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ISSUE 346 | 5 Adar I 5771 | February 9, 2011
PRICE: NY/NJ $3.99 Out of NY/NJ $4.99
Canada CAD $5.50 Israel NIS 11.90 UK £3.20

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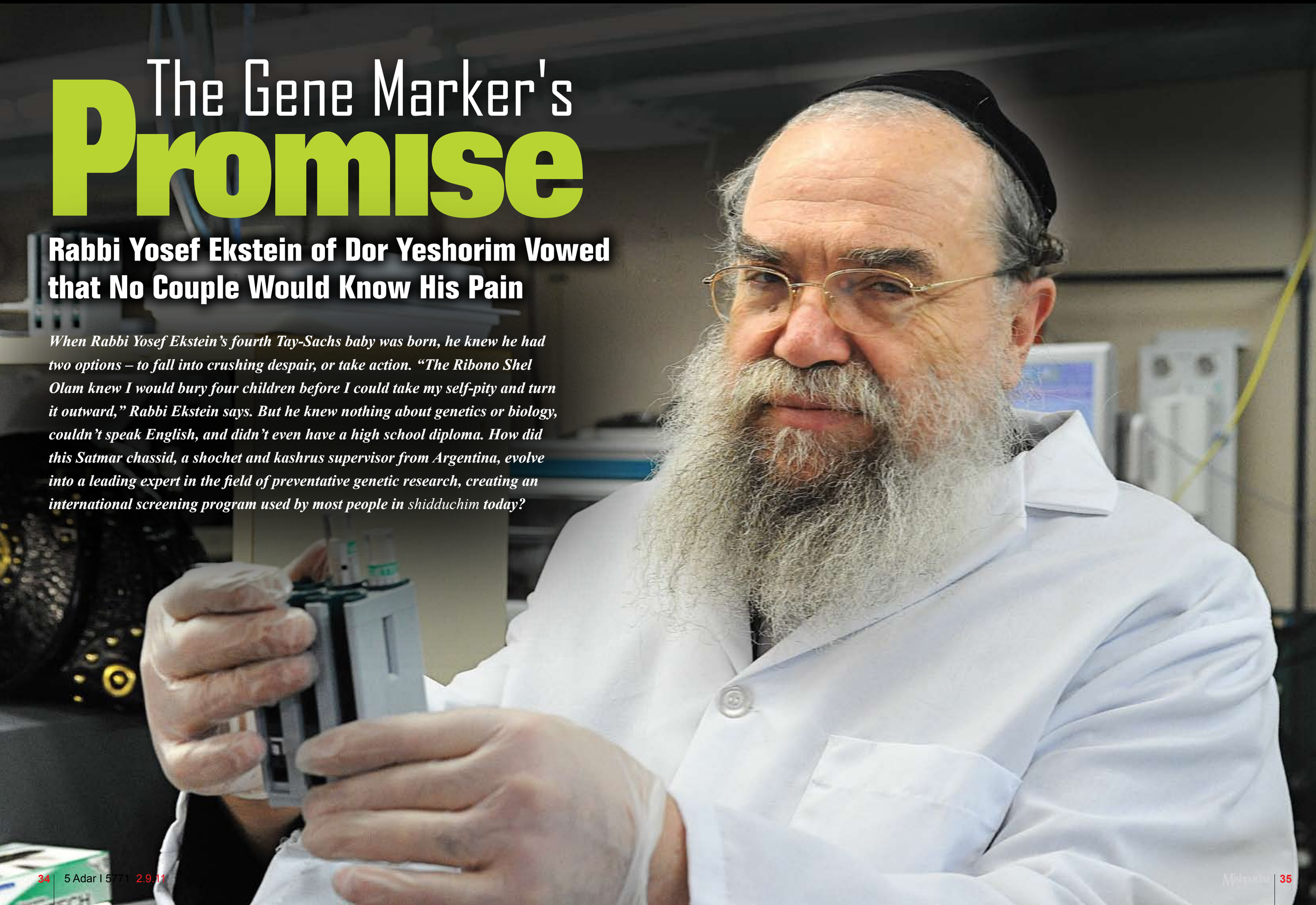
The Gene Marker's Promise

Rabbi Yosef Ekstein of Dor Yeshorim Vowed that No Couple Would Know His Pain

When Rabbi Yosef Ekstein's fourth Tay-Sachs baby was born, he knew he had two options – to fall into crushing despair, or take action. "The Ribono Shel Olam knew I would bury four children before I could take my self-pity and turn it outward," Rabbi Ekstein says. But he knew nothing about genetics or biology, couldn't speak English, and didn't even have a high school diploma. How did this Satmar chassid, a shochet and kashrus supervisor from Argentina, evolve into a leading expert in the field of preventative genetic research, creating an international screening program used by most people in *shidduchim* ***today?***



