Behind the Screen: An Overview of Premarital Genetic Testing in the Jewish Community

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I. Introduction

Genetic screening is a process in which specific genes are searched for within a particular population. Usually, a proband instigates the test, seeking the details of a genetic condition. Carrier screening facilitates the identification of heterozygotes and carriers for certain serious homozygous recessive diseases. Population screening is mainly directed at a population with a known risk for a certain disease to gain insight into the prevalence of the disease in that population and to provide genetic counseling and intervention when necessary.

Genetic screening is a powerful tool that can be used to prevent much heartache and challenging scenarios that may arise from the marriage of two carriers of the same recessive gene. Marriage is an integral part of the Jewish life cycle. Marriage and procreation are among the most important and essential aspects of Judaism. The *Sefer HaChinuch*, a book enumerating the 613 *mitzvos*, lists the *mitzvah* of having children as the first commandment.[1] The author of the *Sefer HaChinuch* explains that the commandment to have children is what underlies the entire system of the commandments, as without humans, there would be no one to fulfill the commandments.[2] Therefore, having healthy children that are able to perform G-d's commandments is undoubtedly one of the most important and essential values of Judaism.

A. Genetics in Classical Jewish Sources

Jewish writings, even as old as the Bible and Talmud, are not foreign to the idea of genetics and genetic diseases.

[1] *Sefer Hachinuch, Mitzvah* 1. Translation from Sefaria.org
[2] Ibid

One example of Talmudical medical knowledge is that of hemophilia and its genetic transmission. The Talmud discusses a case of someone's children dying due to circumcision. The *Gemara* states:

דתניא: מלה הראשון ומת, שני ומת, שלישי — לא תמול, דברי רבי. רבן שמעון בן גמליאל אומר: שלישי תמול, רביעי — לא תמול.

As it is taught in a *baraita*: If a woman **circumcised** her **first** son **and he died** as a result of the circumcision, and she circumcised her **second** son **and he** also **died, she should not circumcise** her **third** son, as the deaths of the first two produce a presumption that this woman's sons die as a result of circumcision. This is **the statement of Rabbi** Yehuda HaNasi. **Rabban Shimon ben Gamliel says: She should circumcise** her **third** son, as there is not considered to be a legal presumption that her sons die from circumcision, but **she should not circumcise** her **fourth** son if her first three sons died from circumcision.[3]

The *Gemara* comments that once a woman has had either two or three sons that have died due to exsanguination as a result of circumcision, the third or fourth son should not be circumcised. The *Gemara* continues with an explanation of the biological underpinnings of this case:

בשלמא גבי מילה, איכא משפחה דרפי דמא ואיכא משפחה דקמיט דמא

The Gemara asks: **Granted with regard to circumcision** a presumption of death due to circumcision can be established because **there are families whose blood is thin** and does not clot well, **and there are families whose blood clots.**[4]

[3] *Talmud Bavli Yevamos* 63b. Translation from Sefaria.org
[4] Ibid

Through the *Gemara's* classification of thin and clotting bloods within familial lines, it reflects the knowledge of genetic acquisition of characteristics. Furthermore, the *Gemara* recognizes the female carrier aspect of hemophilia, directing the warning against circumcision specifically to the woman's, and not the man's, sons. The maternally linked nature of hemophilia was only proven in the wider medical world in the 19th century. The first published article recognizing hemophilia was published in 1803 by Dr. John Conrad Otto.[5] This disease has been classified, through the use of genetics, to be a X-linked recessive hereditary disorder that classically affects males, in agreement with what the Talmud describes as a matrilineally determined disease.[6]

Rabbi Avraham Deri also notes an unusual grammatical usage in the *Gemara*. When referencing circumcision, the *Gemara* uses the feminine usage of the word (מלה) instead of the masculine form (מל). He says the feminine usage of the word reflects the fact that the mother is the source of the disease that leads to the death through circumcision, the X-linked disease, hemophilia.[7]

Another example of genetic knowledge in the Talmud comes from the same discussion as hemophilia. The *Gemara* elaborates that there is a rabbinic enactment against marrying a woman from a family of epileptics.[8] This enactment too wishes to prevent these genetic diseases from being passed to future generations.

A later enactment illustrates the Rabbinic awareness of genetic diseases. Rabbi Yehuda the Pious, a 12-13th century Rabbi, prohibited marriages between first cousins and between

[5]https://www.hemophilia.org/bleeding-disorders-a-z/overview/history#:~:text=In%201803%2C%20John%20Conrad%20Otto,%2C%20New%20Hampshire%2C%20in%201720.

[6] Shoukat HMH, Ghous G, Tarar ZI, Shoukat MM, Ajmal N. Skewed Inactivation of X Chromosome: A Cause of Hemophilia Manifestation in Carrier Females. Cureus. 2020;12(10):e11216. Published 2020 Oct 28. doi:10.7759/cureus.11216

[7] *Otzar Bris Avraham - Hilchos Geirim.* Page 511

[8] Talmud *Bavli Yevamot* 63b

uncles and nieces due to the high frequency of defective births resulting from unions among blood relatives.[9]

These examples further exemplify the Rabbinic awareness and efforts to prevent the transmission of genetic diseases in Jewish tradition.

