**Genetic Responsibility**

**Ayelet Blecher-Prigat, Ruth Zafran**

Prologue

I clutch the “Ancestry DNA” kit, still wrapped in cellophane.

I bought it several months ago. For a year and a half, I had considered buying it. Patiently it waited for me on my wish list. As part of a massive marketing campaign for Mother’s Day, it was offered as a gift at a big discount. I placed it in my shopping cart and made it mine with one click.

It has been sitting on my desk since then. I’ve been tempted to open it, take a genetic sample, send it back, and receive in return a genealogical and medical map. “Find the unique story in [your] DNA,”[[1]](#footnote-1) the blurb urges. My partner’s words echo inside me: “When you get yourself tested, you seal your children’s fate, too. They’ll never be able to be anonymous or enjoy being ignorant.” “Who’s anonymous today, anyway?”[[2]](#footnote-2) I answer to myself, “and who wants to be ignorant?”

When I bought the test, I hoped it would solve three puzzles: first, to answer still-unanswered questions about my family history that have been gnawing at me ever since I was a girl. One-fourth of my family’s origins are unknown. My paternal grandmother was killed in World War II; we have no information about her or her extraction. We don’t know how, when, and under what circumstances she was killed; we don’t know what kin she left behind. Second, I want to satisfy a curiosity that always nestled in me, to complete the picture of my ancestry. Who knows, maybe I’ll discover that I have exotic roots? I always wanted to broaden the family circle. Maybe nearby, unknown to me, lives an aunt who would be pleased to join our small-scale family meals. Third, I am eager to expand my health information and know what my genes have in store for me. Knowledge is power, I believe. Even unpleasant genetic revelations are an opportunity for a positive change in lifestyle.

“Don’t think only about yourself,” I tell myself again. “When you join a genetic database, your children, too (and the rest of your family) join it without your having asked for their permission. Law enforcement will be able to catch them if they commit a crime; a relative will be able to track them down and shed light on an illicit affair; you might uncover hard-to-accommodate medical information that will cast a heavy shadow over the rest of your life, one that will rest on their shoulders, too.”

I open the box, searching for answers.

Introduction

The era of direct-to-consumer, over-the-counter genetic tests[[3]](#footnote-3) presents families with a challenge (and an opportunity) that manifests in various forms. The availability of the tests and the existence of databases that retain this information and allow access to it subvert once-prevalent norms of confidentiality in relation to genetic information, forcing people to reconsider the right way to comport themselves in regard to this information in the family setting. The questions that come up in regard to the information—can (and perhaps should) it be shared among individuals? and with whom, when, and in what way should it be shared?—are part and parcel of a larger question, one that touches upon the standard of responsibility that flows from the fact that two people share a genetic relationship (and information), the existence of which becomes better known and visible due to the existence of these tests: a question that we call one of genetic responsibility.

In this article, we present several situations in which commercial genetic tests, combined with databases that preserve the genetic information that these tests amass, as well as search engines and social media, reveal the need to reconsider the norms that relate to information flows, to transcend the traditional framework of privacy, and to think of information flow in terms of responsibility. More specifically, we wish to test the idea of this responsibility in the context of family relations.

In this article, we present four case studies that yield a panoramic picture of the range of family dilemmas that the tests and their outcomes may raise. We focus on an aspect that is less researched than others today—the implications of the information and its use (including non-use or attempted concealment) in connection with relations among kin. The families that we discuss are diverse—“traditional” and “nontraditional”—as are their relations: genetic, social, or combinations of both. A flow of information among individuals who are kin, both in what may be classified as conventional/old kinship—among members of a family as we are accustomed to defining it and as part of new kinship as defined by Naomi Cahn et al., which includes, for example, donor siblings.

The range of case studies on which we draw illustrates both the dilemmas that such access/exposure to information can generate and also the shifting meanings of data access and privacy in the realm of genetic testing in the broader context of “genetic responsibility,” including situations in which OTC testing:

* Yields negative genetic findings (such as potential illness) that may have an impact on other family members;
* reveals the identity of a parent in an adoption or that of a gamete donor or genetic siblings, unknown to one another;
* is conducted by a gamete donor or genetic parent whose child was adopted and reveals negative genetic findings;
* produces life-changing surprises, such as a father’s discovery that he is not the genetic father of the child whom he has reared as his own (or an offspring’s opposite discovery regarding his assumed father), or discovery by a person that he or she was born via gamete donation.

