

Genetic Testing for Late-Onset Diseases: When a Little Knowledge Might Be a Dangerous Thing

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Introduction

One of the most significant scientific milestones reached this past decade was the completion of the Human Genome Project in 2003. The project's goal was to map out the entire molecular sequence of a human cell's DNA, and then to identify all the genes present in this sea of molecules. Scientists have currently found approximately 22,000-23,000 genes in human DNA, although analysis of these results is ongoing.¹ But finding the genes is only the beginning. It will take much more analysis and research to understand how certain genes can affect everything from a person's body fat index to a person's neurological state. While many diseases are inherited in complex "polygenetic" patterns, which involve a combination of many different genes and multiple variants within each gene, some

1 http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml. Retrieved April 27, 2011.

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diseases are associated with specific genetic mutations. These mutations arise when the molecular “code” of a gene is slightly altered to form a different “code.”² Since almost all cells in the body have two pairs of genes, one inherited from the mother and the other from the father, often a single mutation will not lead to a diseased state. Such genetic diseases are referred to as autosomal³ recessive diseases,⁴ and require two mutated copies of the gene before a person will show the disease. Other mutations require only one mutated copy of the gene before disease is evident, and these diseases are known as autosomal dominant diseases. For dominant diseases, if one parent has the disease, and the other parent is genetically normal, there is a 50% chance that any child of this couple will manifest the disease.⁵ Unlike autosomal recessive diseases, which often manifest the disease from birth or in early childhood, autosomal dominant diseases are usually late-onset diseases that only start showing clinical signs once a person is middle-aged or older.

This paper will discuss genetic testing for late-onset autosomal dominant diseases that have no preventive treatments and no cure. Two examples of such diseases will be described, followed by a discussion of how the medical

2 For example, the code should read “...AGCT...” but instead a person’s DNA reads as “...AGAT...”

3 Autosomal means the gene is unrelated to the person’s sex (cf. X-linked diseases)

4 e.g. Tay-Sachs Disease. In such a case, if someone has one copy of the mutated gene (known as a carrier), they will appear totally normal, but if the spouse also has a mutated copy, there is a 25% chance that the child will inherit both mutated genes, and thus be affected by the disease.

5 Assuming the parent has only one mutated copy of the disease. If the parent has two mutated copies, there will be a 100% chance of passing the disease on to a child.

literature views using genetic tests as a screening tool. After describing medicine's current approach to the issue, an analysis of Jewish law's approach to such a test will be presented. The main issues include when one may reveal a terminal diagnosis to a patient (and when one may lie to hide a diagnosis), whether there is a violation of "*tamim tehiya*" (being wholehearted with Hashem) by being tested, and whether the results may be used to plan for the future.

Two Examples of Autosomal Dominant Diseases

One example of an autosomal dominant disease is early-onset Familial Alzheimer's disease (eFAD). This form of Alzheimer's disease is distinct from the classic form that is found in elderly patients. The classic form of the disease does not have a simple genetic inheritance pattern, but rather is based on a combination of multiple genetic and environmental factors (and therefore there is no genetic test for this form of the disease). However, 6-7% of Alzheimer's cases are associated with a specific genetic mutation.⁶ To date, there are three main genes that when mutated have been implicated in early onset Alzheimer's.⁷ This form of the disease often begins when one is in the prime of his or her life, usually between ages thirty and fifty. Currently, there is no cure for eFAD, nor is there any

6 van der Cammen, T. J., E. A. Croes, et al. (2004). "Genetic testing has no place as a routine diagnostic test in sporadic and familial cases of Alzheimer's disease." *J Am Geriatr Soc* 52(12): 2110-2113.

7 Certain mutations in the APP, PSEN1, and PSEN2 genes lead to almost a 100% chance of developing disease. The mutations are thought to lead to early accumulation of senile plaques, a characteristic finding of Alzheimer's disease. The role of the ApoE gene, of which the E4 subtype has been associated with doubling the risk of getting Alzheimer's, is still a matter of discussion, and even if one has the E4 subtype of the gene, there is still a 70% chance he will never develop the disease.

treatment to slow down the path of the disease. Patients who are affected will slowly develop signs of dementia, with a loss of memory and other mental functions, along with complete dependence on others to take care of daily tasks.⁸ While there is no cure, there are genetic tests available to let people know if they have the genetic mutation that will lead to the disease.

