

# Tay-Sachs & Allied Diseases

## 2020



Imagine all the children free of  
Tay-Sachs and Allied Diseases.

Start this new year with  
the test for life - Be Tested!

*This Calendar-Journal is dedicated to*

# **Dr. Samuel and Ruth Dunkell**

*Founders of NTSAD*

*Pioneering research to find treatments  
and cures, leading the community towards  
progress, hope and innovations*

**Happy 80th Birthday**

**Gus Sirot**

**We Love You!**

**National Tay-Sachs & Allied Diseases Association**

**thanks**

**Sue and Gus Sirot**

**for their dedication to the success of this calendar  
and for their annual contribution  
which pays for the printing**

# Historical Perspective on Tay-Sachs & Allied Diseases

## – NTSAD Leading the Fight for more than 60 Years –

- 1881 - Dr. Warren Tay, British ophthalmologist, describes first recorded case of Tay-Sachs disease.
- 1887 - American neurologist, Dr. Bernard Sachs, describes neurology of Tay-Sachs disease.
- 1942 - Chemistry professor Ernst Klenk of Cologne describes accumulation of gangliosides in brain tissues of affected children.
- 1957 - Founding of National Tay-Sachs & Allied Diseases Association, Inc. (NTSAD) by parents committed to the eradication of Tay-Sachs disease and 40 allied disorders; Ruth Dunkell, President. Scientific Advisory Committee formed by Samuel Dunkell, MD.
- 1958 - Samuel Dunkell, MD and his wife, Ruth proposed a research ward at Jewish Chronic Disease Hospital (now Kingsbrook Jewish Medical Center) in Brooklyn, NY. Dr. Dunkell proposed international symposia for research scientists and organized the first genetic counseling program, with Frances Berkwits, MS, as the genetic counselor. First International Symposium, funded by NTSAD and chaired by Dr. Bruno Volk, exclusively devoted to cause and treatment of Tay-Sachs and Sphingolipidoses.
- 1962 - Lars Svennerholm, Biochemistry Professor at Gothenberg, identifies and characterizes ganglioside GM2 - a possible explanation for Tay-Sachs disease.
- 1965 - Dr. Roscoe Brady of NIH identified the chemical defect in Gaucher's and Niemann-Pick diseases.
- 1969 - Drs. Shintaro Okada and John O'Brien at University of California pinpoint absence of Hexosaminidase A in Tay-Sachs children, lower than normal level in parent carriers.
- 1970 - Drs. Larry Schneck, Bruno Volk and Carlo Valenti at Kingsbrook, Brooklyn, N.Y. use amniocentesis to diagnose Tay-Sachs disease in utero.
- 1971 - Funded in part by NTSAD, Michael Kaback, MD conducted mass community screenings to identify Tay-Sachs carriers which took place in Baltimore and New York. Tay-Sachs disease was established as the first genetic disease meeting criteria necessary for public prevention programs.
- Michael Kaback, MD and Robert S. Zieger, MD - with the help of the National Capital Tay-Sachs Association, conducted the first community-based screening in Bethesda, Maryland to identify carriers of the gene for Tay-Sachs disease. Similar testing followed in the Baltimore and Greater Washington, DC area. Within two years, similar efforts were initiated in Toronto, Montreal, Philadelphia, Milwaukee, Miami, Minneapolis, Cleveland, Boston and New York. Tay-Sachs disease was established as the first genetic disease meeting criteria necessary for public prevention.
- 1973 - Michael Kaback, MD created the California Tay-Sachs Prevention Program and International Quality Control Reference Standard and Data Collection Program for Tay-Sachs disease carrier testing.
- 1975 - First International Conference on Tay-Sachs Disease: Screening and Prevention held in Palm Springs, CA, funded by NTSAD and the March of Dimes. Proceedings were published in a book "Tay-Sachs Disease: Screening & Prevention", edited by Dr. Michael M. Kaback, Dr. John O'Brien, and Dr. David L. Rimoin.
- 1976 - "First International Tay-Sachs Carrier Screening Workshop" Toronto, Canada, organized by J. A. Lowden, MD, PhD and Michael M. Kaback, MD, funded by NTSAD and the National Institutes of Health.
- 1978 - NTSAD First Annual Family Conference held in Philadelphia, PA.
- 1981 - NTSAD sponsors workshop session. "Tay-Sachs Disease: Progress in Testing and New Approaches" at the 32nd Annual Meeting of the American Robert J. Desnick, PhD, MD.

- 1983 - Thomas Jefferson University School of Medicine, Philadelphia, PA, Michael Reese Hospital, Chicago, IL and the Mount Sinai School of Medicine, New York, NY use chorionic villi sampled from the placenta, in utero to diagnose fetal Tay-Sachs disease in the first trimester of pregnancy.
- 1987 - Centennial of Dr. Bernard Sachs' description of first American patients with Tay-Sachs disease observed by an International Scientific Conference in New York, published as Volume 44 of "Advances in Genetics -Tay-Sachs Disease", edited by Dr. Robert J. Desnick and Dr. Michael M. Kaback.
- 1992 - NTSAD sponsors first-ever conference for individuals and families affected by Late Onset Tay-Sachs disease: a rare form of Tay-Sachs disease affecting adults.
- 1993 - Dor Yeshorim, a unique Tay-Sachs carrier screening program serving the Orthodox Jewish community, observes one decade of service; more than 40,000 people tested.
- 1995 - The American College of Obstetrics and Gynecology (ACOG) issued its first opinion statement on Tay-Sachs disease screening followed by its opinion statement three years later on screening for Canavan disease.
- 2002 - NTSAD launches the Research Initiative which disburses grants for cutting-edge research projects that can lead to treatment and cure for lysosomal or leukodystrophy diseases impacting the central nervous system.
- 2003 - NTSAD involved in lawsuit about the Canavan disease gene patent. The settlement ensures royalty free use of the gene in research to treat Canavan disease.
- 2005 - NTSAD partnered with the MPS Society to co-found the Lysosomal Storage Disease Research Consortium. With the NIH, it offered a joint grant program to support research addressing the neurological aspects of lysosomal storage disorders.
- 2007 - More than 2 million people have been screened and thousands of healthy babies have been born as a result of Tay-Sachs carrier screening.  
NTSAD awards grants to the Tay-Sachs Gene Therapy Consortium Research Project (TSGT) for animal research to treat Tay-Sachs and Sandhoff diseases.
- 2009 - National Institutes of Health awards \$3.6 million four year grant to the Tay-Sachs Gene Therapy Consortium Research Project.  
Discovery of naturally occurring Tay-Sachs disease in rare Jacob Sheep. Carrier sheep donated to NTSAD by sheep farmers Fred & Joan Horak for inclusion in the Tay-Sachs Gene Therapy Research Project.  
NTSAD hosted a CME Conference with Brigham & Women's Hospital, "Diagnosis, Management & Treatment of Progressive Neurological Disease from Infancy to Adult using Tay-Sachs Disease as a Model."
- 2011 - The First Annual Day of Hope was held. Over 100 families and their communities have now held events each September to raise funds for research.
- 2013 - The FDA grants Orphan Drug Designation for Tay-Sachs & Sandhoff gene therapy with NTSAD as the sponsor.  
"Parenting a Child with a Life Limiting Illness" video and guide were made to lessen the feelings of isolation that newly diagnosed families experience.
- 2014 - NTSAD Corporate Advisory Council formed. The CAC, through its collective industry experience, serves as a resource to NTSAD to advance research to patients.
- 2016 - First GM-1 Research Meeting held.
- 2018 - NTSAD 40th Annual Family Conference held in Jacksonville, Florida.
- 2019 - NTSAD continues to fund promising innovative research, through the NTSAD Research Initiative, for neurodegenerative diseases that affect the central nervous system.  
- First clinical trial opens for GM1 Gangliosidosis Type II at NIH  
- First clinical trial opens for adult onset GM2 Gangliosidosis at three sites within the US  
- NTSAD officially launched a webinar series on its website to bring the experts to the community to discuss topics ranging from research advances to issues that impact the family.
- 2020 – Clinical trials to be launched

# National Tay-Sachs & Allied Diseases Association

## *Making a Difference*

In 1957 a group of parents came together and formed NTSAD. Thanks to their passion to find answers, we continue to lead the fight to treat and cure Tay-Sachs, Canavan, GM1, Sandhoff and related genetic diseases. We are committed to helping families and individuals coping with these diseases to lead fuller lives in the midst of their day-to-day struggles. These neurodegenerative diseases are fatal in children in their infantile and juvenile forms, and progressively debilitating in adults in their adult-onset form.

### **FAMILY SERVICES**

NTSAD supports families with resources that can help from the day of diagnosis through day-to-day care, tough end-of-life decisions and beyond. With an incredible network of families ready to offer advice and share their experiences to an unforgettable annual family conference, NTSAD is there for families and individuals coping with these diseases.



### **ANNUAL FAMILY CONFERENCE**

The NTSAD Annual Family Conference is the cornerstone of what we provide families and individuals coping with these diseases. This four-day long conference gives families the chance to come together for support, and provides tips and tools to help care for their loved ones. It inevitably recharges them to get them through the year until the next conference.



### **LENDING A HELPING HAND**

Through the inspiring compassion of donors, NTSAD is able to offer its families the opportunity to apply for grants and scholarships to help families affected by rare genetic diseases. Whether helping with care-related expenses or enabling healthy siblings to pursue their educational goals, NTSAD grants and scholarships have been established to help families and individuals lead fuller lives.



### **PARENTING A CHILD WITH LIFE-LIMITING ILLNESS**

NTSAD has produced an innovative film and resource guide to support families, and provide healthcare professionals a deeper understanding of the family perspective. It is now available through [NTSAD.org](http://NTSAD.org).



## AWARENESS

We are all carriers of recessive genetic diseases but standard healthcare practices do not screen everyone for all diseases because the technology does not yet exist to accurately and cost effectively screen everyone. Your doctor and/or genetic counselor can help determine, based on your family history and heritage, which diseases you are at risk to carry.

It is highly recommended to pursue carrier screening *before* pregnancy because the hormones can reduce the test accuracy and screening while pregnant limits reproductive options.



## WHAT IS CARRIER SCREENING?

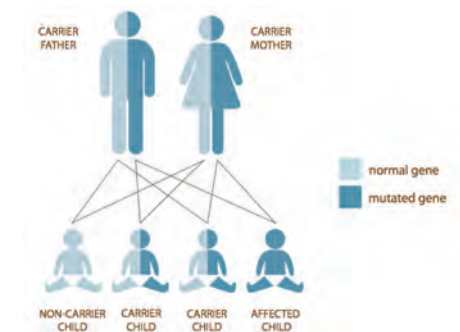
Our genes come in pairs, one from each parent. A carrier of a recessive disease is an individual who has a mutation in one copy of a particular gene that causes the gene not to function properly. Since carriers have a second working copy of the gene, they generally do not develop any symptoms of the disease, but they can pass on the gene with a mutation to their children.