B. History of Jewish Genetic Screening and Tay-Sachs

Perhaps one of the most famous, or infamous, Ashkenazi diseases is Tay-Sachs. As of 2001, the disease incidence in the Jewish Ashkenazi population was about 1 in every 3,500 newborns with the carrier frequency at 1 in every 29 individuals. The dangers associated with Tay-Sachs disease should not be underestimated. Babies born with Tay-Sachs Disease experience slow nervous system deterioration, which diminishes cognitive function, usually seen as the loss of motor skills, vision, hearing, and strength. These symptoms usually lead to death within 3-5 years. Tay-Sachs disease was first observed and described by W. Tay and B. Sachs in 1881. Until 1969, 50 to 60 Jewish children were born each year in the United States and Canada with Tay-Sachs disease. There was an entire medical ward of 16 or 17 beds at Kingsbook Jewish Medical Center in Brooklyn dedicated to treatment of children with Tay-Sachs.[10]

The first screening program was trialed in a synagogue in the Baltimore area in 1971. In the screening program, trained volunteers and physicians drew blood from over 1,500 people in order to ascertain their status as carriers for the disease.[11] After these mass screenings began, the number of Jewish babies born with Tay-Sachs declined to two to five per year.

[9] Rosner F. Judaism, genetic screening and genetic therapy. Mt Sinai J Med. 1998;65(5-6):406-413.
[10] https://www.jta.org/2017/08/11/united-states/how-the-jews-nearly-wiped-out-tay-sachs
[11] https://www.jewishgenetics.org/articles/tay-sachs-and-carrier-screening-how-they-shaped-the-jewish-community/

II. *Halachic* Implications

Given the possibly fatal results of homozygous recessive genetic diseases, it is natural to assume that any method that can be used to prevent a negative outcome should be taken. However, the Gemara in *Brachos*[12] discusses the story of *Chizkiyhua* and *Yeshayahu*. In the story, *Chizkiyahu* is punished with a deadly illness. *Yeshayahu* tells him that he will die in this world and not have a life in the world to come due to his purposeful avoidance of having children. *Chizkiyahu* says he abstained from this, as he saw with *Ruach Hakodesh* that his child will grow up to not be virtuous, referring to *Menashe*, who was later born and did terrible sins. *Chizkiyahu* had thought that it was better to have no children at all, rather than having unsuccessful children. To this *Yishayahu* replies that it is not up to man to intervene in divine decrees, rather, man must follow the commandments that were demanded of him and whatever G-d sees fit, He does.

This story raises a series of questions regarding genetic testing. One can deduce from this story a similar conclusion regarding genetic diseases, namely, that one should not concern themselves with what the consequences of what he is commanded to do. This conclusion, as will be seen, may be ill informed.

Within the halachic scope there are two main views of the *Halacha* in regards to genetic testing. The first possibility is that it is allowed, and one should test for genetic diseases. The second possibility is that it is forbidden to test, as doing so is an affront to belief in G-d.

A. Opinion One: *Halachic* Imperative to Test

Given the seriousness of Tay-Sachs, it is no surprise then that one of the earliest questions in the 20th century in regards to pre-screening couples came about through an inquiry

[12] *Talmud Bavli Brachos 10a*

regarding Tay-Sachs. Rabbi Moshe Feinstein addresses the issues of *bitachon* and genetic testing. In a *Teshuva* he says:

אם יש לבדוק למחלת טיי סאכס קודם הנישואין?

עיינתי בזה וזהו הנראה לע"ד כי אף שהוא מיעוט קטן ילדים נולדים כאלו ושייך לומר על זה הקרא דתמים תהיה עם ה' אלקיך וכפרש"י בחומש שם שכתב התהלך עמו בתמימות ותצפה לו ולא תחקור אחר העתידות, מ"מ כיון שעתה נעשה זה באופן קל לבדוק יש לדון שאם אינו בודק את עצמו הוא כסגירת העינים לראות מה שאפשר לראות, ומכיון שאם ח"ו אירע דבר כזה הוא להורי הילד צער גדול מאד מן הראוי למי שצריך לישא אשה לבדוק את עצמו. ולכן טוב לפרסם הדבר ע"י עתונים ואופנים שידעו העולם שאיכא בדיקה כזו[13]

Should one test for the Tay-Sachs disease before marriage?

I have investigated this and it appears to me, in my humble opinion, that even though there is only a small chance that the children will be born like this, and one can say the verse of "*You must be wholehearted with your G-d"*, and like *Rashi* explains in *Chumash* there "you shall go with him constantly and seek him out and do not seek after the future," still since nowadays one can easily test, it should be considered that if someone does not test it is as if he closes his eyes to see what he is able to see, and since if, *chas v'shalom,* something like this happened it would cause great pain to the parents of the child, it is advisable for someone who needs to marry a woman to test himself. And therefore, it is good to publicize this through newspapers and the like so that the world should know that there is such a test.

Rabbi Moshe Feinstein hints to the fact that there should, in theory, be a contradiction between the general understanding (as understood by *Rashi*) of the *Pasuk* of "*tomim t'hiyeh",* "You must

[13] Feinstein M. Responsa Iggrot Moshe, Even Haezer, Part 4, No. 10. Bnei Brak (Israel); 1985.

be wholehearted with your G-d"[14] that one must follow G-d fully without being concerned with the future outcome and genetic testing. However, Rabbi Moshe Feinstein asserts that although the probability of both parents being carriers is minute, since it is so simple to check for Tay-Sachs it is as if the information is already available. If one were to ignore it, it would be the equivalent of closing one's eyes when the answer is right in front of them. He concludes there is no concern of violating the precept of *"tomim t'hiyeh"*.

