and Witt (2016) note, "maintenance of absolute anonymity, bearing in mind the current progress of genetic techniques, is virtually impossible."²⁰ Therefore, the maintenance of the consumer's privacy let alone the privacy of her loved ones or unknown relatives is an unrealistic promise made by DTC genetic ancestry testing companies and calls for the consent of family members for that exact reason. The public needs to understand the consequences of engaging in testing and have the opportunity to choose whether they wish to relinquish their genetic privacy, for the potential benefit of learning about their genealogy. There are many definitions of privacy. For the purposes of this paper, I define genetic privacy "as a personal right to control the uses of one's data, including enjoying access and using it by oneself."²¹

Submitting DNA has repercussions for all of one's family members, including potential family upset and upheaval due to misattributed paternity and the introduction of half-siblings, potential privacy breach, and ultimately lack of respect for autonomy. This lack of respect for autonomy stems from consumers' nonexistent requests for consent from family members prior to submitting their DNA to DTC genetic ancestry testing companies. Although consent is often sought in the doctor-patient or researcher-participant relationships, I argue that consent is also

necessary during this business transaction for the consumer and her relatives because the genetic information that is shared belongs to one's biological, private information.

Additionally, there have been reports of incongruent test results from different DTC genetic ancestry testing companies, causing confusion and worry among the consumer and her family members.²² Currently, several DTC genetic ancestry testing companies do not require consumers to obtain consent from family members, though they are aware of these familial concerns.²³ An analysis of company privacy policies and terms and conditions documents demonstrated that consent sections vary among DTC genetic ancestry testing companies in terms of encouraging consumers to obtain permission from their family members (biologically related or not).²³ Companies that are identified as more 'traditional' ancestry companies that don't include DNA analysis are more explicit in their terms and mention the importance of consenting one's family members, due to third party repercussions of genealogic information, hinting at privacy implications for others. However, companies that solely use DNA analysis or include DNA analysis in their services tend to focus their terms on client protections and ownership and exclude familial consent terminology in their documents.²³ DTC genetic ancestry testing companies also explicitly note that ancestry data affects entire families, however familial consent for consumer participation is ultimately not required. Such language is insufficient to respect the autonomy of family members who share large segments of DNA with the consumer.

Although it is impossible to get unknown family members' consent, their privacy and autonomy are still implicated in ancestry testing. Unknown family members are autonomous beings and should be able to decide what happens to their genetic data. This creates a problem: how could something that's impossible be obligatory? Isn't this setting up the duty bearer for failure? In western philosophy, there is a commonly accepted understanding that "ought implies

can.”²⁴ Therefore, if one ought to do something, then it must be possible. However, in the current context, while one ought to get consent from family members, it is impossible to do so. The concept of “ought implies can” could then imply that one is not obligated to obtain consent from family members. But, submitting one’s DNA to DTC genetic ancestry testing companies is only permissible if one obtains complete familial consent, and since one cannot seek consent from every family member, let alone guarantee that every family member will grant the consumer permission to submit her DNA, submitting one’s DNA is not morally permissible. Although impossibility is a problem, it does not imply that one should simply forgo seeking consent. Rather, impossibility of familial consent means that one ought not submit one’s genetic data for ancestry testing *because* one is unable to fulfill her obligations to obtain unknown and possibly known family members’ consent. Furthermore, this conclusion entails that DTC genetic ancestry testing companies are likewise morally at fault because these companies are selling a product that no one can permissibly purchase.

Furthermore, because testing can be inaccurate and interpretation of results complicated, the family of the test taker should be able to exert control over whether they are willing to increase the probability of this happening to them. Inaccuracies can easily occur as one has the same amount of similar DNA to a grandparent or halfsibling. Thus, a DTC genetic ancestry testing company may note that the consumer’s half-sibling is their granddaughter.²⁵ This, in conjunction with misattributed paternity and knowledge of other new relatives, has familial implications, and in order to respect relatives’ autonomy, their fully informed consent must be obtained to ensure that they understand the potential risks and agree to take them on. Alternatively, as part of the consent process, relatives should also be able to request that their family member cease participation in DTC genetic ancestry testing. The permissibility of

familial authority over the consumer relies on John Stuart Mill's harm principle, which states "that the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."²⁶

Although one should not submit her genetic information to DTC genetic ancestry testing companies, companies are still going to advertise and continue offering their products. Therefore, I offer the following guidance to companies in order to reduce the severity of the potential harms and immoral actions of consumers. I argue that companies should require consumers to obtain informed consent from known family members (minimally known first- and second-degree relatives) because they too should have the opportunity to make informed decisions regarding whether or not they want their genetic information to become publicly accessible or to be linked to other family members. In practice, this could mean that consumers would be required to supply either a consent document for each family member or a similar form that denotes that permission from family members has been sought. This is minimally what should be required, however, the ability to hold consumers accountable for their honesty in filling out these forms remains almost impossible. Additionally, some first- and second-degree relatives might be estranged from the consumer, thus adding to the limitations of requiring a familial consent process. Currently, 23andMe requires only individual consumers to consent to have access to and utilize what they call the DNA Relatives feature, which connects consumers to their family members. If one chooses not to take advantage of this feature, that individual cannot be publicly connected by 23andMe to other family members and vice versa.⁷ However, one of the main reasons consumers choose to submit their DNA to 23andMe is for this service in particular, which means that many consumers consent to this feature (although it may not be adequately informed), which creates the necessity for their family members' consent as well.²⁷