Rachel Ginsberg

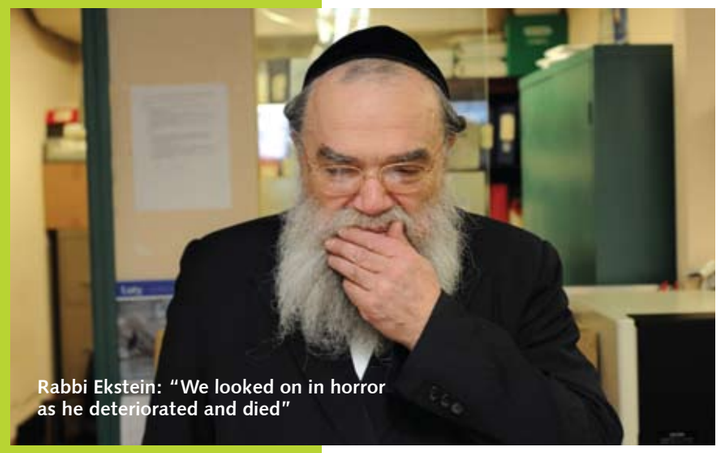
Photos: Meir Haltovsky, Ouria Tadmor

He spoke little English, knew nothing about genetics, and never set foot in a college classroom. So how did Rabbi Yosef Ekstein, a *shochet* from Argentina , manage to create an international system that has virtually eradicated the occurrence of Tay-Sachs and other recessive genetic illnesses common to the Ashkenazic Jewish community?

Today, Dor Yeshorim is a household word, at least among families with *shidduch*-aged children. Who in the Torah world looks into a prospective match without first ascertaining genetic compatibility by calling in their numbers to the Dor Yeshorim hotline? But in 1983, when Rabbi Ekstein first set out to prevent others from experiencing what he was so painfully living through himself, people thought he was a dreamer at best — a digger of skeletons at worst.

Maybe it was because he was a war baby — born while the Budapest building where his mother had taken shelter was being bombed — that Yosef Ekstein became such a stubborn fighter, forging ahead with his program in the face of raised eyebrows and skeptical smirks. Yet at the beginning of his personal journey, his only fight was to get through his own pain.

The year was 1965, and Rabbi Ekstein, a Satmar chassid, *shochet*, and head of kashrus in Argentina, had just become a father to a newborn son. How simple it seemed in this generation, he thought. It was nothing like the situation his parents faced when he had been born.



Rabbi Ekstein: "We looked on in horror as he deteriorated and died"

"Hashem Yisbarach has given us the ability to discern genetic recessive disease compatibility. Why is this more controversial than any other information we process to consider a match?"

These samples are the dividing line of tragedy

His father, Rabbi Kalman Eliezer Ekstein, used to tell him, "You survived by a miracle. I don't know why, but it must be for a purpose."

After his mother, Pessel, crawled out of the rubble of the bombed-out building with her hours-old infant, she hid him for several months until they could plan their escape. Meanwhile, Rabbi Kalman Ekstein was hiding in a pit. Having contacted smugglers who promised to get them over the border to Romania, Pessel and her sister — who looked like a non-Jew and donned a cross around her neck — dressed little Yosef up as a girl (they had given him a bris and didn't want anyone checking) and took a train to the border. At the border station, however, the little group realized they were being followed by *nilosh* — Hungarian bounty hunters who whispered to each other, "They're ours." Then, when one of them excused himself to the bathroom, the other one fell asleep waiting, and the Ekstein trio, hearing the snoring, tore out of the station and hid in the high grass until they could make contact with the smugglers. Rabbi Ekstein, who was to arrive the following night, got word that the smugglers had suddenly gone out of business, and so remained hiding in his pit until the end of the war.

The family was finally reunited and made their way to Israel, where they lived for nine years before moving to South America, where Rabbi Ekstein senior established the *kehillah* in Buenos Aires.

However, for the younger Rabbi Ekstein, twenty years removed from war-torn Europe, becoming a father proved to be far from simple.

"For the first six months, my son seemed to be thriving," Rabbi Ekstein recounts, describing the shock of his first Tay-Sachs baby, the heart-wrenching onset of the disease and its devastating progression, as the infant seemed perfect for the first half-year of his life. "But soon I noticed he began to regress. There is nothing as horrible as watching your child deteriorate in front of you. It began with floppy muscle tone, then he couldn't swallow, and soon it progressed to seizures, paralysis, mental retardation, and blindness."

