

Tay-Sachs & Allied Diseases 2022



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
two special people

In Honor of

Sue Kahn

NTSAD Executive Director

&

In Loving Memory of

Sue Sirot



*This Calendar-Journal is dedicated to
the beloved memory of*

Sue Sirot

Sue, who lost a daughter to Tay-Sachs disease years ago, was dedicated to the mission of NTSAD. Along with her husband Gus, Sue helped to raise funds to support education and carrier screening for prevention and grants for research to find a treatment and cure for Tay-Sachs and related genetic diseases. The Annual Calendar has been the fundraising project that Sue and Gus have led for many decades, raising thousands of dollars each year to fund NTSAD programs. The NTSAD community is grateful for all that Sue did in her lifetime as an NTSAD volunteer in the New York Area and as a super fundraiser. May she rest in peace, knowing we will continue to support the mission of NTSAD.

In Memory of Sue Sirot



Twin Great-Granddaughters Talia & Vania



This Calendar-Journal honors

Sue Kahn

*NTSAD Executive Director for
fourteen incredible years*

We honor Sue for her extraordinary dedication to the mission of NTSAD. We remain grateful to her for creating a culture of unprecedented collaboration, advancing research leading toward multiple clinical trials, and above all else, supporting families. Thanks to Sue's leadership, NTSAD remains a leading patient advocacy organization that provides comprehensive resources, programs and services, while also continuing to drive and fund research.

14 Years of Driving Research, Forging Collaboration and Fostering Community



June 2021

Dear NTSAD Community,

It's with mixed emotions that I share with you that after nearly 14 years, I am stepping down from my role as NTSAD's executive director at the end of October. I am looking forward to starting a new chapter in my life, knowing that NTSAD remains strong. I will help facilitate a smooth transition in leadership and support the board of directors who has initiated the search for my successor.



It has been my great honor to lead NTSAD. I am proud of the extraordinary progress in research as well as our ongoing efforts to put the needs of families first with comprehensive resources, programs, and services. Together, we have accomplished more than I ever hoped when I joined NTSAD in 2007. Currently, there are 14 drug development programs and clinical trials underway, and industry continues to invest in developing therapies for Tay-Sachs, Canavan, GM1 gangliosidosis, and Sandhoff diseases.

NTSAD is one of the oldest and most respected patient advocacy groups in the rare community and remains in a position of financial strength with healthy reserves. I am immensely grateful to our dedicated board of directors and compassionate NTSAD staff.

In addition, NTSAD has a five-year strategic plan in place, and recently broadened research direction focusing on clinical development, early diagnosis, newborn screening, and translational research. During the last two decades, NTSAD invested in much of the early research that has led to today's drug development programs and clinical trials. Since 2002, NTSAD has awarded more than \$4 million in research grants that have been leveraged to more than \$30 million in additional grants from the National Institutes of Health and other institutions.

The people, the organization, and my work all mean so much to me. This role has allowed me to connect with inspiring people, starting with the families who allow us to share in the darkest and brightest days of their journey, and who will move mountains to advocate for their child or themselves, support others, and raise money for research. I also have been honored to work closely with brilliant and dedicated experts who are making a brighter future possible through research, clinical care, or developing new treatments. It has been a blessing to meet so many people who have influenced me and touched my heart.



The work continues, and I look forward to celebrating with you when effective treatments are found. My heart will remain with the NTSAD Community, always.

With gratitude,

A handwritten signature in purple ink that reads "Sue".

SUE KAHN TO RECEIVE THE *WORLD SYMPOSIUM*™ 2022 PATIENT ADVOCATE LEADER (PAL) AWARD

Each year, *WORLD Symposium* recognizes one individual for patient advocacy leadership in the field of lysosomal disease. The Patient Advocate Leader (PAL) award will be presented at *WORLD Symposium* 2022 on February 8, 2022.



Sue Kahn is a leader known for her business acumen and ability to build relationships, collaborate, and drive research at one of the oldest and most respected patient advocacy groups in the rare disease community. For 14 years, Sue has served as the Executive Director of the National Tay-Sachs & Allied Diseases Association (NTSAD) that supports families affected by Tay-Sachs, Canavan, GM1, and Sandhoff.

Since 2007, Sue has used her industry business development experience to broaden NTSAD's network of industry leaders, scientists, and clinicians, thereby deepening NTSAD's commitment to multi-faceted collaborations, including the Tay-Sachs Gene Therapy Consortium. In her role Sue has shepherded NTSAD's investment of more than \$4 million in research grants that have been leveraged to more than \$30 million in additional grants from the National Institutes of Health and other institutions.