Although it is impossible to request permission from all family members, as noted previously, companies should minimally request that consumers provide documented permission or attestation to a statement of permission having been sought and received from all known first- and second-degree relatives. This policy change could reduce the incidence of violations of familial autonomy. Furthermore, the consumer consent process should include elements such as better pre-test disclosure and educational components so that consumers themselves can give true informed consent and gain true informed consent from their corresponding family members.

Currently, genetic and genomic research guidelines suggest that families should be considered during the consent process, and depending on the nature of the results, the participant, patient, or researcher may be obligated to disclose to families genetic test results and incidental findings.²⁸ However, these companies are businesses and do not view individuals submitting their genetic information as patients or research subjects, but rather as consumers or clients. Although DTC genetic ancestry testing companies mention familial considerations during the consent process, I argue that they must do more given the lack of the kind of supportive infrastructure generally provided in other testing contexts. Consumers are often left without assistance, grappling with the news of misattributed paternity, or the decision to introduce a new relative to their immediate family, which are often emotionally and psychologically distressing circumstances.

Additionally, the Genealogy Standards outline the importance of respect for privacy rights, and emphasizes the “test taker’s” privacy, but does not mention the need to respect the test taker’s family’s privacy.¹¹ Genealogists request written consent from living test takers and provide information regarding levels of privacy, benefits, risks, and potential consequences of sharing and submitting genetic information to DTC genetic ancestry companies. However, they

do not mention consent practices for relatives.¹¹ Furthermore, the Genealogist's Code of Ethics outlines the obligation to explain "options for openness and privacy and how other researchers could or could not access the data," and that "there are never any guarantees of complete anonymity and privacy."¹¹ Although the aforementioned written documents mention little about the importance of familial implications of testing, leading genealogist Judy Russell has discussed the importance of thinking about the implications of testing not just for oneself, but also for known and unknown relatives.²⁹ Perhaps thinking about the implications of DTC genetic ancestry testing for individuals other than the consumer will encourage attempts to obtain consent for known, first- and second-degree relatives, in order to minimize privacy harms. However, whenever one submits their DNA to a DTC genetic ancestry company, she will always risk loss of genetic privacy for both herself and her family members.

DTC genetic ancestry testing companies are businesses rather than academic or clinical research institutions and have different ethical obligations towards the public. Although publicly held companies have different obligations towards the public than privately held companies, I focus below on both types of DTC genetic ancestry testing companies in the context of their obligations to their users and their users' relatives. Some companies like 23andMe and Ancestry.com make consumers' genetic information publicly accessible via online sources, whereas many research institutions do not. However, it is important to note that not all DTC genetic testing companies and research institutions have the same policies regarding publicly accessible information, depending on the company's or researcher's goals and mission. What is similar among research institutions is that there tends to be federal oversight and more privacy protections (and therefore more trust) when it comes to biobanks or databases, whereas companies can more easily change terms and conditions and can be bought by other companies,

leading to such changes, resulting in different governance or goals for the biobanks or databases. This necessitates extra protections for consumers and their families. However, DTC genetic ancestry testing companies still see their “client as the single decision-maker on whether their information and any family history, pedigree, or personal data of others with whom they are related or associated should be shared on the company’s database or across companies.”²³ This idea is demonstrated by several DTC genetic ancestry testing companies whose consent forms place sole responsibility for obtaining familial on the individual consumer, and stems from the financial transaction that takes place between the client and the company.²³ More often than not, consumers submit their DNA to DTC genetic ancestry testing companies seeking ancestry and genealogic information without concern for potentially negative implications for family members or neglecting to fully read online consent forms distributed by these companies.²⁷ Therefore, even if online consent forms are changed to be more comprehensive and include a familial consent requirement, or further emphasize familial consent concerns, consumers may continue to simply click through, undermining the obligation of consumer and familial consent. Although requiring familial consent does mitigate some of the potential harms to consumers’ family members, companies may continue to be unable to ensure consumer accountability due to the familial consent form’s online platform. The only way to completely prevent possible harms is to cease from submitting one’s DNA to DTC genetic ancestry testing companies.