[כפוף לשינויים] The first part of the article presents a brief factual background on OTC genetic tests. Part 2 draws the boundaries of the discussion, briefly noting the range of questions that these tests may evoke but that are ***not*** discussed in the article. [לחשוב לאן להעביר את חלק 2].. Part 3 illuminates the dilemmas that were chosen for discussion in the article and presents the four situations in which testing reveals “problematic” genetic information that creates uncertainty in regard to sharing it with family members. All these dilemmas raise similar questions: How is this information classified and what are its implications for its holder’s responsibility to his or her kin? In other words—what does it mean to “hold” such information and who are the “kin”—parents, offspring, or siblings, who maintain meaningful genetic or relational connections in view of this information? These dilemmas may receive answers in the fields of family law, healthcare law, or regulation of information providers, but they demand focused attention to privacy laws. In the context of the privacy laws discussed in Part 4 of the article, this reality, as stated, entails a new conceptualization of the concepts of privacy and privacy law. Instead of the traditional perception of privacy as something intended to create a buffer, set a limit, and differentiate among individuals,[[4]](#footnote-4) and as an alternative to the approach that announces the “death of privacy,”[[5]](#footnote-5) we will propose, in the spirit of Helen Nussbaum’s writings,[[6]](#footnote-6) that the idea of “privacy in context” be adopted. This approach shifts the emphasis from privacy as an element that dictates information confidentiality, if not secrecy, to the regulation of the information flow. The way we propose to think about the flow of information and the content that we wish to invest in regulating information will reflect our proposed concept of “genetic responsibility.” We will elucidate the meaning of genetic responsibility in view of, and in relation to, traditional family relations—what we call old/conventional kinship—and family relations that take shape amid “new kinship,” i.e., those formed against the background of recourse to gamete donation—between a sperm donor or an egg donor and their offspring—and donor siblings. The fifth and last part of the article gives an initial sketch of the way the response to the dilemmas presented in Part 3 should be designed in view of the aforementioned theoretical infrastructure and the concept of genetic responsibility.

1. DNA Testing Kits—Some Factual Background

Genetic investigation by means of OTC genetic testing has become readily available, simple, and easy in recent years.[[7]](#footnote-7) Several large firms dominate the genetic-testing market[[8]](#footnote-8) and various small companies also vie for consumers’ hearts and wallets[[9]](#footnote-9)—some specializing in ancestry information and others purporting to provide medical information as well. The cost of the test, too, has also come down steeply over the years.[[10]](#footnote-10) Today one can take the basic ancestry test that yields information about ethnic and geographic origins and reveals kinship relations [בשבילי - לוודא שכלול שם גם נושא הקשר המשפחתי!] for $50–$100; an expanded test that includes the foregoing along with genetic-medical mapping goes for $150–$200.[[11]](#footnote-11) The outcomes of the tests include, for example, an indication of the testee’s specific geographic origin by region or, at times, by country, and, among other things, disclosure of his or her “Jewish” or “Native American” roots, if any. Certain areas and origin population groups, foremost Asia and Africa, are underrepresented, making the information that these tests may yield incomplete. In addition to ethno-geographical information, one may find genealogical particulars including tracing of kin, making it possible some cases to obtain details with which to contact previously unknown relatives. Some tests ostensibly give information about personality characteristics, preferences, traits, or defects. A few, as stated, provide information of medical importance.

According to a survey published in the scientific journal *Genome Biology*, the total population of testees exceeded 10,000,000 at the beginning of 2018 and, according to a cautious estimate, will grow to 100,000,000 by 2021. According to information sourced to the commercial firms themselves, today—in the middle of 2019—the number already exceeds \_\_\_\_\_. Even though the tests have been on the market since 2007, their use began to surge in 2016[[12]](#footnote-12) due to mass marketing, lavish media exposure, and steep decreases in the price of kits. The market turns over millions of dollars and is expected to grow in coming years from $117 million in 2017 to $611 million in 2026.[[13]](#footnote-13)

In addition to personal information that they receive along with their test outcomes, testees may request inclusion in the commercial firm’s database [???]. They may obtain information about genetic kin and use it to compose a family tree that interlocks with the branches of other individuals’ tree or trees. In some cases, an interface can be created between a family tree put together on a site dedicated to the construction of family trees (such as Geni), on the basis of reportage by family members, and similar family records compiled under the auspices of OTC genetic-test companies.

Some firms provide (or provided) updates of the information. From time to time, testees may receive a newly revised version of the data concerning their ethno-geographical origin (reflecting changes in the genetic pool due to updates prompted by additional data from other testees, yielding a more accurate picture of ancestral origin) and about the revelation of kin (in view of additional relatives who took the tests and are willing to be included in the relative-tracing database).