### Recessive Genetic Diseases

Autosomal recessive diseases are those that develop when both parents are carriers of the same condition and they both pass on their mutations to their child. Many diseases that are common in the Jewish population are inherited in an autosomal recessive pattern.

### Special Circumstances

While carrier screening generally identifies carriers of recessive diseases, some individuals may discover, during the course of carrier screening, that they themselves have two mutations and are at-risk for one of the less severe or late-onset diseases on the testing panel. It is important that results be discussed with a genetic counselor.



## PREVENTION

### Can genetic diseases be prevented?

Until a cure is found education, awareness and prevention are the only ways to avoid heartache and loss. EVERYONE, regardless of heritage, should speak with their doctor about genetic counseling and their risk before getting pregnant.

### How can I be screened for genetic diseases?

Your primary doctor or OB/GYN may order the tests but *it is strongly recommended* to see a genetics professional to discuss the most current information available. Depending on your health insurance, you may need a referral or you can go directly to a genetic counselor in your network to discuss screening.

### Published opinions and resources:

ACOG Committee Opinion - American College of Obstetricians and Gynecologists - <http://www.acog.org>

ACMG - American College of Medical Genetics - <https://www.acmg.net>

NTSAD Position Statement (46 KB) - Tay-Sachs Carrier Screening - <https://www.ntsad.org>

NTSAD Carrier Screening - Public Service Announcement - Video published on YouTube - <https://www.youtube.com/user/NTSAD>

NSGC - National Society of Genetic Counselors - <https://www.nsgc.org>

JGDC - Jewish Genetic Diseases Consortium - <https://www.jewishgeneticdiseases.org>

# Carrier Screening For Tay-Sachs & Allied Diseases

Anyone can be a carrier, so it is important to know your risks. 1 in 250 of the general population is a carrier of the Tay-Sachs gene. 1 in 27 of those of Ashkenazi Jewish, French-Canadian or Cajun descent, and 1 in 50 to 1 in 190 who are Irish-American are at a higher risk for being carriers. We always recommend speaking with a genetic counselor to help you navigate these waters. Historically, screening guidelines are based on ancestry and personal history. However, evolving technologies are gradually moving toward expanded genetic carrier screening, which can be offered regardless of race or ethnicity. Enzyme testing for Tay-Sachs is considered the gold standard.

It is highly recommended to pursue carrier screening *before* pregnancy because the hormones can reduce the test accuracy and screening while pregnant limits reproductive options.

There two types of carrier screening tests: DNA and enzyme (biochemical). Tay-Sachs and Sandhoff carrier screening can be performed using DNA and enzyme testing. *A combination of both DNA and enzyme are recommended for the most accurate results.*

## DNA (Molecular) Screening

DNA carrier screening detects specific known mutations that are "looked" for in the test. A negative DNA carrier result reduces the risk that you are a carrier, but does not eliminate your chances of being a carrier because of the possibility you carry an unknown mutation or one not "looked" for in the test.

## Enzyme (Biochemical) Screening

Biochemical testing is also referred to as an enzyme assay. It detects the level of enzyme in the blood. Enzyme assays can be done using serum or leukocytes isolated from blood.

Serum testing is the standard test but leukocyte testing is recommended when the person being screened is pregnant, on birth control pills or taking any medications that affect hormones; all of these situations can potentially interfere with the accuracy of the serum test.

NOTE: Carrier screening for all of the Jewish genetic diseases by DNA analysis can be done using blood or saliva. For Tay-Sachs disease screening, enzyme analysis using blood is optional, as new research has established that comprehensive DNA sequencing of the Tay-Sachs gene is just as accurate as enzyme analysis. Link to NTSAD Position Statement Update Nov.2019:  
[https://www.jewishgeneticdiseases.org/wp-content/uploads/NTSAD-Position-Statement-TS-Carrier-Screening.2019.11.13.FINAL\\_.pdf](https://www.jewishgeneticdiseases.org/wp-content/uploads/NTSAD-Position-Statement-TS-Carrier-Screening.2019.11.13.FINAL_.pdf)

**NEW CARRIER TESTS MAY BECOME AVAILABLE**  
**CHECK WITH YOUR PHYSICIAN OR GENETIC COUNSELOR FOR THE MOST UP-TO-DATE INFORMATION**

Visit [www.ntsad.org](http://www.ntsad.org) for information about the diseases, where you can be screened, and for additional resources.

**NTSAD 2001 Beacon Street #204 - Boston, MA 02135 - (800) 906-8723 - Email: [info@ntsad.org](mailto:info@ntsad.org)**



This Annual “Day of Hope” Event to Fund Research brings NTSAD families and their communities together for one day every September. From coast to coast, hope is shared through motorcycle rides, scavenger hunts, to hike, custom t-shirts and community gatherings.

It is imperative to keep hope alive by funding important research work that could potentially lead to an effective treatment for these rare diseases. Funds raised on these Days of Hope go directly to funding NTSAD’s Research Initiative.

Through the efforts of families and friends, over \$60,000 was raised during the 2019 Day of Hope. This annual event is a time for our rare and mighty community to come together to make a difference and show that there is always hope.

All proceeds go to the research that NTSAD funds including the work leading to clinical trials. We are closer than ever and together we can be sure to be ready!

**Over \$500,000 has been raised since our First Annual Day of Hope on September 18, 2011**

**Mark Your Calendar for the Tenth Annual Day of Hope September 2020!**

## Annual Family Conference

The NTSAD Annual Family Conference is the cornerstone of our exceptional Family Support Services. It provides parents, grandparents, affected children, healthy siblings, affected adults and their families the unique opportunity to:



- Gather with people that truly understand;
- Learn about latest research and symptom management approaches;
- Discuss other important topics.



### CONFERENCE GOALS

The primary goals of the conference are to empower, support and connect families coping with Tay-Sachs, Canavan, GM-1 or Sandhoff. These diseases are always fatal in children and extremely debilitating in adults. The Annual Family Conference directly achieves our mission to support affected families and individuals in leading fuller lives.

### HELPING HANDS PROGRAMS

Another important goal of the conference is to ensure every family is able to attend the conference especially those who cannot afford it. This goal is achieved through the Helping Hand Grant Program. Each year approximately \$40K is raised through donations and grants. Every dollar raised is awarded directly to families in-need to help cover the expense of attending. Scholarships range in size from covering one night at the hotel to covering hotel, registration and travel expenses for the entire family. Each grant application is considered on an individual basis and priority is given to newly diagnosed families, families that have not attended before, and families that have lost their loved one in the past year.

# 2019 Annual Family Conference

NTSAD 41st Annual Family Conference  
Thursday, April 11 to  
Sunday, April 14, 2019

Raleigh Marriott Crabtree Valley  
4500 Marriott Dr.  
Raleigh, NC 27612



It was a weekend filled to the rim with support, togetherness, tears, laughter, and hope.

From the sessions on the latest research, to those offered on support, education, and advocacy, our families came together to learn, share, and spend their time with others who are walking a similar path. Whether in sessions, during meals, enjoying the Family Lounge, or just out by the fire, the sense of community is always an amazing sight; attached is a snapshot of a few of our families from this year.

Highlights of the 2019 NTSAD Annual Family Conference include:

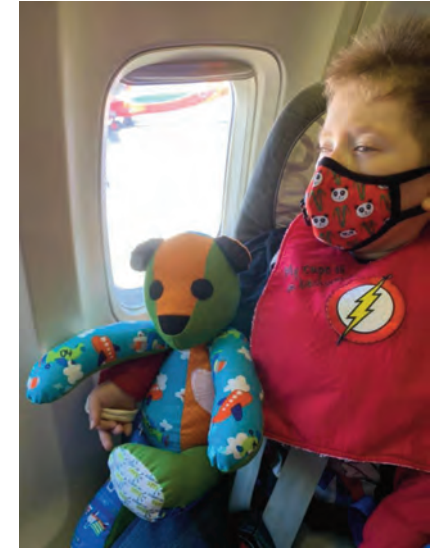
- Over 300 people attended
- Almost 100 families were able to join us
- We offered 33 conference sessions
- 55 families were allocated a Helping Hand Grant to enable their attendance
- Free photo shoots for 50 families, courtesy of Soulumination
- Camp Snuggle and Camp Active were again one-of-a-kind experiences for our affected children
- The Quiet Reflection and Commemoration Ceremonies honored our loved ones in very personal and meaningful ways
- The healthy sibling Youth Group ventured out to Adventure Landing and the North Carolina Museum of Science and Natural History

Many people came together to make this weekend possible and we thank each and every one of them including our generous sponsors of the conference and the Helping Hand Grant Fund.

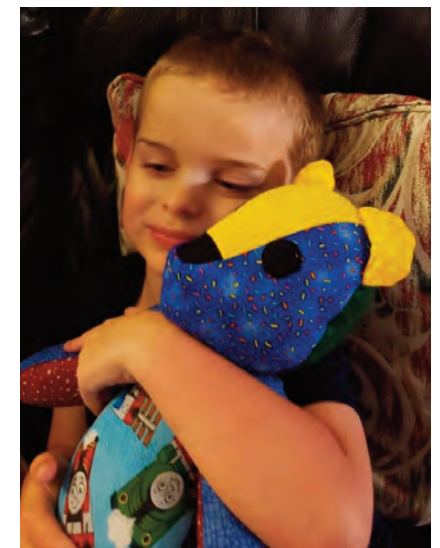
# The Story of the Rare Bears: A Compassionate Touch



NTSAD parent and conference committee member, Noreen Vongrej, connected with the Rare Bear program to provide each of the children attending the conference with a very special bear. Enjoy the pictures of our children with their already loved rare bears.



The Rare Bear program is a community driven initiative and is supported by the ever-growing RARE Bear Army of volunteers that help make one of a kind bears for special one of a kind kids. Gifted RARE bears will have a serial number specifically made for a child in our program.



# 2019 RESEARCH UPDATE



## GM 1 GENE THERAPY

It was big news when it was shared that the first patient was treated with the first ever gene therapy for GM1 Gangliosidosis. It warranted a tea party with the team at NIH led by NTSAD's longtime Scientific Advisory Committee member (and former chair), Cynthia Tifft, MD, PhD.



