



Knowledge. Counseling. Screening.
Jewish Genetic Diseases
www.victorcenter.org

You Can Help Prevent Jewish Genetic Diseases... Find Out How

Learn More | Take Action | Get Screened

A Clergy Toolkit on How to Create Awareness in Your Community created by the National Victor Center for the Prevention of Jewish Genetic Diseases

Your Clergy Packet includes:

- Poster
- Your Genes Matter
- How to Talk to Your Community
- Clergy Quick Facts
- Victor Center - Personalized Medicine Initiative
- Pre-Marital Counseling Talking Points
- A Personal Story
- Screening Rx Pad



For more information, please contact a Victor Center genetic counselor, Deborah Wasserman at **786-624-2671**, via email at deborah.wasserman@nicklaushealth.org or Shari Debowsky at **786-624-2051**, via email at shari.debowsky@nicklaushealth.org



**LEARN
MORE**

**TAKE
ACTION**

**GET
SCREENED!**

**1 in 2 Jews is a carrier for at least
1 Jewish genetic diseases**

Jewish genetic diseases are preventable. All it takes is a simple blood or saliva test to find out if you are a carrier.

**Get screened now... your future
children will thank you later.**

For information about upcoming screenings,
visit victorcenter.org



**Nicklaus
Children's
Hospital**



**Victor
Center**

YOUR GENES MATTER...

Make the promise to future generations to be educated about Jewish Genetic Diseases.

It's not often that you have the opportunity to change the course of someone's life — to prevent a needless tragedy. But in the case of Jewish Genetic Diseases, we know how to inform people of their carrier status and have them avoid passing on a gene mutation for a devastating disease to their children.

1 in 2 Ashkenazi Jews is carrier for at least one "Jewish" genetic condition. There is a different set of genetic diseases for which Sephardi/Mizrachi Jews have a higher carrier rate. More than half of participants in our screening program are carriers for one or more of the 225+ conditions on our expanded carrier screening panel. A carrier is an otherwise healthy person who shows no symptoms of disease but carries an altered copy of a gene that they can pass on. The only way to know if someone is a carrier is for them to have a simple blood or saliva test or give birth to an affected child.

The Victor Center for the Prevention of Jewish Genetic Diseases was founded by Lois Victor who lost two daughters to a Jewish Genetic Disease. Mrs. Victor has made it her life's work to help ensure that no other parent would have to endure this kind of heartache. In the same way the incidence of Tay-Sachs has decreased in the Jewish community due to a public education campaign and screening that began in the 1970s, we have it within our power to ensure that the other diseases can be prevented. You, as clergy, can be the generation of leaders who take on this challenge...and win.

The most optimal time to talk to your community members is before they get married or decide to have children, since that is the time when most family planning options are available to them. The message is simple: a blood or saliva test gives the couple the knowledge to help prevent having an affected child. Parents, grandparents, family and friends are also great influencers so please include them when speaking about Jewish Genetic Diseases.

This toolkit was created to help you take action in your community and with your colleagues. It contains information for you to begin the conversation. The enclosed educational materials will help continue to bring awareness to your community.

- Poster
- Your Genes Matter
- How to Talk to Your Community
- Clergy Quick Facts
- Victor Center - Personalized Medicine Initiative
- Pre-Marital Counseling Talking Points
- A Personal Story
- Screening Rx Pad

Our toolkit materials, can be downloaded on the Victor Center website are continually updated throughout the year. Online resources will include pieces customized for outreach at the High Holy Days, Passover and more. Go to **www.victorcenter.org** for more information.

What could be more important than the birth of healthy children? You can help bring us closer to that reality. It all begins with a conversation. Join us in making this happen.



GENES MATTER... How to Talk to Your Community About Jewish Genetic Diseases (JGDs)

The most optimal time to talk to your community is **BEFORE** they get married or decide to have children since that is the time when the most family planning options are available to them. The only way for them to find out if they are carriers is to have a simple blood or saliva test or have an affected child.