The National Genealogical Society, which includes those who regularly facilitate and utilize DTC genetic ancestry testing, articulates ethical guidelines regarding sharing and disseminating genetic information. Specifically, they note the imperative to not harm any living individual. They explicitly state that “sharing the information of persons other than ourselves is an ethical violation if we do not have consent.”³⁰ This ethical standard refers to consumers

sharing information with others about their DNA matches when the matches did not consent to be shared with others. Individuals often feel compelled to share their information with others to grow their family tree or tell their loved ones of news that may be life-changing to them and their family members. However, this is impermissible if the match did not consent to the sharing of their information. Ultimately, this ethical consideration identified among genealogists forms a direct parallel with my argument, in that it supports the claim that familial consent is imperative during the testing process and should be emphasized in DTC genetic ancestry testing companies' privacy policies due to the potential harms that testing may cause families.

Legal and Psychological Implications

DTC genetic ancestry testing companies are successful, in part, because consumer information does not remain private. When a consumer who purposefully seeks other relatives submits her DNA to a company, she wishes for her relatives to have access to her information, and for her to have access to their information. This is how family trees are created. This ability to connect distant family members to the consumer was used to solve the Golden State Killer case.³ The site that was used to find the Golden State Killer is called GEDMatch, which is a third party public genealogy website that allows individuals to upload their DTC genetic test results. The Golden State Killer case was a cold case until the man who raped and killed many women was identified using GEDMatch, after searching for him for forty years. Detectives input the DNA from the forensic sample thought to be from the killer into GEDMatch and found a distant relative who had uploaded her genetic data into GEDMatch due to a desire to create a family tree and determine her ancestry.³ Many genealogists are beginning to shy away from using GEDMatch because of its inadequate privacy measures that made finding the Golden State Killer

possible.³⁰ However, immediately following the Golden State Killer case, GEDMatch changed their terms of service several times. One update permitted law enforcement to submit more DNA samples to identify other alleged criminals.⁶ Today, GEDMatch's privacy settings allow users to opt-in to allow law enforcement to view their data during police searches.³¹

Unlike GEDMatch's original law enforcement policy, DTC genetic ancestry testing companies explicitly note their relationship and interactions with law enforcement publicly on their websites. As of August 16th, 2020, Ancestry states that they will only divulge customer information to law enforcement "in response to a valid trial, grand jury, or administrative subpoena."³² Furthermore, the 2019 Transparency Report states that nine data requests were received that calendar year, and of those requests eight of them were related to criminal investigations involving financial crimes.³³ However, one request did seek access to Ancestry's DNA database. Ancestry challenged this request and ultimately did not provide any customer information, but law enforcement may increasingly request genetic information in the future.³³ This suggests that, although law enforcement can utilize its authority to attempt to obtain private financial or genetic information from Ancestry, they are more likely to seek the publicly accessible information that anyone can view with enough knowledge and resources, as in the Golden State Killer case. Such legal ramifications of DTC genetic ancestry testing need to be understood for the consumer to give full informed consent. However, family members must also understand these potential consequences when their relative seeks their consent. But, as noted previously, this still does not solve the problem of missing familial consent.

In addition to legal ramifications, personal and familial distress can result when consumers learn that their parents, siblings, or other family members are not blood relatives. A quintessential misattributed paternity case is described in Dani Shapiro's memoir, *Inheritance*,

where she describes learning from a DNA test that her father was not her biological father, and her half-sister was not a genetic relative at all. She learns that her genetic father was a medical student who studied near the in vitro fertilization (IVF) clinic where her mother and social father were thought to have contributed their gametes for IVF. This medical student's sperm, instead of her father's sperm, was used to inseminate her mother's egg, not an uncommon occurrence in the 1960s.¹² This resulted in psychological distress for Shapiro, and an upheaval of her sense of self, which was once grounded in Orthodox Judaism practiced by the man she thought was her genetic father and with whom she was very close.¹² This case highlights both individual consumer and familial impact. Shapiro's living relatives are also necessarily involved and were forced to psychologically unpack this information without a full prior warning of this possibility. As Shapiro notes in her memoir, 23andMe merely cautioned that "[she] may discover things about [herself] and/or [her] family members that may be upsetting."¹² Through the use of Ancestry.com and public internet searches, she was quickly able to locate her biological father just like many individuals have done upon learning similar news from their test. Learning that she shared genes with a stranger affected her connection to household family photographs, and her medical history, including telling her doctor that her "father was no longer deceased."¹² However, it is important to note here, that despite Shapiro's life upheaval, she does not regret participating in DTC genetic testing, nor does she regret learning the truth of her parentage.³⁴ It remains unclear whether other members of her family who were affected feel similarly. Nevertheless, the possibility of psychological impact on the consumer and her family members remains.

This is only one of many stories that showcases how DTC genetic ancestry testing affects individual and familial physical and mental health and sense of identity, arising from an

incomplete or absent prior understanding of the possibility of misattributed paternity when participating in DTC genetic ancestry testing. One of the reasons that learning this information is significant is that one cannot unlearn it.²² Once one reads through her genetic test results, one cannot simply unread her results or unlearn that her father who raised her wasn't her biological father. These physical and mental health impacts are further cause for requiring familial informed consent. Unfortunately, as noted above, even if family members are contacted and adequately informed about the possibilities of the harm that could ensue, the task of consenting all individuals who could be affected by engaging in testing is still impossible. However, even if familial consent could be sought and received, it is still the case that genetic information held by DTC genetic ancestry companies is not adequately protected.