## GM 2 GENE THERAPY

Axovant Gene Therapies has kept NTSAD and Cure Tay-Sachs Foundation (CTSF) informed as they continue to work toward filing the Investigational New Drug application (IND) - an important and necessary step toward opening a GM2 clinical trial. They invited NTSAD, CTSF and Cure GM1 to a town hall meeting in July to speak with the Axovant team to keep them connected to the family community.

## CANAVAN GENE THERAPY

On Wednesday, the 28th of August, Canavan Foundation, Canavan Research Illinois and NTSAD met with Aspa Therapeutics to discuss updates on their gene therapy program. Aspa reported they have been in discussions with FDA and that they remain on track for a gene therapy treatment trial to be open for enrollment in 2020. Agreement has been reached on the preclinical requirements, and manufacturing is on schedule.

## RETROTYPE

At the May 2019 American Academy of Neurology Scientific Sessions, Dr. Robert Molinari presented Retrotope's poster presentation entitled: "RT001 to Treat Neurodegeneration--Case Study: Improvement in a Single Patient with Late Onset Tay-Sachs Disease (LOTS). RT001 is a di-deuterated isotope of linoleic acid (D-LA) that is readily incorporated into membranes and prevents oxidative damage.

## SITE AT MAYO CLINIC OPENED FOR INTRABIO IB1001 CLINICAL TRIAL

A second site at the Mayo Clinic in Rochester, MN, has opened for the IntraBio clinical trial for N-Acetyl-L-Leucine for GM2 Gangliosidosis (Tay-Sachs and Sandhoff Disease).

NTSAD's first webinar featured a presentation by IntraBio and a researcher who worked on the compound, N-Acetyl-L-Leucine.

## ***BREAKING NEWS***

IntraBio announced their clinical trial for N-Acetyl-L-Leucine for GM2 Gangliosidosis has opened for recruitment in the United Kingdom. Sites will be at the Royal Manchester Children's Hospital and the Salford Royal NHS Foundation Trust.

# WEBINARS & CLINICAL TRIALS

## **NTSAD Launches Webinar Series**

NTSAD officially has launched a webinar series to bring the experts to the community to discuss topics ranging from research advances to issues that impact the family. More information at [www.ntsad.org](http://www.ntsad.org).

## **Clinical Trials Q & A**

The gene therapy programs for GM1 Gangliosidosis and GM2 Tay-Sachs and Sandhoff have been licensed, from University of Massachusetts Medical School (UMMS), by Axovant Sciences, Inc., and the gene therapy program for Canavan disease, also from UMMS, has been licensed by Aspa Therapeutics, a BridgeBio company.

## **What is a clinical trial?**

In a clinical trial, participants receive specific interventions according to a research plan or protocol created by the investigators. The investigators try to determine the safety and efficacy of the intervention by measuring certain outcomes in the participants. These interventions (which include therapies) can be done to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes. (<https://www.clinicaltrials.gov/ct2/about-studies/learn>)

## **How do we know if a therapy is working? What are endpoints?**

Endpoints are the outcomes evaluated in a clinical study. These are determined before the study begins, often by studying the progression of the disease in patients. For example, one endpoint for a child with infantile Tay-Sachs could be the milestone of sitting up or crawling. If a child in a trial is treated and meets that milestone with success, then it shows the therapy may be working. This is why participating in the PIN and natural history studies is important and critical.

## **Why are natural history studies and the Patient Insights Networks (PIN) important to clinical trials?**

Natural history studies document the progression of the disease. The more data there is about the progression of the disease from medical data and patient experience, the clearer the endpoints are to determine whether a therapy is working or not. The PIN is a format to help families contribute this information. Therefore, participating in the PIN and natural history studies is important and critical.

## NATURAL HISTORY STUDIES TO INFORM CLINICAL TRIALS

On Wednesday, the 28th of August, Canavan Foundation, Canavan Research Illinois and NTSAD met with Aspa Therapeutics to discuss updates on their gene therapy program. Aspa reported they have been in discussions with FDA and that they remain on track for a gene therapy treatment trial to be open for enrollment in 2020. Agreement has been reached on the preclinical requirements, and manufacturing is on schedule.

- **Passage Bio** announced their launch of a GM1 Gangliosidosis natural history study for the infantile and juvenile forms of the disease.
- **Aspa Therapeutics** launched CAN-Inform to begin the process of building a comprehensive natural history study for Canavan disease. To enroll in the natural history study, CAN-Inform, a family will need their child's medical record. Aspa is providing a free service to families to collect the medical record. 15 families have signed up for record retrieval so far. For those families who are able to travel to the clinical site, Aspa is providing travel support. It is important for families to sign up soon as it can take some time to obtain all records. Families who have lost a loved one are also encouraged to participate.

## JSCREEN AND NEXT GENERATION SEQUENCING (NGS)

NTSAD has partnered with JScreen for several years and co-funded the work leading to this newly published study, that has been highlighted in the press.

"NTSAD was a pioneer in the prevention of Tay-Sachs in the Ashkenazi Jewish community through carrier screening programs and education. 'While the utilization of Tay-Sachs carrier screening has been impactful and regarded by many as a model public health genetic screening initiative, affected babies are still being born to Jewish, interfaith and non-Jewish couples who are not offered testing,' said Staci Kallish, DO, NTSAD Board President."

*Co-funded with our affiliates the Cameron & Hayden Lord Foundation and Mathew Forbes Romer Foundation, and the New York Area and Evan Lee Ungerleider Funds of NTSAD.*



## **Tay-Sachs in the 21st Century**

**Albert Einstein College of Medicine | Wednesday, December 4th**



### **7th Annual Isabelle Rapin Conference on Communication Disorders: Tay-Sachs Disease in the 21st Century**

NTSAD Scientific Advisory Committee (SAC) members, Dr. Ed Kolodny (right) and Dr. Cynthia Tiff, spoke along with other Tay-Sachs experts about gene therapy, biomarkers, gene editing, natural history studies, and other topics. Dr. Steve Walkley, an NTSAD SAC member, was also a speaker and the organizer of this meeting. NTSAD family members, Tim Lord, Alexis and Katie Buryk spoke about their personal experiences with Tay-Sachs.

The conference was recorded and live streamed with a grant from NTSAD.

A video of the conference will soon be available on the NTSAD website.

## **GM1 Newborn Screening Effort: Call to Action**

The Cure GM1 Foundation is working with researchers at the University of Washington on finding the necessary biomarkers to help with a future newborn screening assay when a treatment is approved for GM1 Gangliosidosis. NTSAD wants to help spread the word to GM1 families to ask for your help.



## **GM1 Biomarker Study Published**

The study "The skeletal phenotype of intermediate GM1 gangliosidosis: Clinical, radiographic and densitometric features, and implications for clinical monitoring and intervention" was recently published with Dr. Cynthia Tiff as one of the authors of this study.

The team "demonstrated that all late infantile patients have some degree of odontoid hypoplasia suggesting the need for cervical spine evaluation particularly prior to anesthesia, whereas juvenile patients had variable skeletal involvement often affecting activities of daily living. Type 2 GM1 gangliosidosis patients have skeletal abnormalities that are both an early indication of their diagnosis, and require monitoring and management to ensure the highest possible quality of life."

## Axovant Receives Orphan Drug Designation for the Treatment of GM1 Gangliosidosis

“We are pleased to receive orphan drug designation for our GM1 gangliosidosis program as we advance the development of this potentially transformative, one-time gene therapy,” said Dr. Gavin Corcoran, chief R&D officer at Axovant. “There are currently no FDA approved therapies for patients with GM1 gangliosidosis, and the orphan drug designation underscores the significant unmet medical need. We look forward to increased interaction with the FDA to facilitate the development of AXO-AAV-GM1 and address this unmet need.”

## CRISPR: Highlight from Q&A with David Liu, PhD

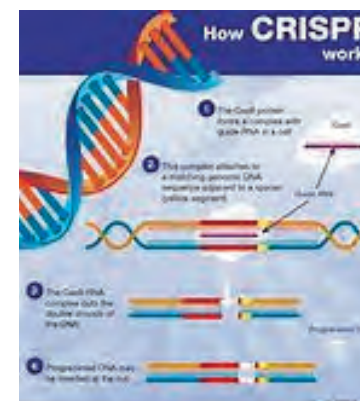
The news recently broke about a scientist, David Liu, PhD, in Cambridge, MA who successfully "corrected the mutations that cause sickle cell anemia and Tay-Sachs disease" using genome editing. Shortly thereafter there was a Q&A with David Liu and we want to highlight a question an NTSAD grandmother posed to him below.

Note: We abbreviated the question for the sake of space.

My granddaughter was born with Tay-Sachs disease and thanks to palliative medicine I would say she is doing well given her age and alternatives. I am sure CRISPR-Cas9 is a very promising therapy. Is it possible for her to participate in a clinical trial for this treatment? How?

"While we showed in our paper that prime editing is capable of making the precise four-base deletion that corrects the most common cause of Tay-Sachs disease, demonstrating that an editing agent is able to fix a causative mutation is only one of many components towards developing a potential treatment that is suitable for a clinical trial.

For example, establishing that the agent can be delivered in an animal model in a manner that reaches the target tissue, understanding to the extent possible any potential side-effects and how to best manage them, optimizing editing efficiency in the target tissue in animals, developing practical ways to manufacture the candidate therapeutic at the high quality and consistency level required for use in humans, and several other key requirements are also crucial to developing new therapies. Addressing these challenges takes years, but is important to maximizing the likelihood that patients benefit from a new therapy."



### *Note from NTSAD*

Investments and research in gene editing is growing rapidly and attracting much attention. We are following all the developments and gaining an understanding more about its potential for our group of diseases - Canavan, GM1, Sandhoff and Tay-Sachs diseases - and what role NTSAD can play in this growing field of research.

# GRANT UPDATES FROM NTSAD-FUNDED RESEARCH PROJECTS

When NTSAD funds any research project, it is a requirement to receive timely progress reports throughout the two-year grant. The following are short summaries from three researchers on their funded projects.

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**Alessandra d'Azzo, PhD** - Department of Genetics, St. Jude Children's Research Hospital

## **Role of Plasma membrane-ER Contact Sites in GM1-mediated Neuronal Cell Death**

GM1-gangliosidosis, caused by deficiency of lysosomal  $\beta$ -Galactosidase ( $\beta$ -Gal), is a catastrophic neurodegenerative lysosomal disease in children and adolescents. With the funding provided by the NTSAD we have initiated a series of studies aimed to elucidate how the primary substrate of  $\beta$ -Gal, GM1 ganglioside, a resident glycosphingolipid of neuronal plasma membranes, affects molecular pathways at specific membrane contact sites formed between the endoplasmic reticulum (ER) membranes and the plasma membrane of neurons, named PAMs. We believe that these novel studies will set the stage for a better understanding of the neuropathological implications of GM1 accumulation at specific membrane contact sites, like the PAMs, that function as signaling hubs and play a role in the control of neuronal membrane homeostasis. Ultimately, these studies may also reveal novel or alternative therapeutic avenues for patients affected by GM1 gangliosidosis.