In 1965, there was no testing or diagnostic method available for Tay-Sachs, other than seeing a red patch that eventually develops on the retina. Finally, at age two, the now severely disabled child was diagnosed with Tay-Sachs, an incurable genetic disorder that always results in a very young death.

"We looked on in horror as he turned into a vegetable and died at age four."

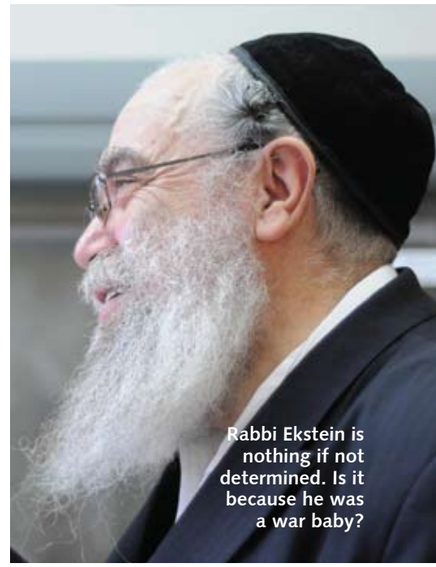
The next child, a girl, was also afflicted with the disease. "With every child born the suspense was horrible, waiting to see if the child would be healthy or not."

The Eksteins had buried two children, but forged ahead faithfully. The third child was healthy. But the next two …

In 1983, the Eksteins' fourth Tay-Sachs baby was born.

"The Ribono shel Olam knew it would take four children for me to get out of my own self-pity and turn my pain outward," Rabbi Ekstein says. "I had two choices: despair or action. It took me nearly twenty years to get the message. But He paid me back with interest. Since starting Dor Yeshorim, we've been *zocheh* to five more healthy children.

"You have to understand the culture then. Everyone would hide their sick children, especially if we were talking about a genetic disease. It would put a black mark on the family. Who would want to do a *shidduch* with a genetically diseased family? At the time, we were living in Monroe. I was probably the first individual in our community who came out and said, 'I have a problem. I'm bleeding to death. Let's make sure no one else has to go through this.' "



Rabbi Ekstein is nothing if not determined. Is it because he was a war baby?

We're All Carriers Without genetic screening, the Eksteins, and thousands of couples like them, could never have known in advance that they were carriers for Tay-Sachs, a genetic mutation noted for its frequency among Ashkenazic Jews of Eastern European descent. This is because it is biologically impossible for a carrier to actually have the disease himself. However, if two carriers marry, each child born will have a 25 percent chance of falling ill.

Truth be told, everyone is a carrier of various genetic mutations and recessive lethal diseases that we'll never be aware of — sickle-cell anemia, cystic fibrosis, Tay-Sachs, spinal muscle atrophy, familial dysautonomia, and Bloom syndrome, to name a few. But because our parents bestow upon us two "copies" of every gene, as long as there is only one genetic mutation between the two, the carrier will not be affected by the mutation.

That genetic mutation is still transmitted, however, and makes the person who receives it a "carrier." As long as both parents are not carriers, there is no danger of their child being affected by the mutation carried by only one parent. However, if both parents possess the same genetic mutation, their children are at risk of inheriting a matched set of mutant genes. These genetic mutations can pass quietly for generations until two carriers marry; then their children have a one-in-four chance of being afflicted with the disease.

Rabbi Ekstein set out to establish a protocol to prevent recessive genetic diseases by helping matching carriers avoid marriage (although both carriers could safely marry other non-carriers). Rabbi Ekstein's vision was to embark on a mass screening process to provide protection from diseases that are prevalent among Jews. But he also wanted to make sure to safeguard individuals from the psychological stigma of carrier status knowledge, and prevent the labeling of any person or family with carrier status.

Going public with Tay-Sachs was groundbreaking in itself, and he took the personal risk — even though his wife didn't want to go public. How would the *frum* community ever go along with this if there were to be large-scale disclosure? So, with the participation and advice of leading medical experts and *gedolim* from the spectrum of Torah Judaism, Dor Yeshorim's ground rules were established. Participants are clearly informed that the Dor Yeshorim program does not include

One blood test and a phone call and Tay-Sachs has virtually disappeared

information about personal carrier status; they are only informed if their prospective match is compatible or not.

