Uncovering A Genetic Mystery
Pre-Marital Genetic Testing
NOT JUST FOR ASHKENAZIM

Passion & Commitment
A LETTER FROM RABBI EKSTEIN

Q&A WITH THE SHADCHAN
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Dor Yeshorim: Eliminating the incidence of fatal & debilitating recessive genetic diseases & assisting families who have children affected with genetic disorders.
Dear Friends,

“Help me help your children.” This is the prayer the Dor Yeshorim researchers, professors, doctors, lab technicians, the outreach and development teams and myself say whenever we are working. With Hashem’s help, Dor Yeshorim has been able to make a tremendous impact on Jewish families across the globe. From helping extinguish common genetic diseases within the Jewish nation, to assisting families suffering from rare or unidentified genetic diseases we take our work very seriously and continue our efforts to ensure B’ezras Hashem the health of future generations.

The continued support for Dor Yeshorim from Jews around the world has given me an unbelievable sense of appreciation and an even stronger motivation to aid in all aspects of genetic disease prevention.

Thanks to Hakadosh Baruch Hu, our groundbreaking efforts have B”H made it possible to test for, and thereby eradicate numerous fatal and or debilitating recessive genetic disease prevalent in our communities as well as many that are found in the Sephardic communities. Sephardim, who unfortunately are also susceptible to genetic disease, can now receive testing for those diseases most prevalent in the Sephardic population.

Utilizing our experienced team of geneticists and years of research and development, Dor Yeshorim helps identify and develop testing for rare mutations to ensure the disease is stopped in its tracks. We develop case-specific familial testing and screening to help save hundreds of families from future despair.

In addition to Dor Yeshorim’s well-known premarital genetic screening program, we offer support for families suffering from the anguish of a genetic disease. We offer guidance and aid in the form of medical referrals, financial assistance, genetic education and more. Dealing with a family member stricken by a disease is a difficult proposition as it is. We do everything in our power to make life easier, while preventing any more damage.

As we continue to invest tremendous resources to ensure we provide the most reliable and cost-effective genetic testing, our hope is that the true passion and commitment of our organization shines bright.

Sincerely,

Yosef Ekstein
Founder, Dor Yeshorim
When Eli and Dina had three children diagnosed with a rare genetic disorder, they didn’t know what to do.

They turned to us for help.

For 33 years, Dor Yeshorim has worked tirelessly to eliminate the fear and confusion that is caused by harmful genetic disorders.

Utilizing advanced research and development, we aim to identify the disease-causing mutation and develop testing in order to prevent debilitating diseases from reoccurring.

We firmly stand with those affected and do everything in our power to help guide and assist individuals and their families towards the proper solutions.

When there are no answers, Dor Yeshorim is the answer.

To learn more about Dor Yeshorim, call 718.384.6060 or visit DorYeshorim.org
Nothing can ever truly prepare a parent for the heartache and hardship of a child born with a severe handicap. For the Perlowski family this was especially true when their third and then their fourth child were born with a severe vision impairment. They were told that the condition is unfortunately known to degenerate and in many cases, cause complete blindness.

After two perfectly healthy children, the double occurrence was a clear indicator that something was seriously wrong, especially considering that there were other extended family members whose children were born with similar symptoms.

Along with the challenges of raising children who cannot see, came an increasing concern as the older, sighted children reached marriageable age. “Shidduchim is a difficult enough parsha to begin with,” worried Mrs. Perlowski. “Will anyone want to marry into our family?!”

Night after night she tossed and turned, contemplating the future. “Our family is so wonderful! Everyone is well adjusted and happy. I can’t let shidduchim ruin that!” Determined, Mrs. Perlowski picked up the phone and made the call that would change everything. She called Dor Yeshorim.

Unbeknownst to many, Dor Yeshorim, the preeminent premarital genetic screening organization, is also the premier worldwide source of information, guidance, and research when it comes to genetic conditions. Rabbi Ekstein, the founder, simply cannot rest when he hears of children suffering from genetic diseases. His mission of healthy generations, developed from his personal devastating loss of four children to Tay Sachs, has never wavered. “When he knows that there’s a sick child out there, it impacts him personally,” remarks Dr. Berish Y. Rubin, Ph.D. Professor, Department of Biological Sciences, at Fordham University.

After assuring the family that they would remain at their side every step of the way, Dor Yeshorim invited the parents to meet with...
us in the New York headquarters. We took a detailed history and discussed the concerns at hand. The information provided, coupled with the knowledge that extended family members also suffered from severe vision impairment, led Rabbi Ekstein and his team to strongly suspect that there was indeed a genetic component at play.