**Heather Gray-Edwards, PhD, DVM** - Department of Radiology, UMass Medical School

## **Minimally invasive delivery of AAV gene therapy in the Tay-Sachs sheep**

The goal is to determine the efficacy of adeno associated viral (AAV) gene therapy after cerebrospinal fluid (CSF) delivery in Tay-Sachs disease (TSD) sheep. The Tay-Sachs sheep treated by CSF AAV delivery remain alive, therefore the results have not yet been analyzed. However, due to the extended survival, we are planning on moving this therapy forward in the treatment of late onset Tay-Sachs and Sandhoff disease (LOTS/LOS). TSD sheep treated by AAV gene therapy were treated by a combination of methods because the TSD sheep develop advanced disease globally throughout the brain. This is in contrast to LOTS/LOS patients, where the parts of the brain affected are most prominently the cerebellum and spinal cord. For this reason, we believe that the therapeutic strategy applied to the TSD sheep is likely more invasive than what would be required for LOTS/LOS patients. We believe that this catheter-based delivery is applicable for AAV gene therapy for LOTS/LOS. A manuscript summarizing the catheter delivery method is currently under peer review.

**Xuntian Jiang, PhD** - Metabolomics Facility, Washington University in St. Louis

## **Oligosaccharide Biomarkers for Disease Progression and AAV Therapeutic Efficacy in GM1 Gangliosidosis**

A major challenge for developing treatments for GM1 gangliosidosis (GM1) disease is difficulty in evaluation of efficacy. This is complicated by limited patient numbers, and heterogeneity in age, severity, and stage of disease progression. Biomarkers that reflect disease status could provide a valuable surrogate endpoint for assessment of treatment effect and reasonably predict clinical benefit. The goal of this project is to evaluate this marker as a surrogate outcome measure of treatment for GM1. This project will provide a much-needed tool for assessing GM1 disease severity and therapeutic efficacy. After synthesis enough H3N2b and d6-H3N2b, we will develop FDA-compliant clinical assays for the oligosaccharide biomarker, determine the relationship between oligosaccharide biomarker levels and disease severity using biospecimens and clinical data collected in the NIH natural history study, and evaluate the response of oligosaccharide biomarker to AAV gene therapy through quantification of the biomarker in urine, plasma, and CSF collected in Phase 1/2 trial.

*In Loving Memory Of*

# Stanley Michelman

*We give thanks for your commitment and dedication to the  
elimination of the tragedy of genetic diseases.*

*We miss you and will continue the  
quest for treatment and cure!*

**In Honor of the Volunteers of the New York Chapter of the  
National Tay-Sachs & Allied Diseases Association**

*Your dedication and hard work are truly appreciated*

**Love,  
Ruby and Rosa**

**In Honor of our dear friends**

**Marion and Charlie**

**Love,  
Ruby and Rosa**



## **In Memory of Fran Berkwits** *with love and great admiration*

*Your extraordinary and tireless commitment in the effort to eradicate the tragedy of genetic diseases has made a difference.*

*Your efforts in raising awareness, community carrier screening and genetic counseling touched the lives of many, bringing hope and promise of healthy families.*

*Your wisdom and guidance kept us on a steady course to prevention.*

*May each day bring us closer to finding a treatment and cure.*

*Thank you for all the years you served NTSAD.*

*We will continue the work you started - you showed us how.*

**We miss you.**

# Thank You To Our Supporters

*You give generously to support research and care for families.*

*On behalf of the NTSAD Board of Directors and staff,*

*we express our deep gratitude to you.*

*It is a rare gift that is appreciated by these families and so many others worldwide.*

# In Memory of Ruth and Samuel Dunkell

*Together they were at the heart of a heroic struggle against the unknown  
- Tay-Sachs and Related Diseases -*

*We thank them for their vision and tireless commitment  
in support of the early research that has brought us  
to the brink of a treatment and cure*

**NTSAD**  
**Board of Directors and Staff**  
**Families and Volunteers**

In Honor of all the Beautiful  
Sirot, Damato & Levenson Grandchildren

Sarah

Hadara

Daniel

Elijah

Jay

Jill

Julia

Tyler

Jonah

Sydney

Jacob

Kaitlin

Samantha

Brielle

Justin

Rebecca

Jeremiah



*In Loving Memory of*

## **Sylvia and Harry Silberfarb**

In appreciation for all their nurturing support, guidance and love.

They are greatly missed and will be remembered  
with the greatest of affection always!

With much love from their family,

**Barry and Carol Silberfarb**

**Daniel, Anna, Zoe and Jake Silberfarb**

**Sharon, Will, Brayden, Caleb & Vienna Greenhut**

*In Beloved Memory of*

***Barbara, Burt & Donna***

*and*

***All Our Loved Ones***

***In The Marcowitz, Salomon and Kahn Families***

*They have touched our lives with such love and joy that  
they are forever a living part of our everyday lives*

***Claire & Cliff***

To all our wonderful grandchildren  
who give us so much pleasure

*Nicole*

*Michael*

*Julie*

*Jake*

*and Harry who left us too soon*

All our love,  
Grandma Judy & Grandpa Gerry

*In loving memory of  
our dear friend*

**Steve Schwarz**

*We miss you!*

**Gus & Sue**

*In memory of*

# **The Pingers**

*Sarah & Alex Pinger*

*Lester Pinger*

*Beatrice Gecht*

*Sylvia Farber*

*Stella Zimmer*

*Miriam Finkel*

*In memory of*

**Anita Amerio**

*and*

**Jerry Sirot**

*Joyce Erwin*

*In Loving Memory of*

**Michael Alan Zeiger**

*and*

**Daniel Jacobson**

*Forces in their individual ways  
in fighting Tay-Sachs Disease*

*We Miss You Both!*

**The Zeiger & Jacobson Families**

*In Memory of Our Parents*

**Barbara & Burton Salomon**

*With Much Love,*

**Doug & Alan Salomon**

*In memory of  
our beloved brother*

**Mark Howard**

**1968-1971**

*Bruce & Linda Feingold*

*In loving memory of*

**Barbara & Burt  
Salomon**

*In memory of*

**Jerry Sirot**

*Beloved brother of Gus Sirot*

**Marion & Charlie Yanovsky**

*In loving memory of  
NTSAD Super Volunteers*

**Bea Gecht  
Sylvia Farber  
Sylvia Silberfarb  
Stella Zimmer  
Estelle Gordon  
Estelle Goldstein  
Miriam Finkel  
Sheila Wasserman  
Marcia Feinberg  
Estelle Krakaur**

# **In Loving Memory of Lawrence R. Shapiro MD**

*A giant of a man.*

*We are sad you left us so soon.*

*Thank you for all you did to help prevent genetic diseases.*

*It was an honor to work with you,  
providing carrier screening over many decades.*

*You are missed.*

**Marion Yanovsky**

***Leading the fight for a cure***

**Judy & Corey Lev**

*In loving memory of*  
**Helen Greenblatt**

*A wonderful friend*

Sue & Gus Sirot

*For Audrey*

*You will always be remembered*

*Much love,*

**Doug**

**December 2019**

1	2	3	4	5	6	7
8	9	10	11	12	13	14
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22	23	24	25	26	27	28
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**February 2020**

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23	24	25	26	27	28	29

# January 2020

**SUNDAY**

**MONDAY**

**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

<div style="border: 2px solid black; padding: 5px;"> <p style="text-align: center;"><u>In Memoriam</u></p> <p>Harry Silberfarb     January 3              Rose Weisfeld     January 5              Herbert Gordon     January 6              Samuel Eisenberg     January 7              Harold Feldman     January 12              Sylvia Silberfarb     January 17              Margo Isselbacher     January 17              Beatrice Gecht     January 28              Jane Eisenberg     January 29</p> </div>			<p>1</p> <p><b>NEW YEAR'S DAY</b></p>	<p>2</p>	<p>3</p> <p style="text-align: right;"> 4:21</p> <p style="text-align: right;"> Rona Devane</p>	<p>4</p>
<p>5</p>	<p>6</p> <p style="text-align: right;"> Emily Kate Gentile   Marissa Heringer   Rebecca Heringer</p>	<p>7</p> <p style="text-align: right;"> Rose Price Cooley</p>	<p>8</p> <p style="text-align: right;"> David Sirof</p>	<p>9</p> <p style="text-align: right;"> Noah Philip Devane</p>	<p>10</p> <p style="text-align: right;"> 4:28</p>	<p>11</p> <p style="text-align: right;"> Geoffrey Zack Wasserman   Andrew David Markinson</p>
<p>12</p> <p style="text-align: right;"> Sue &amp; Gus Sirof</p>	<p>13</p>	<p>14</p> <p style="text-align: right;"> Robyn Finkel Kohen</p>	<p>15</p>	<p>16</p>	<p>17</p> <p style="text-align: right;"> 4:36</p> <p style="text-align: right;"> Renée Hasman   Nolan Russell Wasserman</p>	<p>18</p>
<p>19</p>	<p>20</p> <p><b>MARTIN LUTHER KING, Jr              BIRTHDAY OBSERVED</b></p>	<p>21</p> <p style="text-align: right;"> Mia Levy</p>	<p>22</p> <p style="text-align: right;"> Charlie Levy</p>	<p>23</p>	<p>24</p> <p style="text-align: right;"> 4:44</p>	<p>25</p>
<p>26</p> <p style="text-align: right;"> Barbara &amp; Gary Feldman</p>	<p>27</p> <p style="text-align: right;"> Olivia Vairo</p>	<p>28</p>	<p>29</p>	<p>30</p>	<p>31</p> <p style="text-align: right;"> 4:53</p>	

*Thank you to our*  
***Board of Directors***  
***Staff & Volunteers***  
***Scientific Advisory Council***  
***Corporate Advisory Council***  
*for their dedication to the mission of NTSAD*

In loving memory of  
**Jerome Sirot**

Remembered and Loved Always

*Saul, Gloria, Sandy, Debbie, Jeff, Kaitlin, Samantha and Rebecca*

**January 2020**

		1	2	3	4
5	6	7	8	9	10
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18	19	20	21	22	23
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30	31				