Under Sue's leadership, NTSAD is on the cusp of having effective treatments for the patients affected by the four diseases that NTSAD represents. Currently, there are 14 drug development programs and clinical trials underway, and industry continues to invest in developing therapies. Sue ensures that the patients' voices and experiences are heard and incorporated into these programs.

In addition, Sue has grown the organization's assets, staff, and program offerings, including comprehensive resources, programs, and services for families. Recently, Sue led the process to broaden NTSAD's research direction to focus on clinical development, early diagnosis, newborn screening, and translational research. These programs will be advanced with the hiring of NTSAD's first Research Director.

CONGRATULATIONS, Sue, for this well-deserved award!

Sanofi Genzyme Honors Dr. Edwin Kolodny and Makes a Gift to NTSAD



Sanofi Genzyme honored rare disease pioneer Dr. Edwin Kolodny during the 30th Anniversary celebration of the company's Rare Humanitarian Program. The Rare Humanitarian Program was created by former Genzyme CEO Henri Termeer to ensure treatments for rare diseases are made available globally, and so that no patient is ever left behind.

Through the Rare Humanitarian Program, Dr. Kolodny provided care to individuals and trained healthcare professionals around the world. **At the celebration Sanofi Genzyme made an extraordinary \$30,000 gift to NTSAD in honor of Dr. Kolodny's lifetime of service to the rare community.**

Thank you Dr. Kolodny for your enduring legacy and selfless care of the rare community, and thank you Sanofi Genzyme for your contribution, support, and partnership.

Sue Kahn helped pay tribute to Dr. Kolodny speaking at the event:

"Dr. Kolodny, it is an incredible honor to be here to recognize you and represent the countless NTSAD families you have served for more than 50 years.

From when we first met in 2007, I have been awed by you and your remarkable recollections of each patient and their families. Whether it's a child or an adult, you see the person, not just their disease. One Mom told me that you're her HERO! Another Mom shared how much it meant to her that you simply wanted to help her daughter.

Dr. Kolodny, your life has been marked by graciousness, compassion, and chesed; your overflowing loving-kindness for your patients and their families. Thank you from the bottom of our hearts.

And thank you, Sanofi Genzyme, for your generous donation to NTSAD and unwavering support of rare families around the world."

NTSAD Welcomes New Leader



Dear NTSAD Community,

I am honored to serve as NTSAD's next leader. Having dedicated several years to healthcare advocacy organizations during three decades in the corporate, academic, and non-profit sectors, I look forward to building on NTSAD's past successes and embracing its future. With more than a dozen drug development and clinical trials underway, it is undoubtedly a time of great promise for NTSAD families. In the coming weeks, I welcome the opportunity to connect with our courageous families, Board members, industry stakeholders, researchers, and clinicians and join my voice with theirs in the fight against Tay-Sachs, Canavan, GM1, and Sandhoff diseases.

Kathleen M. Flynn, CEO, NTSAD



Supporting Families: Navigating Clinical Trials



Today there are 8 active clinical trials to find effective treatments for Canavan, GM1, Tay-Sachs and Sandhoff diseases because 64 years ago six families came together, had hope and got to work.

Clinical trials are experiments. There are risks. A few have promise, but it is still too soon to know. But we won't give up our efforts until we find effective treatments.



Current Clinical Trials

Aspa Therapeutics – Canavan gene therapy

Myrtelle – Canavan gene therapy

Lysogene – GM1 gene therapy

Passage Bio – GM1 gene therapy

Sio Gene Therapies – GM1 gene therapy

**Sanofi Genzyme – substrate reduction therapy for GM2
(adults and secondary arm for juvenile GM1, GM2)**

Sio Gene Therapies – GM2 gene therapy

Taysha Gene Therapy – GM2 gene therapy

Clinical Trials: What You Need to Know

In 2020-2021, a number of clinical trials were opened for enrollment for Canavan, GM1 Gangliosidosis, GM2 Sandhoff and Tay-Sachs in each of their forms.

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.

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. Therefore, participating in the PIN and natural history studies is important and critical.

How is it Decided Who Can Be in the Trial?

The inclusion standards are set before a clinical trial begins during the trial design, and candidates must meet those standards in order to be considered for participating in a trial. Because these diseases are rare, the number of eligible participants is limited for the first phase of this first-in-human clinical trial.

Why Do Patients Have to Meet Certain Criteria to Be Accepted Into the Trial?

Inclusion criteria are necessary for a successful clinical trial. Inclusion criteria also help minimize risk in a clinical trial and ensure the proposed therapy is safe and effective. Having a successful trial in which risks are minimized and success of the therapy can be shown is important to allow therapies to continue in future trials and to lead to eventual approval.

