Dear Fellow Jew:

I could not tell you how many times I have heard those words—spoken by broken-hearted young fathers and mothers sobbing in anguish over the suffering and loss of their precious little babies. And I would know—it happened to me. Four awful times.

That’s why we founded Dor Yeshorim—so that no one would ever have to go through such pain and anguish.

Consider our community’s situation 30 years ago: The only way young adults seeking partners in marriage would find out if they were Tay-Sachs carriers was by taking a voluntary genetic test. The screening available then was unacceptable for Torah observant Jews. Tragically, the only alternative was finding out too late—when children were diagnosed with the fatal Tay-Sachs disease.

So Dor Yeshorim began with one simple idea: Preventing tragedy and suffering by ensuring that carriers only married non-carriers—and by using anonymous IDs, not names, to avoid the unnecessary harm caused by stigmatizing individuals and their families.

Dor Yeshorim was founded in 1983, under the guidance of Gedolei Yisroel represented by virtually every community in Klal Yisroel. Dor Yeshorim has performed close to 400,000 genetic blood screenings—sparing over 4,200 families the horror of losing children and serving Klal Yisroel with reliable and proven relief.

Today, Dor Yeshorim has expanded well beyond its original mission of preventing Tay-Sachs by testing for several devastating genetic diseases, providing peace of mind with anonymity and dignity, researching causes and prevention of genetic disease, advocacy, support for families facing the worst, and so much more.

Thanks to Dor Yeshorim, our community has come so far. But there is more to do. Let’s keep screening our young men and women—and keep working on ever-new fronts of preventing genetic disease.

Yosef Ekstein
Founder, Dor Yeshorim
Today's society, genetic testing is an important part of the shidduch process. Is it really so imperative when considering shidduchim?

Yes! Genetic testing is a crucial part of researching a shidduch. When you are interested in pursuing a shidduch, it is the responsibility of every shadchan to insist upon genetic testing early on in the process of a shidduch; perhaps even before the families or individuals meet. Ideally, part of the initial research should be running the numbers by Dor Yeshorim, before anyone is too emotionally invested in a relationship, and pain can be avoided.

In fact, this is why Dor Yeshorim does not test an already engaged couple. Dor Yeshorim does not intend to break shidduchim; it exists to prevent avoidable pain and suffering in Klal Yisroel.

Exchanging numbers to check compatibility is not a commitment—it is simply part of the research. It is also advisable for individuals to be screened early, before a potential shidduch arises. This is why Dor Yeshorim arranges screening in high schools. Getting screened early helps compatibility checks be a simple and smooth part of researching a shidduch.

Imagine the peace of mind of a parent walking her child down to the chuppah, armed with the knowledge that she did her hishtadlus to prevent pain and suffering in future generations of Klal Yisroel!
Dor Yeshorim is world-renowned for its testing of known genetic diseases.

What is less known, is that Dor Yeshorim helps many families each year affected by obscure, under-researched genetic diseases.

For these families, standard testing is insufficient, as the genetic mutation must be identified and thoroughly researched — only then can reliable testing methods be developed. Dor Yeshorim spares no expense in applying its expertise so that when the time comes, testing will be available for these families, and siblings will have the means to ensure healthy families of their own. Many times these efforts lead to the addition of more diseases to Dor Yeshorim’s screening panel, preventing further tragedy in Klal Yisroel.

Grassroots Magazine spoke with Dr. Dvorah Abeliovich, professor of Human Genetics, regarding Dor Yeshorim’s advanced genetic research initiatives in identifying and testing for unexplored genetic diseases and mutations.

GRASSROOTS MAGAZINE: Tell us about Dor Yeshorim’s developing advances in researching genetic diseases and mutations, and why this is so important.

Dr. Dvorah Abeliovich: The main purpose of Dor Yeshorim is to cease the transmission of genetic disorders frequent among the Jewish community and to prevent the recurrence of genetic diseases in families with affected children. Its objective is to minimize, and where possible, eliminate the incidence of hereditary genetic disorders and serious recessive diseases common in the Jewish community.

Advancement in testing has helped Dor Yeshorim further achieve its mission of preventing tragedy. Today, we are able to test for an extremely high number of potentially dangerous mutations. We even have the ability to test for rare genetic disorders among the individual families who turn to Dor Yeshorim for additional testing. When Dor Yeshorim was established in 1983, its goal was to prevent Tay-Sachs disease that was prevalent among the Ashkenazic population. At that time, the mutation causing Tay-Sachs disease was unknown and we used enzymatic tests to determine carrier status. The human genome project has made it possible to identify the mutations causing many genetic diseases using DNA technology. Since the Ashkenazi Jews have a common ancestral origin they share mutations — “founder mutations” which trace back to the original “mother and father” of the Ashkenazi population. Mutations causing recessive disease can therefore exist within a healthy population; only if both parents are carriers of a recessive mutation are their children at risk. Screening individuals for the recessive mutation has allowed the prevention of the birth of children affected by severe recessive diseases.

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The Dor Yeshorim program was created with great effort and care under the advice of Torah luminaries, both present and past, as well as with the world’s foremost experts and researchers in the field of genetics. Dor Yeshorim strictly adheres to the dictates of the Gedolim never revealing carrier status and only testing for absolutely necessary diseases.

**In the Words of Our Gedolim**

**The process of identifying founder mutations is very complex, laborious and expensive.** Dor Yeshorim initiates many research projects and organizes teams of clinicians, scientists and bioinformatics experts with the goal of identifying more disease-causing mutations found in the Jewish population.