Another example of an autosomal dominant disease is Huntington's disease. This disease is caused when the Huntingtin gene is mutated so that part of the DNA that codes for the gene is repeated over and over,⁹ leading to formation of a protein that causes neurological damage. Patients usually begin to show signs of the disease in the fourth or fifth decade of life. At first, patients will start to lose their balance and have trouble with simple coordination. The classic finding of progressed disease is that of involuntary writhing movements (chorea), as well as cognitive decline and eventual dementia.¹⁰ Due to progression of disease, full time nursing care of the patient is often required, and life expectancy is approximately twenty years from onset of symptoms. As with eFAD, there is no cure for Huntington's, and there are no preventive treatments available. The only treatment that exists is symptomatic control of motor function.

In both of these cases, should one undergo genetic testing for a disease that has no cure? On the one hand, perhaps

8 <http://www.alzforum.org/eFAD/diagenetics/essay3.asp> Retrieved April 27, 2011.

9 This is known as a trinucleotide repeat. In Huntington's disease the repeat is "CAG." There usually are less than 28 sets of CAG in the DNA that code for the gene, and if there are more than 36-40 repeats the disease will occur.

10 Walker, F. O. (2007). "Huntington's disease." *Lancet* **369**(9557): 218-228.

testing will quell the anxiety bred by the uncertainty people feel when they realize there is a fifty percent chance they are latent carriers of a terminal illness. On the other hand, perhaps a positive result will lead to depression and loss of hope. Some may want to know the results to better plan for the future of the family, career, etc. What approach do current medical ethicists take? How should an observant Jew approach these issues? This paper will outline various topics that relate to genetic testing for late-onset diseases that have neither cure nor preventative treatment available for those who are positive, and for which a definitive genetic test exists (i.e. a positive test means there is close to a 100% chance of having the disease).

Criteria for Screening

Genetic testing is often viewed as a “screening test” in the medical literature. A screening test is one in which people are tested for disease even if they do not show any signs or symptoms of disease. Clearly, there must be some form of criteria met in order to decide which tests are useful screening tests, and which are not.¹¹ In 1968, the World Health Organization, in response to questions over how to implement and use new medical tests that were being created by a rapid technological advances, commissioned a report from Dr. Wilson, the Principal Medical Officer at the Ministry of Health in London. Dr. Wilson, together with Dr. Junger, published a set of guidelines regarding the

¹¹ For example, most people’s instincts would agree that a blood pressure check at the doctor to screen for high blood pressure is a valid screening test, but a yearly kidney biopsy (which is invasive, painful, and expensive) to screen for kidney disease is not a valid screening test. What are the guiding principles behind this instinctive feeling?

use of screening tests; these criteria are simply known as the “Wilson and Junger” criteria,¹² and they are still in use and relevant today. There are 10 required criteria, including the need for an important health problem that has a suitable test which is acceptable to the population, and that the test recognizes the disease in a latent or early stage. There also needs to be an acceptable treatment for the patient, along with available facilities for treatment and an agreed policy of who needs to be treated. In addition, the cost of screening should be balanced economically when compared to overall medical costs.¹³

These criteria have undergone various forms of modification over the years. Some have criticized the criteria as being too vague and theoretical, with no clear way to use them.¹⁴ Recently, the World Health Organization proposed revised criteria¹⁵ that focus on

12 Wilson JMG, Jungner G. *Principles and practice of screening for disease* Geneva: WHO; 1968.

13 In table form, the 10 criteria are:

1. The condition is an important health problem	6. The test should be acceptable to the population
2. There should be a treatment for the condition	7. Natural history of disease is adequately understood
3. Available facilities for diagnosis and treatment	8. There should be an agreed policy on who to treat
4. There should be a latent stage of the disease	9. The cost of finding a case should be economically balanced in relation to medical expenditure as a whole
5. There should be a test for the condition	10. Screening should be a continuous process

14 See Khoury, M. J., L. L. McCabe, et al. (2003). “Population screening in the age of genomic medicine.” *N Engl J Med* **348**(1): 50-58.