Database Privacy Risks

A historical solution to the risk of personal and familial privacy breaches is the process of deidentification. Deidentifying genetic data removes personal information that connects the subject back to the data. However, due to the dramatic increase in the availability of genetic information on the U.S. population, deidentification is no longer adequate, as one's genetic data can easily be re-identified.^{15,35,36} Genome Wide Association Studies (GWAS) look at thousands of variations in genomes to determine segments of DNA involved in human disease. In one study, researchers were able to reidentify individuals who were participants in a GWAS study.³⁷ In a separate study, researchers were able to identify research participant surnames through the use of recreational genetic genealogy databases in conjunction with web-based searches.¹⁵ Furthermore, individuals and their relatives can be linked back to their data through public voter registries.³⁵ This is done by matching demographic information listed on an individual's public

genetic profile to the same demographic information (e.g., birth date, zip code, etc.) found on public voter registries. Matching this data will lead to the identification of the individual's name, and thus re-identifying the once de-identified genetic data. Therefore, the process of deidentifying data no longer accomplishes its goal of protecting the privacy of genetic information.

Furthermore, recent research suggests the possibility of accessing genetic data without permission from third-party genomic databases, such as GEDMatch.³⁸ When users submit their genetic information to these databases, the company searches for similar or identical segments of DNA to the user's DNA, to identify genetic relatives. The amount and length of these similar or identical segments increase based on familial closeness of the user and other individuals in the database. If an individual uploads her DNA, searches for relatives, and obtains an alleged relative's segment length and location similar to her DNA, she now has identifiable information about this relative.³⁹ What makes this process open to malicious intent or privacy breach is that anyone can upload anyone else's genetic information gathered from public databases to these services and, through a process called identical-by-state (IBS) tiling, obtain meaningful genetic information from a large percentage of the U.S. population. In GEDMatch, it was determined that one can obtain an individual's entire genome due to the site's comparison and reporting methods.³⁹ Once genetic privacy is lost because of open access to public genetic databases, DTC genetic testing companies, and widespread internet use, this loss is impossible to reverse. However, Carmi suggests that privacy risks can be decreased and potentially eliminated if DTC genetic ancestry companies or genetic databases do not inform the user "where the IBS segments are located within the genome."³⁹

But are privacy breaches common? Although there are significant vulnerabilities that could be exploited, are any of these events likely to occur? In short, yes. Within the past ten years, health data violations constituted 40% of all data breaches, and of those health data violations, 63% of them constituted breaches of medical records.²² It is estimated, that the possibility for privacy harms will only increase as it becomes easier and more known how to use the above methods to apprehend the public's private genetic information. This makes breaches of privacy a very real and pressing harm that consumers and their families can fall victim to as a result of at least one family member participating in DTC genetic ancestry testing. During the week of July 20th, 2020, there were two related privacy breaches of DTC data. These occurred first through GEDMatch, resulting in a subsequent breach at MyHeritage, a DTC genetic ancestry testing company from which many GEDMatch users upload their data.³¹ Following law enforcement use of the site to find the Golden State Killer, GEDMatch created privacy settings that permit users to choose whether they want their account to be made public, and whether they want their account to be searchable by law enforcement officials. The 2020 security breach not only made every user's account public, but also made every user's account searchable by law enforcement.³¹ By making all accounts publicly accessible, the hackers were able to access all users' genetic information and family trees. GEDMatch users are shown up to 3000 of their closest matches, thus making this privacy breach not only a breach for the individual user, but also for all of those with whom they are connected, and their genetic and social relatives.³⁸ The hackers were also able to access all email addresses that were associated with MyHeritage accounts, resulting in the second privacy breach. The hackers then proceeded to send a phishing email to MyHeritage users in order to access their passwords and account information, which includes their genetic information and family tree data.⁴⁰ Ultimately, these privacy breaches will

not be the only privacy breaches to occur as long as consumers continue to purchase DTC genetic ancestry tests and upload them to third party databases.

Weighing the Benefits Against the Harms of Genetic Ancestry Testing

Critics may argue that the harm principle does not outweigh a human being's "fundamental right to know their genetic origins."⁴¹ If it is the individual's right to know her ancestry, then the state or governing body must seek to respect, protect, and fulfill this right. This rights claim is based on the belief that individuals are harmed and severely wronged if they are unaware of their genetic parents.⁴¹ Other potential benefits of knowing one's genetic parents or family medical history include increased well-being and knowledge of potential health risks. Adoption studies have demonstrated that adoptees who are aware of their genetic parents have fewer psychological problems and a clearer sense of self-identity.⁴¹ These results are similarly found in individuals who were conceived with anonymous sperm and egg donation.⁴¹ Additionally, many cultures and religions emphasize that knowledge of one's ancestry is important in defining the individual.⁴¹ For example, in Judaism, it is imperative to know one's ancestry to discern what obligations an individual has and to determine if one is Jewish. According to Orthodox Judaism, a person is Jewish if her mother is Jewish.⁴² Therefore, one cannot glean a sense of self-identity in the Orthodox religious community without this information. Additionally, providing evidence of kinship via genetic ancestry test results can also aid in demonstrating indigenous tribal membership.⁴ Ultimately, genetic genealogical information may be important for the individual's sense of self and can be advantageous to the individual if known. Thus, refusing to permit a consumer to undergo paternity testing would be failing to uphold this fundamental right.⁴³