What Does Phase I/II Mean?

Phase I typically looks at the safety and dosage of the proposed therapy, and Phase II focuses on the efficacy (benefits, effectiveness, does it help) and potential side effects. However, with rare diseases, where there are a limited number of potential candidates, the FDA will often allow the combination of phase I & II which can use fewer patients and may answer the research questions more quickly.

NTSAD Welcomes First Research Director

Valerie Greger, Ph.D. has joined NTSAD as the organization's first Research Director. She is an accomplished academic, scientist and leader with extensive experience in human genetics, genomics, molecular biology, and bioinformatics.

In her role, Valerie will lead NTSAD's research grant program and implement initiatives in clinical development, newborn screening, and early diagnosis. She also will be a resource for communicating scientific and medical information to patients.



Valerie is passionate about creating value from scientific discoveries, transforming ideas into reality and making an impact on patients' lives. Valerie will be working part-time at NTSAD, as she also works with the Yaya Foundation for 4H Leukodystrophy. Her combined experience at these organizations will enhance research in the rare leukodystrophy community.

NTSAD's Board of Directors recently welcomed Valerie where she shared, ***"Knowledge alone doesn't mean anything until it leads to the building of a product—that's when knowledge can make an impactful change."***

Since 2002, NTSAD's Research Initiative has made direct investments of more than \$4 million in grants that have been leveraged to more than \$30 million of investments in additional research, leading to new therapies.

NTSAD Launches New Round of Research Funding

In partnership with Blu Genes Foundation and Cure for Tay-Sachs Foundation, NTSAD will launch and RFP (request for proposal) process in January for researchers seeking seed grants ranging from \$70,000 - \$140,000 for one or two years, respectively.

NTSAD will be soliciting proposals for innovative research projects that involve basic research, translational studies or clinical studies in the following diseases: Tay-Sachs, Canavan, GM1, and Sandhoff diseases.

We are interested in all aspects of therapeutic discovery. Projects that focus on understanding the pathophysiology and the role of inflammation in these four disease areas, or the process of myelination and how it is affected by disease are of particular interest.

NTSAD remains committed to advancing and funding research, and first launched its Research Initiative in 2002, which to date has made more than \$4 million in grants that have been leveraged to more than \$30 million of additional investments in research by other institutions, leading to new therapies.

LOTSS Think Tank Advances Therapies and Research

Nearly 30 researchers, clinicians, industry members, and patient advocates gathered for the 4th Annual Late Onset Tay-Sachs and Sandhoff Disease (LOTSS) Think Tank, a two-day symposium designed to accelerate research toward effective treatments.

During the October event, the group discussed pre-clinical research and innovative methods, new experimental therapeutic approaches, early findings for ongoing clinical trials, the development of meaningful outcome measures, and efforts to establish newborn screening for GM2 as well as GM1 and Canavan disease.

Keynote speaker Jeremy Schmahmann, MD, Massachusetts General Hospital and Harvard Medical School, shared a new perspective on the brain's cerebellar function known for coordinating movement, but it may also regulate cognition and emotional function. Throughout his speech, he emphasized the importance of listening to patients and having them be at the very center of the therapeutic process.

The Think Tank was sparked by Alexis Buryk and was inspired by her twin daughters, who are living with LOTSS. Together the family has raised more than \$700,000 for LOTSS research via the [Katie & Allie Buryk Fund](#), and they are sponsors of The Think Tank. NTSAD and National Human Genome Research Institute (NHGRI) help organize the event and steward its ongoing priorities. Special thanks to Cynthia Tifft MD, PhD (NHGRI) and Steve Walkley DVM, PhD (Albert Einstein College of Medicine) for organizing and co-chairing the meeting.

Late Onset Community's Journey to Diagnosis

At **NORD's** recent Breakthrough Summit, Sanofi Genzyme presented the company's poster illustrating the often-arduous diagnostic journey of patients, caregivers, and families affected by Late-Onset GM2 Gangliosidosis. As the Summit is the largest gathering of key stakeholders in the rare disease community, the information heightens awareness of the heterogeneity of the disease and will help accelerate future diagnosis.

Late-onset GM2 Gangliosidosis Patient Journey

LATE-ONSET TAY SACHS/SANDHOFF (GM2)

- Rare, neurodegenerative lysosomal storage disorders
- Tay Sachs disease is caused by mutations in the HEXA gene which result in excessive accumulation of gangliosides (lipids) in the brain and nerve cells*
- Sandhoff disease results from mutations in the HEXB gene*

OBJECTIVES

Understand the physical and emotional aspects of the patient's journey, including symptom onset, diagnosis, and ongoing disease management.