15 Andermann, A., I. Blancquaert, et al. (2008). “Revisiting Wilson and Jungner in the genomic age: a review of screening criteria over the past 40 years.” *Bull World Health Organ* **86**(4): 317-319.

integration of education, clinical services, and program management. They also mention the need for informed consent, confidentiality and patient autonomy. Finally, the benefits of the test must outweigh any harm. Instead of focusing on the role of treatment, they merely require that “objectives of screening” be defined at the outset.

Applying the Criteria

Using the two sets of criteria listed above, where does genetic testing for a disease with no cure or preventative treatment fit in? Since there is no cure, it would seem that such a test does not meet the requirements set forth by Wilson and Junger. However, one could make the argument that for some patients, even though there is no medicinal “cure,” in the realm of the psychosocial, such knowledge would be empowering and a form of treatment in and of itself.¹⁶ The only other need would be for a strong support network of counselors and family, along with proper education and explanation of what the test can and cannot do.

In practice, of all people who are eligible for genetic testing for Huntington’s disease, less than 5% actually are tested.¹⁷ All patients undergo a series of counseling sessions and appointments to clarify the test and discuss the reasons for undergoing testing. There is a 40% dropout rate after the first appointment. Interestingly, most people who are tested already have children and want to be tested to “relieve uncertainty.”¹⁸ Others wish to know their status for career

16 This might be implied in the second set of criteria, where the stress is on the “objectives” of screening, which leaves open what the goal of screening is.

17 Walker, F. O. (2007). “Huntington’s disease.” *Lancet* **369**(9557): 218-228.

18 Hayden, M. R. (2003). “Predictive testing for Huntington’s disease: a universal model?” *Lancet Neurol* **2**(3): 141-142.

or family planning purposes. Once a patient is tested, a positive test can lead to increased stress immediately after the results are told to the patient; however, two years after the test, the stress level is decreased when compared to before testing.¹⁹ A negative result also can lead to increased stress levels, due to a phenomenon known as “survivor’s guilt,” whereby a person feels he has done something wrong by surviving in a situation where others have not.

Halakha’s Approach

Having outlined the general principles that are used in current medical practice, let us now turn to Jewish law’s approach to such a test. The main issues that will be discussed include the appropriateness of revealing a terminal diagnosis to a patient, the permissibility to lie in certain situations, the requirement of “*tamim tehiya*” (being wholehearted with Hashem), and the approach one should have in using the results to plan for the future.

Disclosure of Illness

In the cases mentioned above, a positive genetic test is the equivalent of diagnosing a terminal illness. When a doctor discovers that a patient has a terminal disease with no possible treatment that can extend the patient’s life, should the doctor disclose this information to the

19 It is important to note the rare but serious risk of suicide that has been documented in some cases. All protocols for testing include screening for any suicidal ideation.

patient or lie about the results?²⁰ Rabbi J.D. Bleich, in *Medicine and Jewish Law*²¹, discusses this dilemma. His discussion focuses on a *halakhic* concept known as “*tiruf ha-da’as*,” i.e. there is emotional toll placed on the patient by telling the truth that might lead to a quicker demise. There are several examples where *tiruf ha-da’as* plays a significant role. When one wishes to inform a sick person that a close friend or relative has died, the Shulchan Aruch²² rules one may NOT report this news, lest the sick person experience *tiruf ha-da’as*. Moreover, we do not even perform *kriyah* (ripping a garment over the deceased) in front of the sick person, even though this is a positive commandment. Rabbi Bleich explains that while not all people react in such a strong negative way upon hearing bad news, since some people do respond in this manner, there is a possible danger to life (*safek pikuach nefesh*), and therefore no sick person may be told about any passing. In addition, Rabbi Moshe Feinstein²³ rules that hospital staff may not move one patient who is