Medical information is limited, in principle, to the testee’s personal use.[[14]](#footnote-14) However, information pertaining to the kinship of other testees and other family members who did not take the genetic test, but whose particulars were fed by other testee/testees to genealogy sites (some of which are linked to firms that disclose genetic information elicited by such tests), may be accessible to anyone who applies to join the database even if they do not take a genetic test themselves. [בשבילי - לבדוק מה גלוי לכולם, מה רק למי שנבדק]

The information yielded by these tests is incomplete. Many genetic indicators, including illnesses or traits, have not yet been mapped. Even mapped diseases or defects are not reflected with certainty (or even near-certainty) in the test outcomes. First, a personal disparity may occur due to variance in the testee’s lifestyle, nutrition, exposure to air pollution, and so on (given that environmental effects are among the precipitants of disease).[[15]](#footnote-15) Second, the test performed is incomplete and covers neither the full set of genetic mutations that exist for a given illness nor even all mutations mapped at the present time. In detecting breast and ovarian cancer, for example, only a small portion of currently known indicators that may shed broader light on the risks of morbidity are tested. Consequently, a result proclaiming the testee free of suspect genetic findings does not suggest that the testee is not predisposed to them.[[16]](#footnote-16) In addition, the reliability of the tests is less than absolute. The outcomes of different commercial tests taken by one testee, for example, are perceptibly different. This may trace, among other possibilities, to differences among the testing companies in their databases and algorithms. Some observers define the results of these tests as statistical guesswork or estimation.[[17]](#footnote-17) However, in the derivatives with which this article deals, both in questions of tracing relatives and in positive discovery of a limited number of genetic defects that may lead to late-onset illness (as distinct from dismissing such a potential), the findings that these tests may provide are certain enough to constitute life-changing events. For example, they may rule out with 100 percent certainty the genetic parentage of a person whom the testee regards as his or her parent, identify another person as a parent at a high level of certainty, and point to genetic variations associated with higher risk of late-onset Alzheimer’s disease, breast cancer, and Parkinson’s disease.

[האם יש מגבלת גיל? מה לגבי קטינים?]

Given that genetic (i.e., blood) relatives have shared genes, the discovery of information by a testee may have implications for his or her relatives. Natalie Ram explains the genetic implications of this fact in simple terms:

Genetic information about one individual can be used to identify or learn about that individual’s close genetic relatives—with clinical, research, and criminal consequences.

That is so because genetic information is inherited in specific and predictable ways, such that close genetic relatives are more genetically similar than unrelated individuals. An individual inherits 50% of her genetic material from each parent and is expected to have roughly 50% of her genes in common with any full sibling. In humans, that genetic material is organized into twenty-three pairs of chromosomes. In each generation, different portions of the DNA sequence in the chromosomes from each parent are passed on to each child. As a result, each child is unique, though she shares some parts of her sequence with her parents and also with her siblings, who likewise inherited parental DNA—but in a different combination.[[18]](#footnote-18)

This explanation suffices for our purposes for two reasons. First, it signals both the possibility of identifying a given individual as someone’s kin of a given degree on the basis of two genetic samples: his or her own and that of his or her family relation. Second, it suggests a higher probability that first-degree kin will share a genetic predisposition that amplifies the risk of a given disease. As Ram puts it: [לשקול אם נחוץ או אפשר לוותר על הציטוט הזה ---]

[…] The information disclosed through this testing may be significant for that individual’s close genetic relatives. Genes for medical traits, if present in a child, disclose that at least one parent similarly carries the gene in question because, as mentioned above, children inherit half of their genetic material from each parent. Moreover, if a parent or sibling carries a particular gene variant, then that indicates an increased probability that the variant is also present in another family member.[[19]](#footnote-19)

2. DNA Testing Kits—Limits of the Discussion

Before we delve into the chosen case studies, it is important to define the limits of the discussion due to the vast range of dilemmas that arise in regard to OTC genetic testing. This article *does not* deal with criminal or forensic dilemmas. Thus, it does not concern itself with the way investigative authorities treat test findings, including access to findings of tests conducted by suspects’ kin, as they try to track down criminals,[[20]](#footnote-20) or with the reliability of these findings in solving criminal cases.[[21]](#footnote-21) Similarly, the article does not examine the role of insurance companies,[[22]](#footnote-22) employers,[[23]](#footnote-23) or medical-service providers,[[24]](#footnote-24) the way they should use such information, and the fear that they will discriminate against people who have certain genetic-medical profiles.[[25]](#footnote-25) The article does not delve into questions of invasion of testees’ privacy that the state or the aforementioned economic institutions may commit in the course of their work.[[26]](#footnote-26) Neither does it tackle the question of regulating the commercial firms that provide this service.[[27]](#footnote-27) An example of such an issue is how the databases that these firms manage are kept secure.[[28]](#footnote-28) Are they susceptible to hacking by hostile private or outside players, and is the anonymity that the firms promise in gathering and safeguarding the data possible at all?[[29]](#footnote-29) The article does not ask how the information is shared with the customer and what information or warnings customers receive before they take the test or before its results are divulged, the incompleteness of the information, the extent of its credibility, or “surprises” that customers may encounter once they receive it. The article does not worry about the fear of customers’ being misled by the way the product is marketed[[30]](#footnote-30) or about conflicts of interest when, for example, the firm accompanies its medical findings by recommending supplements to improve the customer’s medical condition in view of the genetic profile findings—supplements that the firm itself sells.[[31]](#footnote-31)

The article centers on the family. The implications of the information for family members who maintain kinship relations of the kind formally recognized by law—parent–child relations and ties among siblings born to the same parents and within the same family setting; for kin (parents, offspring, and siblings) whose legal relationship has been severed by adoption; for siblings born of one gamete donation,[[32]](#footnote-32) and between gamete donors and their offspring.[[33]](#footnote-33) By presenting the case studies and the dilemmas that may arise in the context of “problematic” genetic discoveries, we construct a context for discussion of the proposed theoretical measure that will conceptualize the norm of “genetic responsibility.” The section that follows expands on the aforementioned situations and the dilemmas to which they give rise.