We suspected that the children were affected with Achromatopsia, a disease that is known to cause blindness. However, after testing blood samples from both parents as well as their two children, the results were surprising: no one was a carrier for any of the known mutations for Achromatopsia!

The lack of positive proof of a disease is usually good news. Not in this case. No definitive results presented a complicated challenge. Without a clear cause of the disease, we could not begin working on developing a reliable compatibility test that would enable the older children to proceed with shidduchim.

An individual can be born with a multitude of genetic variations that are harmless, such as distinct eye or hair color, or a benign polymorphism, variation in the DNA, which doesn’t change anything in the body,” explains Yoel Hirsch of the genetic research department at Dor Yeshorim. “The challenge becomes pinpointing the cause of the disease.”

We needed to conduct more extensive testing to help figure out the underlying cause of the blindness. In order to do so, we would need DNA samples from the healthy children in the family as well as all the extended family members who had a history of the mysterious disease. This would better help us with identifying the specific genetic mutation.

Dor Yeshorim contacted all the family members in question and with sensitivity and patience, we explained the complicated case and how pivotal their DNA samples would be to untangle the cause of the disease. Their help could well provide the answers that would save future generations from blindness.

We Found the Gene!
Three months later, Mrs. Perlowski answered her ringing phone. “We found the mutation!” exclaimed Rabbi Ekstein with joy. Finding the answer had taken hours and hours of intense and extremely costly research and analysis, done with the most sophisticated laboratory equipment available. The results showed that the extended family had a rare and hitherto undocumented mutation causing the blindness.

Knowing the exact mutation meant that Dor Yeshorim now had the information needed to develop case-specific genetic testing. This tailor-made test will allow the healthy Perlowski siblings and relatives to enter into shiduchim with peace of mind, knowing that Dor Yeshorim has the necessary means to ensure both parties are not carriers of the genetic mutation causing the vision impairment.

The story does not end there.

With the genetic mutation clearly defined, Dor Yeshorim is currently working with a group of professors researching the option of gene therapy for this gene, which could potentially stop the regression of the disease. The hope is that one day we can call the family and say: “We have unraveled the genetic mystery and hopefully with hashem’s help improve and/or stop the regression of your children’s eyesight.”

Thanks to Dor Yeshorim and tremendous siyata d’Shmaya, the Mr. and Mrs. Perlowski were recently zoche to walk their two eldest children to the chuppah, hearts brimming with simcha, anticipating the nachas they so rightfully deserve. Their feeling of immense relief and joy fuels Dor Yeshorim’s ongoing efforts on behalf of klal Yisroel.

*names have been changed to protect the privacy of individuals.
My husband and I are both regular SY’s [Syrians]. We both come from typical families in Deal and there are no traces of Ashkenazic blood in either of our families. Therefore, before we got married, we were told that it was not necessary to go through Dor Yeshorim; there was no reason to have to do so. But when I was expecting, I went for routine blood work and lo’ and behold, we found out we were BOTH carriers of Cystic Fibrosis, a serious genetic disease. After much research, we found out that it would be extremely difficult to have children in the future.

This letter comes not to just tell you of our personal life, but to share a message: Dor Yeshorim is here to help us build our families. Baruch Hashem, we were the lucky ones, who found out we were carriers before, chas v’shalom, we had an affected child with Cystic Fibrosis.

We are so happy that Community Magazine and Dor Yeshorim came together and brought out the serious truth that threatens the Syrians and Ashkenazim alike. We’re begging fellow community members to go for a simple blood test before starting their lives together. It is well worth it.

—Mrs. A.
The letter on the previous page appeared in the July 2016 Community Magazine, in response to an article which introduced the Sephardi community to Dor Yeshorim. The renowned pre-marital genetic testing organization has in fact been preforming a vital service for the Klal for more than three decades. Why then, was the organization first making waves in the Sephardic community in 2016?

For many years, the prevalent thought was that Sephardic Jews need not undergo genetic testing. This misconception unfortunately resulted in the growing occurrence of children within the Sephardic community born with horrible genetic diseases. Although oftentimes these children were not spoken about, the horror and heartache of their suffering, not to mention their parents’ anguish, were very much a reality.

