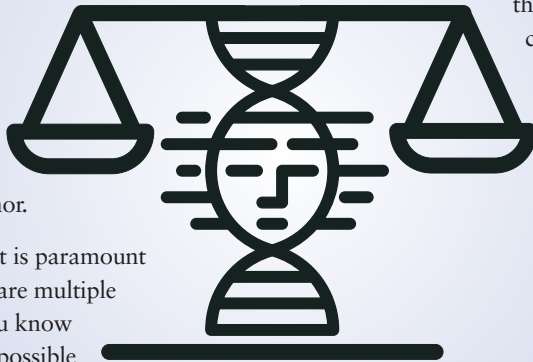


ROE VS. WADE – IMPACT ON GENETIC SCREENING

With the Supreme Court's recent decision to overturn Roe vs. Wade, there has been a renewed focus on pre-natal and pre-conception genetic testing for diseases like Tay-Sachs and Canavan. While there are impassioned beliefs on both sides of the issue, access to abortion care is a significant consideration for carrier couples. With this issue currently resting in state governments, it is possible that the legality of abortion could shift every four years based on who is elected governor.

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. While it is impossible to know what the next few years will bring, we do know that the risk of having an affected child is present with each pregnancy and that every generation produces carriers of these recessive genetic conditions.



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. ❄️

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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Association of
Delaware Valley

**WINTER
2022**

NATIONAL TAY-SACHS & ALLIED DISEASES ASSOCIATION OF DELAWARE VALLEY (NTSAD-DV)

CELEBRATING 50 YEARS OF EDUCATION, SCREENING AND PREVENTION

This year marks the 50th anniversary of the Tay-Sachs Prevention Program. It is a truly remarkable milestone for our organization. More than fifty years ago a dedicated group of individuals were brought together through a shared tragedy, a family history of Tay-Sachs disease. Before the gene that causes Tay-Sachs disease was identified, too many families learned their carrier status with the birth of an affected child. Once the gene was identified and a test became available, these families worked tirelessly to ensure that every person who was at-risk of being a carrier would have the opportunity to get screened.

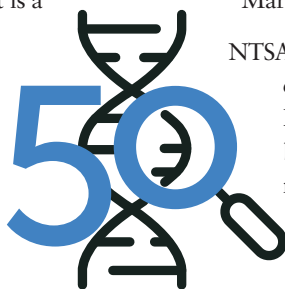
Needing a medical partner, these families found a true ally in our dearly departed friend Laird Jackson, MD. After being turned away from multiple institutions, Laird Jackson accepted the challenge and the Tay-Sachs Prevention Program at Thomas Jefferson University Hospital was born. At the very first screening in October 1972, more than 800 individuals lined up to get tested after seeing Tay-Sachs

disease featured on the popular tv show "Marcus Welby, MD".

NTSAD-DV needed to fund 100% of the lab costs when the program started.

Dr. Jackson had to run the first 2,000 blood samples by hand because we had not yet raised enough money to buy an auto-analyzer that would automate the testing procedure. There were bake sales, fashion shows, car washes, and direct appeals to the community.

Fast forward 50 years and the advances made in genetics, notably the mapping of the Human Genome, make our first screenings seem quaint. The role of genetics in medicine today cannot be overstated. However, the underlying principles of genetic disease screening for recessive conditions remains the same. Both parents need to be a carrier to have an affected child and the risk is with each pregnancy. Fifty years ago, Tay-Sachs was the only disease with screening available. Today carrier screening panels test for more than 300 conditions.



CELEBRATING 50 YEARS OF



EDUCATION, SCREENING AND PREVENTION



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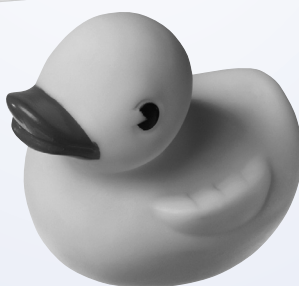


CELEBRATING 50 YEARS OF EDUCATION, SCREENING AND PREVENTION

If you are reading this *IMPACT*, you have played a role in our success over the past five decades. This issue is dedicated to each of you. Every person who has ever donated to our cause. Every volunteer, past and present, who has given so generously of their time. Every person who has been screened through our program and

most especially in honor of every healthy child who has been born as a result of our program.

We hope you enjoy the photos of all of these events and the people who made this organization what it is featured throughout this issue. ❄️



FUN FACTS 1972



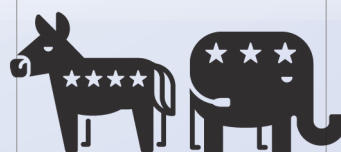
The Top Song was
The First Time Ever
I Saw Your Face by
Roberta Flack

The Movies to Watch
included *The Godfather*,
The Getaway,
What's Up Doc and
The Poseidon Adventure



On average,
the cost of gas in the
U.S. in 1972 was 36
cents per gallon

On June 17, 1972, the
Watergate scandal began
when five men broke into
the Democratic National
Committee headquarters
in Washington, D.C.



President Richard
Nixon and NASA
Administrator
James Fletcher
introduced the
Space Shuttle Program
on Jan. 5, 1972.

EXECUTIVE COMMITTEE MESSAGE

Dear Friends:

T*hank you.* Thank you for decades of support and tireless devotion to NTSAD-DV. Each of us on the Executive Committee has an intensely personal connection to this organization. Our hope has always been the same thing, to put ourselves out of business. While we no longer have to hold a bake sale to buy an auto-analyzer, we are still an incredibly grass-roots organization that relies directly on your support. Our work is far from over. We must continue our education and screening efforts. The advances in genetic medicine are truly astonishing, yet our message is much the same as it was 50 years ago ... **GET TESTED!**

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



THANK YOU TO OUR VIRTUAL RACE SPONSORS AND PARTICIPANTS!

This past September, NTSAD-DV held its first virtual race. A most sincere thank you to all of our sponsors and participants who made this COVID-safe event fun and successful.



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

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more information.