METHODS

- 18 surveys and interviews with late-onset Tay Sachs/Sandhoff (GM2) patients (n=13) and caregivers (n=5) in the US
- All patients/caregivers 18+ years of age
- 5 interviews with GM2 expert physicians in the US, UK, DE, and ES
- Research currently ongoing; poster summarizes interim findings

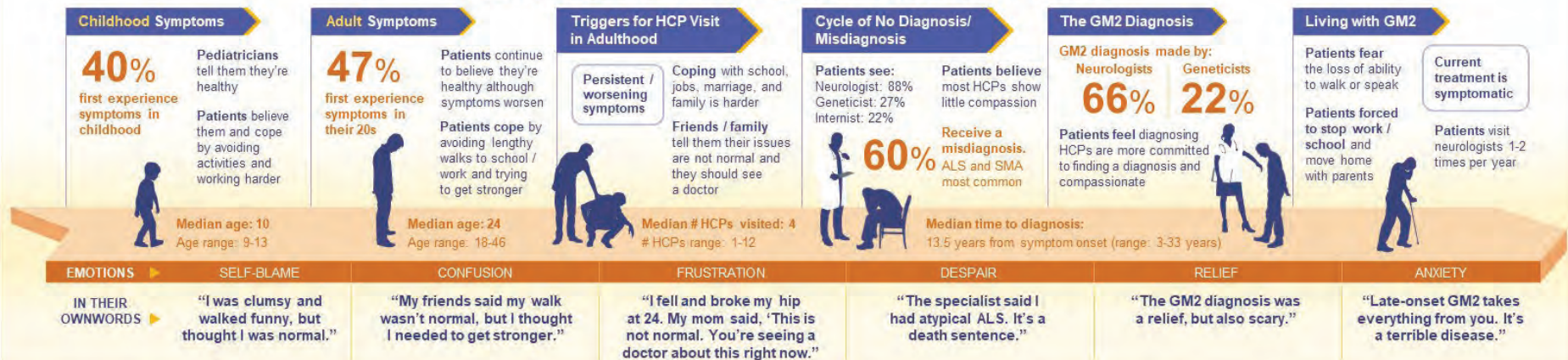
CONCLUSIONS

Symptoms typically emerge in childhood or young adulthood. Diagnosis often takes over a decade; common misdiagnoses include Amyotrophic Lateral Sclerosis (ALS) and Spinal Muscular Atrophy (SMA). Treatment is limited to symptomatic management and patients are often frustrated with healthcare providers. Patients lose the ability to perform activities of daily living and fear the complete loss of an independent life.

AUTHORS

Mariah C. LOPSHIRE, MS¹
 Selena FREISENS, MD¹
 Milos PETROVIC, MD, PhD¹
 Mason M. BENJAMIN, PharmD¹
 John BURNS, PhD²
 Rebecca GOULD²
 Kathy NGUYEN²
¹ Sanofi Genzyme, Cambridge, MA, USA
² Fulcrum Research Group, Waltham, MA, USA

THE LATE-ONSET TAY SACHS/SANDHOFF (GM2) PATIENT JOURNEY



EARLIER SYMPTOMS				LATER SYMPTOMS			
% Who Experience				% Who Experience			
Always use handrails on stairs; climb stairs with two feet on each step	Awkward walking / running / waddling	Legs weak and tire easily after running / walking	80%	Legs	90%	Can't climb stairs; move to single floor home; install ramps / rails	Walk only with cane, walker, or in wheelchair
Frequent falls; difficulty playing sports				Balance	75%	Falls even more frequent, sometimes resulting in fractured or broken bones	
Tire more easily than others				Fatigue	75%	Tire walking any distance; always fatigued; difficult to work	
Depression resulting from symptomatology	Mood swings resulting from symptomatology	Short-term memory loss	Inability to focus	Mental Health	50%	Less depressed after diagnosis; diagnosis a relief that reduces self-blame	Short-term memory loss intensifies; lose ability to manage daily tasks (e.g., dressing, bathing)
Arm weakness, difficulty with sports				Arms	70%	Arms too weak to push up from sitting position; requires assistance	Inability to focus makes work difficult/impossible
Clumsy, always dropping things				Speech	50%	Difficulty grasping, carrying, opening objects; unable to perform daily tasks in home	
Slurred, slowed speech						Worsening speech, sometimes becoming incomprehensible	

EXPERT PHYSICIAN PERSPECTIVE

"Neurologists in the community would almost never diagnose GM2. It's difficult for me, and I specialize in rare conditions. It's a multi-systemic storage disorder and extremely rare. We need early referrals and genetic testing to diagnose tough patient cases like GM2."