20 This issue is often viewed as a conflict between patient autonomy and truth-telling vs. beneficence (doing what’s best for the patient). There are also legal arguments that can be made, which is not the focus of this paper. As we will see, halakha has a very different approach to the topic, as it seems clear from all sources that autonomy has no power to stand in the way of the patient’s health. Even in medical ethics there is something called “therapeutic privilege” which grants a provider the right not to disclose information to a patient if it will lead to a serious psychological threat, but the use of this principle is very limited in scope. For more information, see the American Medical Association’s report on “Withholding Information from Patients” (available at <http://www.ama-assn.org/resources/doc/code-medical-ethics/8082a.pdf>) and the associated section in the AMA’s Code of Medical Ethics, Opinion 8.082 (available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion8082.page?>).

21 Rosner, Fred. *Medicine and Jewish Law*. Jason Aronson Inc., New Jersey. 1990.

22 Y.D. 337:1

23 *Iggros Moshe Choshen Mishpat* 2:73

terminally ill out of the ICU in order to bring in someone who is deemed a more “curable” patient. The reason he gives is that such a move can lead to *tiruf ha-da’as* of the terminally ill patient, since he might realize that the move is due to his incurable nature. Therefore, Rabbi Bleich concludes one may not voluntarily reveal the nature of a terminal illness to the patient due to fear of *tiruf ha-da’as*. However, Rabbi Bleich, as well as the *Nishmas Avraham*,²⁴ does agree there are certain cases where the diagnosis must be revealed. These include cases where the patient is too knowledgeable about his condition²⁵, he will discover the diagnosis anyway, or he will develop *tiruf ha-da’as* from the lack of knowing his diagnosis. Clearly, disclosure of an illness focuses on one point alone – will the knowledge gained help or harm the patient.

Permission to “lie”

It is easy in the abstract to suggest a physician not disclose a terminal diagnosis to a patient. However, what happens if the patient asks about his or her condition? May one go so far as to lie in such an instance? The root of this issue is addressed by the *gemara* in *Kesubos*²⁶ that discusses an argument between *Bais Shaamai* and *Bais Hillel* regarding what one tells a groom regarding his wife on his wedding day:

24 *Nishmas Avraham* Y.D. 338:3

25 e.g. a doctor, a healthcare professional, (and perhaps even one who will find the information on the Internet).

26 16b-17a

How does one dance in front of the bride?²⁷ *Bais Shaamai* say: The bride as she is²⁸, while *Bais Hillel* say: The bride is nice and kind. *Bais Shaamai* said to *Bais Hillel*: But if she is lame or blind how can you say she is nice and kind? Does the Torah not say ‘Distance yourself from speaking words of falsehood’? *Bais Hillel* replied: If one buys a bad purchase from the marketplace, should one praise it in his [the buyer’s] eyes or denigrate it in his eyes? Of course, one praises it. From here, the Rabbis said: Always, a person’s mindset should be one with all people.

On the surface, the sages are arguing over the permissibility of lying in front of a bride and groom. However, the *gemara* leaves a key issue unresolved²⁹: how do *Bais Hillel* refute *Bais Shaamai*’s question that the Torah tells us not to lie?³⁰ The *Ritva* comments on this *gemara* that the prohibition not to lie is not inviolable. There are certain situations known as *darchei shalom* (ways of peace) where lying is permitted.³¹ If telling the truth would lead to hurt feelings and arguments, one should dispose of the

27 *Rashi*: What does one say in front of her?

28 *Rashi*: Based on her beauty and stature you praise her

29 Another issue that can be raised is that according to *Bais Shaamai* should one really tell a groom that his wife is lame or undesirable? *Tosfos* answer that either one should remain quiet in such situations or find a nice feature to mention about this bride.