Other Jewish commentators and deciders discuss the issue of human intervention in unknown future events as well. The *Shulchan Aruch* rules that 'We do not make inquiries to astrological seers, nor to the fates [about the future]'.[15] The *Rema* and *Shach* explain that these practices do not fall under the prohibition of sorcery but are not advisable due to the precept of "*tomim t'hiyeh*" to be faithful to G-d. Rabbi Nosson Gestetner[16] explained "t*omim t'hiyeh*" in the context of seeking purported kabbalists for advice, fortune telling, amulets, palm and face reading. Rabbi Gestetner distinguishes fortune telling from healing with an amulet. The prohibition elaborated amongst the *Rishonim* is only to gaze into the future in order to know what will occur. However, healing with an amulet is not an act of telling the future, but the harnessing of supernatural powers in order to heal. While he questions the effectiveness and truthfulness of using amulets, they do not violate "*tomim t'hiyeh*" if the objective is not to tell the future. In this limited view of "*tomim t'hiyeh*" genetic testing would not be included in the prohibition. As he explained, only practices similar to fortune telling are prohibited. Although the determination of one's genetic makeup may lead to knowing the genetic makeup of a future

[14] *Devarim* 18:13
[15] *Shulchan Aruch, Yoreh De'ah* 179:1. Translation from Sefaria.org
[16] *Lehoros Nosson* 6:78-83

child, it can be argued that the results of a genetic test only refer to facts that are in the present, of the two parents, not of the future child.

There is another principle in Judaism known as "*shomer p'saim Hashem" "G-d protects the simple."*[17] The basic understanding of this dictum is that if one simply believes in G-d, no harm will befall him.[18] This may lead one to believe that the best solution to screening for genetic diseases is to not test all, and trust in G-d that the children of the marriage will be healthy. However, Rabbi Asher Weiss repudiates this view. He quotes Rabbi Yisroel Isserlin, author of the *Terumos Hadeshen*, who limits the application of the dictum. In his response to a question regarding marrying women who have been widowed two times or more, he says that while a great Torah scholar may possibly rely upon the concept of *shomer p'saim Hashem* to protect him, it does not equally apply to normal people where the danger is known.[19] Therefore, Rabbi Asher Weiss says one must test for genetic diseases that can pose a danger to the children of the couple. He also addresses the *Gemara* in *Brachos* mentioned above in regard to *Chizkiyahu*. He says that the story of *Chizkiyahu* cannot be used to prove that one must not test. First of all, in that case he divined the knowledge through the use of "*Ruach Hakodesh"*. Genetic testing though is a matter of nature. Furthermore, the concern in that case was that his future son would sin, which is a choice of man's free will. That type of concern is not a sufficient reason to prevent having children. However, genetic diseases are unpreventable and therefore one may intervene to prevent such an outcome.

[17] *Tehillim* 116:6
[18] See *Orchos Tzadikim* 9:31
[19] *Terumas Hadeshen, Siman* 211

Ultimately, these *Halachic* deciders highlight the fact that testing for genetic diseases that can pose a risk to future progeny is important and permissible within the framework of Jewish ethics and beliefs.

B. Opinion Two: *Halachic* Prohibition to Test

A second opinion, though in the minority, is that of Rabbi Menashe Klein. Rabbi Klein, also known as the Ungvarer Rabbi, was a 20th century Hasidic Rebbe and *posek*. In a *Teshuva*, he discusses his opinion on genetic testing before marriage. In his view genetic testing is forbidden according to Jewish law. He goes as far as to mourn the many matches that could have been made, and the healthy children that could have been born, had these tests not prevented their marriages. He also quips that the genetic testing organization *Dor Yesharim* (literally "a straight generation") should not lead to a *Dor Ikeish U'Pisiltul* (literally "a stubborn and crooked generation"). Rabbi Klein goes as far as to call the people that test for genetic diseases indirect murderers!

The crux of his argument rests upon the fact that in his view genetic testing violates the precepts of "*M'Hashem Isha L'ish"* (from G-d is a woman to a man), and that G-d protects those who serve him.

The precept of *M'Hashem Isha L'ish* appears in the *Gemara* and is rooted in *Tanach*. The *Gemara* in *Moed Kattan*[20] brings proofs from *Torah*, *Neviim*, and *Kesuvim* that G-d arranges marriages. The Gemara states:

הכי אמר רב משום רבי ראובן בן אצטרובילי: מן התורה ומן הנביאים ומן הכתובים — מה׳ אשה לאיש. מן התורה, דכתיב: ״ויען לבן ובתואל ויאמרו מה׳ יצא הדבר״. מן הנביאים, דכתיב: ״ואביו ואמו לא ידעו כי מה׳ היא״. מן הכתובים, דכתיב: ״בית והון נחלת אבות ומה׳ אשה משכלת״.

[20] *Talmud Bavli Moed Kattan* 18b

Rabbi said in the name of Rabbi Reuven ben Itzterobili as follows: From the Torah, and from the Prophets, and from the Writings; it implies that the decree that a specific **woman** is destined to be married **to** a specific **man** is **from G-d.** From where is this derived? It is **from the Torah, as it is written: "Then Laban and Bethuel answered and said: The thing comes from the Lord,** we cannot speak to you either bad or good" (Genesis 24:50). **From the Prophets, as it is written: "But his father and his mother knew not that it was of the Lord"** (Judges 14:4). **From the Writings, as it is written: "House and riches are the inheritance of fathers; but a prudent woman is from the Lord"** (Proverbs 19:14).[21]

This part of the *Gemara* lays the scriptural foundation for divinely decreed matchmaking. He quotes a later paragraph in the same discussion for support of his position. The *Gemara* there says:

כי הא דרבא שמעיה להההוא גברא דבעי רחמי ואמר: תזדמן לי פלניתא. אמר ליה: לא תיבעי רחמי הכי. אי חזיא לך — לא אזלא מינך, ואי לא — כפרת בה׳. בתר הכי, שמעיה דקאמר: או איהו לימות מקמה, או איהי תמות מקמיה. אמר ליה: לאו אמינא לך לא תיבעי עלה דמילתא?