However, DTC genetic ancestry testing isn't the only way to establish paternity. Before the popularity of DTC genetic ancestry testing companies, individuals who had unknown paternity, or suspected that their father wasn't a genetic relative, would obtain a traditional paternity test. Traditional paternity testing is not unanimously considered to be ethical, in part because there is debate over whether individuals have the right to know who their genetic parents are, and conducting a traditional paternity test does not always uphold that right.⁴¹ Traditional paternity tests require DNA from both the individual and the supposed genetic parent. These tests can determine if two individuals are related using both parties' DNA samples, but cannot determine who is the genetic father if the company does not have his DNA. Additionally, traditional testing does not provide DNA analysis that reveals the genes the two individuals share, unlike current DTC genetic ancestry testing.⁴ In this way, traditional paternity tests are unlike the tests offered by DTC genetic ancestry testing companies, as they provide less information.⁴⁴ Additionally, traditional paternity testing does not violate familial autonomy, nor is it prone to privacy breaches, unlike DTC genetic ancestry testing, due to the lack of data storage in biobanks, large-scale testing, and relative finder features. However, if an individual adheres to the following three criteria, then traditional paternity testing becomes an ethical alternative to DTC genetic ancestry testing: (1) it is accepted that the individual has a right to know her genetic parents, (2) she and her suspected father consent to participating in paternity testing, and (3) testing is done legally. Although traditional paternity tests are an ethical alternative to DTC genetic ancestry testing, they may not successfully uphold the right to know one's genetic parents, because these tests do not have access to the millions of data points that connect individuals to their genetic relatives.³⁶ The inability of traditional paternity testing to connect the consumer to her genetic parent does not imply that DTC genetic ancestry testing is

an appropriate or ethical alternative. Just because one option does not achieve one's goal, does not mean that the effective but morally problematic option should be pursued. The question then follows: is it more harmful to not know one's genetic parents or to possibly know one's genetic parents but lose one's genetic privacy and reveal the family's genetic information to the public eye?

This dilemma results in a tension between the harms inflicted on the individual of not knowing one's genetic parents, and the harms inflicted on one's consenting family members. However, these two harms aren't the only factors affecting the permissibility of submitting DNA to DTC genetic ancestry testing companies. For the individual alone, several possibilities for harm exist including negative psychological effects from misattributed paternity, loss of a prior sense of self, legal implications, and loss of genetic privacy. All of these harms can be simultaneously experienced by the individual and one's family due to the ability of DNA analysis to connect to close and distant known and unknown relatives.

In order to discern whether the risks outweigh the benefits, I turn to utilitarian philosophy. Mill articulates that one should engage in behaviors that maximize utility, or happiness, for the greatest number of people.⁸ According to this principle, a consumer should not submit her DNA to an ancestry company solely for her benefit, at the expense of her family members. She will not be maximizing utility for the greatest number of people, but rather only for herself. And even that is questionable, as she may be harmed by discovering the identities of unknown family members, or by the misuse of her genetic data due to inadequate privacy controls. Ultimately, consumers should not submit their DNA to DTC genetic ancestry companies, even though the identity of the genetic parents may remain uncertain, because it is unethical to behave in a way that advances one's gain at the expense of one's family members.

Ultimately, there are many ethical issues involved in DTC genetic ancestry testing. Above, I note concerns about respect for individual and familial autonomy and privacy, which arise due to the shared nature of genetic information and the lack of adequate deidentification and privacy protections. As a result of an inability to consent all biologically and socially related known and unknown family members, consumers of genetic ancestry tests risk violating individual and familial autonomy. Thus, DTC genetic ancestry testing is unethical, and consumers should not participate in it. Perhaps, in the future, with the advent of new technologies and privacy protections, DTC genetic ancestry testing could become an ethical service, as is genetic testing from reputable laboratories for medical and health reasons. Until then, it is morally imperative for consumers to refrain from engaging with these companies.

Objections

Although there are several plausible objections to my argument that individuals are morally obligated to refrain from submitting their DNA for ancestry testing because of potential violations to familial autonomy and privacy, I will outline three objections below, with corresponding rebuttals.