**March 2020**

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22	23	24	25	26	27	28
29	30	31				

# February 2020

**SUNDAY**

**MONDAY**

**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

<div style="border: 1px solid black; padding: 5px; text-align: center;"> <p><i>In Memoriam</i></p> <p>Sydney Levy February 9              Charlotte Stark February 11              William Yanovsky February 15              Harrison Hoffman February 17              Burton Salomon February 22              Bernard Gecht February 24</p> </div>	<div style="border: 1px solid black; padding: 10px; display: inline-block;"> <p><b>Visit our website: www.ntsad.org</b></p> </div>					<p>1</p> <p><b>GROUNDHOG DAY</b></p>
<p>2</p>	<p>3</p> <p> Bernard Finkel</p>	<p>4</p> <p> Alyson Lifshitz</p>	<p>5</p>	<p>6</p>	<p>7</p> <p> 5:02</p>	<p>8</p>
<p>9</p> <p> Nicole Mansour Dzitire</p>	<p>10</p>	<p>11</p> <p> Brayden Harris Greenhut   Binyamin Naftalowitz</p>	<p>12</p> <p> Bobby Handwerker   Tzvi Naftalowitz   Caroline Zamel</p>	<p>13</p>	<p>14</p> <p> 5:10</p> <p> Bryan Zachery Roden</p> <p><b>VALENTINE'S DAY</b></p>	<p>15</p>
<p>16</p>	<p>17</p> <p> Dave &amp; Esmeralda Siroc</p> <p><b>PRESIDENT'S DAY</b></p>	<p>18</p> <p> Anaelle Bedziner</p>	<p>19</p>	<p>20</p>	<p>21</p> <p> 5:19</p> <p> Reese Goldstein</p>	<p>22</p> <p> Bryan Markinson</p>
<p>23</p> <p> Steven Yanovsky</p>	<p>24</p> <p> Sheila Cohen</p>	<p>25</p>	<p>26</p> <p> Adam Davis</p>	<p>27</p>	<p>28</p> <p> 5:27</p>	<p>29</p>

# **The Mathew Forbes Romer Foundation**

salutes

# **NTSAD**

*as its partner in the fight against Children's Genetic Diseases.*

*We cherish the memories of Mathew,  
who lost his fight to Tay-Sachs in March 2003.*

In Honor of

# **Marion & Charlie Yanovsky**

We are the luckiest children and grandchildren.

You are the best!

We love you,

Susan, Alan, Jason & Bryan



*In Loving Memory of*  
**Harriet Lurie**

**Love and miss you, Emma**

*The Zimmermans are thankful for  
the amazing friends we've met through this  
terrible journey of Tay-Sachs*

**March 2020**

1	2	3	4	5	6	7
8	9	10	11	12	13	14
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**May 2020**

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17	18	19	20	21	22	23	
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31							

# April 2020

**SUNDAY**

**MONDAY**

**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

<p style="text-align: center;">— In Memoriam —</p> <table style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%;">Alex Lifshitz</td><td style="width: 50%;">April 12</td></tr> <tr><td>Alan Thaler</td><td>April 16</td></tr> <tr><td>Albert Eisenberg</td><td>April 21</td></tr> <tr><td>Barbara Salomon</td><td>April 24</td></tr> <tr><td>Elaine Verona</td><td>April 29</td></tr> </table>		Alex Lifshitz	April 12	Alan Thaler	April 16	Albert Eisenberg	April 21	Barbara Salomon	April 24	Elaine Verona	April 29	1	2	3	4
Alex Lifshitz	April 12														
Alan Thaler	April 16														
Albert Eisenberg	April 21														
Barbara Salomon	April 24														
Elaine Verona	April 29														
		APRIL FOOL'S DAY	Lee Finkel	7:08											
5	6	7	8	9	10	11									
Roberta Meyers David Goldstein <b>PALM SUNDAY</b>	Hadara Abdul-Ghani		1ST SEDER EREV PASSOVER	2ND SEDER PASSOVER	7:16  GOOD FRIDAY PASSOVER	Chaim Thaler  PASSOVER									
12	13	14	15	16	17	18									
EASTER PASSOVER	PASSOVER	PASSOVER	TAX DAY PASSOVER	Gregory Hasman  PASSOVER	7:23  Hayden Skyler Roimisher Yocheved Thaler										
19	20	21	22	23	24	25									
Ross Silberfarb	Ethan Cantor		Hal Lifshitz  EARTH DAY		7:31  ARBOR DAY	Susan & Alan Roden Amanda Megan Gecht									
26	27	28	29	30											
Easton Benbasset	Diane Toner Gentile		Taylor Ceil Benbasset												

With all our love to our wonderful  
and beautiful grandchildren

**HADARA**  
**ELIJAH**  
**JONAH**  
**and**  
**JEREMIAH**

*POPPI GUS & GRANDMA SUE*

*In memory of*

**Frances Berkwits**  
**Seymour Goldman**  
**Shirley Goldman**  
**Fred Wichler**

Keep up the good work  
**The Sacks Family**

With love to the beautiful  
& special children

Sami Elena Mansour

*Love,*  
*Esther & Alan Fleishman*

In honor of our grandchildren  
**Sydney, Ben, Esther & Anna**

Lynda & Mel Schriever

*In Loving Memory of*  
*Our Beloved Sister & Brother*

**Sharyn Snyderman**  
**Fred Schriever**

*Lynda & Mel Schriever & Family*

**April 2020**

			1	2	3	4
5	6	7	8	9	10	11
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**June 2020**

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21	22	23	24	25	26	27		
28	29	30						

# May 2020

**SUNDAY**

**MONDAY**
















**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

<div style="border: 1px solid black; padding: 5px; text-align: center;"> <p><i>In Memoriam</i></p> <p>Errol Yanovsky                      May 2  Stanley Michelman                May 7  Jack Zimmer                        May 8  Benjamin Gecht                    May 9  Anne Yanovsky                      May 19</p> </div>					1	 7:35	2
							 Corie Shapiro
3	4	5	6	7	8	 7:43	9
							 Richard David Chudnick
10	11	12	13	14	15	 7:50	16
 Alice Finkel Markinson <b>MOTHER'S DAY</b>		 Samira Zamel Troncoso					
17	18	19	20	21	22	 7:56	23
 Noa Levy	 David & Heather Levy  Nadia Zamel	 Gary Gecht		 Matthew Forbes Romer			
24	25	26	27	28	29	 8:02	30
 Michele Goldman							 David Fine  Elise Heringer  Charles Yanovsky
31	<b>MEMORIAL DAY</b>			 Ron & Michael Devane			
 Michelle Finkel  Jennifer Colton							



## **In Memory of Lawrence R. Shapiro, MD**

*Valued Board Member and Friend*

*Extraordinary Clinical Geneticist*

*An Advocate for Carrier Screening from its Very Beginnings*

### **The NTSAD New York Area Chapter**

*Is grateful for the many decades of his dedication to the prevention of genetic diseases through research, education and carrier screening*

**We thank him for all he did for so many**

*In memory of our loving uncle*

## **Jerry Sirot**

*We love you and wish you to Rest in Peace Forever*

**Debbie, Jeff, Kaitlin,  
Samantha, Rebecca Otto**

**May 2020**

					1	2
3	4	5	6	7	8	9
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24	25	26	27	28	29	30
31						

**July 2019**

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19	20	21	22	23	24	25
26	27	28	29	30	31	

# June 2020

**SUNDAY**

**MONDAY**

**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

	1  Brian Finkel Esmeralda Sirot	2	3	4	5  8:07	6																												
7  Matthew Feldman Lior Levy	8  Lee Cohen	9	10  Michael Silberfarb	11  Shawn Silberfarb	12  8:11  Lillian Sherman Natan Thaler Lisa & Griffith Kolland	13  Scott Harris Gentile																												
14  FLAG DAY	15  Stacy Campbell	16	17	18	19  8:13	20  Heath Feldman																												
21  Matthew Lawrence Gentile  SUMMER BEGINS FATHER'S DAY	22  Jayden Campbell	23  Sharon Silberfarb Blise & Emil Keringer	24  Jason Shapiro	25	26  8:14	27  Miriam Thaler Mitchell Gordon																												
28  Susan & Bill Boorstein	29	30			<table border="1"> <thead> <tr> <th colspan="4">In Memoriam</th> </tr> </thead> <tbody> <tr> <td>Harold Gottlieb</td> <td>June 4</td> <td>William Romer</td> <td>June 21</td> </tr> <tr> <td>Esther Sider</td> <td>June 4</td> <td>Gita Katz</td> <td>June 24</td> </tr> <tr> <td>Sarah Finkel</td> <td>June 8</td> <td>Nathan Zimmer</td> <td>June 25</td> </tr> <tr> <td>Charles Goldstein</td> <td>June 8</td> <td>Sidney Finkel</td> <td>June 26</td> </tr> <tr> <td>Harold Goldstein</td> <td>June 13</td> <td>Sheila Donner</td> <td>June 27</td> </tr> <tr> <td>Sami Elena Mansour</td> <td>June 13</td> <td>Frances Berkwits</td> <td>June 29</td> </tr> </tbody> </table>		In Memoriam				Harold Gottlieb	June 4	William Romer	June 21	Esther Sider	June 4	Gita Katz	June 24	Sarah Finkel	June 8	Nathan Zimmer	June 25	Charles Goldstein	June 8	Sidney Finkel	June 26	Harold Goldstein	June 13	Sheila Donner	June 27	Sami Elena Mansour	June 13	Frances Berkwits	June 29
In Memoriam																																		
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Harold Goldstein	June 13	Sheila Donner	June 27																															
Sami Elena Mansour	June 13	Frances Berkwits	June 29																															

*In loving memory of*

***Helaine Seccia***

*“A lifelong friend”*

*Gus Sirot*



# Frances Berkwits

*For her enduring efforts and dedication to easing the pain of the afflicted  
and promoting practical and scientific understanding*

*We remember her,*

*Gloria Berkwits,*

*Leland, Jeffrey and Michael Berkwits*

*In memory of our parents*

**Florence & Irving Turetsky**

*and our sister*

**Susan Barbara**

**1953-1955**

*Elaine & Barry Heimowitz*

*Linda & Steve Selip*

**July 2020**

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5	6	7	8	9	10
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**September 2020**