This is **like this** incident, in **which Rabbia heard a certain man asking for mercy,** i.e., praying, **who said: Grant me so-and-so** as a wife. Rabbia **said to him: Do not** pray and **ask for mercy** in **this** way. **If** she **is fit for you,** and it has been decreed that she will be your wife, **she will not go away from you. And if** she is **not** destined to be your wife, **you will** come to **deny the Lord** when you see that your prayer is not answered. **After** the man married this woman, Rabbia **heard him say** in prayer: Please **either let him die before her or let her die before**

[21] Ibid. Translation from Sefaria.org

him. He was speaking about himself and his wife because he had grown to hate her so much. Rabbia **said to him: Did I not say to you not to pray for this matter?**[22]

The *Gemara's* story relates a man who prayed for a certain woman to marry him, which he does, and in the end he regrets it. *Rabbia* tells the man that if she is meant for him by G-d the marriage will be successful, and if not, the marriage will not be. In Rabbi Menashe Klein's view, this story indicates that all matchmaking is prescribed by G-d and any attempt of human intervention will only lead to failure, as indicated by the fact that *Rabbia* berated the man for requesting who to marry, and from the fact that ultimately the man's marriage fails. It would follow that any human intervention, including genetic testing to determine who one should marry, would be in violation of this precept.

His second argument that G-d will not cause harm to someone who follows Him is sourced in *tomim t'hiyeh* (see above regarding the definition and understanding of *tomim t'hiyeh)* and a comment of the Ibn Ezra. The Ibn Ezra comments on the *Pasuk* of *V'hasiroisi Machala M'kirbecha* ("And I will remove illness from your midst") that the blessing refers to someone who keeps all the *Mitzvos* in the *Torah*.[23] If he follows them scrupulously, he will be rewarded with protection from G-d. Rabbi Klein concludes that trying to predict what diseases may come about through this marriage is unnecessary and shows a lack of trust in G-d. He also asks rhetorically, if people are really so concerned about compatibility for marriage, why not also test to see if the potential spouses can even bear children in the first place? The phenomenon of infertility is unfortunately 100s of times more likely than most genetic diseases!

[22] Ibid
[23] *Shemos* 23:25

Overall, this viewpoint stands in opposition to the practice of genetic testing before marriage, advocating for a complete trust in G-d's plan for matchmaking and protection.

C. Response to Rabbi Menashe Klein's Opinion

The complete prohibition of genetic testing, the view held by Rabbi Menashe Klein, is not commonly accepted in the Jewish community. The arguments defending his position can be offset by the opinions of the Rambam. In response to the argument of *M'Hashem Isha L'ish*, the Rambam in his introduction to *Pirkei Avos* is relevant. In the introduction he addresses the issue of divinely arranged marriages.[24] There he says:

> אלא שהרבה פעמים יטעו בני אדם ויחשבו קצת פעולות האדם הבאות בבחירתו שהוא מוכרח עליהם כזווג פלוני, או היות זה הממון בידו, וזה בלתי אמת, כי זאת האשה אם לקחה בכתובה וקדושין והיא כשרה לו ולקחה לו לפריה ורביה והיא מצוה והשם לא יגזור בעשיית מצות, ואם יהיה בנשואיה איסור היא עבירה והשם לא יגזור עבירה… אבל כל פעולות האדם הבאות בבחירתו בהם בלא ספק ימצאו המצות והעבירות כי כבר בארנו בפרק השני שמצות התורה ואזהרותיה הם בפעולות אשר לאדם בהם בחירה שיעשה ושלא יעשם…
>
> Men are, however, very often prone to err in supposing that many of their actions, in reality the result of their own free will, are forced upon them, as, for instance, marrying a certain woman, or acquiring a certain amount of money. Such a supposition is untrue. If a man espouses and marry a woman legally, then she becomes his lawful wife, and by his marrying her he has fulfilled the divine command to increase and multiply. G-d, however, does not decree the fulfillment of a commandment. If, on the other hand, a man has consummated with a woman an unlawful marriage, he has committed a transgression. But G-d does not decree that a man shall sin. … Such, however, is not the case, but rather that

[24] *Shemona Perakim l'Rambam Perek* 8

> all of man's actions, which are subject to his free will, undoubtedly either comply with, or transgress, G-d's commands; for, as has been explained in Chapter 2, the commands and prohibitions of the Law refer only to those actions with regard to which man has absolute free choice to do, or refrain from doing.[25]

The Rambam states that there are those who erroneously think that G-d forces them to marry a certain woman. He posits that, in reality, as long as the marriage is one of a permissible nature, he fulfills his obligation of marriage. This is supported by the Rambam's philosophy on prohibitions of law, in that in order to be punished for an act he must have the free choice to do or refrain from following it. In this case that extends to his choice to marry someone who is either permitted or prohibited to him. Therefore, there is no specific woman with whom he is destined to marry to which the prevention of a marriage due to genetic testing would go against G-d's decree. As long as he marries a woman that is *Halachically* acceptable to him, she is an acceptable spouse. If it is found that the children from a potential spouse would be genetically unfavorable, the couple would be viewed as incompatible, and find someone else to marry. This would in no way interfere with any divine plans, as he will be able to find another spouse who is compatible without violating the precept of divinely decreed marriages.