3. **Four Case Studies and the Familial Dilemmas They Raise**

**(1) Case Study 1:**

**Negative health-related genetic findings that may have an impact on other family members**

לפתוח במקרה לדוגמה

People who take OTC genetic tests may receive information that has negative health-related implications. Such data may include, among other things, genetic predisposition to a variety of illnesses, including life-threatening conditions such as breast and ovarian cancer, prostate cancer, heart disease, diabetes, various degenerative diseases (including Alzheimer’s), and mental illness, to name only a few. Tests for early detection of additional illnesses are introduced each year, commensurate with the growing effectiveness of science and permission granted by regulatory agencies.[[34]](#footnote-34) In the test, an attempt is made to present a numerical estimate of the percent probability of developing the disease in view of the detection of genetic predispositions relative to the population at large.[[35]](#footnote-35) Even though the reliability of the tests is disputed, foremost in view of the high rate of false negatives—test results that incorrectly indicate that a particular condition or attribute is absent[[36]](#footnote-36)—an indication of the existence of a mutation is a strong evidence of a higher risk of developing the disease.

The discovery of such data may have perceptible mental and medical implications for the testee. The more severe the illness is, particularly if it is life-threatening, for which higher risk exists in the course of one’s life, the more its revelation may trigger anxiety, sadness, and even depression and suicidal feelings. Among other testees, the information may kindle other or additional sentiments. Some testees will choose to take preventive action by making lifestyle changes in both health-related (nutrition, sports, avoidance of smoking, etc.) and other respects (e.g., to “make the most of life” from their standpoint, to “live for the moment,” to fulfill a dream). The information may affect medical decision-making, abet early detection of the illness, treat it in its early stages, and even take preventive measures as a dependency of the type and risk of the illness.

Such information may have a powerful impact not only on those who discover it but also on their family members.[[37]](#footnote-37) Apart from the indirect effect of the information on kin (parents, siblings, and, of course, spouses) in regard to their present and future relations with those subject to this heightened risk of illness (an aspect that we do not take up within this framework),[[38]](#footnote-38) the finding of a genetic predisposition to an illness or a defect in the testee may be indicative of a high risk of its presence among his or her genetic relatives.[[39]](#footnote-39) The genetic kin of relevance are, first and foremost, offspring relative to siblings, offspring relative to parents, and parents relative to offspring. Even more distant kinships, particularly uncles/aunts and cousins, are somewhat relevant as well.[[40]](#footnote-40)

In the routine legal discourse, the discovery of “negative” medical information by a testee may trigger the question of whether he or she has the “right” to withhold the information from others even if said others may be affected by it. Is it the testee’s “duty” to share the information with a relative? Assuming that the answer is in the affirmative, the question is how the information can and should be shared, and with whom.

On the other side of the divide, those who receive news about their medical condition may wish to share it only with those whom they choose—who may or may not be first-degree relatives. Degrees of kinship and ties among family members are individual and may vary from one case to the next. A testee may opt personally for a way of life that will disregard the test findings and ensure that no one pities him or her or meddles with his or her medical or personal choices. At times, even when one feels emotionally close to a relative or perhaps precisely because of this love, one will find it hard to share such information with the relative, who, as stated, may also be affected by it, due to the wish to refrain from hurting the relative and undermining his or her life.

Ostensibly and at first glance, the right to privacy in its “traditional” sense may provide an across-the-board justification of a testee’s choice to keep the information under wraps, particularly in the case of medical information that is entitled to strong legal protection. When the matter is seen through the conventional discourse on privacy, plainly it also evokes considerations of “the right not to know” nature. Such a calculus abets an outlook by which a given family member has the right to be shielded from the information, a view that would also justify a result that calls for withholding the information. Conversely, the perception of a genetic connection as something that creates responsibility among genetically related partners, as set forth in the next section of this article, may point in a different direction.

The type of information discovered, the likelihood of risk, the type of illness, the possible timing of its eruption, the question of its treatability, and the potential of preventive action against it may dictate the contours of the decision and modify the results that the decision wishes to achieve. The age of the family member (or his or her being a minor) and his or her current state of health may also affect this outcome.