Today, Dor Yeshorim screens for fatal or catastrophically debilitating recessive genetic diseases as part of its program. Participation in the chareidi community, where dating occurs solely through the *shidduch* system, hovers around 98 percent, and Tay-Sachs has been virtually eradicated from this community. The Kingsbrook Medical Center Tay-Sachs unit, which once had a long waiting list, recently closed due to the success of Dor Yeshorim.

No One Showed Up Rabbi Ekstein has fought an uphill, sometimes vertical battle to achieve these results. Turnout for the first screening in 1983 was dismal: forty-five people came, mostly as a personal favor after efforts of pleading and door-knocking. The next year it was up to 175 people. His breakthrough came when one school agreed to screening; and today, screening is standard in most religious schools, and its 80,000 calls a year are the first step in the initial research of a *shidduch* prospect.

Rabbi Ekstein, whose goal was to spare people the pain and suffering he knew so well, didn't take the difficult start personally.

"In the beginning, people would say, 'Who is this Ekstein who thinks he can decide who will marry who?' But the minute they have a problem, they come running. Someone who tastes the tragedy is no longer a critic. There was a very *chashuve askan* who was against me in the beginning. Then, when he was looking for a *shidduch* for his daughter, the father of the boy insisted on Dor Yeshorim, so he had no choice.

"Well, it came back not compatible. So now this *askan* knows his daughter is a carrier of something, and he's in hysteria. He calls me. 'What will be with my children who are already married? I never tested them. What if their spouses are carriers?' So I told him, those not yet married you test, those already married you have *bitachon*.'"

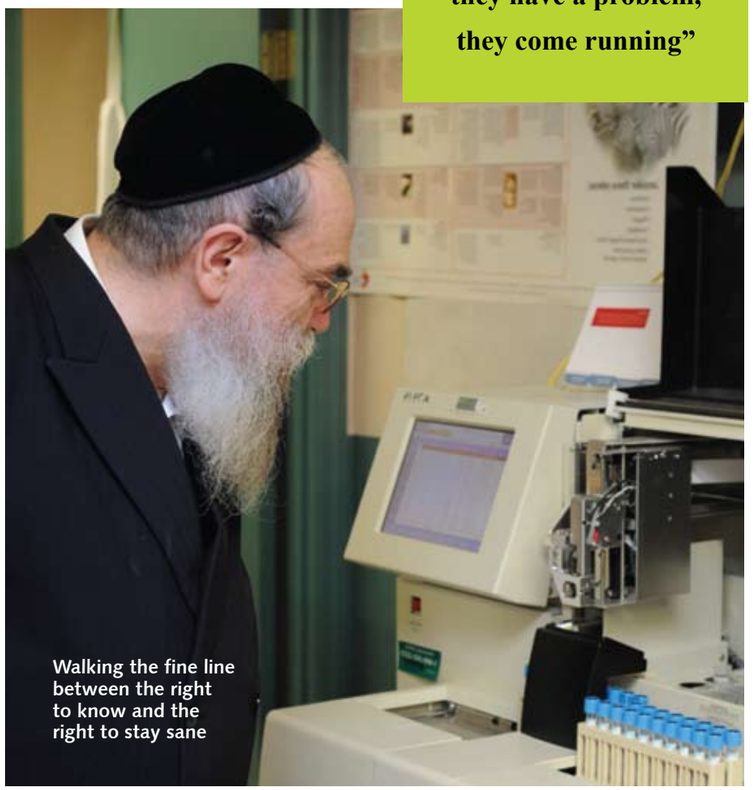
For some, the very idea of screening was confusing. Isn't every baby, no matter how ill or unviable, a holy *neshamah*? Why not forgo the testing, just go ahead with the *shidduch*, and leave the results up to Hashem? Doesn't this get too close, they asked, to the philosophy of eugenics, making "superior" babies by selective breeding?

Rabbi Ekstein waves his hand in dismissal. He's been through the excruciating pain.

"This," he says, "is why the program is premarital. We do not screen married people. We do not even screen engaged couples. By that time, you're off our radar screen. This has nothing to do with whether or not a baby should be born, *chas v'shalom*. This is one more piece of information, a genetic point of view, that a prospective couple can use to decide whether a *shidduch* should go forward. Hashem Yisbarach has given us the ability to discern genetic recessive disease compatibility. Why is this more controversial than any other information we process to consider a match?"

Once you've been on the other side, he says, you can't look at the one who says "anyway, it won't happen to me" without wincing.

"In the beginning, people would say, 'Who is this Ekstein who thinks he can decide who will marry who?' But the minute they have a problem, they come running"



Walking the fine line between the right to know and the right to stay sane

Call Before You Meet While the Dor Yeshorim team would like to see everyone screened before the *shidduch* goes anywhere, what about those couples who have been dating, are thinking about marriage (before the actual engagement), and then go for screening, only to discover that they are "incompatible"?

