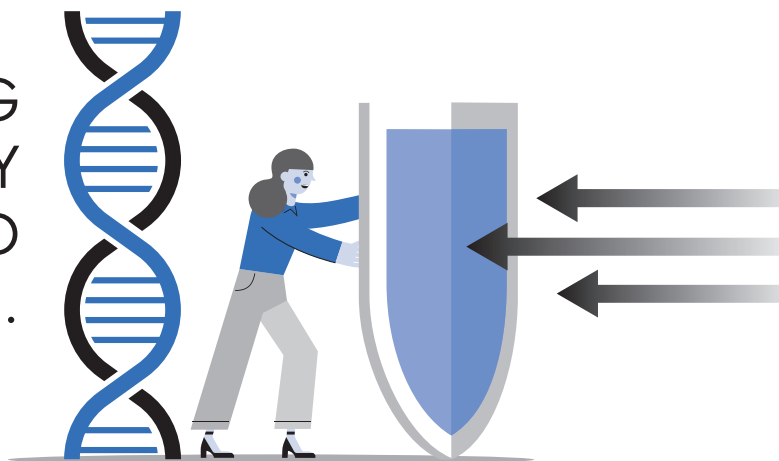


PROTECTING YOUR PRIVACY NOW AND IN THE FUTURE.



In past issues of the IMPACT, we have explored the risks of using at-home genetic testing kits such as Ancestry and 23andMe. At the time of this writing, it is reported that 23andMe is on the verge of bankruptcy. The company's single biggest asset is the vast amount of genetic data it has amassed and sold to other companies. A major data breach last year exposed more than 6.9 million members with hackers specifically targeting individuals of Chinese and Ashkenazi Jewish descent. With a potential bankruptcy, many are left questioning what will become of their genetic data. 23andMe's privacy policy allows the company to sell customers' genetic data if the company goes bankrupt, is merged or acquired.

Your DNA cannot be changed. Unlike canceling a subscription service or replacing a credit card, even deidentified genetic data will always be unique to you. Adding another privacy concern, your DNA can also be linked to members of your family. So even if you have never sent in a home DNA test, if one of your relatives has submitted their data, your privacy may be compromised.

Many users erroneously believe that the use of these home DNA tests are protected under the Health Insurance Portability and Accountability Act (HIPPA). HIPPA, a federal law, "gives you rights over your health information and sets rules and limits on who can look at and receive your health information. The Privacy Rule applies to all forms of individuals' protected health information, whether electronic, written, or oral." However, HIPPA only applies to "covered entities" such as hospitals, healthcare providers and health plans. Unfortunately, even though your DNA contains a tremendous amount of health information, if you have shared your DNA with a private company such as Ancestry or 23andMe, it is NOT protected by HIPPA.

The recent financial troubles at 23andMe are not the only disturbing news coming out of the home DNA

test realm. A proposed class action lawsuit filed in August 2024 claims the operator of GEDmatch.com has violated an Illinois privacy law by secretly sharing users' genetic information with Facebook. The suit claims GEDmatch used the Meta pixel to illegally record users' interactions with the site and disclose their confidential genetic information to Facebook. According to ClassAction.org, "The lawsuit claims that these transmissions help GEDmatch improve its highly targeted online advertising campaigns, particularly because the tracking technology collects enough information to link a visitor's interactions on the website with their identity."

SO, WHAT NOW?

If you have submitted your DNA to 23andMe, there are steps you can take to limit the sharing of your data. You can delete your 23andMe account as well as request that your data be deleted. If you have opted into their research program, your data will no longer be shared with researchers once you delete your account.

Continued on next page

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

WINTER
2024

PROTECTING YOUR PRIVACY NOW AND IN THE FUTURE.

Continued



If you would like to download your raw genotyping data before deleting your account, follow the steps outlined below:

1. Log into your 23andMe account.
2. Head to **Settings** and in a browser scroll to the bottom and tap **View** next to 23andMe Data. In the app, scroll to the bottom of Settings and tap **Access your data** under 23andMe data.
3. Here you can pick which information you want to download before you delete your account, including an overview of your 23andMe reports, your ancestry composition raw data, your family tree data and your raw genetic data.

When you are ready to delete your account:

1. Head to **Settings** again, scroll down to 23andMe Data, and tap **View**. You may be asked to verify your birthdate to continue.
2. If you've already downloaded or otherwise captured all the information you want to keep, scroll to the bottom and tap the **Permanently Delete Data** button.
3. 23andMe will send you an email asking you to confirm your request. Once you do, the company will begin the deletion process and you will lose access to your account. If you had the company store your genetic samples, it will discard them.

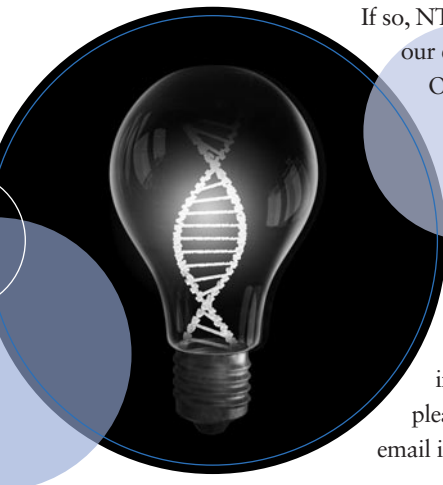
The genotyping lab contracted by 23andMe will still have your data for the next three years to comply with federal and state regulations. After three years, the genotyping lab will delete your data as well.