The first objection is that one person's actions would not affect the databases or result in less harm since other family members have already sent their information. As cited in climate change debates, there is an argument that one individual's actions do not have a significant impact on large-scale problems.⁴⁵ Relevant to ancestry testing, the immense problem is that large biobanks exist which include millions of data points and are controlled by DTC genetic testing companies. Biobanks become problematic because of the inadequate privacy protections in conjunction with the value to be gained by hacking into it. Further problems arise due to the

reality that DTC genetic testing companies use biobanks paired with a variation of a relative finder feature to connect individuals to their relatives, creating the potential for wide-reaching breaches of privacy. Thus, one could apply the climate change analogy here: if one person does not submit their DNA to a DTC genetic ancestry testing company, the impact would be negligible because there are millions of other data points, and the same violation of respect for familial autonomy and privacy infringement is likely to occur, just by some other individual. This objection to the significance of individual obligations is called the casual impotence objection.⁴⁵

However, the claim that individual action is negligible is predicated on the idea that individuals are the only ones who are acting, not the collective. It shouldn't be that only one person is deciding not to test. In reality, everyone should stop submitting their DNA to DTC genetic ancestry testing companies. If all consumers stopped engaging in this type of testing today, all things being equal, some of the privacy problems caused by submitting DNA wouldn't be problems of those in the 8th generation. If one is required to not submit one's DNA to these companies, then it follows that no one should be submitting their DNA. If everyone who would have submitted their genetic information chooses to refrain from doing so, then the company databases would become obsolete. This is because as generations continue, it becomes increasingly difficult to connect family members. After all, there is less shared DNA from one generation to the next. For example, after the 8th generation of individuals, approximately 200 years after the last time an individual submitted her genetic information to a DTC genetic ancestry testing company, that individual and the 8th generation individual would not be able to be connected because their DNA would not be similar enough. Therefore, stopping testing now would have an impact on future generations and the state of their privacy.

Lastly, I argue that individual action does result in significant consequences. As noted previously, individual action isn't negligible in the case of DTC genetic ancestry testing, due to how the companies provide context for one's genetic analysis. One only learns information about others if there is information to share. The companies only have access to a family members' genetic and personal information if said family member provided it. Therefore, the problem isn't that individual action is negligible, but rather individual action is significant because it will provide insight to the consumer. This was demonstrated in the case of the Golden State Killer. If the one distant relative had not submitted her DNA, identifying the Golden State Killer through GEDMatch would have proved to be immensely more difficult, and arguably would only have been able to occur if another family member uploaded her DNA instead of this one. Ultimately, individual action does matter in the context of genetic testing.

Conclusion

In summary, I argue that engaging in DTC genetic ancestry testing is morally impermissible. When an individual chooses to submit her DNA, she is not only risking her own genetic privacy and psychological upset but also that of her known and unknown relatives due to the shared nature of DNA. In order to respect familial autonomy, informed familial consent of all known and unknown family members is required. But obtaining such consent is impossible. DTC genetic ancestry testing companies do not even minimally request consent from close, known family members. If they did, the likelihood of autonomy violations would be minimized. In the absence of familial consent, individuals should stop participating in DTC genetic ancestry testing. Although the genetic privacy of many existing individuals is lost due to the current popularity of DTC genetic ancestry tests, there is still hope for future generations. If everyone

today declines to purchase testing kits and submit their DNA to these companies, future generations may have intact genetic privacy due to the decreasing percentages of similar DNA down the generations.

References

1. National Institutes of Health. What is direct-to-consumer genetic testing? Genetics Home Reference. Published June 9, 2020. Accessed February 9, 2020. <https://ghr.nlm.nih.gov/primer/dtcgeneticstesting/directtoconsumer>
2. Su P. Direct-to-consumer genetic testing: a comprehensive view. *Yale J Biol Med.* 2013;86(3):359-365.
3. Gafni M, Krieger L. Here's the "open-source" genealogy DNA website that helped crack the Golden State Killer case. *The Mercury News.* <https://www.mercurynews.com/2018/04/26/ancestry-23andme-deny-assisting-law-enforcement-in-east-area-rape-case/>. Published April 30, 2018. Accessed February 9, 2020.
4. Kirkpatrick BE, Rashkin MD. Ancestry Testing and the Practice of Genetic Counseling. *J Genet Couns.* 2017;26(1):6-20. doi:10.1007/s10897-016-0014-2
5. Roth WD, Lyon KA. Genetic Ancestry Tests and Race: Who Takes Them, Why, and How Do They Affect Racial Identities? In: *Reconsidering Race.* Oxford University Press; 2018. doi:10.1093/oso/9780190465285.003.0008
6. King J. "Becoming Part of Something Bigger": Direct to Consumer Genetic Testing, Privacy, and Personal Disclosure. *Proc ACM Hum-Comput Interact.* 2019;3(CSCW). doi:10.1145/3359260
7. 23andMe. DNA Relatives: Detecting relatives and predicting relationships. Accessed February 24, 2020. <https://customercare.23andme.com/hc/en-us/articles/212170958-DNA-Relatives-Detecting-Relatives-and-Predicting-Relationships>
8. Mill JS. *Utilitarianism.* Parker, Son, and Bouron; 1863.
9. Murray T. Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different than Other Medical Information? In: *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era.* Yale University Press; 1997:60-73.
10. Murray T. Is genetic exceptionalism past its sell-by date? On genomic diaries, context, and content. *Am J Bioeth.* 19(1):13-15.
11. Board for Certification of Genealogists. *Genealogy Standards.* 2nd ed. Ancestry.com; 2019.
12. Franklin R. Dani Shapiro's new memoir uncovers a life-changing family secret. *The New York Times.* <https://www.nytimes.com/2019/01/15/books/review/dani-shapiro-inheritance.html>. Published January 15, 2019. Accessed February 9, 2020.
13. National Institutes of Health. Genetics vs. genomics fact sheet. Genetics Home Reference. Published September 7, 2018. Accessed February 24, 2020. <https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics>