According to Dor Yeshorim, if the prospective *shidduch* did not meet yet, or are not yet emotionally invested, they should be able to hear they are incompatible and move on to the next *shidduch*, which probably will be compatible.

However, if they are already emotionally invested, Dor Yeshorim offers

TIED TO THE CORD

Stem cell transplants might sound futuristic, but in recent years over 100,000 of these transplants have been performed successfully, to treat over 70 blood diseases such as leukemia and Fanconi anemia. Umbilical-cord-blood stem cells have significant advantages because they are young and not yet developed, extremely viable, and don't require a complete patient-donor tissue match. But while the world at large is benefiting from this medical breakthrough, the singular genetic profiles of Jewish patients often make it impossible to find a match in the registries when needed.

When a relative of Rabbi Ekstein couldn't find a match for a life-saving transplant, he knew what he had to do. He built a Jewish cord-blood bank himself. Initially there were two centers, Kehila Cord in New York and Bedomaich Chayi in Jerusalem; the cost of processing is prohibitive, and budgetary constraints forced the US office to close, but the Jerusalem center is busy processing and storing the stem-cell-rich plasma from umbilical-cord blood at the rate they can afford to process. Each sample costs the lab $1,300 to tissue-type, process, freeze, and put into the registry.

Cord blood is easy to donate — it's simply gathered after birth with no risk or pain and sent to the lab for processing. Bedomaich Chayi gathers blood samples from the labor rooms of Shaarei Zedek and Bikur Cholim hospitals (that's as much as they can process at this time, although mothers from other hospitals are constantly requesting to donate); checks the quality of the blood at the lab; uses only the quality samples; separates 25cc of the plasma that contains the stem cells; and deep-freezes the sample in a marked cassette that goes into a highly organized, computerized freezer that stores the plasma at -188 degrees Celsius (-306 degrees Fahrenheit).

"These cells can be retained for at least twenty years," says Shimi Rabinowitz, the lab's operations manager.

The freezer looks something like a witch's brew, with the liquid nitrogen billowing out when the vat is opened, but inside is life-saving potion: 3,500 samples, each one specifically tissue-typed and filed.

"We need twenty times this much," says Rabinowitz. "We hope to get to a point where any Jew in need can contact us and have a good chance for a match. Ten thousand stored cord-blood units can save a hundred lives a year." He says that Israel, a melting pot of ethnic diversity within Jewish families, is a good place for donors who can match the unique insular ethnic combinations of today's Jews who need a bone marrow or stem cell donor match.

Public cord blood banking is considered better quality than privately stored cord blood, although the latter has turned into big business. A person who stores his baby's cord blood will pay over $1,800 for retrieval and processing, plus $125 a year for storage. While Bedomaich Chayi disregards three-quarters of the samples they receive because of inferior quality, most private labs don't do a thorough check to see if the sample is really high-quality enough (in terms of bacteria and the stem-cell count) to make freezing worthwhile. This is because chances are minuscule that the sample will ever be used in the first place. There is only a one-quarter of one percent chance that private stem cells will ever be retrieved for use, because they can only be used by the person they "belong" to. Furthermore, in many cases the genetic mutation causing the disease is already present in the cord blood that was collected from that person years ago, making it useless for treating him.

In fact, out of the hundred-plus thousand stem cell transplants from various sources including peripheral blood and bone marrow, more than 20,000 of these transplants have been performed using stem cells from public cord blood banks, while only a few dozen were performed from private commercial banks, although they contain a much larger inventory.

Shimi Rabinowitz and his frozen samples. "The cells can be retained for at least twenty years"

THE TRAGIC RECESSIVES

Dor Yeshorim currently tests for the following genetic mutations that cause severe genetic diseases common to Jews of Ashkenazic descent:

Tay-Sachs: The most well-known of Jewish genetic disorders. The infant looks normal at birth, but at about six months, the central nervous system begins to deteriorate. By age two, the child can't sit or crawl, and eventually loses his ability to swallow and breathe normally, finally collapsing into blindness, mental retardation, and paralysis, usually dying by age five after suffering horribly for most of his short life.

Canavan Disease: A neurodegenerative disease, where the child first appears normal and then begins displaying an enlarged head, loss of muscle control, seizures, and eventually becomes blind and paralyzed. Most die by age one, but some live in suffering until their teenage years.