What are JGDs?	Jewish genetic diseases are a group of severe and often fatal disorders that have a high carrier rate among Jews of eastern or central European descent (Ashkenazi). There is a different set of genetic diseases for which Sephardi/Mizrachi Jews have a higher carrier rate.
What does it mean to be a carrier of a JGD?	1 in 2 Jews is at risk of being a carrier for at least one preventable JGD. The term "carrier" means that a person has an altered copy of a gene in their genetic makeup that can be passed on. Being a carrier usually has no impact on their health but could impact the health of their future children. If they and their partner are both carriers for the same disease, there is a 25% chance with each pregnancy of having an affected child.
What should your community know about screening?	A simple blood test is all it takes to find out a person's carrier status. Everyone should screen before becoming pregnant and update their screening panel if testing for new diseases becomes available. They should check back with the Victor Center to see if the testing panel has expanded.
What should your community members do if they are carriers?	Their partner must also be screened. If they are both carriers for the same disease, there are options available for having healthy children. Their siblings are also at risk to be carriers and should be tested. Genetic counseling is recommended.
How can couples have healthy children if they are both carriers for the same disease?	A genetics professional can speak with them about their options. These include egg/sperm donation, in vitro fertilization (IVF) with pre-implantation genetic diagnosis (PGD) and prenatal diagnosis.
Who should be screened?	<ul style="list-style-type: none"> Any individual with Ashkenazi Jewish ancestry (who came from Eastern or Central Europe, such as Russia, Poland, Germany, Ukraine, Lithuania...), Sephardic (Northern Africa or Spain) or Mizrachi (Mid-East). Any individual whose partner has Ashkenazi, Sephardic or Mizrachi Jewish ancestry. Any partner of an individual found to be a carrier for a Jewish genetic disease. Any person interested in pre-conception population carrier screening. Interfaith couples both individuals should be screened. Gay or Lesbian couples who will be using an egg or sperm donor.
Where can they get screened?	<ul style="list-style-type: none"> At their physician or OB/GYN, request to be screened for the most up to date expanded panel. If their doctor does not screen for the expanded panel, reach out to the Victor Center. Please contact Deborah Wasserman at 786-624-2671, via email at deborah.wasserman@nicklaushealth.org or Shari Debowsky at 786-624-2051, via email at shari.debowsky@nicklaushealth.org Community screenings, sponsored by the Victor Center. Check our website for upcoming dates. The Victor Center office

If you have any questions or would like to discuss any of this information prior to speaking with your community members, please contact the Victor Center at 786-624-2671 or 786-624-2051.



www.victorcenter.org



A Simple Question Can Make All the Difference

"Have you been screened or have you updated your Ashkenazi Jewish Panel? Did you know one in two Jews of Ashkenazi descent is a carrier for at least one preventable genetic disease of those tested?"

As a clergy, your role is crucial...

As a member of the clergy you are uniquely prepared to make a difference in the lives of couples preparing for marriage and anyone making decisions about family planning. All it takes is a simple question, followed by a simple blood or saliva test.

Begin the conversation in your synagogue and community about the impact that a single blood or saliva test can have. Educate around the importance of genetic counseling and screening prior to pregnancy. Your intervention can lead to educated decisions and help build generations of healthy Jewish families.

What can you do?

- Counsel your congregants who are preparing for marriage and/or considering becoming pregnant (see the quick facts on the back of this flyer), and refer them to the Victor Center for information about the full panel of

Jewish genetic diseases and how to get screened.

- Organize a community screening with the Victor Center at your synagogue.
- Maximize social media (Facebook, Twitter, blogs) to alert your community to one of our most critical health issues.
- Use the Jewish holidays and synagogue social groups and meetings as entry points to educate your congregation about the importance of screening. The Victor Center will work with you to provide materials and programming ideas.
- Identify physicians and lay leaders in your congregations who can participate in an outreach effort.
- Create training opportunities with the Victor Center for other clergy in your community.
- Spread the word about screening and updating screening for the full panel of Ashkenazi Jewish genetic diseases at denominational conferences, regional chapter meetings and to fellow clergy across denominations.