Assuming that the weighting of interests justifies the disclosure of this information, the question is how it should be conveyed. Should it be shared in its entirety, disclosed in part, presented via a caregiver (a physician), etc.?

להשלים מתוך החומרים רועי גילבר}

Below are references in case law to the requirement of revealing such information (from Ram, p. 936):

More interestingly, bioethical norms and even some case law

have indicated that an obligation to share the results of genetic testing

may exist. At least one court has expressly recognized that physicians

involved in genetic testing are legally obligated to take “reasonable

steps . . . to assure that the [genetic testing] information reaches those

likely to be affected or is made available for their benefit.”366 Biomedical

ethicists similarly have concluded that individuals seeking genetic testing,

or their physicians, may in some instances be expected to disclose genetic

testing results to at-risk family members [f”n 367: Inst. of Med., Assessing Genetic Risks: Implications for Health and Social Policy

278 (Lori B. Andrews et al. eds., 1994) (recommending disclosure of genetic risk to

relatives “only when elicit[ing] voluntary disclosure fail[s],” “high probability of

irreversible or fatal harm [exists],” “disclosure of information will prevent harm . . . [and]

is limited to the information necessary for diagnosis or treatment of the relative,” and

“there is no other reasonable way to avert . . . harm”); Opinion 2.131—Disclosure of

Familial Risk in Genetic Testing, Am. Med. Ass’n (Dec. 2003), http://www.amaassn.

org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2131

.page (on file with the Columbia Law Review) (“Physicians also should identify circumstances

under which they would expect patients to notify biological relatives of the

availability of information related to risk of disease.”).]

**(2) Case Study 2:**

**Revelations about the identity of the genetic parent in the context of adoption or that of a gamete donor or genetic siblings**

לפתוח במקרה לדוגמה

The second case study deals with a different kind of revelation. Offspring who know that they were adopted or are the products of a gamete donation (sperm, egg, or both) may use the test to trace genetic relatives or even, at times, a genetic parent or siblings born from the same donation or given over to adoption by other families. The identity of a testee’s genetic parents or siblings may come to light in one of two ways. Direct discovery takes place after the identifying particulars of the parent or sibling appear overtly in the test results; this happens when such persons take the test by themselves and allow their particulars to be disclosed to other kin. Indirect revelation occurs when only some of their information appears in the detailed presentation of their outcomes [נניח ללא פרטים מזהים --- יש דבר כזה?] or when the particulars revealed belong to another and more distant relative. Under these circumstances, a testee can obtain full information about his or her identity by contacting the relative (insofar as contact details are provided) and asking the relative to put him or her in touch with the genetic parent, or by cross-referencing and using partial information provided in the test results via online search engines (such as Google) or social networks (Facebook, etc.). This kind of tracing may lead the testee to a parent who gave him or her up for adoption, to a gamete donor (a genetic parent), or to siblings. Obviously but not needless to say, insofar as the offspring is exposed to these individuals’ particulars and/or wishes to trace them, the opposite situation, in which the genetic parent—the person who put his or her child up for adoption (or whose child was taken away for adoption) or who made a gamete donation may trace the offspring. When the sides are not equally willing to share information or establish contact, the situations become more complex.[[41]](#footnote-41)

Earlier research on adoptees[[42]](#footnote-42) and more recent studies on offspring of gamete donors[[43]](#footnote-43) indicate that both sides are highly motivated to trace genetic roots. Adoptees have been striving for decades to secure their right to access information that would allow them to trace mothers who had surrendered them for adoption under duress.[[44]](#footnote-44) They act indefatigably to track their genetic mothers down, sometimes with no assistance from the adoption agencies and even in contravention of the law.[[45]](#footnote-45) Offspring of sperm donors (and, to a lesser extent, of egg donors) also take action to locate donors and find siblings born of the same person’s donation.

The combination of OTC genetic tests and dedicated online forums[[46]](#footnote-46)—or, as stated, general social networks or search engines—broadens the possibilities of finding each other, filling in missing information, writing life-narratives, and even meeting their progenitors and creating new-kinship relations with them.

On occasion, when the information is fully accessible, no real dilemma occurs. Both sides apply for testing independently due to a specific or general wish to uncover information that will allow the sides to trace each other. It is clear, however, that even when both parties are willing to share information and even to meet, thought should be given to the right setting for the sharing of information and optimal establishment of relations for both sides and for the other members of their families. Consideration might be given to the location of the offspring’s parents, particularly if the offspring is young, as to the optimal way to make the connection. In other and more complex cases, only one party wishes to come out in the open and track down the gamete donor, sibling, or offspring. Then, discovery may take place by tracing another family member whose particulars the testee discovers—a relative who may or may not be aware of the adoption or the gamete donation. Tracing the family member by means of a genetic database, combined with cross-referencing of other data available online or contacting the relative directly, may lead to the parent, sibling, or offspring him or herself. The response of the latter may range from delight over the revelation (despite its being surprising) to fierce objection to the disclosure of their identity, the sharing of information, or the act of making contact. In the classic privacy discourse, this would be seen as an invasion of the privacy of a mother who surrendered a child for adoption or of the gamete donor, generating opposition to the initiative on privacy grounds. These concerns are rooted in stigmas that were once common (and may be partly so even today) against mothers who are forced to put up their children for adoption and against men (or women) who sell their gametes to the highest bidder, as it were. The approach that flows from the revised conceptualization proposed here is explained in the last part of the article.