In response to Rabbi Klein's argument of *tomim t'hiyeh* and following G-d's commandments without worrying about the outcome, another statement of the Rambam is relevant. The Rambam states in one of his medical works[26]:

> החסיד השוטה המואס בעזרתו של רופא ונשען רק על עזרת ה' דומה לאיש רעב המואס מאכילת לחם ומקוה שה' ישמרנו וירפאנו מן המחלה הזאת הנקראת רעב...

[25] Ibid. Translation from Sefaria.org
[26] Introduction to Rambam's Treatise on Asthma. *Hakotzeres.* Pg. 47

> The foolish follower who rejects the help of a doctor and relies only on G-d's help is similar to a hungry man who rejects eating bread and hopes that G-d will protect us and heal us from this disease called hunger…

In the Rambam's view seeking medical intervention is not only acceptable, but necessary. If one were to wholly rely upon G-d while refusing to take the help of medical professionals, they would be culpable for the outcome. It follows that in the Rambam's view one would not be lacking in the precept of *tomim t'hiyeh* by seeking genetic testing. In fact, by following medical advice to prevent marriages that would produce children with fatal genetic diseases, one would be following G-d's intention.

III. Genetic Testing Methodology

A. Privacy

Taking for granted that the accepted position in the Jewish community is to test for genetically inherited homozygous recessive diseases, one of the major concerns of those being tested is privacy. Rabbi Moshe Feinstein was asked if it is appropriate for those of marriageable age to be tested for Tay-Sachs. He answered that it is advisable for one preparing to be married to have himself tested. He further said that the availability of such a test should be publicized throughout the Jewish community. He did however add a limitation to the practice. He said:

> It is clear and certain that absolute secrecy must be maintained to prevent anyone from learning the result of such a test performed on another. The physician must not reveal these to anyone . . . these tests must be performed in private, and, consequently, it is not

proper to schedule these tests in large groups as, for example, in Yeshivas, schools, or other similar situations.[27]

While Rabbi Moshe Feinstein encouraged testing for all individuals and publicizing the availability of testing, he was wary of publicizing the actual results and testing process. Rabbi Moshe Feinstein adds that the reason for this level of secrecy is due to the fact that there is a perceived notion in Jewish American society that inconsequential things, such as being a carrier for disease, is viewed negatively by others. Therefore, he requires that measures to ensure confidentiality of test results be maintained.

Rabbi J. David Bleich discusses the same topic but takes a slightly different approach. While he agrees with Rabbi Moshe regarding the positive aspects of testing, he believes it should be taken further. He says, as Rabbi Moshe Feinstein acknowledges, that there is no real reason for anyone to be concerned with being a carrier, as there is no risk to the child if the other partner is not a carrier. Any psychological trauma caused from such information is solely based on misinformation. He therefore encourages the launching of an informative campaign in the Jewish community to clarify the scientific mechanisms of genetics and assure people that there is nothing negative involved in these tests.[28]

Rabbi Moshe Feinstein's sentiments in regard to stigma of carriers does reflect the general sentiment of the time. In multiple studies from the 1980s it was found that most people felt that being a carrier for a recessive disease would have some negative bearing on how they

[27] Feinstein M. Responsa *Iggrot Moshe, Even Haezer*, Part 4, No. 10. Bnei Brak (Israel); 1985. Translation from Rosner F. Judaism, genetic screening and genetic therapy. Mt Sinai J Med. 1998;65(5-6):406-413.
[28] Bleich JD. Genetic screening: survey of recent Halakhic periodical literature. Tradition. 2000;34(1):63-87.

lived their lives.[29] One study found that most college students surveyed felt that being a carrier would alter their social status and reproductive behavior.[30] Yet another study found a small, but significant, link between carrier status and poor self-esteem and anxiety.[31]

While Rabbi Bleich's assertion that from a medical and scientific standpoint there is absolutely no reason for one to look down upon a carrier of a disease, as a matter of public policy and emotions, it appears Rabbi Moshe's view of confidentiality seems more practical. Though, as Rabbi Bleich suggests, a community run organization teaching awareness regarding the status of carriers seems like the most logical approach, in practicality, it may be difficult to implement. People's preconceived notions and attitudes take time to change, and while in certain communities such an education program may succeed, in others it may not. Furthermore, even after people are told that being a carrier for a disease bares no negative implications in it of itself, it may still be difficult for people to emotionally comprehend that reality.

B. Two Major Approaches to Genetic Testing

The differing approaches of Rabbi Moshe Feinstein and of Rabbi Bleich manifest themselves in two of the major organizations involved in screening for recessive diseases in the Orthodox Jewish community in the United States.

i. Dor Yeshorim

One of the organizations is *Dor Yeshorim*. Founded in 1983 by Rabbi Yosef Ekstein, *Dor Yeshorim* has become the premier genetic screening for Orthodox Jews. Rabbi Ekstein

[29] Levin M. Screening Jews and genes: a consideration of the ethics of genetic screening within the Jewish community: challenges and responses. Genet Test. 1999;3(2):207-213. doi:10.1089/gte.1999.3.207
[30] Austein CF, Seashore MR, Mick SS. Knowledge and attitudes toward Tay-Sachs disease among a college student population. Yale J Biol Med. 1981;54(5):345-354.
[31] Clark M, Palmer R, Kontras S. Community-based genetic education: sources of information in a Tay Sachs disease screening program. Ohio State Med J. 1982;78(3):218-220.