In this issue, you will see an update from our new partner, jscreen. If you have gone through the jscreen process, you know it is an at-home genetic testing kit. So, what makes this any different than 23andMe? The most important difference is that this is a **medical** test ordered by a covered provider which means it is protected under HIPPA. The genetic counseling piece is also protected under HIPPA. Genetic testing offers invaluable information for consumers to make informed decisions about everything from pregnancy to cancer

screening. However, until privacy regulations catch up with the marketplace, it is imperative for people to understand the implications of sharing your genetic information. The decision to undergo screening is a personal decision that should be made with the support of a genetic counselor to understand the risks, benefits and limitations. Interpretation of results is something a qualified medical professional should handle. Genetic testing and counseling are protected by HIPPA when performed by a covered entity. If you are sharing your DNA with any other direct to consumer organizations, please carefully review the privacy policies and be sure you can opt-out of any data sharing. ❀

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



EXECUTIVE COMMITTEE MESSAGE

Dear Friends:

For the past several issues, we have had to highlight the importance of knowing your carrier status before pregnancy to ensure you have the most options if you are determined to be a carrier of one of Tay-Sachs, Canavan or one of the allied diseases. By the time you read this issue, the election will be over, but issues surrounding reproductive health care, including abortion and IVE, will remain at the forefront. NTSAD-DV is not a political organization, and we are not advocating for you to vote a certain way. Reproductive medicine is deeply intertwined with genetic testing. We will continue to advocate, educate and provide access to screening for anyone who wants to know their carrier status. What you do with that information should remain between you and your healthcare provider.

Your support makes our work possible. Your support made the birth of Zac and countless other children possible.

Thank you for your generosity.

NANCY DONEGAN MICHAEL J. OSSIP LAURI SUSSMAN SIEGEL



JSCREEN UPDATE

As we told you in the Winter 2023 IMPACT, NTSAD-DV has entered into a partnership with jscreen. Pursuant to this partnership, we have established a screening fund with jscreen to access its ReproGen kit with no out-of-pocket cost when used with insurance. If you are uninsured or underinsured, this fund will cover the full cost of the kit. As part of our partnership, we will sponsor at least one community screening and educational outreach throughout the year.

It has been a year of big change for jscreen as it closes out a decade of life-saving genetic testing, counseling, and education for the Jewish community. This organization has embarked on a new chapter led by CEO Matthew Goldstein, MD, PhD, fueled by his own devastating loss of a child to Tay-Sachs disease, a background in biotech, and a passion for advancing preventive genetics. jscreen is on a new trajectory for massive growth and financial sustainability.

In the last 12 months, jscreen has made meaningful progress:

- A new commercial model including a partnership with a market leading diagnostic lab (Myriad).
- A new organizational structure; independent and spun out as its own non-profit outside of Emory University (currently pending 501c3 status); creation of a new board.
- A new brand look and a “supercharged” and well-resourced marketing strategy.

October 1st was the official launch of the new jscreen website (jscreen.org) and its goal to meaningfully increase the number of people receiving both cancer and carrier screening. Its team has grown, adding education/outreach managers throughout the country, a robust digital marketing campaign, and a focus on content creation. A new fundraising strategy and effort to further secure jscreen financially is also underway.



Jscreen’s mission is to ensure every adult in the United States has access to preventive genetic testing and counseling to inform their reproductive options and understanding of their own hereditary cancer risks. In the long-term, jscreen hopes to expand this service to support world-class preventive genetic care for everyone, everywhere. With a newly envisioned approach to genetic care navigation, jscreen believes that by combining cutting edge genetic testing technology, genetic care navigation via telehealth, with seamless insurance and provider coordination, many more families can avoid the tragedy that Dr. Goldstein’s family endured.

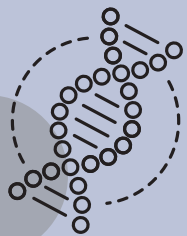
We look forward to continuing to work with our friends at jscreen. ❄️

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.



Since last year, jscreen has gone through some major changes. We asked jscreen to share an update with our readers.



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A NEW CARD TO SUPPORT OUR MISSION



This spring NTSAD-DV has developed a new honor/memory card to commemorate more than 50 years of prevention and education. With generous support from the Alison Ossip Fund, the "Zac" card was launched. Zac Ossip is the grandson of NTSAD-DV Co-President Mike Ossip. As our readers know, Mike and his wife Karen had a beautiful daughter Alison who passed away from Canavan. While the front of the card shares an image of Zac, the back speaks to the heart of our mission.

"This card has been designed in celebration of more than 50 years of prevention of Tay-Sachs and Canavan Diseases; in honor of all those whose untiring effort and vision brought the Tay-Sachs Prevention Program to our community; and in memory of Alison Ossip, a child born with Canavan disease, whose memory remains an inspiration for all of us to strive for a better world – one healthy baby at a time."

On the cover is Alison's nephew Zac, who was born healthy because his parents had access to genetic testing through NTSAD-DV."

When you wish to make a charitable donation to honor a special event (e.g. birthday, graduation, wedding, bar/bat mitzvah, etc.) or in memory of a loved one or friend, please consider donating to NTSAD-DV. ❄️

YOUNG LEADERSHIP COMMITTEE

 ur 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>