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# August 2020

**SUNDAY**

**MONDAY**


**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

	<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center;"><i>In Memoriam</i></p> <p>Sarah Pinger August 7                  Phyllis Chavis August 9                  Shirley Leib August 10                  Wendy Gordon August 16                  Scott Peter Colton August 16                  Jerry Sirot August 20                  Ray Colton August 22                  Saul Donner August 26                  Adam Davis August 28</p> </div>					1
2	3	4   <i>Samantha Gordon</i>	5   <i>Charlie Gecht</i>	6	7   7:46   <i>Steven Greg Chudnick</i>	8
9	10	11	12	13	14   7:36   <i>Scott Finkel</i>  <i>Alyse Gordon</i>	15
16   <i>Elaine Levy</i>	17	18   <i>Scott Brian Fine</i>  <i>Daniel Silberfrab</i>  <i>Avraham Thaler</i>	19	20	21   7:26   <i>Marc Robinson</i>	22
23	24	25   <i>Stacy &amp; Noah Cantor</i>  <i>James Colton</i>	26   <i>Joan Kantz</i>	27   <i>Jill Feldman</i>	28   7:15   <i>Layla Campbell</i>	29
30	31					

**In loving memory of  
Harold & Toby Gottlieb**  
*Henry & Sylvia Kleiner*

**In Loving Memory of  
Scott Peter Colton  
&  
Carole & Ray Colton**  
*Love,  
Gerri Colton & James Colton*

*Wishing our friends*  
**Sue & Gus Sirot**  
*a Healthy and Happy New Year!*  
**Caren & Craig Hirsch**

*In loving memory of*  
**Rose & Mike Weisfeld**

*In Loving Memory of*  
**Bea Gecht**

Custom Dry Cleaning & Friendly Service  
with a "Touch of Class"

**Touch of Class  
Cleaners**

of Pomona

Route 202 Pacesetter Park  
(845) 354-1440

*In memory of our beautiful*  
**Brooke Chase Gettleman**  
*Robin & Harvey Finkel*

**August 2020**

						1
2	3	4	5	6	7	8
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23	24	25	26	27	28	29
30	31					

**October 2020**

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18	19	20	21	22	23	24
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# September 2020

**SUNDAY**

**MONDAY**

**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

<p><b>MYTH:</b> Only one partner needs to be tested for Tay-Sachs and Allied Diseases.</p> <p><b>FACT:</b> Both partners should be tested</p>		<p>1</p>	<p>2</p> <p> Jonah Goldstein</p>	<p>3</p>	<p>4</p> <p> 7:02</p>	<p>5</p> <p> Ryan Andrew Silberfarb</p>												
<p>6</p>	<p>7</p> <p><b>LABOR DAY</b></p>	<p>8</p> <p> Jacob Silberfarb  Ellen Fine  Alia Zamel</p>	<p>9</p>	<p>10</p> <p> Jady Kohen</p>	<p>11</p> <p> 6:50</p> <p> Griffith (Skip) Holland  Michael Gary Chudnick</p>	<p>12</p> <p> Cody Miles Gecht</p>												
<p>13</p> <p> Brandon Spencer Gecht  Dayna Lynn Gecht</p>	<p>14</p>	<p>15</p>	<p>16</p>	<p>17</p> <p> Gerri Colton</p>	<p>18</p> <p> 6:38</p> <p> Emma Zimmerman <b>EREV ROSH HASHANAH</b></p>	<p>19</p> <p> Samuel Wager Chudnick <b>ROSH HASHANAH I</b></p>												
<p>20</p> <p> Miriam Anna Gentile <b>ROSH HASHANAH I</b></p>	<p>21</p> <p> Sophie Goldstein</p>	<p>22</p> <p> Katherine Gentile Vairo <b>AUTUMN BEGINS</b></p>	<p>23</p>	<p>24</p> <p> Sue Sirot  Andrew Militscher</p>	<p>25</p> <p> 6:26</p> <p> Caroline Wager Chudnick</p>	<p>26</p> <p> Leah Paige Wasserman</p>												
<p>27</p> <p><b>EREV YOM KIPPUR</b></p>	<p>28</p> <p> Michael S. Goldman <b>YOM KIPPUR</b></p>	<p>29</p> <p> Mitchell Ray Jacobs</p>	<p>30</p> <p> Evelyn Goldman  Justin Frank Zimmer  Matthew Neil Zimmer</p>	<table border="1"> <tr> <td colspan="2" style="text-align: center;"><b>In Memoriam</b></td> </tr> <tr> <td>Ceil Benbasset</td> <td>September 9</td> </tr> <tr> <td>Sheila Wasserman</td> <td>September 10</td> </tr> <tr> <td>Leo Diamond</td> <td>September 14</td> </tr> <tr> <td>Jack Finkel</td> <td>September 16</td> </tr> <tr> <td>Carole Colton</td> <td>September 29</td> </tr> </table>			<b>In Memoriam</b>		Ceil Benbasset	September 9	Sheila Wasserman	September 10	Leo Diamond	September 14	Jack Finkel	September 16	Carole Colton	September 29
<b>In Memoriam</b>																		
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Sheila Wasserman	September 10																	
Leo Diamond	September 14																	
Jack Finkel	September 16																	
Carole Colton	September 29																	

**Grandma Betty**

and

**Papoo Louis S. Hazan**

*“Forever In Our Hearts”*

**Elyssa, Billy, Jason, Natalie, Corie, George  
Jaden, Devin, Brooke, Avery & Kaia**

Compliments of

**Leslie Schwarz**

*In loving memory of*

**Gerry Goldberg**

*A Special Man*

**Marion & Charlie Yanovsky**

*In Honor of Our Grandchildren*

***Reese Leah Finkel***

***Grant Zachary Finkel***

***Dean Harrison Finkel***

***Mallory Chase Finkel***

***Gus Anderson Finkel***

*With Love,*

***Robin & Harvey Finkel***

**I am grateful for my precious grandchildren**

Jessica Lynn

Leah Paige

Benjamin Matthew

Russell Matthew

Mitchell Ray

William Scott

Nolan Russell

Robert Nathan

Geoffrey Zack

Great Grandson - Gabriel David

Great Granddaughter - Serena Jo

***Norman Wasserman***

**September 2020**

	1	2	3	4	5	
6	7	8	9	10	11	12
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20	21	22	23	24	25	26
27	28	29	30			

**November 2020**

1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					

# October 2020

**SUNDAY**

**MONDAY**

**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center;"><b>In Memoriam</b></p> <table border="0" style="width: 100%; font-size: small;"> <tr><td>Geraldine Finkel</td><td>October 3</td><td>Steven Berg</td><td>October 19</td></tr> <tr><td>Roberta Meyers</td><td>October 3</td><td>Joseph Gentile</td><td>October 26</td></tr> <tr><td>Alex Pinger</td><td>October 4</td><td>Stella Zimmer</td><td>October 27</td></tr> <tr><td>Harriet Lurie</td><td>October 5</td><td>Dorothy Zaretsky</td><td>October 28</td></tr> <tr><td>Anna Finkel</td><td>October 8</td><td>Leon Jacobson</td><td>October 29</td></tr> <tr><td>Henry Sirot</td><td>October 9</td><td>Miriam Finkel</td><td>October 30</td></tr> <tr><td>Sophie Gecht</td><td>October 12</td><td></td><td></td></tr> </table> </div>		Geraldine Finkel	October 3	Steven Berg	October 19	Roberta Meyers	October 3	Joseph Gentile	October 26	Alex Pinger	October 4	Stella Zimmer	October 27	Harriet Lurie	October 5	Dorothy Zaretsky	October 28	Anna Finkel	October 8	Leon Jacobson	October 29	Henry Sirot	October 9	Miriam Finkel	October 30	Sophie Gecht	October 12			1	2  6:16	3
		Geraldine Finkel	October 3	Steven Berg	October 19																											
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			Spencer Markinson	Riley Paige Roimisher																												
4  Elise Rae Gecht	5  William Gentile	6	7	8  Daniel Ian D'Amato	9  6:05  Meryl Gordon	10																										
11  Michael Devane Joe Rattien Michael Gary Chudnick	12  <b>COLUMBUS DAY</b>	13  Barbara Hasman	14  Susan Roden	15	16  5:54  Maya Jade Benbasset	17  Matthew Gordon																										
18  Elijah Dzitrie	19	20  Erin Finkel	21  Jack Zimmerman Jerimah T.C. Snyder Anthony Gentile Jack Zimmerman	22  Arlene Gecht Koral	23  5:43  Davie Benbasset	24																										
25  Caroline Wager Chudnick Brittany Sari Zimmer	26  David Silberfarb	27  Robert Nathan Wasserman Eric Jason Fine <b>EREV YOM KIPPUR</b>	28  Pasquale Vairo <b>YOM KIPPUR</b>	29  Adam Brian Gecht	30  5:34	31  Zachary Cantor Marion Yanovsky <b>HALLOWEEN</b>																										

*In Honor of Our  
35th Wedding Anniversary*

***November 24th***

*Sheila & Lee Cohen*

*In memory of*  
***Marcia Feinberg***

*and*

***Aaron Feinberg***

*Ann Hanover*

*Thank you to the*

***Jewish Genetic Disease Consortium***

*educating medical professionals, rabbis & the community  
for the prevention of Jewish Genetic Diseases*

*[www.jewishgeneticdiseases.org](http://www.jewishgeneticdiseases.org)*

**October 2020**

				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

**December 2020**

			1	2	3	4	5
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13	14	15	16	17	18	19	
20	21	22	23	24	25	26	
27	28	29	30	31			