30 Rabbi Bleich, *ibid.*, answers that *Bais Hillel* maintain the prohibition not to lie is limited to courts of law, and has no relevance to social situations. Thus, lying to a patient is unrelated to the prohibition of “Distance oneself from speaking falsehood”

31 It may even be that in such situations, the “lie” is not a lie. Regardless, one is permitted to tell the non-truth.

truth and dispense with the lie in its stead. The *Maharsha* explains *Bais Hillel's* opinion differently, that in this case there is no lie, because in the groom's eyes the bride is nice and kind. Just as when people buy items from the market they view their purchase as a good buy, so too does a groom view his bride in a positive light. One is merely reporting the truth that the other person sees (even if one disagrees).

In the case of the terminally ill patient who is asking for his diagnosis, clearly if divulging the truth will lead to *tiruf ha-da'as*, the doctor should lie simply because of *pikuah nefesh*, the requirement to save even a few minutes of life. Even if there is a situation where there is no *tiruf ha-da'as*, perhaps the lie will be permitted based on the premise of *darchei shalom*. Furthermore, according to the *Maharsha*, that when there are two "truths" one may report the truth that his friend sees rather than what he himself sees, the same may apply to a case of disclosing a diagnosis. As Rabbi Avraham Yitzchak Kook explains,³² a classical diagnosis is in the realm of doubt, not one of 100% certainty. Thus, it makes sense that in reality there are two "truths" present to the doctor – the truth he sees (a terminally ill patient), and the truth that a different doctor might see (a curable patient). When the doctor then reports to the patient that he is not terminally ill, the doctor is merely choosing one of the two truths, which is no different from a friend choosing to praise a buy rather than denigrating the buy.³³

32 Quoted in *Assia* 1987, p.18

33 *Ibid*. It is unclear if this last approach would apply to a genetic test, which on the surface seems to be a clear-cut matter. It might be that the slight chance of lab error would preserve the two "truths," or maybe the fact that scientific knowledge is constantly evolving is enough to make every case a *safek*.

In concluding this part of the discussion, it appears that disclosure of a terminal illness to the patient depends on the patient's mindset and access to the facts. The *halakha* is focused on one key point – will the information be beneficial or detrimental to sustaining life, something that must be decided on a case-by-case basis.

The Requirement to be Wholehearted with *Hashem*

Let us now return to our case of testing for late-onset genetic diseases. Obviously, if the doctors, genetic counselors, and social workers determine that genetic testing of a patient may lead to a situation of *tiruf ha-da'as*, the test may not be undergone. But what if a patient passes the *tiruf ha-da'as* evaluation, and it is deemed that disclosure will not harm him, or perhaps it might even help ease any *tiruf* that he has? Are there any *halakhic* objections to undergoing genetic testing in such a situation? When discussing genetic testing for Tay-Sachs disease in potential marriage-partners, Rabbi Feinstein³⁴ addresses if genetic testing may violate the prohibition of “*tamim tehiya*,”³⁵ which *Rashi* explains to mean that one should not seek out the future.³⁶ He says that the prohibition should not apply to testing for Tay-Sachs because:

34 *Iggros Moshe* E.H. 4:10

35 *Devarim* 18:13

36 Of note is that the *Rambam* leaves out “*tamim tehiya*” from his count of the 613 Biblical commandments. This may be because he views “*tamim tehiya*” as a general principle, which does not count as one of the 613 commandments, or because “*tamim tehiya*” is not a commandment, but a promise from Hashem that if one is *tamim* with Hashem, then he will be “*im Hashem Elokecha*.” *Ramban* does count it as a positive commandment, explaining it requires one to seek his needs only from Hashem, and to recognize that Hashem is omniscient and omnipotent. Rabbi Feinstein does not discuss the *Rambam* or *Ramban* in his response.

Since it is now done in an easy way to check, one needs to judge if one does not check this might be like “closing one’s eyes” from seeing what one can see. In addition, since if Heaven forbid, something like this [having a Tay-Sachs child] were to occur to the parents it would be very painful, it is appropriate for one who needs to marry to be tested. And therefore it is good to publicize the matter via magazines and media that the world will know there is such a test.