**Nicklaus
Children's
Hospital**



**Victor
Center**

Quick Facts

What you should know before you talk to your congregants:

What are Jewish genetic diseases?

They are a group of disorders that occur with significant frequency in the Ashkenazi Jewish population, (Those of eastern or central European descent). Visit victorcenter.org for the full list of diseases. Many of the diseases are severe and some are fatal in childhood.

Which of your congregants should you talk to about being screened?

- Jews whose ancestors come from Eastern or Central Europe, Northern Africa, Spain and the Mideast (Ashkenazi, Sephardic and Mizrahi).
- Patients who have any Jewish heritage, even if just one grandparent was Jewish.
- Interfaith couples (diseases occur in the general population, although at a lower frequency).
- Anyone who is considering becoming pregnant through donor egg/sperm and has Ashkenazi ancestry should be screened. If possible it is best to have the patient and donor both screen prior to any procedures being done. Anyone considering IVF with PGD should be referred for genetic counseling.
- Since a pan ethnic panel is now available, the test is for anyone who wishes to have preconception screening.

How can someone know if he/she is a carrier?

- There are only two ways to know, through screening or if an affected child is born. A simple blood or saliva test examines a person's genes for specific mutations.
- Once an individual is identified as a carrier, refer him or her for genetic counseling to review the test and discuss family planning options. To find a genetic counselor near you, please contact the Victor Center.

When should your congregants be screened?

- Before considering becoming pregnant.
- Update screening before every subsequent pregnancy. Advances in technology may enable testing for new diseases.

What does screening entail?

- It's a simple blood or saliva test. The results show whether you have an altered copy of a gene in your genetic makeup. The only other way to know if you are a carrier is to have an affected child.

Where can your congregants go for screening?

- To their OB/GYNs office if they do the expanded panel. If their doctor does not screen for the expanded panel contact the Victor Center for more information.
- Community screenings in your area. Contact the Victor Center for updates.

What do your congregants need to know about insurance coverage?

- They should ask their insurance company about coverage for the panel or call the Victor Center for CPT codes or more information.
- If your congregants have questions about navigating the verification process for medical insurance, have them contact the Victor Center.

Who we are?

The Victor Center for the Prevention of Jewish Genetic Diseases at Nicklaus Children's Hospital, founded by Lois Victor, offers genetic counseling and screenings, and builds awareness about genetic diseases affecting Ashkenazi Jews. We work in partnership with healthcare professionals, clergy and the community to educate about the simple steps that can be taken to prevent these severe and often life-threatening diseases.

Please visit victorcenter.org to ask genetic experts about genetic diseases and how they can be prevented.

If you would like to be part of a local rabbinic advisory council, please let us know.

Jewish Genetic Diseases. The Facts.



What Are Jewish Genetic Diseases?

Jewish genetic diseases are a group of recessive, inherited disorders that occur with increased frequency in the Ashkenazi Jewish community. This means individuals of Ashkenazi descent have higher carrier rates for diseases like Tay-Sachs, Canavan, Familial Dysautonomia and Gaucher.

What Does It Mean To Be A Carrier?

A carrier is an individual who has an altered copy of a gene in his/her genetic makeup. Being a carrier does not usually affect an individual's health; however, it could impact the health of his/her future children if both partners or an individual and his/her sperm or egg donor are carriers for the same disease. Carrier-Carrier couples have a 25-percent chance of having an affected child with each pregnancy.

Who Should Be Screened?

- Individuals who are Ashkenazi Jewish.
- Individuals who have at least one Jewish grandparent.
- Both partners of an interfaith couple.
- Individuals or couples considering the use of donor eggs or sperm for pregnancy where one person/donor is Jewish.
- Individuals who are adopted and do not know ancestral roots.
- If already pregnant, both partners need to be screened at the same time.

Are Jewish Genetic Diseases Curable?

There are some treatments but no cures for Jewish genetic diseases. Most of these disorders cause terrible suffering and premature death. That's why prevention, through education, counseling and screening, is so critical.