established Dor Yeshorim after losing four of his own children to Tay-Sachs disease. The testing panel *for Dor Yeshorim* has expanded to include many more Ashkenazi prevalent recessive genetic diseases such as: Cystic Fibrosis, Familial Dysautonomia, Canavan Disease, and many other genetic diseases. The methodology of *Dor Yeshorim*'s tests is in line with how Rabbi Moshe Feinstein described the process. Individuals are tested for several recessive genetic diseases at a young age before marriage and are not informed of the results of the test. The information is anonymously stored in *Dor Yeshorim's* system and can only be retrieved using a code that is given to the screened individual. The codes of two prospective partners are used to compare the results and check if they are carriers of the same genetic disease. People who are carriers of a mutation for the same recessive condition have a 1 in 4 chance of having an affected child. Therefore, in such a case, the prospective couple is told that marriage is "not advisable".[32] This method follows the concerns raised by Rabbi Moshe Feinstein, keeping all information confidential, only revealing if the prospective couple are compatible or not.

ii. Jscreen

The alternative method is to test openly and to reveal all the results to the individual, such as how Jscreen tests. Jscreen is an organization based in Atlanta at Emory University's Department of Human Genetics and is a national nonprofit public health initiative dedicated to preventing Jewish genetic diseases. They say in their mission statement that:

[32] Ekstein J, Katzenstein H. The Dor Yeshorim story: community-based carrier screening for Tay-Sachs disease. Adv Genet. 2001;44:297-310. doi:10.1016/s0065-2660(01)44087-9

JScreen believes the combination of education, access to premier gene screening technologies and personalized, confidential support are the keys to preventing these devastating diseases.[33]

In their methodology, individuals purchase a saliva collection kit online, and are sent the kit with a pre-paid envelope to send the sample to the lab. In this test, over 200 recessive diseases are tested for.[34] After about 3 weeks a 15-20 minute phone consultation with a genetic counselor is required for most participants, after which the individual receives a copy of their results. The phone consultation mitigates risks of misinterpretation of results, ensuring that the participant does not assume being a carrier entails worse results than it scientifically does. Unlike Dor Yeshorim which is made almost exclusively for the Orthodox Jewish community, Jscreen is made for society at large, with an emphasis on the Jewish community. Furthermore, they are not concerned for the stigma involved with knowing the results of a genetic test. They are of the philosophy that with more free and open information, people will gain awareness of the science of genetic testing. Thus, the stigma related to being a genetic carrier would be mitigated.

The methodology employed is more similar to the one proposed by Rabbi Bleich. He believes that there is no issue with disclosing the information to the individuals involved in the testing. He believes that more community awareness of the details of genetic testing should be made public, not kept behind closed doors. Rabbi Bleich also offers a more cost-effective method than either of the two organizations. The ideal system would be to draw blood for a Tay-Sachs test in conjunction with a routine blood test performed by a pediatrician during childhood.

[33]https://www.jscreen.org/blog/non-profit-community-based-genetic-screening-leader-jscreen-offers-discount-on-screenings-to-honor-rare-disease-day/
[34] https://www.jscreen.org/genetic-conditions-tested-in-expanded-panel/

Since one is already paying for the initial blood test for a routine checkup, they will only incur a minimal fee, if any, to add on other testing pallets. He further contends that a cost-saving initiative would be to test both parents of a family. If neither parent is a Tay- Sachs carrier there is no way that any of their children can possibly be a carrier. "It is certainly cheaper and more efficient to screen two adults, even if they are beyond child-bearing age, than to test each child of a union blessed with multiple offspring."[35]

In the same article, Rabbi Bleich critiques the methods employed by Dor Yeshorim. Rabbi Bleich says:

> To their eternal credit, a number of sincere and self-sacrificing individuals have dedicated themselves to the eradication of Tay-Sachs disease as well as of a number of other genetic diseases prevalent in the Jewish community… However, in refusing to divulge the results of genetic tests to either the young men and women affected or to their parents, a negative stereotype is dramatically reinforced. The hocus-pocus of assigning numbers and later announcing that the prospective marriage of the bearers of matched numbers will either be propitious or will not be propitious imbues the process with a Byzantine-like quality. Assuredly, refusal to test for the carrier state until announcement of an engagement is imminent takes a toll in psychological trauma during the waiting period, not to speak of heartache caused those forced to abandon wedding plans already formulated and to go their separate ways. The entire process confirms and reinforces a certain primitiveness and know-nothingism prevalent in certain sectors of our community.

[35] Bleich JD. Genetic screening: survey of recent Halakhic periodical literature. Tradition. 2000;34(1):70.

While Rabbi Bleich does recognize the great contribution of *Dor Yeshorim* to the health and wellbeing of the Jewish community, he also believes that the system currently employed by *Dor Yeshorim* is primitive and counterproductive. It is much simpler to have everyone know what their status as a carrier is, and the potential couple can compare it themselves. Using a confidential number system in which an organization decides whether or not the individuals are compatible only enforces negative stigmas and stereotypes in the community. The fact one cannot openly speak about testing, the "know-nothingnism", only reinforces the narrative that being a carrier inherently negative. He concludes that having this organization as a final decider reflects more broadly on the certain primitiveness of certain Jewish communities.