Since its inception more than thirty years ago, Dor Yeshorim has worked tirelessly to develop the testing methods necessary to detect the most prevalent recessive genetic diseases within our Jewish communities. The system works on the basic premise that boys and girls approaching marriageable age provide a small blood sample, generally during mass school screenings conducted in schools and yeshivas around the world. The sample is then tested, and results entered into Dor Yeshorim’s state of the art computer system. No names are ever exchanged. Every participant receives a nine-digit Dor Yeshorim identification number which serves as the means by which to conduct a free and completely anonymous genetic compatibility check whenever a match is suggested.

In order for a recessive disease to be passed along to a child, both parents must be carriers of the same genetic mutation. If only one is a carrier, it is genetically impossible to pass along the disease and the mutation has no effect on the carrier; it is therefore not necessary for participants to know their status. The confidentiality of Dor Yeshorim is one of its founding principles and has ensured no stigma be attached to any family who are simply carriers, but not sufferers of a recessive genetic disease.

Unfortunately, for many years, decades in fact, it was erroneously thought that genetic diseases do not occur in the Sephardic community. In fact, due to the close-knit bonds of the Sephardic community, where common practice has Sephardim marrying Sephardim, the prevalent genetic diseases were in reality becoming increasingly more common.

So, although the misconception regarding a lack of pre-marital testing remained, more and more Sephardic parents began reaching out to Dor Yeshorim, quietly yet desperately seeking assistance with their children who had been born with genetic diseases that were in fact, avoidable.

For many years, the prevalent thought was that Sephardic Jews need not undergo genetic testing.

“The contrast was stark and very sad”, shares Rabbi Ekstein, Founder. “On one hand, we had the majority of the Sephardic community who felt that Dor Yeshorim testing did not apply to them. Parents were allowing their children to marry without conducting any genetic testing. On the other hand, numerous Sephardic families had actually reached out to Dor Yeshorim in terrible anguish; crying and desperate for assistance for their children who were born with terrible genetic diseases, including MLD, Cystic Fibrosis, mental retardation, vision and hearing loss, and many others.”

Dor Yeshorim was formed with a singular mission: to protect generations of Klal Yisroel. Regardless of the popularity or lack thereof, they developed a specialized Sephardic panel to screen for diseases prevalent in these communities. Utilizing the existing data of thousands of DNA samples, Dor Yeshorim dedicated countless hours, resources and money to develop reliable testing for the Sephardic community, that would meet the organization’s rigorous standards.

However, even as these Sephardic parents reached out to Dor Yeshorim, the lack of awareness for the need of Dor Yeshorim testing remained the persistent norm.

That changed in May of 2015, when HaChacham Yitzhak Yosef, shlita, called upon all Sephardim to be tested through Dor Yeshorim. The Chacham shared his personal pain; a close friend whose child was born with a genetic disease that would have been prevented had he and his wife undergone genetic screening before getting engaged.

For many years, the prevalent thought was that Sephardic Jews need not undergo genetic testing.

The Chacham had spoken and the wheels of change began to slowly turn.

It is understandably difficult and challenging to change a strongly held conviction. For so many years, the Sephardic community had been approaching marriage thinking genetic testing did not apply to their children. However, as more and more highly regarded Rabbis within the Sephardi community came forward to endorse Dor Yeshorim and urge all Sephardim to be tested, the tides began to turn. Powerful endorsements came from several Sephardic Gedolim including: Harav Yaakov Hillel, Harav Shimon Badani, Harav Moshe Mayah, Harav Reuven Elbaz and Harav David Yosef (the son of Harav Ovadiah zt’l), shlita.

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The field of genetics is constantly evolving and BS"D, Dor Yeshorim is leading the way.

Dor Yeshorim is credited with singlehandedly eradicating Tay Sachs from the Jewish community and (B”H) effectively closing the Tay Sachs ward at Kingsbrook Medical Center forever.

— Hua-Chin Chen M.D.
Director of Pediatrics, Kingsbrook Jewish Medical Center
Countless hours and resources invested into sophisticated research and development have B’H allowed Dor Yeshorim to provide the most accurate and up-to-date genetic testing for Jewish communities worldwide, including the Sephardic population, thereby protecting Klal Yisroel from potential untold heartache.

Over three decades of pre-marital screening, genetic research and helping families has enabled us to improve our proficiency and correctly identify harmful mutations. Our experience of conducting many case-specific studies on rare or unknown genetic diseases and their disease-causing mutations, and the power of our extensive DNA database has provided us with the proven ability to tackle any genetic challenge.

WE DO NOT REST UNTIL WE CAN IDENTIFY AND PREVENT A DISEASE WITH THE UTMOST ACCURACY.”