[לחשוב איפה לשלב את הסיפור בנוגע לסנקציה של בנק הזרע שמונעת מהאם שימוש בתרומה...]

לקחת ממאמר אחים... }

**(3) Case Study 3:**

**Negative genetic findings discovered by a genetic parent in the context of adoption or gamete donation**

The third case study conflates the first two. It pertains to circumstances under which a parent discovers that their child was put up for adoption or makes a gamete donation and obtains genetic information that has potentially serious adverse medical implications, such as the kind illuminated in the first case study above. When these circumstances are present, the question is whether the parent should share the information with his or her genetic offspring, whether he or she may withhold it, and how he or she should manage the information-sharing transaction. This case study is unique because it fine-tunes the question of genetic kinship for a situation in which the relationship is not accompanied by family relations in the emotional sense. The question here is what this kinship entails in terms of the responsibility that it imposes on the possessor of the information vis-à-vis those whom it might affect.

This case study, one presumes, rarely occurs in reality. For it to come about, two conditions must be satisfied, one of which is itself uncommon—the discovery of potentially serious negative genetic medical information by a testee who is a gamete donor or by a parent whose child was put up for adoption. This case study raises the question of whether a testee who does not maintain family relations (or perhaps any relations) with his or her offspring or sibling should have to share with them medical information that may affect them, and, if so, how and in what manner.

If one views this instance in the traditional way, one may well find no explicit requirement at all. First, no family relations would be seen to exist in this case, it being presumed that the legal parent–offspring relationship has been severed (by means of adoption)[[47]](#footnote-47) or not created to begin with (via a gamete donation).[[48]](#footnote-48) Second, insofar as one can speak about family ties at all, then the traditional structuring of privacy is such that it would identify the testee as the owner of the information and allow him or her not to reveal it to anyone. We chose this special case study for our discussion even though its coming about is improbable because it hones the question of the obligation that inheres to the genetic relationship itself, even if the relationship is not accompanied by a familial emotional bond in the ordinary sense of the term. Another aspect underscored in this context pertains to the difference, if any, between a genetic obligation that comes about from parent to offspring and one that forms in the direction of offspring to parent. Even horizontal relations among genetic siblings evoke curiosity. The question, in other words, concerns the extent to which an offspring’s responsibility to his or her progenitrix (e.g., a mother who gave birth for adoption purposes) or to a person who assisted in his or her birth (e.g., a gamete donor) is equal to these persons’ obligation toward him or her. After we unfurl our theoretical proposal for a new understanding of privacy in the current era, generally and in the context of genetic information particularly, we shall attempt to suggest an initial direction of thinking in this context.

**(4) Case Study 4:**

**Life-changing surprises regarding familial affiliation and identity**

“I have my PhD in cell and molecular biology. When I saw that I share about 22 percent of my genome with a person, I thought, ‘That's huge.’ It took a bit of time to realize that Thomas and I actually share the same genome with my father…. I called my dad. All I had was his name, Thomas, and the fact that he's male. I just asked my dad, ‘Does this name sound familiar?’ He said no… Dad checked it [on his own 23andMe results], and Thomas' name appeared in his list. 23andMe said dad was 50 percent related with Thomas and that he was a predicted son.

“I freaked out. I said, ‘Can I call you back later?’ I hung up the phone. I pulled out my genetics textbooks, called my contact at 23andMe, and asked if it was wrong. I called my sister and for three days, we agonized about what to do, we got into a fight, and thought, ‘Do we say something? Do we not say something?’…

“I reached out to Thomas over 23andMe and soon found out he had been adopted at birth and was searching for his birth parents for years. I immediately felt empathetic: … I thought, ‘He has a right to know. Who am I to stand in the way and say, “You can't talk to my dad—it might hurt my feelings?”’

“At first, I was thinking this is the coolest genetics story, my own personal genetics story. I wasn’t particularly upset about it initially, until the rest of the family found out. Their reaction was different. Years of repressed memories and emotions uncorked and resulted in tumultuous times that have torn my nuclear family apart. My parents divorced. No one is talking to my dad. We’re not anywhere close to being healed yet and I don’t know how long it will take to put the pieces back together.”