Dor Yeshorim themselves seem to respond to the suggestions and criticisms of Rabbi Bleich in their discussion of confidentiality where they state:

> The life altering success of the Dor Yeshorim program is due to the absolute confidentiality inherent within the system. Everyone wants the very best for their children's future. If Dor Yeshorim was to disclose testing results, those who are not carriers would certainly feel relief. But what about the boys and girls who turn out to be carrying a genetic disease? What does one do with that knowledge? Announce to the public "I am a carrier"?? Share the information with the shadchan and jeopardize shidduchim before they even begin?
>
> Even the most highly educated individuals have difficulty using intellect to dominate the emotions of knowing that he or she, or a potential mate carries a genetic disease. To avoid any stigmatization, and based on the dictates of numerous Torah luminaries, Dor Yeshorim's infrastructure was therefore created with inherent confidentiality. This is [sic]

no way negates the intelligence of the general public or their ability to comprehend and assess results.[36]

Ironically, *Dor Yeshorim* claims that they are removing stigma from the individual by ensuring no one knows the results. When no one knows what their status is, no one can be labeled as a carrier, thus skirting any issues of ostracization in the "*shidduch* world". Furthermore, they respond to his claim that there are certain sects of the community that are uneducated by stating that one cannot use rational thinking in an emotional matter. They would contend that while more education regarding the nature of genetics could be spread, it still would not resolve the emotional consequences of being told one's carrier status.

As stated before, Rabbi Bleich would suggest that a community wide education program would remove the stigmas and negative attributes associated with carriers. The point of contention between the two approaches appears to be different philosophies of how a community approaches a problem. In *Dor Yeshorim's* view, the simplest way to deal with the stigma involved in genetic testing is to avoid the problem entirely. In this case that is accomplished through keeping the status of all carriers anonymous, and therefore no one can be excluded. In Rabbi Bleich's view, such an approach is primitive. In his view, the proper way to approach a problem is with full disclosure without hiding any medical facts. In this case, the solution is educating an entire community, not just the individuals, in order that no one would even have a negative emotional response to being told they are a carrier for a disease.

[36] https://doryeshorim.org/our-philosophy/#confidentiality

IV. The Ethical Extent of Testing

A moral question that arises from genetic testing is to what extent diseases can and should a community test for? There are many heritable genetic diseases that can be passed from parents to offspring. These can range from diseases and disorders with negligible effects on quality of life to others that can have major life-threatening consequences. The consequences of choosing what to test for is not one that should be taken lightly. At some point, preventing marriages to avoid the possibility of any disease becomes eerily similar to eugenics. As Rabbi Moshe Tendler points out, the availability of genetic testing can lead to social pressures that can lead to parents opting for perfect donor sperm, eggs, or compulsory contraception.[37] This can be a slippery slope in which we begin to exclude a potential spousal match where even the slightest deficiency in outcome is possible.

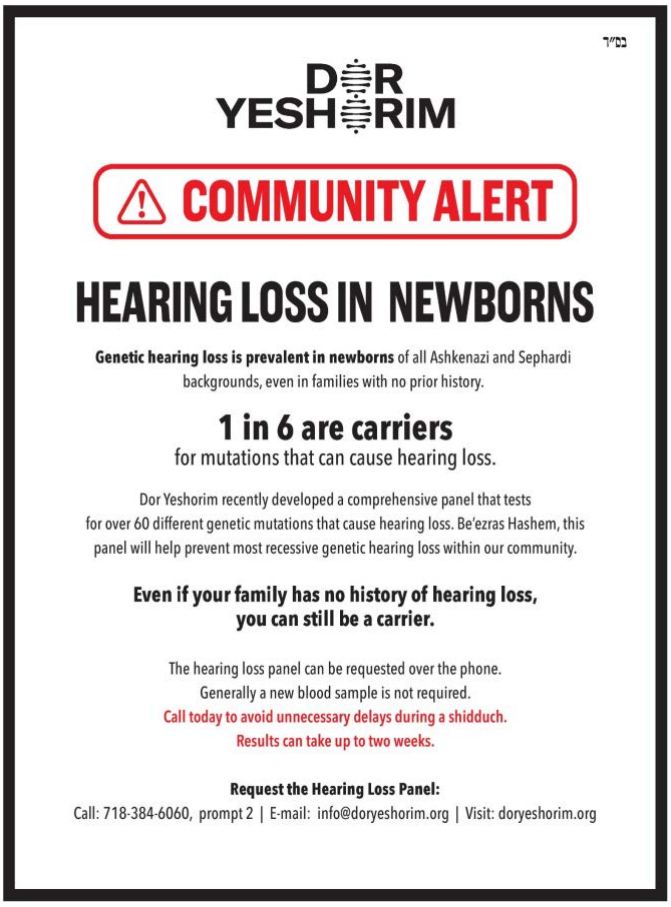
A. Hearing Loss as a Case Study

A recent campaign published by *Dor Yeshorim* has been addressing genetic hearing loss. As part of this campaign, *Dor Yeshorim* encouraged anyone testing for inheritable genetic diseases to also test for a genetic form of hearing loss. *Dor Yeshorim* says the reason for this campaign is that there are currently almost one thousand families in the Orthodox community experiencing unexplained hearing loss. They have identified over 20 genes and more than 60 genetic mutations that can cause genetic hearing loss.[38] In their research they have discovered a

[37] Tendler MD. Alzheimer dementia: the Judaeo-Biblical perspective on patient care and genetic predestination or neurocalvinism. Alzheimer Dis Assoc Disord. 1998;12 Suppl 3:S21-S23.
[38] https://doryeshorim.org/understanding-dor-yeshorims-hearing-loss-panel/

link between mutations in the gene *MYO15A* and autosomal recessive nonsyndromic hearing loss in four Ashkenazi Jewish families.[39]

In this campaign, *Dor Yeshorim* placed ads in Jewish newspapers, WhatsApp groups, and email lists. An example of one of these advertisements is shown below.