14. 23andMe. Average percent DNA shared between relatives. Accessed May 5, 2020. <https://customercare.23andme.com/hc/en-us/articles/212170668-Average-percent-DNA-shared-between-relatives>
15. Gymrek M, McGuire A, Golan D, Halperin E, Erlich Y. Identifying personal genomes by surname inference. *Science*. 2013;339(6117):321-324.
16. Hallowell N. Consent to genetic testing: a family affair? In: *The Limits of Consent: A Socio-Ethical Approach to Human Subject Research in Medicine*. Oxford University Press; 2009.
17. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 8th ed. Oxford University Press; 2019.
18. Marcus AD. When Your Ancestry Test Entangles Others. *The Wall Street Journal*. <https://www.wsj.com/articles/when-your-ancestry-test-entangles-others-11581696061>. Published February 14, 2020. Accessed August 7, 2020.
19. Marcus AD. Why People Are Sharing Their Family Secrets with Strangers in Public. *The Wall Street Journal*. <https://www.wsj.com/articles/why-people-are-sharing-their-family-secrets-with-strangers-in-public-11583260168?mod=searchresults&page=1&pos=4>. Published March 3, 2020. Accessed August 7, 2020.
20. Witt M, Witt M. Privacy and confidentiality measures in genetic testing and counselling: arguing on genetic exceptionalism again? *J Appl Genet*. 2016; 57:483-485.
21. Clayton EW, Evans, BJ, Hazel JW, Rothstein MA. The law of genetic privacy: applications, implications, and limitations. *J Law Biosci*. 2019;6(1):1-36.
22. Garner S, Kim J. The privacy risks of direct-to-consumer genetic testing: A case study of 23andme and Ancestry. *Wash Univ Law Rev*. 2019;96(6):1219-1266.
23. Wallace S, Gournas E, Nikolova V, Sheehan N. Family tree and ancestry inference: is there a need for a “generational” consent? *BMC Medical Ethics*. 2015;16(87):1-9.
24. Dahl NO. Ought implies can and deontic logic. *Philosophia*. 1974;4(4):485-511.
25. Hercher L, Jamal L. An old problem in a new age: Revisiting the clinical dilemma of misattributed paternity. *Appl Transl Genom*. 2016; 8:36-39.
26. Mill J. *On Liberty*. Cambridge University Press; 2011. doi:10.1017/CBO9781139149785
27. Su Y, Howard HC, Borry P. Users’ motivations to purchase direct-to-consumer genome-wide testing: an exploratory study of personal stories. *J Community Genet*. 2011;2(3):135-146. doi:10.1007/s12687-011-0048-y
28. National Human Genome Research Institute. Special considerations for genomics research. Informed Consent. Published October 2, 2019. Accessed February 26, 2020. <https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics>