When a rare genetic mutation is found in a family, Dor Yeshorim relies on sophisticated analysis to ensure it never destroys another family’s lives. “If it’s a problem in one Jewish family,” asserts Dr. David Zeevi, a researcher at Dor Yeshorim’s Israeli headquarters, “there’s a high likelihood that it will be a problem in another Jewish family that doesn’t even know about the problem.”

Once a new mutation has been identified, we conduct a frequency study to view how these new mutations affect other families. No matter how rare, if the mutation is deemed by our medical advisory team to be fatal and/or debilitating with no cure and meets our testing policy criteria, it is added to our existing panel of screened mutations.

We embark on a daunting journey to develop testing to efficiently screen the general population with utmost accuracy so that carriers of the same genetic disease can avoid an incompatible shidduch.

Dor Yeshorim is a world-renowned resource for laboratories, scientists and genomic experts and continues to pave the way for further insights into recessive genetic disorders. Dor Yeshorim is responsible for identifying the mutations for Canavan Disease, Familial Dysautonomia, Nemaline Myopathy Joubert Syndrome and more. Rabbi Ekstein and his colleagues have been featured in nearly three dozen medical journals.

“We do all we can in order to remain at the forefront of genetic science,” says Chaim Brown, Director of Development at Dor Yeshorim, “and will not spare any resources to make sure the Jewish population stays protected.”

“I am absolutely amazed and gratified by what the program has been able to accomplish,” says Dr. Edwin H. Kolodny, director of Neurogenetics at NYU. “Dor Yeshorim has done what no other organization in the world has been able to do, reaching a broad community throughout the world.”

- Mass screenings are conducted at over 400 schools in 11 countries worldwide
- 25,000 individuals are screened every year
- Over 450,000 individuals have already joined the Dor Yeshorim program
- $5k-25k specialized test for each case specific research
- Each test is subsidized by generous donors
- 9.5 million annual Dor Yeshorim budget

“Dor Yeshorim has done what no other organization in the world has been able to do, reaching a broad community throughout the world.”
— Dr. Edwin H. Kolodny, NYU
We have already married off several children and are reaping much nachas from them B”H. A few weeks ago, we were ready to close a shidduch.

Everything was progressing smoothly. The replies were quick, and there was a good chemistry between us. We already envisioned the happy Mazal Tov wishes.

Following standard procedure, we reached the stage of undergoing the routine “Dor Yeshorim” compatibility check. We gave our ID number to the other side and with that completed our role. Since the response we’ve always received was “suitable for marriage,” we ourselves didn’t bother to check any details.

The next day we received a slap in the face that rings until now: Not a match!

We were obviously in shock; all our children and extended family are healthy B”H, so how could this have happened to us? And from what we heard, the other side was also bewildered. Of course we discontinued the shidduch.

That’s our story, and now we are afraid of future shidduchim. Are we required to mention it?

Have you ever encountered such a story as a shadchan? And what do you advise others on this matter?

— M. Family
Dear M. Family,

It pains me to hear of a shidduch that developed so well, and then fell through. But how fortunate you are to be made aware of this now, and not when it would have been too late. Not only that, but you have also been spared until this point. Often Hashem performs a neis with a person, and he won’t even know about it. Like Chazal say, “אֵין זַכַּל מָנָה מַרְשָׁם.” Thank Hashem that you had no reason until now to know about this; thank Him for your health and for your children’s health.

Now, before answering your questions, I would like to provide some background on this topic. Important to know…

yet we shouldn’t know of it

For many years, when two parents were both carriers of a defective gene, a large percentage of their children died young from various diseases r”l. The disorders Dor Yeshorim screens for are all genetic, debilitating and fatal. With some of the diseases, those afflicted, ch”v, don’t survive past the age of five or six. With others, the terrible nightmare continues for years.

If you ever glanced at the diseases DY screens for, you definitely said, “We should never know of them”; and indeed, that goal makes these tests a privilege that is also an obligation. Many people are carriers of a disease and are completely unaware of it. But as long as a carrier doesn’t marry another carrier of the same disease, the gene will not harm their children, b’ezras Hashem.

In general, most shidduchim are compatible. I would guess that this time, from a statistical point, you belonged to the “one out of every hundred checks that don’t match”.

Incompatible is case specific and isn’t relevant for other prospective matches

So therefore, you can be very calm regarding any future shidduchim, as the results you got this time aren’t relevant for a different shidduch.

Better sooner than later

Yes, this has definitely happened to me as a shadchan. And for that reason I proclaim: Better sooner than later.