# November 2020

**SUNDAY**

**MONDAY**

**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

1          <b>DAYLIGHT SAVINGS ENDS MOVE CLOCK BACK</b>	2	3          <b>ELECTION DAY</b>	4	5          Brian Craig Koral Hasan Zamel	6          4:26	7          Lisa Holland																																				
8          Rivka Naftalowitz	9          Hailey Silberfarb	10	11          Lew Kantz Nathan Edward Devane <b>VETERANS DAY</b>	12	13          4:19          <i>Ayson &amp; Joshua Karvot</i>	14          Cyrus Jude Benbasset Mitchell Ira Fine																																				
15	16          Alan Finkel	17	18          William Scott Jacobs Serena Hope Markinson	19	20          4:14	21          Cameron Troncoso																																				
22	23          <i>Maddie &amp; Herb Roimisher</i> Edith Berg	24          <i>Sheila &amp; Lee Cohen</i> Alisa Lifshitz	25	26          Brenna Finkel <b>THANKSGIVING DAY</b>	27          4:10          William Romer	28																																				
29          Rachel Thaler	30	<table border="1"> <thead> <tr> <th colspan="4"><b>In Memoriam</b></th> </tr> </thead> <tbody> <tr> <td>Billie Hoffman</td> <td>November 1</td> <td>Emma Zimmerman</td> <td>November 18</td> </tr> <tr> <td>Adele Zimmer</td> <td>November 2</td> <td>Lawrence Shapiro</td> <td>November 20</td> </tr> <tr> <td>Miriam Lifshitz</td> <td>November 4</td> <td>Jill Goldberg</td> <td>November 21</td> </tr> <tr> <td>Daniel Jacobson</td> <td>November 7</td> <td>Helen Diamond</td> <td>November 23</td> </tr> <tr> <td>Aaron Lifshitz</td> <td>November 9</td> <td>Lester Pinger</td> <td>November 24</td> </tr> <tr> <td>Abner Berkwits</td> <td>November 10</td> <td>Harry Verona</td> <td>November 25</td> </tr> <tr> <td>Stephen Silberfarb</td> <td>November 15</td> <td>Irving Zaretsky</td> <td>November 25</td> </tr> <tr> <td>Owen Brandt</td> <td>November 17</td> <td>Noah Jarashow</td> <td>November 30</td> </tr> </tbody> </table>					<b>In Memoriam</b>				Billie Hoffman	November 1	Emma Zimmerman	November 18	Adele Zimmer	November 2	Lawrence Shapiro	November 20	Miriam Lifshitz	November 4	Jill Goldberg	November 21	Daniel Jacobson	November 7	Helen Diamond	November 23	Aaron Lifshitz	November 9	Lester Pinger	November 24	Abner Berkwits	November 10	Harry Verona	November 25	Stephen Silberfarb	November 15	Irving Zaretsky	November 25	Owen Brandt	November 17	Noah Jarashow	November 30
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*In loving memory of an incredible woman*

# **Fran Berkwits**

*A Special & Dear Friend Never to be Forgotten*

*Always in our Hearts*

*We miss you very much,*

**Marion & Charlie Yanovsky**

*In Memory of*

***Stanley Kravet***

*In loving memory  
of the best grandparents*

**Helen & Leo Diamond**

***Susan Yanovsky Roden***



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Study (516) 489-4618  
Fax (516) 489-3354

***NAM MYOHO RENGE KYO***  
***BRUCE SINGLETON***

*Compliments of*  
***Sandi & Bob Plotkin***  
***and Family***

**Compliments of**  
***Philip & Gloria Darvin***

**Compliments of**  
**A Friend of Hadara**

**December 2020**

	1	2	3	4	5	
6	7	8	9	10	11	12
13	14	15	16	17	18	19
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**February 2021**

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7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28						

# January 2021

**SUNDAY**

**MONDAY**

**TUESDAY**

**WEDNESDAY**

**THURSDAY**

**FRIDAY**

**SATURDAY**

<div style="border: 1px solid black; padding: 5px;"> <p style="text-align: center;"><u>In Memoriam</u></p> <table border="0"> <tr><td>Harry Silberfarb</td><td>January 3</td></tr> <tr><td>Rose Weisfeld</td><td>January 5</td></tr> <tr><td>Herbert Gordon</td><td>January 6</td></tr> <tr><td>Samuel Eisenberg</td><td>January 7</td></tr> <tr><td>Harold Feldman</td><td>January 12</td></tr> <tr><td>Sylvia Silberfarb</td><td>January 17</td></tr> <tr><td>Margo Isselbacher</td><td>January 17</td></tr> <tr><td>Beatrice Gecht</td><td>January 28</td></tr> <tr><td>Jane Eisenberg</td><td>January 29</td></tr> </table> </div>		Harry Silberfarb	January 3	Rose Weisfeld	January 5	Herbert Gordon	January 6	Samuel Eisenberg	January 7	Harold Feldman	January 12	Sylvia Silberfarb	January 17	Margo Isselbacher	January 17	Beatrice Gecht	January 28	Jane Eisenberg	January 29				1	 4:20	2
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Beatrice Gecht	January 28																								
Jane Eisenberg	January 29																								
					<b>NEW YEAR'S DAY</b>																				
3	4	5	6	7	8	9																			
 Rona Devane			 Emily Kate Gentile  Marissa Heringer  Rebecca Heringer	 Rose Price Cooley	 David Sirof	 Noah Philip Devane																			
10	11	12	13	14	15	16																			
	 Geoffrey Zack Wasserman  Andrew David Markinson	♥ Sue & Gus Sirof		 Robyn Finkel Kohen	 4:34																				
17	18	19	20	21	22	23																			
 Renée Hasman  Nolan Russell Wasserman	<b>MARTIN LUTHER KING, Jr BIRTHDAY OBSERVED</b>			 Mia Levy	 4:43   Charlie Levy																				
24	25	26	27	28	29	30																			
					 4:51																				
31		♥ Barbara & Gary Feldman																							

*In Loving Memory of*

**Gerry Goldberg**

*“Harry’s Grandpa”*

*With thanks for his generous support  
for the programs of NTSAD*

*Members of NTSAD New York Area*

**Compliments  
of**

**The Rosenthal Family**

In loving memory of

**Frances Berkwits, MS, CSW**

and

**Abner Berkwits, MD**

*In loving memory of*  
**Uncle Stanley & Aunt Joyce**

**You are missed!**

*Rest in peace*

*Love,*

*Sue & Gus*

*Nicole, Hadara, Elijah, Jonah & Jeremiah*

**Good Luck & Thank You**  
**to the scientists of the**  
**Tay-Sachs Gene Therapy Consortium**

**Billie & Harold Hoffman**

# **In Memory of Our Beloved Harriet**

*who worked tirelessly all these many years  
for NTSAD and Niemann-Pick Disease Research  
in Donna's memory*

**Claire, Cliff, Ronni and Josh  
Andy, Monique and Sophie**

IN MEMORY OF OUR BELOVED DAUGHTER

**RACHEL MEREDITH**

FOREVER IN OUR HEARTS

IN HONOR OF OUR GRANDSONS

**TYLER MATTHEW**

**ANDREW JARED**

**RHODA & FRED KANTER**

In loving memory of

*Henry & Pearl Sirot*  
*Harold & Toby Gottlieb*  
*Sami Elena Mansour*  
*Jerry Sirot*

The Sirot Family

*In Loving Memory of*  
**Great Grandma Francie Berkwits**



*Your love, unwavering devotion, and the lives you spared from hardship and grief will inspire us and generations to come.*

**Annie & Zoe Elberg**

*In Loving Memory of*  
***Francie Berkwits***



*A shining example of a life well-lived.*

*Your memory is a blessing to us all.*

***Jake, Lacey, Annie & Zoe Elberg***

*In loving memory of*

**TOBY & HAROLD GOTTLIEB**

**SAMI ELENA MANSOUR**

*Together Forever*

Sue & Gus Sirot and Family

In Loving Memory Of

***ALLEN & MARGIE FEIN***

***JOE & CEIL BENBASSET***

***EVELYN & LENNY SUSSMAN***

***LIBBY & NORMAN MOSBERG***

***JOE ROSEN***

***ROSE & MIKE WEISFELD***

Merri & Murray Benbasset

Jason & Melissa, Maya & Taylor

Corey & Hope, Easton, Harlow, Cyrus & Davie

*In Loving Memory of*

**SAMI ELENA MANSOUR**

*“A Moment of Joy”*

*Sue & Gus Sirot and Nicole*

*Best Wishes  
for  
Continued Success!*

*Bryan and Meredith Verona*

In loving memory of

*Pearl Sirot*

*Henry Sirot*

*Jerry Sirot*

*Toby Gottlieb*

*Harold H. Gottlieb*

*and*

*Sami Elena Mansour*

With thanks for the joy of

*Hadara - April 6, 1994*

*Elijah - October 18, 1996*

*Jonah - July 25, 2000*

*and*

*Jeremiah - October 21, 2015*

*Sue & Gus Sirot*

*In loving memory of our  
son & brother*

***RAPHI HABERBERG***

*Gili, Benjamin, Ari & Karen*

IN MEMORY OF  
**EVELYN and LEONARD SUSSMAN**  
(1918-2000) (1916-2001)

**RICKI BETH SUSSMAN**  
(1953-1957)

and

**ROSE and MIKE WEISFELD**

*Founders of NTSAD whose energy and  
selfless devotion helped NTSAD  
to reach many of its goals*

**PETER and MICHAEL SUSSMAN**

*In memory of my beloved parents*

**Jeanette and Seymour Thaler**

*and my brother*

**Alan Mark Thaler**

*Together forever in Gan Eden*

Phyllis Thaler

**For the Blessings of  
My Wonderful Children  
& Grandchildren  
Who Fill My World With Love**  
*Ann Brandt*

In loving memory of my parents  
**Helen & Leo Diamond**  
Ann Brandt

In Honor of My Amazing Sister,  
**Marion Yanovsky**  
With love, Ann

*In loving memory of*  
**Owen Brandt**  
*Your love is always with us*  
Ann, Lisa, Skip, Rona, Michael  
Nathan, Noah & Joshua

*In Memory of  
and in Tribute to  
our mother*

*'A Woman of Valor'*

*אשת חיל*

*Jennie Gottlieb*

**Du Du Liegst Mier In Herzen**



**For  
Honeydew and Gus**

*Love,  
Angus*

*In loving memory of*  
**Owen Brandt**  
*Beloved Brother-In-Law & Uncle*

Marion & Charlie  
Susan, Alan, Jason & Bryan  
Steven & Asher

*In memory of*  
**Gertrude Bertinthal**

*Deborah, Arthur,  
& Seth Kupperman*

*Elyse & Matt Chaifetz  
Mili & Harris Kupperman*

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GREAT NECK, NEW YORK 11021

*With heartfelt appreciation, we celebrate our outstanding NTSAD staff,  
our dedicated doctors and researchers, our affected families and their team of friends and loved ones,  
all of our devoted volunteers (with extra kudos for our unwavering, remarkable Marion Yanovsky)  
for all your hard work and support bringing us closer to a cure and treatment  
for Tay Sachs and the Allied Diseases*

*With much thanks,*

**The Heringers**

In Loving Memory of

**Stanley Michelman**

We miss your kind and loving ways

We miss your friendship

We are sad you left us so soon

**Marion & Charlie Yanovsky**

In loving memory

**Estelle Krakaur**

**Lauri Jill Adelsberg**

**Gertrude Adelsberg**

**George Corn**

**Lilly Corn**

*In Support of Research*

**Sandy & Allen  
Levine**

*In loving memory of*

**Anita & Larry  
Kessler**

*Keep up the good work!*

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*In Memory Of*

**Audrey Schwartz**

*Beloved to Douglas, Claire and Cliff,*

*Ronni and Josh,*

*Andy, Monique and Sophie*

...“For it’s the laughter,  
we shall always remember the way it was.”