29. Crow AJ. The Ethics of Genetic Genealogy: Tips from Judy Russell, the Legal Genealogist. Published online October 12, 2017. Accessed June 23, 2020. <https://www.youtube.com/watch?v=3-c8PQTib4U>
30. Russell JG. Ethical Underpinnings of Genetic Genealogy. In: Wayne DP, ed. *Advanced Genetic Genealogy: Techniques and Case Studies*. Wayne Research; 2019.
31. Whittaker Z. GEDMatch confirms data breach after users' DNA profile data made available to police. <https://techcrunch.com/2020/07/22/gedmatch-investigating-dna-profile-law-enforcement/>. Published July 22, 2020. Accessed July 23, 2020.
32. Ancestry. Ancestry Guide for Law Enforcement. Ancestry. Accessed August 16, 2020. <https://www.ancestry.com/cs/legal/lawenforcement>
33. Ancestry. Ancestry 2019 Transparency Report. Ancestry. Accessed August 16, 2020. <https://www.ancestry.com/cs/transparency-2019>
34. Shapiro D. Conversation with Dani Shapiro, author of the NYT best-selling memoir "Inheritance." Presented at the: January 13, 2020; Johns Hopkins Hospital.
35. Sweeney L, Abu A, Winn J. Identifying participants in the Personal Genome Project by Name. *Data Priv Lab IQSS Harv Univ*. Published online 2013.
36. Kaplanis J, Gordo A, Wahl M, et al. Quantitative analysis of population-scale family trees with millions of relatives. *Science*. 2018;360(6385):1-42.
37. Im H, Gamazon E, Nicolae D, Cox N. On sharing quantitative trait GWAS results in an era of multiple-omics data and the limits of genomic privacy. *Am J Hum Genet*. 2012; 90:591-598.
38. Edge MD, Coop G. Attacks on genetic privacy via uploads to genealogical databases. *eLife*. 2020;9: e51810. doi:10.7554/eLife.51810
39. Carmi S. The challenges of maintaining genetic privacy. *eLife*. 2020;9(e54467).
40. Admin. Security alert: malicious phishing attempt detected, possibly connected to GEDMatch breach. MyHeritage Blog. Published July 21, 2020. Accessed July 23, 2020. <https://blog.myheritage.com/2020/07/security-alert-malicious-phishing-attempt-detected-possibly-connected-to-gedmatch-breach/>
41. Ravelingien A, Pennings G. The right to know your genetic parents: from open-identity gamete donation to routine paternity testing. *Am J Bioeth*. 2013;13(5):33-41.
42. Freeman T, Shurpin Y. Why is Jewishness matrilineal? Chabad.org. Published February 25, 2020. https://www.chabad.org/library/article_cdo/aid/601092/jewish/Why-Is-Jewishness-Matrilineal.htm

43. Moray N, Pink K, Borry P, Larmusear MH. Paternity testing under the cloak of recreational genetics. *Eur J Hum Genet.* 2017; 25:768-770.
44. DNA Paternity Test. DNA Diagnostics Center. Accessed February 29, 2020. <https://dnacenter.com/dna-paternity-test/legal-dna-paternity-test/>.
45. Rieder TN, Bernstein J. The Case for “Contributory Ethics” Or How to Think about Individual Ethics in a Time of Global Problems. *Ethics Policy Environ.* Published online 2020.

Curriculum Vitae

B E T T Y C O H N

bcohn2@jh.edu [linkedin.com/in/bettycohn/](https://www.linkedin.com/in/bettycohn/)

EDUCATION

JOHNS HOPKINS UNIVERSITY, BALTIMORE, MD
Master of Bioethics candidate, expected graduation August 2020
Johns Hopkins Berman Institute of Bioethics

- Completed the COVID-19 Contact Tracer Course
- Completed a Practicum titled: Defining Bioethical Issues in the Clinical Setting of the Prenatal/Preconception Genetic Counselor

BINGHAMTON UNIVERSITY, BINGHAMTON, NY
B.A. Individualized Major Program: Biomedical Ethics; Minor: Biological Anthropology
Harpur College of Arts and Sciences, May 2019, GPA: 3.62

- Completed thesis titled “The Ethics of Genetic Testing”
- IRB Experience
- Skills: Microsoft Word, Excel, and PowerPoint, R, and NVivo

RESEARCH EXPERIENCE

JOHNS HOPKINS UNIVERSITY, BALTIMORE, MD
Research Assistant for Anne Barnhill, April 2020-June 2020

- Created a Home Health Aides Briefing Booklet under The Essential Workers Project addressing the needs of essential workers during and after the COVID-19 Pandemic
- Co-author of the working paper: “Hidden Essential Work at the Spaces Between Life & Death”

JOHNS HOPKINS UNIVERSITY, BALTIMORE, MD
Research Assistant for Joe Ali, October 2019- present

- Conducted a literature review, created a spreadsheet, and coded using qualitative research software (NVivo) to organize and code literature on the guidelines, acts, and policies in African countries addressing genomics and genetics research.

ISRAEL ORGANIZATIONAL BEHAVIOR CONFERENCE, TEL AVIV UNIVERSITY
Poster Presentation, January 5-7th 2020

- Accepted paper: “The Ethics of Big Pharma: A Response to ‘Developing Drugs for Developing Countries’”

SUMMER RESEARCH PROGRAM IN THE SCIENCES AT TEL AVIV UNIVERSITY
Research Assistant for Noam Shomron, June 2017-August 2017

- Completed a paper and presentation on “The Ethics of Individualized Genomic Analysis.”
- Used SPSS and Excel to perform statistical analysis on a questionnaire using logistic regression and chi-square analysis.

WORK AND LEADERSHIP EXPERIENCE

NEW YORK INSTITUTE OF TECHNOLOGY, NEW YORK, NY
Guest Lecturer for Professional Enrichment Program, June 25, 2020

- Medical Ethical Issues in a COVID-19 World

JSCREEN, IN ASSOCIATION WITH EMORY UNIVERSITY

*Jscreen is a not-for-profit, at-home education and carrier screening program for Jewish genetic diseases.
Intern, Binghamton University, Fall 2016*

- Successfully coordinated an on campus genetic screening event (screened 95 participants).
- Created awareness about Jewish genetic screening on campus through online and on-the-ground efforts.