It would seem from the first part of the answer that any genetic test should be allowed, since not testing is merely closing one’s eyes to the reality that lies before him. However, it is unclear why Rabbi Feinstein felt the need to include the caveat that not testing would cause great pain to the parents. If there is no prohibition, then even in cases where there is no pain one should be allowed to test. And if there is a prohibition, why would the possible future pain of parents be a *heter* (permission) for violating that prohibition? Perhaps the intent of Rabbi Feinstein is that there is no prohibition to undergo genetic testing, based on the concept that not testing is merely “closing one’s eyes.” However, this reason alone would not be grounds to institute an informational campaign to tell everyone to be tested. Only after considering the possible pain a couple might go through if they are not tested does Rabbi Feinstein then advocate publicizing the need for testing. According to this explanation, in the case of late-onset genetic diseases, there should be no prohibition to be tested from the aspect of “*tamim tehiyah*,” as there is no distinction between recessive and dominant genetic

diseases when it comes to “closing one’s eyes.” However, there is also no need to form a mass screening campaign as the issue of avoiding “great pain for the parents” does not exist (since the disease cannot be prevented).³⁷

Planning for the Future

As mentioned earlier, some of those who decide to undergo genetic testing explain that they did so because they wanted to know the results to help plan their future. For example, a twenty-year-old college student is deciding on a career path, and the student really feels drawn toward the field of pediatric neurosurgery (something that requires at least 12 years of medical school and medical training). However, based on the family history, there is a fifty percent chance the student is carrying a genetic disease, and in such a situation the mental effects could start right as he is finishing training. The student therefore wishes to be tested to decide if pediatric neurosurgery is the career for him, or if he is better off in a field with less training. How should a Jewish person approach the issue?

If one looks at the *gemara* in *Brachos*,³⁸ there is a story where King Hezekiah becomes severely sick. *Hashem* sends the prophet Isaiah to inform the king that he will “die and not live.” The *gemara* explains that Isaiah was informing Hezekiah that he was to die in this world, and have no

37 It is hard to base any decisive ruling using such inferences from the responsum. Rabbi Feinstein himself writes in Y.D. 3:91 that one of the reasons he is against a translation of his responsum into English is lest people come to compare one situation to another when such a comparison is invalid. It should therefore be obvious that the above discussion is merely theoretical in nature, trying to deduce what Rabbi Feinstein might maintain in our situation, and that any actual situation must be discussed with a contemporary *posek*, Rabbinic authority.

38 10a

portion in the world to come, due to his not having any children. Hezekiah defends his decision to not procreate because he saw through *ruach haKodesh* (divine spirit) that his progeny would be wicked.³⁹ The response of Isaiah is fundamental to Judaism: “With the hidden matters of Heaven why do you bother? What you are commanded to do, you must do; and what is pleasing before God, He will do.” At first glance, it appears Isaiah is rebuking the king for using his power of knowing the future⁴⁰ to plan his life. Would the same be true of altering a career based on genetic information?

It appears there are two major criteria that differentiate the story recorded in *Brachos* from our case. First, the punishment for Hezekiah related to his failing to have any children, something that is a Biblical commandment, i.e. the obligation of “*peru u’revu* (be fruitful and multiply).”⁴¹ As the *Nefesh HaChayim*⁴² explains, even though Hezekiah had great intentions in not fathering a child, no one has permission to abrogate any of the commandments given in the Torah, regardless of any logical or rational reasoning.⁴³

39 Indeed, the son that Hezekiah did have was Manashe, who brought idols into the Temple, and during whose reign, G-d “sealed” the fate of Jerusalem for destruction.

40 The issue of free will in the face of Divine foreknowledge is complex and will not be discussed here. For a fascinating application of this *gemara*, see *Poras Yosef* (printed in the back of the *gemara*) to *Nedarim* 30b.

41 Genesis 1:28

42 1:22

43 Rabbi Goldberg, in his *sefer U’Vacharta B’chayim* on the *Nefesh HaChayim*, comments that this is why *Moshe* was praised by G-d for breaking the *Lucho*s (Two Tablets). For the *gemara* tells us *Moshe* used a *kal v’chomer*, one of the hermeneutical principles, to learn that he should shatter the tablets. Even though *Moshe* could have reasoned to himself that if he breaks the tablets “what will be with the Jewish people and the Torah,” he performed G-d’s will without letting those issues interfere.