Niemann-Pick Disease (A and B): Another neurodegenerative disease with symptoms beginning at about six months, including feeding difficulty, vomiting, enlarged spleen and liver, loss of motor skills and poor growth. Death usually occurs by age three.

Familial Dysautonomia: An incurable disease that affects the central nervous system, influencing blood pressure stability, motor function, and the ability to swallow, perspire, cry, and feel pain, among other functions. Eventually it affects the digestive, respiratory, and circulatory systems. Today improvements have been made in the treatment protocol.

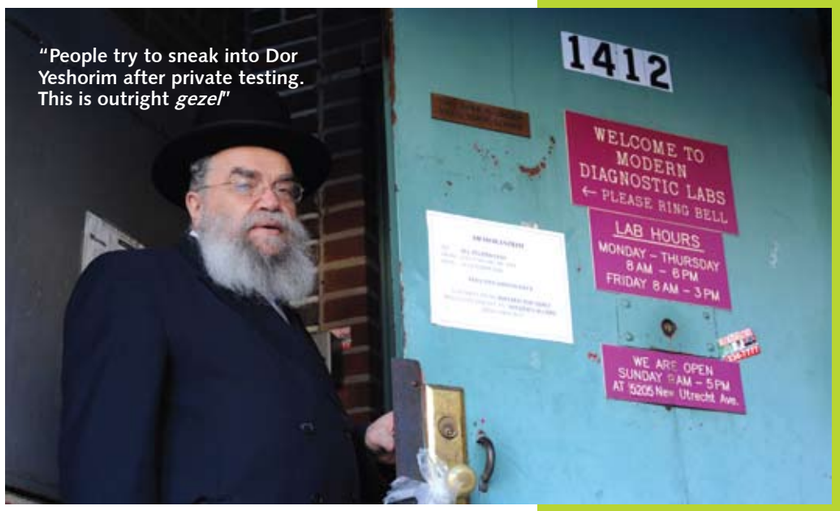
Cystic Fibrosis (CF): Manifested in serious respiratory ailments, ongoing suffering, and frequent, lengthy hospitalizations. With proper care, patients can live into their thirties, although many die as teenagers. Males with the disease are infertile.

Fanconi Anemia Type C: Severe anemia, congenital defects in the extremities, and a tendency toward cancer and leukemia. Treatment entails frequent blood transfusions. The only possibility of cure is through bone marrow or umbilical-cord stem cell transplantation.

Glycogen Storage Type A: An inability to break down glycogen, resulting in complicated diabetes and severe digestive complications. Frequently leads to liver tumors, and can be fatal.

Bloom Syndrome: Typified by dwarfism, malignant tumors, and mental retardation.

Mucolipidosis Type 4: A severe degenerative disease of the brain that hampers development and causes blindness. Some patients reach adulthood, but never develop beyond the level of a one-year-old.



"People try to sneak into Dor Yeshorim after private testing. This is outright *gezel*!"

to rescreen at a severely reduced rate and will, when asked, tell them what they were incompatible for. The organization does not give out this information to curiosity-seekers, but in a crisis situation, the staff spends time and resources working with these cases, explaining and counseling about the best and worst-case scenarios, and lets them make their decision.

"But that's why we want people to call for compatibility *before* they meet the first time," says Rabbi Ekstein.

If some critics claim that Rabbi Ekstein "ruins lives" by spoiling their marriage plans, he is the first to agree that this screening program does not work in the secular world, where emotional involvement comes before basic research. "This is like a custom-tailored suit," he says. "This is not a one-size-fits-all."

Rabbi Ekstein says he got his degree in genetics at "Hardway University," and although Yiddish is his preferred language of expression (he speaks Yiddish, Spanish, Hungarian, Ivrit, and now English) and he looks more like a seforim store salesman than an expert in preventative genetics, his knowledge is expansive. He has served on medical panels, and as medical technology has advanced, he has been in the forefront of using DNA screening for compatibility checks instead of the less reliable bio-medical markers. Despite his traditional chassidic garb, heavy accent, and lack of a high school diploma, Rabbi Ekstein is viewed by top geneticists as a visionary who has provided the Jewish community with a genetic screening program unmatched by any other program in the world.

When Rabbi Ekstein began to explore his own tragedy, he knew nothing about genetics or biology — although he was an expert at the physiology of a cow. He didn't understand the language of the experts, and certainly couldn't read a medical text. But he was determined, and so he sought out people who spoke his language. He begged, he *nudged*, he dug, until he understood. He began to read medical journals and technical papers. Today his name is on at least fifteen scientific papers, either leading or collaborating on cutting-edge research.