[Excerpted from: <https://www.vox.com/2014/9/9/5975653/with-genetic-testing-i-gave-my-parents-the-gift-of-divorce-23andme>]

The case described above is not unique. News sites, blogs, and social networks abound with stories of this kind: life-changing surprises[[49]](#footnote-49) such as a father’s discovery that he is not the genetic father of the child whom he reared as his own (or an offspring who makes the opposite discovery about his assumed father) or a person who was not aware of being born via gamete donation who now finds out.

Even these “surprising” discoveries may evoke questions about what should be done with the information. The case study presented here reveals something of this dilemma by uncovering the personal (and familial) vacillations that take place over whether to disclose the information and the possible implications of doing so.

When test findings produce surprising revelations in the family context, and particularly when they subvert a father’s “true” identity by showing that the testee is the product of a gamete donation hitherto unknown to him or her, or in view of the existence of an extramarital affair, repercussions are likely in several contexts. While not all possible implications of this situation relate to regulatory aspects, all of them tie into the topic of this article. Unlike worrisome medical outcomes that every reasonable testee should bear in mind as possibilities, revelations of the existence (or absence) of first-degree kinship may be totally unexpected. In this sense, a testee born to parents who raised him or her as their own child all their lives may, as a result of the test, be exposed to information that he or she would prefer to keep under wraps. This aspect of the matter does not touch on the question of privacy; it may, however, justify regulatory action that will require firms selling OTC tests to take stronger action to “warn” clients about such results. In legal systems that do not require gamete donors to sever parental ties with their offspring, the availability of such tests in the market must be accompanied by legislation explicitly providing that gamete donors are not legal parents and that neither they nor their relatives may be presented with legal, economic, or other demands. One aspect of this situation was covered in the second case study: the possibility of tracking down the genetic parent as soon as his or her existence becomes known. This aspect relates to sharing information about the existence of a surprising family tie (and the subversion of another one) with the rest of the family. Does a testee have the right to withhold such information from anyone, including siblings with whom he or she was raised in the same household and with whom he shared his parents’ care, by force of his or her right to privacy? Does a testee have the right (and, perhaps, the obligation) to bring paternalistic considerations to bear in deciding whether to notify some or all family members and in handling similar matters?

The foregoing case studies turned the spotlight on a range of fascinating dilemmas, some common to all the cases and others tangentially related to all or a special in a way that varies from case to case. In principle, all the questions asked pertain to the flow of genetic information that the test elicits, in respect either to sharing it, revealing it, or managing it among family members. These questions, elucidated in light of the case studies above, form a platform on which we may test a new concept that, as stated, we wish to develop—genetic responsibility.

This concept, explained in the next part of the article, creates a structure within which discretion can be shaped as to the correct manner of using genetic information among family members. This includes the disclosure of information, the non-disclosure of information, the conditions for the disclosure of information, and the form and manner of disclosure among stakeholders in the information. As part of this concept, we will argue that the very existence of a genetic relationship as such (i.e., not only the discovery of a genetic connection between two individuals) creates an obligation among the principals in this connection, even if the relationship is legally recognized as a formal familial one.

1. **From Privacy to Responsibility**
1. As their online advertisement says: <https://www.ancestrydna.com/kits/?s_kwcid=ancestry+dna&gclid=EAIaIQobChMIzZGmrNid4QIVQRh9Ch3clwkQEAAYASAAEgK7iPD_BwE&gclsrc=aw.ds&o_xid=79107&o_lid=79107&o_sch=Paid+Search+Brand>, March 23, 2019. [↑](#footnote-ref-1)
2. According to Yaniv Erlich et al., 60 percent of searches for individuals of European descent result in a match at the third-cousin or closer level, theoretically allowing them to be identified by means of demographic markers. Moreover, the technique could implicate nearly any U.S. individual of European descent in the near future. <http://science.sciencemag.org/content/362/6415/690.long> [↑](#footnote-ref-2)
3. Hereinafter, for simplicity’s sake, we refer to them as OTC genetic tests. [↑](#footnote-ref-3)
4. Samuel D. Warren & Louis D. Brandeis, The Right to Privacy, 4 Harv. L. Rev.193, 213 (1890). [↑](#footnote-ref-4)
5. [↑](#footnote-ref-5)
6. [↑](#footnote-ref-6)
7. These tests first appeared in the consumer market in 2007. Most of them require the testee to give a sample of saliva; others entail a sample of cells from the inside surface of the cheek. The testee prepares the samples at home and mails them to the testing company. The answers are reported by means of electronic mail several weeks later. [↑](#footnote-ref-7)
8. According to reported estimates, the company that has the largest pool of testees (exceeding that of all other companies combined) is Ancestry DNA (with more than seven million as of 2018 [לנסות לחלץ מידע], followed by 23andMe, with two million testees, and My Heritage. [↑](#footnote-ref-8)
9. Examples are Family Tree DNA (<https://www.familytreedna.com/>), Ftdna, Natgeo, Vitagene, Helix, Orig3n, and Living DNA. [↑](#footnote-ref-9)
10. For several years at the outset, such a test cost $1,000. The price then fell to $400 and has leveled off in the past few years at $100–$200 depending on the type of test, as explained below. For prices in recent years, see Andrew Pollack, DNA Profile Provider Is Cutting its Prices, *The New York Times,* Sept. 9. 2008, <https://www.nytimes.com/2008/09/09/business/09gene.html> [↑](#footnote-ref-10)
11. This information is based on online commercial advertising that may be viewed on firms’ sites or on marketing platforms such as Amazon.com. [↑](#footnote-ref-11)
12. Razib Khan and David Mittelman, Consumer genomics will change your life, whether you get tested or not. *Genome Biology* 20, August 2018; Antonio Regalado: 2017 was the year consumer DNA testing took off, February 12, 2018: <https://www.technologyreview.com/s/610233/2017-was-the-year-consumer-dna-testing-blew-up/> [↑](#footnote-ref-12)
13. לחפש אסמכתא ב- – [את זה לקחתי מכתבה, צריך לחפש את המחקר עצמו...]