Can Carrier-Carrier Couples Have Healthy Children?

Yes! There are many options available for couples where each partner is a carrier for the same disease. Genetics professionals can explain these procedures, which include: egg/sperm donation, in vitro fertilization (IVF) with pre-implantation genetic diagnosis (PGD) and prenatal diagnostic testing.

How Much Does This Screening Cost?

The cost of screening is generally affordable for most people. Some insurance providers cover preconception screening, but testing costs and coverage amounts vary widely. Check with your insurance provider or the Victor Center.

If you have any questions or would like to discuss any of this information prior to speaking with your community members, please contact the Victor Center at 786-624-2671.



GET YOUR INSIDE STORY.

For more information contact: Deborah.Wasserman@nicklaushealth.org | nicklauschildrens.org/VictorCenter 786-624-2671

Nicklaus Children's Hospital Advanced Pediatric Care Pavilion. Equipped with the most advanced tools and technology available, our pavilion is home to Neonatal (NICU), Pediatric (PICU) and Cardiac (CICU) critical care units, as well as Neurology/Neurosurgery and Hematology-Oncology units.



The Personalized Medicine Initiative (PMI)

The Personalized Medicine Initiative (PMI) at Nicklaus Children's Hospital, part of Nicklaus Children's Health System, is one of the first programs in the U.S. completely focused on precision and personalized medicine for children's health and wellness. Personalized medicine involves a more comprehensive approach and tailoring medical management to each child's individual characteristics, needs and preferences

during all stages of care including prevention, diagnosis, treatment and follow-up. The PMI at Nicklaus Children's supports an array of service lines such as cardiology and cardiovascular surgery, cancer, neurosciences, The Victor Center, plastic surgery, genomics and radiology and is leading the way to improve the health of children and families in South Florida and beyond.



**Nicklaus
Children's
Hospital**

Screening = Knowledge

In 2002, The Victor Center for the Prevention of Jewish Genetic Diseases was created in partnership with Einstein Healthcare Network and Lois Victor who lost two daughters to a Jewish genetic disease. Mrs. Victor has made it her life's work to help ensure that no other parent would have to endure this kind of heartache.

In 2017, Nicklaus Children's Hospital in Miami became the home of the National Victor Center, with an affiliate Victor Center in Philadelphia. We work in partnership with healthcare professionals, clergy and the community to create awareness and organize screenings for Jewish genetic diseases.

1 in 2 Jews is a carrier for at least one preventable genetic disease. All it takes is a simple blood or saliva test to find out if you are a carrier.

Though most Jewish people have heard about Tay Sachs disease, many are unaware there are currently over 200 genetic disorders of which some occur at a higher rate in the Ashkenazi Jews. The new expanded screening panels include all Jewish genetic diseases and other diseases that apply to all populations. It is our aim to spread awareness of these diseases and re-educate the population about their mode of inheritance as well as the additional diseases which occur across the pan-ethnic populations.

By partnering with clergy, synagogues, community centers, medical practices, health fairs and young professional groups throughout the United States, we will educate, counsel and test those at risk. The ultimate goal is to educate about one's reproductive options and current management options that are available.

As your congregants embark on their new journey of marriage or to have children, they can help us educate the community, raise awareness and pass on this message *L'Dor V'Dor* so all young adults obtain this valued information prior to conceiving. We need their help to sustain this program through philanthropic gifts or grants from local Jewish agencies to continue our efforts locally, statewide, nationally and internationally.

Tell them to:

- Register for a gift of screening on their bridal registry
- Host a bridal shower for their bridesmaids and groomsmen to be screened
- Tell everyone at their baby shower that they were screened for Jewish genetic diseases
- Invite us to speak at their home, temple, or community
- Give the gift of screening (please visit www.victorcenter.org)
- Make sure their panel is updated before each pregnancy as the panel of diseases may increase over time

Get screened before becoming pregnant and share this information with everyone you know and care about.





