

A NEW PARTNERSHIP

For more than 50 years, NTSAD-DV has provided genetic screening, first for Tay-Sachs disease then Canavan and eventually a panel of more than 200 genetic diseases. Access to genetic testing and counseling is at the very core of our mission. In order for us to live our mission more fully, we are thrilled to announce a new partnership that will extend our ability to connect you to reliable testing and counseling through telehealth.

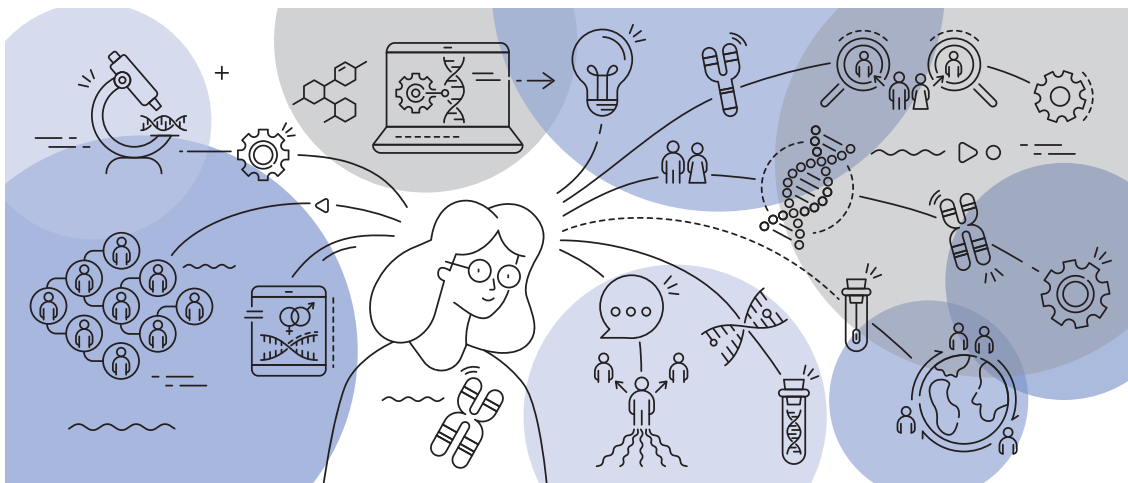
Starting next month, NTSAD-DV will partner with JScreen. Headquartered in Atlanta at Emory University's Department of Human Genetics, JScreen is a national non-profit offering at-home comprehensive and affordable genetic testing and counseling. In alignment with the mission of NTSAD-DV, JScreen believes that a combination of education, access to state-of-the-art testing technology, and personalized support by qualified medical

professionals are key to preventing devastating genetic diseases.

Funded through your generous donations, NTSAD-DV will partner with JScreen in two different ways. First, we will establish a screening fund with JScreen to access their ReproGen kit with no out-of-pocket cost when used with insurance. For our members who are uninsured or underinsured, it will cover the full cost of the kit. The JScreen ReproGen test is easy to use and reliable. The panel is appropriate for pan-ethnic testing. American College of Medical Genetics (ACMG) supports extended carrier screening in all populations. The second part of our partnership will include at least one community screening and educational outreach throughout the year.

ABOUT JSscreen'S REPROGEN TEST

- Determines risk for having a child with a genetic disease
- At-home, saliva test
- Low program fee
- Designed for individuals between the ages of 18-45
- State-of-the-art sequencing technology with highest detection rates
- Comprehensive panel with 200+ diseases
- Genetic counseling included



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"TAY-SACHS
AND CANAVAN
TESTING IN EVERY
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FOR
GENERATIONS
TO COME."

Impact is a
publication of
National Tay-Sachs
& Allied Diseases
Association of
Delaware Valley

WINTER
2023

FOUR SIMPLE STEPS TO TEST



1

Complete the secure, online kit request. You will need to include information about your doctor so that JScreen can coordinate a test order on your behalf.



2

Once a valid test order from your doctor is received, JScreen will mail you a saliva collection kit with a pre-paid envelope to send the sample to the lab.



3

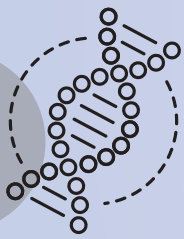
Results are typically available within 3 weeks, and a 15–20-minute phone consultation with a genetic counselor is required for most participants.



4

When the entire process is complete, a copy of your results will be emailed to you and sent to your ordering provider. If a person or couples' risk is elevated, genetic counselors will privately address the results, options, and resources to help plan for a healthy future

(JScreen also offers a second panel of testing to determine cancer risk, CancerGen. This panel is outside the mission of NTSAD-DV; however, you will be able to request this kit which tests for genetic changes that increase risk for many types of cancer.)



It is important to note that our partnership with Einstein (now part of Jefferson Health) continues. Maintaining our partnership at Einstein is important for our members who may need access to immediate screening and counseling. For every person considering pregnancy, it is paramount that you know your carrier status. There are multiple options for carrier couples, but only if you know your status pre-conception. The risk of having an affected child is present with each pregnancy and every generation produces carriers of these recessive genetic conditions.