"You think this is an easy thing?" Rabbi Ekstein is hurt. People accused him of "ruining *shidduchim*." "That's when they decide to call the night before the *l'chayim*. This is why we want people to call before the couple even meets. It should be a basic part of the research, like any other item that's being checked out"

The Stem Cell Frontier Rabbi Ekstein is hyper-focused on his mission, although he's neither a medical professional nor a smooth talker. Actually, he's not much of a talker at all, and he is extremely wary of the press, rarely granting interviews. He says that journalists love contention, that "they don't understand the issues, and they write things that are incorrect, especially with delicate issues like these."

He did agree to speak with **Mishpacha**, however, and even provided a tour of Dor Yeshorim's newest project, which is unrelated to genetic screening. It's a state-of-the-art public stem cell bank called Bedomaich Chayi. The bank has nothing to do with spousal compatibility, but everything to do with Rabbi Ekstein's own determination to apply cutting-edge technology toward solutions to medical crises at all costs.

When a relative needed a stem cell transplant but no match was available, Rabbi Ekstein used his resources for a new mission: to create a pool of donor stem-cell-rich plasma from umbilical-cord blood, so that any Jew in need will be able to find a match. Jews in general have limited chances of finding a stem cell match in the general registries because of tissue-typing compatibility. Stem cells from cord blood, however, only require 60 percent compatibility, because these cells are young, naïve, and have a greater tendency to grow and reproduce. [See sidebar.]

Some medical philosophers say DNA research and accompanying breakthroughs in reproductive genetic techniques — the ability to see if embryos are "genetically compromised," and DNA mapping of a person's entire genetic makeup, including risk factors for various diseases — are the slippery slope of modern science. Abortion, embryo destruction, and worries about eugenics, or selective breeding to rid a population of unwanted traits, are the concerns that accompany runaway research.

Ironically, although Rabbi Ekstein is one of the leaders in pushing for creative medical solutions with this new technology — solutions like the Bedomaich Chayi cord-blood bank, and isolating genetic markers to uncover the codes for more recessive genetic diseases — he is almost a reactionary in one area he's dead-set against: testing for personal dominant gene mutations that may have links to someone contracting a disease in the future. An example is the BRCA gene, which may be linked to the future onset of women's cancers.

"Testing is only a good thing when you can have some positive result from it," he says. "Why add the burden of knowledge to something you can't do any good about? So that you'll consider removing organs and other crazy things on the outside chance that you'll get sick?"

But today's politically correct attitude insists that everyone has the right to know everything about himself, in order to be prepared psychologically for any event.

How catastrophic must an illness be to enter the testing panel?

"Prepare psychologically," says Rabbi Ekstein, "means drive yourself crazy." He notes that much of the current literature about DNA mapping indicates a significant psychological burden placed on those who learn of their carrier status.

This is the fine line Rabbi Ekstein is worried about — will readers understand the difference between a person's right to know and his right to remain sane because of his self-imposed ignorance? This is one reason he's so adamant about Dor Yeshorim's position in not revealing any genetic information to the participant, although the information is available. This is a main point of contention among Dor Yeshorim's detractors. Does withholding available information contravene the client's civil rights, that he has the "right to know" all the results contained in those vials of blood?

For someone on the cutting edge of DNA research, and the new morality notwithstanding, his reaction is surprisingly unequivocal: "No."

First of all, he explains that unlike a private screening lab, those blood samples you gave don't belong to you. You are not paying for a blood test. You are a participant in a broad program which includes screening, research, counseling, volunteers and staff all over the world, and compatibility checking to prevent tragedies.

"This is not a testing facility. For that, I could have opened a lab."

In Dor Yeshorim, Rabbi Ekstein stands firm. Confidentiality must never be compromised. And it's not only because many people not well versed in genetics would find it traumatic to cope with the knowledge that they are carriers (which has absolutely no bearing on their own health or even on the health of their children as long as they don't marry someone "incompatible"), but also because there are many people who — ignorant or not — will reject a *shidduch* with a positive carrier.

"We've said 'not compatible' 1,700 times. True, that means 1,700 times tragedy was averted. It's rare. It usually doesn't happen. And when it does happen it's a salvation. But each time I cry. It means I've stopped a *shidduch*"

For this reason, Rabbi Ekstein, the Dor Yeshorim board, and its rabbinic advisors laid down another iron-clad rule. Gripes or not, absolutely no one who has done private testing through another source may avail themselves of Dor Yesharim's services.