I am not affiliated with DY in any way; I merely hear the replies from the families. In fact, as a shadchan I cannot reach out in their stead and get the answers for them. Only the parents, or the people in question, can receive the results.

It has happened – although very rarely – that a shidduch I suggested started to look more promising, and only then did the boy or girl remember that they were never tested.

Other times, both parties’ unique ID numbers were submitted at the last minute, as they considered it to be mere protocol. They were convinced that they would be compatible, and they usually were. But at this crucial time when they just wanted to announce the engagement, everyone sat on edge waiting.

Checking compatibility early

I want to add “better sooner than later” also applies to checking compatibility. It is wrong to assume that suggesting to the other side, “Let’s request the results,” will imply, “We are ready to close the shidduch.” It’s simply another query in the process of looking into a shidduch. It’s not binding. At some point, you’ll anyway do this, and if so, why delay?

I will conclude with a story that happened many years ago; consider it food for thought.

I initiated a shidduch and it progressed until the final stages. The parents had already booked a hall for the engagement! A few hours before the Vort they remembered that they hadn’t called Dor Yeshorim to make sure that they were genetically compatible.

Completely not as expected, the future chosson and kallah were found to be carriers of the same disease. The shidduch obviously fell apart and I’m certain that since then, checking compatibility was the first step both sides took in every shidduch.

This past Rosh Hashana, I saw that prospective kallah, now married to someone else, with her family. They came to say Tashlich at the same pond where I was. I couldn’t refrain from staring at her children who were jumping around. They seemed happy and content, and most of all, healthy.

In such cases, extra time was spent waiting for them to do a DY expedited test.

Only I knew that their mother was about to marry a different man, and that they could have appeared quite different r”l.

_PROPERTIES_  

asher פתאים השם"}

As long as a carrier doesn’t marry another carrier of the same disease, the gene will not harm their children, b’ezras Hashem.
Below is an excerpt of just one of the letters several Sephardic Gedolim penned for the community at large:

וכבר חוקק במשענתו מרן המאור הגדול הראשון לציון ומרא דארעא דישראל מרנא ורבנא' הגר’ע יוסף זצוק”ל במכתב קודשו לאמור: “שהם עוסקים בדברים שהם ברומו של עולם, ומחזק את ידיהם, שהבחורים והבחורות העומדים להינשא יעברו את הבדיקות, כדי שלא יאonta להם כל אוון, ויזכו לזרע ברך ה’. ויעשו את כל זהיפה שעה אחת קודם”, עד כאן לשונו הקדוש.

In his statement regarding this crucial matter, the Gadol Hador Maran HaRav Ovadia Yosef zt”l said: “These people are involved in highly important work and I agree with them fully that young men and women of marriageable age should undergo this testing in order to prevent whatever disease can be prevented and to be blessed with healthy children. And all this should be done as early as possible.”

Those who erroneously believe that genetic diseases are only relevant to the Ashkenazi community should be aware that in Sephardic communities, as well, there have been cases of children born with devastating genetic illnesses, rachmana litzlan.

Individuals who joined the Dor Yeshorim program after January of 2016 and indicated that they are of Sephardic descent were automatically screened for both Ashkenazic and Sephardic panels. Those who were tested by Dor Yeshorim before this time period should call the Dor Yeshorim office to update their information. In most cases, an additional blood specimen is not required.

And for those Sephardim who are joining Dor Yeshorim for the first time, chazak v’amatz! Your courage to join in changing the terrible tide of genetic diseases within the Sephardic community should be rewarded with many generations of healthy children.

Be Aware!

Dor Yeshorim urges the public to be aware that Sephardim and Ashkenazim alike should be screened and checked for compatibility — regardless of their partner’s ancestry. There are some diseases that are shared by both Sephardim and Ashkenazim, like Tay Sachs and Cystic Fibrosis.

Growing Awareness

In the last 3 years 12,000 Sephardim have been tested worldwide. Today, Dor Yeshorim testing has become the norm for most Israeli Sephardim.

With Siyata d’Shmaya this reality will, with the help of education and outreach, become prevalent in America as well.

Did You Know?

Dor Yeshorim compatibility checks are free and unlimited.

It is imperative to check compatibility before meeting for the first time. A Dor Yeshorim compatibility check is not a commitment. It is the most important piece of information you need to assure the shidduch has future potential!

For more information or to schedule a screening please call: 718.384.6060
info@DorYeshorim.org
www.DorYeshorim.org