Accordingly, the results of a genetic test would not waive a man's requirement to have children. The second difference between the case in *Brachos* and genetic testing is that Hezekiah was looking into the future, searching for signs. In our case, the genetic disease already exists inside the person, i.e. it is inherently part of someone. It therefore might not be forbidden to alter one's career path based on that knowledge, as the matter is not a "secret of Heaven"; rather, as Rabbi Feinstein pointed out, it is right in front of one's eyes.

Need for Privacy

As with all personal information, the need to keep the results of any genetic test private is of utmost importance. In addition to the obvious social and legal reasons, there is also a *hashkafic* reason as well. In the previous story, when Isaiah tells Hezekiah he is about to die, Hezekiah replies "[Isaiah] son of Amoz, end your prophecy and leave."⁴⁴ The Vilna Gaon⁴⁵ focuses on the specific order of Hezekiah's retort, i.e. that first he tells Isaiah to end the prophecy, and then to leave. He explains that Hezekiah was telling the prophet he should not repeat the message once he leaves the palace, for "a matter that is well known is hard to annul except with great difficulty." Similarly, the *gemara*⁴⁶ advises that one who becomes sick should not reveal the illness on the first day of the sickness, for such publicity can make it harder for one's prayers to be answered due to the public's knowledge. Rabbi Yosef Shalom Eliashiv⁴⁷ explains that

⁴⁴ *Brachos* 10a

⁴⁵ *Imrei Noam* on *Brachos* 10a

⁴⁶ *Nedarim* 40a

⁴⁷ Quoted in footnote in the *Mosad HaRav Kook* edition of *Imrei Noam*

there is an inherent difference between “open miracles” and “hidden miracles.” The majority of people are not meritorious enough to deserve the Divine Providence required to produce an open miracle, one where everyone will know that a supernatural change of events has occurred (e.g. the 10 plagues in Egypt). However, more people are worthy to have a hidden change of events occur, and therefore it is crucial to keep the information “hidden” from the public.⁴⁸ By doing so, there is a greater likelihood of having one’s prayers answered.

Conclusion

This paper has sought to raise awareness of various issues that arise in genetic testing for late-onset diseases with no known cure. Whether or not such a test can be deemed an appropriate “screening test” is debatable. Even if one undergoes testing, there is the potential for considerable fallout to occur based on the results. In determining what Judaism’s view is regarding genetic testing for late-onset diseases, there does not seem to be any prohibition per-se, as the *issur* of “*tamim tehiya*” is limited to actively seeking out the future, not to opening one’s eyes to what is in front of him. There also does not seem to be a problem of using the test results to plan a future career, as long as one does not avoid performing any commandments, such as marrying

⁴⁸ Regarding praying to have a negative test result, it seems that such actions would be comparable to the case in the *Mishna* on *Brachos* 54a, which states that if a woman is pregnant and her husband prays that the baby should be a male (after 40 days from conception), it is a prayer in vain. The reason is that since the fetus has already formed, praying to change nature is something only a prophet or the truly righteous can do. A genetic mutation seems to be similar to the status of a fetus in-utero, since both gender and presence of mutation are unknown at the time of the prayer. Rather, one could pray that the disease either take effect later in life or be a milder form etc.

and having children. The main issue that remains from both a medical point-of-view and a *halakhic* point-of-view is deciding how the patient who wants to be tested would react to the results. It is crucial for the genetic counseling team (doctors, counselors, psychologists, etc.) to determine that there would be no *tiruf-ha-da'as* for the patient who is undergoing testing. If necessary, it would seem that the team is even allowed to lie to the patient if doing so would be required for the benefit of the patient (although in reality such a possibility is unlikely). Nonetheless, regardless of the path pursued, it is integral to keep any information confidential, largely because of the hope that doing so would help the prayers of those involved be more likely heard and answered by the Almighty.