A Personal Story About the Importance of Pre-Conception Testing

Written by: Shari R. Debowsky

In every corner of Judaism, both culturally and spiritually, we are commanded to "celebrate life." That was precisely my intent in the spring of 2008 as I (and my husband Stuart) prepared to start a family. It was an extremely exciting time for us and, like most couples, we did not think about the risk of Jewish genetic diseases.

Once we confirmed our pregnancy, we were thrilled about the prospect of expecting our first child later that fall. As a matter of course, during our (routine) eight-week check-up, my OB/GYN asked for permission to run the "Jewish panel" blood test. Of course, we agreed. When my results came back as a carrier for Tay Sachs disease, we knew that Stuart needed to be tested. Soon after, Stuart's results came back and indicated that he, too, was a Tay Sachs carrier.

Now a bit more than just concerned, our doctor immediately referred us to meet with a genetic counselor to further understand our risks and options and to schedule an appointment for an amniocentesis. Already now 16 weeks along, this was a nervous time for us as a young couple, as this procedure's results would be able to accurately predict whether we had both passed on the autosomal recessive gene mutation. More specifically, this is "a pattern of inheritance in which disease only results when an individual inherits two gene mutations (one from each parent) for a particular disease. If both members of a couple are carriers of the same gene mutation, there is a one in four (25 percent) chance with each pregnancy for a child to be affected."

The test results took about three-and-a-half weeks (so now our pregnancy was 20 weeks along) and it was confirmed, much to our horror and disbelief, that our unborn baby was indeed unfortunately affected with Tay Sachs, a curse that leads to certain suffering and inevitable death, usually very early in life. We made the unbearable decision to terminate our pregnancy and not bring an affected Tay Sachs baby into the world. As a result, we are undeniably determined to raise awareness of the numerous Jewish genetic diseases that exist, most of which are still the subject of research to find cures.

After the termination, a friend of ours introduced us to the Victor Center for the Prevention of Jewish Genetic Diseases, an organization that was founded by Lois Victor. Mrs. Victor lost two children to a Jewish genetic disease and is passionate in her mission to ensure that no family endures the heartache of a preventable illness. Through her leadership and support, the Victor Center serves this important purpose of raising awareness and offering clinical expertise in the areas of genetic screening, education and counseling. It is so vital for all those embarking on the adventure of family planning (not just those of Jewish ethnicity) to know their risk and be well-informed about genetic carrier screening. Most couples probably do not realize that insurance companies vary in their coverage for pre-conception screening and some may only cover the test once you are already pregnant, but as you have learned, this can be too late. I have been volunteering, sharing my story, and encouraging as many people as I could to get screened before they were ready to start their families.

I have worked in the non-profit Jewish sector for over 15 years and I am proud to announce that this past November 2018, I became the Senior Outreach Associate for the Victor Center for the Prevention of Jewish Genetic Diseases. The National office for the Victor Center is now at Nicklaus Children's Hospital in Miami.

If you or someone you know needs to be screened please connect them with the Victor Center for the Prevention of Jewish Genetic Diseases. More information can be found by visiting www.victorcenter.org.



Shari R. Debowsky, *Senior Outreach Associate*
Victor Center for the Prevention of Jewish Genetic Diseases
Office: **786.624.2051** • Mobile: **305.794.7358** • Email: Shari.Debowsky@nicklaushealth.org



Nicklaus
Children's
Hospital



Victor
Center

www.victorcenter.org | 786-624-2671

Name: _____ Age: _____

Address: _____ Date: _____



A prescription for the health of your future children.

Three ways to get screened:

- Your physician or OB/GYN.
- At a **Victor Center** location.
- At a **Victor Center** community screening.
Find an upcoming screening in your area
at **www.victorcenter.org**

Learn More | Take Action | Get Screened

For more information, please contact a Victor Center genetic counselor, Deborah Wasserman at **786-624-2671**, via email at deborah.wasserman@nicklaushealth.org or Shari Debowsky at **786-624-2051**, via email at shari.debowsky@nicklaushealth.org

Next screening: _____