He outlines two main reasons: If a person knows from outside testing that he's a carrier for a particular disease, then he would know the carrier status (positive or negative) of the person he called about — some girl suggested as a *shidduch* — compromising the original premise that everyone's privacy must be protected. Furthermore, a person who has tested privately will only run to Dor Yeshorim for one reason — he tested positive, and needs to know the status of his prospective *shidduch*.

"People do their own thing and then try to sneak into Dor Yesharim after private testing. This is outright *gezel*," laments Rabbi Ekstein. With the influx of positive-tested carriers, Dor Yeshorim would simply become the "carrier" organization and create the very stigma for participants they are trying to avoid.

"If we don't stick to this at all costs," says Rabbi Ekstein, "the very foundation of the program is at risk."

Today, with the proliferation of private genetic testing agencies that people can hook into online, having only to provide a saliva sample, everyone can get tested and receive their results — not just for nine or ten mutations, but for over a hundred mutations that they could be carriers for. Rabbi Ekstein is not against testing privately for recessive genetic mutations per se; he just doesn't want them trying to enter the Dor Yeshorim program after they find they are a carrier.

"I don't force anyone to choose our way. I'm just being practical. Let's say someone gets a printout of all his genetic mutations and conditions of carrier status. What does he do with that? Take his printout on the first date? The fourth date? And should he demand the lab results from the other side and make sure they are certified?"

Drawing the Line For Rabbi Ekstein, the lines of DNA research are clearly drawn. If the knowledge won't help you, don't do it. But if it will help, turn over the world.

So when Rabbi Ekstein learned that Dr. Berish Rubin — chairman of the Department of Biological Sciences at Fordham University — had expertise in the field of molecular biology, he didn't let Dr. Rubin off the hook until he agreed to search for a genetic basis for familial dysautonomia (FD), an often fatal "Jewish" genetic disease affecting the central nervous system, with a carrier frequency equal to that of Tay-Sachs. Rabbi Ekstein was in touch with numerous families whose children tragically died of FD, and who could not find *shidduchim* for their healthy children because of the stigma. Within a few months, Dr. Rubin discovered the FD-causing mutations, and Rabbi Ekstein wasted no time in expanding his testing panel to include this fatal condition. His was the first organization in the world to use FD in its screening.

Still, where does Dor Yeshorim draw the line? How catastrophic must an illness be to enter the testing panel, where a negative compatibility result would mean the canceling of a *shidduch*?

"We will only screen for extremely debilitating disorders like cystic fibrosis or Bloom Syndrome, or fatal diseases like Tay-Sachs and Canavan," Rabbi Ekstein explains. "We are not looking for a 'perfect' gene pool. We used to test for Gaucher's, but that has been dropped because it has been found to be often asymptomatic, and there is now a successful treatment protocol — even Israel's Ministry of Health no longer recommends screening for Gaucher's. When we started screening for it, we only saw the very difficult cases because the DNA test was not yet available, and the medical world wasn't even aware that there was a more frequent, mild form which often didn't even present. Once the DNA test was used, we realized that we'd have to stop twenty *shidduchim* before one child might have a problem. And today there is treatment. When we started there was no treatment."

Dor Yeshorim, and by extension Rabbi Ekstein himself, takes responsibility for telling a potential couple, "not compatible."

"You think this is an easy thing?" Rabbi Ekstein is hurt. People accused him of "ruining *shidduchim*." "That's when they decide to call the night before the *l'chayim*. This is why we want people to call before the couple even meets. It should be a basic part of the research, like any other item that's being checked out."

Putting the statistics into perspective, in the last twenty-eight years, how many prospective matches have actually been canceled?

"We've said 'not compatible' 1,700 times. True, that means 1,700 times tragedy was averted. That's 3,400 families. It's rare. It usually doesn't happen. And when it does happen it's a salvation. But each time I cry. It means I've stopped a *shidduch*."

"But you should know, for me, saying 'compatible' is an even bigger responsibility. I take this burden on my shoulders hundreds of times a day. It means we have to have *siyata d'Shmaya* and be 100 percent accurate. It means we have to double- and triple-check even the data entry. It means we need to take multiple precautions to make sure there are no mistakes. One mistake could mean an irreparable family tragedy."

"This is not a testing facility. For that I could have opened a lab"

Rabbi Ekstein's original forty-five do-good volunteers have mushroomed into a database of over 320,000. But although the incidence of Tay-Sachs and other genetic diseases have virtually been eradicated in the community for those who utilize the program, those genes are never erased. And so, says Rabbi Ekstein, "My goal doesn't go by numbers. This is going to continue until Mashiach, as long as people are doing *shidduchim*." ■

Photo placement courtesy of Modern Diagnostic Laboratory