Credence Research [↑](#footnote-ref-13)
14. Some allege, however, that data available online and distributed by electronic mail to customers may be prone to hacking. [אסמכתא] [↑](#footnote-ref-14)
15. The outcome presented may, for example, indicate that a testee has an above-average chance of developing prostate cancer and may express this probability in approximate numerical data. [↑](#footnote-ref-15)
16. The test even falls short of complete genetic tests that physicians can order today at much higher cost to elicit a broader picture of morbidity risk factors. [↑](#footnote-ref-16)
17. אסמכתא [↑](#footnote-ref-17)
18. Natalie Ram 876. [↑](#footnote-ref-18)
19. Natalia Ram, DNA by the Entirety 115 Columbia Law Review 873 (2015) 890. [↑](#footnote-ref-19)
20. In this context, see, for example, \_\_\_. [↑](#footnote-ref-20)
21. In this context, see, for example, \_\_\_. [↑](#footnote-ref-21)
22. In this context, see, for example, \_\_\_. [↑](#footnote-ref-22)
23. In this context, see, for example, \_\_\_. [↑](#footnote-ref-23)
24. In this context, see, for example, \_\_\_. [↑](#footnote-ref-24)
25. In this context, see, for example, \_\_\_. [↑](#footnote-ref-25)
26. In this context, see, for example, \_\_\_. [↑](#footnote-ref-26)
27. Although, as explained in the last part of the article, some of the regulation that we wish to consider should be done by these companies. [↑](#footnote-ref-27)
28. Yaniv Erlich. [↑](#footnote-ref-28)
29. See the aforementioned articles in Natalia Ram, note 82. [האם יש הערה כזו?] [↑](#footnote-ref-29)
30. In this context, see, for example, \_\_\_. [↑](#footnote-ref-30)
31. In this context, see, for example, \_\_\_. [↑](#footnote-ref-31)
32. [↑](#footnote-ref-32)
33. [↑](#footnote-ref-33)
34. Such as the FDA [הפניה]. [↑](#footnote-ref-34)
35. For overviews such as these, see, for example, \_\_\_. [↑](#footnote-ref-35)
36. Source of definition: Google Dictionary. [↑](#footnote-ref-36)
37. See, generally, \_\_\_. [↑](#footnote-ref-37)
38. Those potentially affected by the testee’s future illness. [האם לאפשר לאתר כתיבה שעסקה בכך בכלל?] [↑](#footnote-ref-38)
39. For a genetic overview, see \_\_\_. [↑](#footnote-ref-39)
40. Genetic sharing is much weaker in more distant kinships. See Ram, 901. [↑](#footnote-ref-40)
41. Sometimes, a person traces a gamete donor or sibling purposely by joining a database of donors and donees that is meant to match the sides. [↑](#footnote-ref-41)
42. הפניות – לקחת מהמאמר שלי על אימוץ [↑](#footnote-ref-42)
43. הפניות, לקחת ממאמר אחים בנסיבות של תרומה [↑](#footnote-ref-43)
44. [↑](#footnote-ref-44)
45. [↑](#footnote-ref-45)
46. Such as the Donor Siblings Registry: <https://www.donorsiblingregistry.com/> and We Are Donor Conceived, <https://www.wearedonorconceived.com/>,
הפעיל ביותר --- אחאים, לקחת מאמר אחים... [↑](#footnote-ref-46)
47. [↑](#footnote-ref-47)
48. [↑](#footnote-ref-48)
49. For additional stories published in recent years, see, for example,

<https://www.thecut.com/2018/12/elizabeth-wurtzel-on-discovering-the-truth-about-her-parents.html>

<https://www.nytimes.com/2019/01/15/books/review/dani-shapiro-inheritance.html?module=inline> [↑](#footnote-ref-49)