*In loving memory of  
my beloved daughter Lisa Cheryl  
and my husband Stanley*

**Rhoda Kravet**

**SHAPIRO LAW OFFICES**

**JASON S. SHAPIRO**  
ATTORNEY AT LAW

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[JS@SHAPIROLAWOFFICES.COM](mailto:JS@SHAPIROLAWOFFICES.COM)

*In memory of my aunt*

**Marcia Feinberg**

*She was a woman of enormous strength  
abundant love and unending generosity*

**Susan Z. Cohen**

*In Loving Memory of*

**Marcia Feinberg**

*Marion & Charlie Yanovsky*

*In Loving Memory of*

**Anne & William Yanovsky**

**Karl Yanovsky**

**Errol Yanovsky**

**In Loving Memory of  
Sheila Wasserman**

*A kind and caring friend  
We celebrate her life*

**Marion & Charlie Yanovsky**

*In memory of*

**Henry-Hilda-Margo**

**Harry-Helga**

# ***National Tay-Sachs & Allied Diseases Association***

*Thanks*

## ***The Tay-Sachs Gene Therapy Consortium***

*For Driving Key Initiatives in Gene Therapy*

*In Loving Memory of*

### ***Sheila Wasserman***

*A most warm, kind and giving person, super terrific and family-oriented*

*Always there to help everyone and anyone*

*Never wanting anything in return*

*She will always be missed*

**With much love,**

**Norman, Stuart & Kathy, Paul & Andrea Wasserman**

**Lisa & Lonnie Jacobs**

**Herb & Madeline Roimisher**

In Loving Memory of  
**Harrison Hoffman**

“A Person’s a Person  
No Matter How Small”

Love,  
Mommy, Daddy & Jake

*In loving memory of*

**Helen & Leo Diamond**

*wonderful parents & grandparents*

*Marion & Charlie Yanovsky*

*In memory of*

**Jeanette & Seymour  
Thaler**

**In Memory of a Special Woman**

*Fran's warm smile, dedication to the  
prevention of Tay Sachs disease,  
and passion for all she did, will live on  
in all those she touched.*

*We love you and miss you.*

**Susan and Alan Roden**

**Jason and Bryan**

*In Loving Memory of*

**Billie Hoffman**

*“Harry's Grandma”*

*With thanks for her generous support  
for the programs of NTSAD*

*Members of NTSAD New York Area*

In celebration of our precious grandchildren

**Asher, Jason & Bryan**

Marion & Charles Yanovsky

*In loving memory of*

**Jeanette & Seymour Thaler**

*and*

**Alan Thaler**

*Martin Thaler & Family*

*In honor of our grandchildren*

**Adam Taylor Chaitin  
Alexandria Rae Chaitin  
Jeremy Scott Chaitin  
Paul Nunzio Chaitin**

*Paul & Sandra Chaitin*

**May there soon be no need  
for fund drives such as this.**

*Phyllis Pullman*

*Compliments of*  
**Gary Gecht**

*Dear*

**Grandma Sylvia &  
Grandpa Harry**

*We continue to keep your memory  
alive as you live on within us.*

*We miss you very much.*

*Love always,*

**Sharon, Will, Brayden,  
Caleb & Vienna**

*In memory of*  
**Ricki Beth Sussman**

**1953-1957**

In Memory of

**Ahny**

Her love of children lives on

*We proudly support the achievements of NTSAD*

- *Research for Treatment & Cure*
- *Education for Prevention*
- *Support for Affected Families*

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*As we are now working together to prevent and cure **Late Onset Tay-Sachs**, let us now, also provide effective treatment for those of us presently facing the everyday "ordinary" steps of life with the extra-ordinary efforts, fortitude, perseverance and heroics that are demanded by the challenges of **Late-Onset Tay-Sachs**.*

***Optimistically,***  
***Carol S. Handwerker***

*In memory of*  
**Sylvia Farber**  
*The Lifshitz Family*

Compliments of  
**The Rattien Family**

*Compliments*  
*of*  
**Honey Rosenberg**

**Friends of**  
**Gus & Sue Sirot**

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*In Honor of*  
*Our Wonderful Grandchildren*  
**Matthew Ryan Jacobson**  
**Steven Kyle Jacobson**  
**Chad Tyler Malinowski**  
**Brett Spencer Malinowski**  
**Isabella Tori Zahl**  
*Marcia & Harvey Jacobson*

*In Beloved Memory of*

# **Barbara Salomon**

*Tireless worker and contributor  
dedicated to NTSAD for over 55 years*

*“i carry your heart with me (i carry it in my heart)  
i am never without it (anywhere i go, you go, my dear)...”*

**Claire, Cliff, Ronni, Joshua, Andy, Monique and Sophie**

*In Loving Memory of*

# **Toby & Harold Gottlieb**

*Eliana & Avi Mordekovich and Family*



**In loving memory of  
Morty & Marcia Feinberg,  
dedicated NTSAD parents and  
volunteers all of their lives and  
especially Aaron Feinberg  
(1964–1970)**

– Ruth & Ed Feldman

*In loving memory of our dear cousin*

*Sylvia Schwartz*

*With love,*

*Sue, Gus and Sari*

# In Memoriam

Harry Silberfarb ..... January 3  
 Rose Weisfeld ..... January 5  
 Herbert Gordon ..... January 6  
 Samuel Eisenberg ..... January 7  
 Harold Feldman ..... January 12  
 Sylvia Silberfarb ..... January 17  
 Margo Isselbacher ..... January 17  
 Pearl Sirot ..... January 19  
 Beatrice Gecht ..... January 28  
 Jane Eisenberg ..... January 29  
 Sydney Levy ..... February 9  
 Charlotte Stark ..... February 11  
 William Yanovsky ..... February 15  
 Harrison Hoffman ..... February 17  
 Burton Salomon ..... February 22  
 Bernard Gecht ..... February 24  
 Estelle Goldstein ..... March 3  
 Matthew Forbes Romer ..... March 8  
 Nathan Sider ..... March 10  
 Alan Berg ..... March 12  
 Joel Chavis ..... March 17  
 Marcia Feinberg ..... March 24  
 Mary K. Uscky ..... March 25  
 Toby Gottlieb ..... March 25  
 Alex Lifshitz ..... April 12  
 Alan Thaler ..... April 16  
 Albert Eisenberg ..... April 21  
 Barbara Salomon ..... April 24  
 Elaine Verona ..... April 29  
 Errol Yanovsky ..... May 2  
 Stanley Michelman ..... May 7  
 Jack Zimmer ..... May 8  
 Benjamin Gecht ..... May 9  
 Anne Yanovsky ..... May 19  
 Esther Sider ..... June 4  
 Harold Gottlieb ..... June 4  
 Sarah Finkel ..... June 7  
 Charles Goldstein ..... June 8  
 Harold Goldstein ..... June 13  
 Sami Elena Mansour ..... June 13  
 William Romer ..... June 21  
 Gita Katz ..... June 24  
 Nathan Zimmer ..... June 25  
 Sidney Finkel ..... June 26  
 Sheila Donner ..... June 27  
 Frances Berkwits ..... June 29  
 Leon Finkel ..... July 3  
 Dillon Henry ..... July 6  
 Sylvia Farber ..... July 18  
 Leonard Chudnick ..... July 20  
 Irwin Ungerleider ..... July 21  
 Karl Yanovsky ..... July 31  
 Sarah Pinger ..... August 7  
 Phyllis Chavis ..... August 9  
 Shirley Leib ..... August 10  
 Scott Peter Colton ..... August 16

Wendy Gordon ..... August 16  
 Jerry Sirot ..... August 20  
 Ray Colton ..... August 22  
 Saul Donner ..... August 26  
 Adam Davis ..... August 28  
 Ceil Benbasset ..... September 9  
 Sheila Wasserman ..... September 10  
 Leo Diamond ..... September 14  
 Jack Finkel ..... September 16  
 Susan Ungerleider ..... September 27  
 Carole Colton ..... September 29  
 Geraldine Finkel ..... October 3  
 Roberta Meyers ..... October 3  
 Alex Pinger ..... October 4  
 Anna Finkel ..... October 8  
 Henry Sirot ..... October 9  
 Sophie Gecht ..... October 12  
 Steven Berg ..... October 19  
 Joseph Gentile ..... October 26  
 Stella Zimmer ..... October 27  
 Leon Jacobson ..... October 29  
 Dorothy Zaretsky ..... October 28  
 Miriam Finkel ..... October 30  
 Billie Hoffman ..... November 1  
 Adele Zimmer ..... November 2  
 Daniel Jacobson ..... November 7  
 Abner Berkwits ..... November 10  
 Aaron Lifshitz ..... November 9  
 Stephen Silberfarb ..... November 15  
 Owen Brandt ..... November 17  
 Emma Zimmerman ..... November 18  
 Lawrence Shapiro ..... November 20  
 Jill Goldberg ..... November 21  
 Helen Diamond ..... November 23  
 Lester Pinger ..... November 24  
 Irving Zaretsky ..... November 25  
 Harry Verona ..... November 25  
 Lorraine Gettleman ..... December 4  
 Noah Jarashow ..... November 30  
 Jeanette Thaler ..... December 7  
 Estelle Gordon ..... December 8  
 Seymour Thaler ..... December 16  
 Hayden Lord ..... December 22  
 Evan Ungerleider ..... December 23  
 Fred Goldberg ..... December 23  
 Freida Bittner ..... Herb Bittner  
 Jean McKenna ..... Seena Schneiderman  
 Bob Salomon ..... Lillyan Salomon  
 Evelyn Sussman ..... Lenny Sussman  
 Sophie Lorito ..... Betty Hazan  
 Ted Salomon ..... Ethel Berkman  
 Lynden Badal ..... Arnold Feingold  
 Howard Greenberg ..... Sheldon Greenberg  
 Allen Fein ..... Ruth Dunkell  
 Stanley Kravet ..... Anita Kessler  
 Estelle Krakaur ..... Margo Isselbacher



# NATIONAL TAY-SACHS & ALLIED DISEASES ASSOCIATION

*The mission of the National-Tay Sachs & Allied Diseases Association is to lead the fight to treat and cure Tay-Sachs, Canavan and related genetic diseases and to support affected families and individuals in leading fuller lives. We will accomplish our mission by funding global cutting edge research, by helping to provide families with compassionate care and support and by collaborating effectively with the healthcare community to achieve our goals.*

***Supporting NTSAD makes a difference!***

***Thank you to all who donated to this calendar.***

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