Both programs we are supporting include genetic counseling. If you are considering getting screened, are a carrier or carrier couple, we urge you to meet with a genetic counselor. Genetic counselors are an important part of the healthcare team. They work with patients and their families to help them understand genetic testing, guide them through the process, and help them make informed choices based on their individual genetic testing results. There are several questions a genetic counselor may help you answer such as:

- What treatments are available for this genetic disease?
- What impact would the genetic test results have on your family?
- What happens if the results are uncertain or inconclusive?
- Should I share these results with family members?

Genetic counselors can go over all the options with you to assist with making the choice that is right for your family. ❄️



EXECUTIVE COMMITTEE MESSAGE

Dear Friends:

We are all incredibly excited by our new partnership with JScreen. This partnership would not be possible without your support. For more than 50 years, you have helped bring healthy children into our midst. It is truly amazing to look back on our work and see all the amazing advancements made in testing. The field of genetics continues to expand every year, but what never changes is the need for screening and counseling.

The world has been a scary place for the past few years. Tremendous upheaval, the pandemic and conflict nationally and internationally have left many of us feeling overwhelmed and anxious. As the world gets louder and more uncertain, each of us has taken comfort in the work we do with NTSAD-DV. We know how to prevent these terrible diseases, we know how to help couples ensure their children are born free of Tay-Sachs and Canavan disease. Your generosity and support ensure that we can continue in this most worthy cause – the birth of healthy children in this generation and for generations to come.

Thank you for your generosity.

NANCY DONEGAN MICHAEL J. OSSIP LAURI SUSSMAN SIEGEL



NTSAD-DV

directly benefits from your **United Way** donation when you fill out a Donor Choice form with our five-digit code: **00983**. Call 215-887-0877 for more information.



KNOWLEDGE IS POWER – VIRTUAL AVAILABLE



Do you teach a high school biology or genetics course? Do you work with a community group that could benefit by learning about Tay-Sachs and Canavan diseases and how to get screened?

If so, NTSAD-DV will provide you with a free copy of our educational video “Knowledge is Power – Check Out Your Gene Pool”. Our Speakers Bureau for interested schools or organizations is available virtually for the duration of the pandemic. Speakers will present the video to your group, answer questions and provide information about Tay-Sachs and Canavan. If you would like us to virtually visit your community event or school, or would like more information about our DVD and brochures, please visit our website at www.tay-sachs.org or email info@tay-sachs.org.

WAYS TO GIVE

*There are several options to support NTSAD-DV.
We are grateful for your support.*



You can make a secure donation online at <http://www.tay-sachs.org/donations.php>



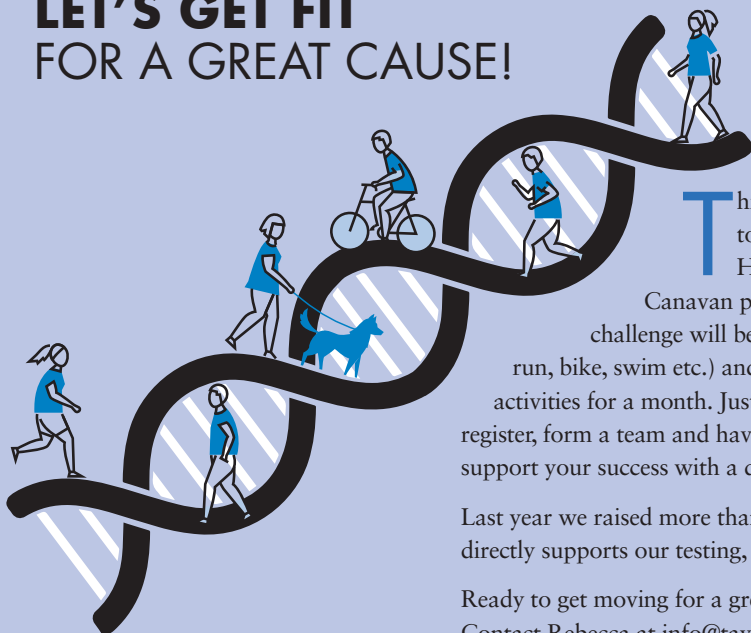
Return the enclosed envelope



Designate NTSAD-DV as the recipient of your United Way donation Donor Choice 00983



LET'S GET FIT FOR A GREAT CAUSE!



This spring we are once again planning to run a virtual fitness challenge. Help us get fit for Tay-Sachs and Canavan prevention! Participants in our challenge will be able to track their activity (walk, run, bike, swim etc.) and record their steps completing those activities for a month. Just like in a 5K or a Walk, you will register, form a team and have the opportunity to have friends support your success with a donation to our prevention efforts.

Last year we raised more than \$30,000 through this event which directly supports our testing, education and outreach efforts.

Ready to get moving for a great cause? Sponsorships are available. Contact Rebecca at info@tay-sachs.org for more information.



YOUNG LEADERSHIP COMMITTEE

Our Young Leadership Committee continues to engage with the next generation of NTSAD-DV supporters. The YLC is always looking for new members who want to be involved and help us continue our mission.

If you're interested please email ylc@tay-sachs.org

THANK YOU FOR YOUR GENEROSITY in returning the enclosed envelope.
You can also make a secure donation online at <http://www.tay-sachs.org/donations.php>

National Tay-Sachs & Allied Diseases Association of Delaware Valley

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