**GRASSROOTS MAGAZINE:** How does the process work?

**Dr. Abeliovich:** At first, we identify families with children who suffer from genetic recessive disorder. Using blood samples gathered from the affected children, their parents and family members, we can study the DNA and search for mutations. Finding a mutation can take many months—sometimes years. When a mutation is found, we must then prove that it is responsible for the disease, by studying how the mutation affects the individuals. When we are certain that the familial mutation was identified, we must then determine whether this mutation is a “founder mutation” in the Ashkenazi Jewish population by testing thousands of Ashkenazi individuals to prove that it is not just a rare onetime mutation. Once a new founder mutation is identified it can be included in the preventive program of Dor Yeshorim.

**GRASSROOTS MAGAZINE:** What technological advancements have been helpful?

**Dr. Abeliovich:** The use of robotics has done wonders for testing. We have progressed from human hand laboratory work to robotics. This is a tremendous leap forward. Robotics provide the advantages of ensured speed, precision, and high exactitude, with a much smaller possibility of human error in the process. Robots can reliably test high volumes of blood samples, with much stricter quality control than before. In the research stage, robots can process thousands of tests and produce a tremendous amount of reliable data within a reasonable time period.

We work with excellent laboratories and medical centers which utilize the highest quality cutting-edge technology. The initiative’s scope is incredible. Though the research process is very costly, it is worth all of the expense and effort. Dor Yeshorim has been successful thanks to Rabbi Ekstein and the devoted workers involved in the various stages of the process, allowing Dor Yeshorim to continue preventing tragic genetic diseases.
Through providing compatibility checks, leading research and offering counseling, Dor Yeshorim has grown into a tremendous force fighting genetic disease in Klal Yisroel. Since its inception in 1983 as a Tay-Sachs testing program, Dor Yeshorim has expanded its testing to numerous other genetic recessive disorders, including Cystic Fibrosis, Familial Dysautonomia, Canavan Disease and more. Dor Yeshorim also actively participates in medical research of genetic diseases and offers counseling and support to families suffering from genetic illness. These services are made possible mainly through generous contributions from donors who realize the importance of Dor Yeshorim’s mission. The minimal fee participants pay covers only a fraction of the program’s costs. Dor Yeshorim runs mostly on donations and sponsorships.

The first step in the process involves the collection of DNA samples. To promote accuracy, DNA is taken from blood samples which provide more accurate results than DNA taken from swab tests. Each participant receives an identification number – no names are used in the process to ensure complete confidentiality. The samples are then sent to a laboratory where a panel of tests are run and the information is saved in a database. No expense is spared to ensure that the tests are precise and comprehensive. Throughout the process, details are double-checked by at least two experts to ensure that everything is done with utmost accuracy.

When someone calls requesting a compatibility check, the individuals’ test results are compared. If both are found to be carriers for a recessive disease, they are informed that they are incompatible. Even so, exact details of carrier status is generally not revealed. Keeping carrier status unknown prevents stigma, anxiety and undue stress associated with the knowledge that one is a carrier. Dor Yeshorim offers genetic counseling for those found incompatible. Dor Yeshorim does not test for every genetic disease. The primary goal of Dor Yeshorim is to protect Klal Yisroel from devastating recessive diseases which result from both parents being carriers. Dor Yeshorim exists to build, not break shidduchim. Therefore, Dor Yeshorim keeps up-to-date on new treatments and medical findings so that if a disease is found to be treatable, Dor Yeshorim can reconsider whether to continue testing for it as opposed to, how constructive it is in light of creating shidduchim. Families who are affected by rare genetic illness will often contact Dor Yeshorim, who will use all the resources necessary to find the cause for the disease and provide medical guidance. The nature, frequency and severity of these obscure diseases are carefully studied and may be added to the testing panel.

Dor Yeshorim and its generous supporters work B’ezras Hashem, to help research and eliminate devastating genetic diseases in Klal Yisroel as well as provide resources and counseling to affected families. Dor Yeshorim works tirelessly and feels privileged to be entrusted with ensuring the health and future of our doros.

“Thousands of people have heard a similar message, but how many realize the extent to which Dor Yeshorim goes to help the tzibbur?”

“I’m calling from Dor Yeshorim... your numbers are compatible. We wish you mazal and bracha.”

DOR YESHORIM 718.384.6060
Did You Know

Thanks to Dor Yeshorim, the prevalence of devastating genetic diseases has dropped dramatically within the Jewish community. For example, Kingsbrook Hospital once had one of the largest Tay-Sachs wards, with a waiting list of patients. Thanks to the work of Dor Yeshorim, the ward has been closed for good.

Dor Yeshorim arranges mass screenings at over 400 schools in 11 countries worldwide, screening over 20,000 new individuals per year. Dor Yeshorim also has representatives in every populated Jewish city around the globe for individual screenings as well.

The discounted testing fees, kept minimal to ensure access to all, reflect only a small portion of the actual overall cost the organization incurs to research, screen, test, and handle unlimited compatibility checks and meticulous data entry. Individuals can request compatibility results numerous times without incurring additional fees.

Dor Yeshorim sets an industry standard for genetic testing, utilizing cutting edge technology, and testing methods alongside an innovative, highly regulated system renowned for its inherent confidentiality and ease of access.

Dor Yeshorim processes an astounding 22,000 compatibility requests annually. Dor Yeshorim also provides genetic counseling and medical guidance for families with children affected with genetic diseases and couples found to be incompatible.

Dor Yeshorim remains at the forefront of genetic research, collaborating with world renowned geneticists and medical institutions to research new advancements in education, treatment and prevention of genetic diseases.

Dor Yeshorim receives and handles hundreds of requests for guidance and resources from families afflicted with obscure genetic diseases. Dor Yeshorim painstakingly identifies their mutations and develops reliable screening methods to prevent the recurrence of those diseases in their families.

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DOR YESHORIM
COMMITTEE FOR PREVENTION OF JEWISH GENETIC DISEASES

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