Dor Yeshorim Advertisement to Test for Hearing Loss Testing Panel

In the advertisement, *Dor Yeshorim* warns of the prevalence of carriers for genetic mutations that cause hearing loss in both Ashkenazi and Sephardi Jews. They therefore

[39] Booth KT, Hirsch Y, Vardaro AC, et al. Identification of Novel and Recurrent Variants in MYO15A in Ashkenazi Jewish Patients With Autosomal Recessive Nonsyndromic Hearing Loss. Front Genet. 2021;12:737782. Published 2021 Oct 18. doi:10.3389/fgene.2021.737782

encourage anyone involved in *shidduchim* to include the hearing loss panel in their genetic tests. There are two approaches as to how the issue of this disorder should be handled.

i. Broadened Testing

One approach, as recommended by *Dor Yeshorim*, is to test for and phase out any risk of the disorder in the Jewish community. Through testing and preventing the marriage of two carriers of the disorder, the potential issue of genetic hearing disorders can be eradicated from future generations. *Dor Yeshorim* hopes that these screenings will lead to a similar outcome as the successful campaign for reduction of Tay-Sachs babies through genetic screening of parents. While it is certainly the case that genetic hearing loss is a terrible disorder that affects the quality of life of those that suffer from it, some have argued that preventing a marriage in its entirety due to the risk of hearing loss is unethical.

ii. Limited Testing

The second approach, in contrast to the view espoused by *Dor Yeshorim*, is to not prevent a marriage based upon the risk of genetically inherited hearing loss. In this view, genetic hearing loss should not be tested for at all. In fact, there is a movement amongst parents with certain disabilities, including deafness, to perform pre-implantation genetic diagnosis (PGD) to select for an embryo with certain disability markers and select which to implant via in vitro fertilization (IVF).[40] As it would be quite difficult for a deaf parent to raise a child with normal hearing capabilities, parents sometimes elect to have their own children inherit the trait for deafness. In fact, according to one study in the United States "[t]hree percent of IVF–PGD clinics report having provided PGD to couples who seek to use PGD to select an embryo for the presence of a

[40] Sermon K, Van Steirteghem A, Liebaers I. Preimplantation genetic diagnosis. Lancet. 2004;363(9421):1633-1641. doi:10.1016/S0140-6736(04)16209-0

disability."[41] There is much discussion amongst the medical community regarding the morality of this practice.[42] Some argue that by selecting for the gene the parents would deprive the child of living their fullest and healthiest life and should be prevented. However, there is a serious argument for allowing parents to choose to have deaf children. One study phrases the argument as follows:

> "One person's disability can be another person's culture or community—for example, in the case of close-knit communities like the deaf. Some deaf parents even request PGD so that they can ensure their children will be born deaf, and thus take part in their culture and lifestyle."[43]

While *Dor Yeshorim's* testing of genetic deafness usually involves able-hearing parents, the fact that there are deaf communities, and even those that purposely include deaf causing genes, puts into question the prevention of a marriage due to the risk of deafness.

In the Jewish community there has been some opposition to this hearing panel as well. A mother of two children with hearing loss responded to the testing panel with ten points of clarification regarding raising children with hearing loss. Among her points are that hearing loss does not necessarily mean deafness, just a weakened sense of hearing, which may require the use of cochlear implants or another type of hearing aid. She also makes note that hearing loss does not legally fall under a disability in the United States barring someone who is profoundly deaf. She does mention the hardships of raising children with hearing loss, and that the early years of development can require a lot of therapy. But at the same time, the experience of children with a

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[41] Baruch Susannah, Kaufman David, Hudson Kathy L. Genetic testing of embryos: Practices and perspectives of US in vitro fertilization clinics. Fertility and Sterility. 2008;89(5):1053–1058. doi: 10.1016/j.fertnstert.2007.05.048.
[42] Wallis JM. Is it ever morally permissible to select for deafness in one's child?. Med Health Care Philos. 2020;23(1):3-15. doi:10.1007/s11019-019-09922-6
[43] Dance A. Better beings?. Nat Biotechnol. 2017;35(11):1006-1011. doi:10.1038/nbt.3998

hearing disability is comparable to children with other learning challenges and who, with extra effort and care, succeed in life.[44]

Ultimately, determining the boundaries of premarital testing requires striking a delicate balance between the desire to prevent suffering and the respect for individual choices.

V. Conclusion

Given Judaism's emphasis on marriage and child rearing, the practice of genetic testing in the Jewish community is one of great importance. The use of genetic testing can help reduce or even eliminate the risks of certain diseases. One of the earliest lethal recessive diseases tested for was Tay-Sachs. While there is some disagreement amongst the *Poskim,* the use of genetic testing in order to eradicate Tay-Sachs has been almost universally accepted. Due to this, in recent years there have been two notable organizations that have made genetic screening accessible to the masses. These are Dor Yeshorim and Jscreen. Both these organizations employ different methodologies of how information from these tests is accessed, with *Dor Yeshorim* opting for a more confidential model, and Jscreen opting for a more open policy. While ethical considerations arise regarding the extent of testing and the potential prevention of marriages based on the risk of certain genetic disorders, each community can decide how to best balance the potential to prevent suffering and individual choice within *Halacha*.

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[44]Raichik C. "10 Myths of Hearing Loss". collive.com. www.collive.com/10-myths-of-hearing-loss-from-personal-knowledge/

intersection of topics in bioethics and *Halacha*. I would also like to thank the members of the Jay and Jeanie Schottenstein Honors Program for the opportunities they have given me towards my success in Yeshiva University and beyond.

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