— Physician, UK

SANOFI GENZYME

*Adapted from National Organization of Rare Disorders (<https://rarediseases.org/rare-diseases/tay-sachs-disease/>)

Advocacy Efforts Lead to Newborn Screening Law in North Carolina

Newborn screening (NBS) is essential for early diagnosis and treatment of rare genetic diseases, like Tay-Sachs, Canavan, GM1 and Sandhoff, particularly for participation in clinical trials. To help ensure that babies born in every state have the same opportunity for early diagnosis and treatment, advocacy groups are working to pass legislation on the local level. The laws, referred to as RUSP (Recommended Uniform Screening Panel) alignment legislation, require states to screen newborn babies for any disorder on the federal RUSP panel. The laws also implement a timeline in which the screening must begin and ensure that resources will be available to fund all conditions added to the RUSP in the future.

Six states have adopted RUSP alignment legislation, including California in 2016, Florida in 2017, and Georgia, Ohio, Arizona, and now North Carolina in 2021. The current momentum of passing this potentially life-saving legislation is a result of the tireless efforts of advocates urging states to keep pace with science.

NTSAD Awards Grant to Sustain Tay-Sachs Sheep



NTSAD has awarded a grant to Heather Gray-Edwards, PhD at the University of Massachusetts Medical School (UMMS) to sustain the flock of Tay-Sachs sheep for the next year for researchers as this sheep model is considered to be the most similar to the Late Onset form of Tay-Sachs in humans.

Animal models that mimic human diseases are essential at all stages of research but are often difficult and expensive to create. Large animals, such as the Tay-Sachs Disease sheep, are particularly valuable for preclinical work that ensures the safety of

a treatment or a drug. Therefore, maintaining the TSD sheep flock is important to enable future research towards developing a cure for Tay-Sachs and Sandhoff diseases.

During the last 12 years, NTSAD has invested more than \$400,000 toward research involving the TSD sheep model, including maintenance when the flock was first identified at the Horaks' farm in Texas, and then when they were housed at Auburn University. Previously, NTSAD made a grant to Doug Martin PhD and Auburn University to prove safety and efficacy in the Tay-Sachs sheep model. Later, after Dr. Gray-Edwards and the sheep relocated to UMass Medical School, NTSAD awarded another grant to determine the efficacy of adeno associated viral (AAV) gene therapy after cerebrospinal fluid (CSF) delivery in the TSD sheep.

Thank you [Katie & Allie Buryk Research Fund](#), [the Heringer Fund](#), the LOTS Research & Educational Foundation, and [Vera's Fund](#) for support to sustain the flock of sheep.

Gottlieb Scholarship Recipients

For 16 years, Judy Gottlieb has been showing support of NTSAD families via the Jeffrey Alan Gottlieb and Stanley N. Gottlieb Memorial Scholarships established in May 2005 in honor of her youngest son, Jeffrey Alan Gottlieb, who succumbed to Tay-Sachs in 1975, and her husband, Stanley N. Gottlieb, who passed away in 2001. The Scholarships provide funds for college to healthy siblings in families affected by Tay-Sachs, Canavan, GM1, and Sandhoff diseases.

The 2021 Jeffrey Alan Gottlieb and Stanley N. Gottlieb Memorial Scholarship recipients are:

Matthew Kennedy, brother of Caitlin, who had Sandhoff disease, is a first-year student attending Schreiner University. Matthew is studying pre-nursing, in honor of his sister and the many nurses who cared for her.

“Through helping other people when they are ill and extending help to their family, I can return the support and kindness offered to Caitlin and my family through our difficult journey.”



Gavin Levine, brother of Lila, who had Tay-Sachs disease, is a freshman in the Honors Program at Ohio State University. Gavin is pursuing a degree in biology and his interests include biotechnology and research, which he hopes to use to prevent others from losing a child.

“I envision I will use my study of biology to honor Lila’s life by working to give those like her a chance to live.”



Gottlieb Scholarship Recipients

Zachary Richards, brother of Cooper, who had GM-1 disease, is inspired by his brother and the nurses who cared for him. Zachary is studying nursing at Curry College.

"My dream is to become a nurse, so I can give back and work with children that have genetic disorders like Cooper...My brother lived a life that was important."



Aaron Ronaldson, the brother of Mollie and Madelyn who both have Juvenile Sandhoff disease, is a freshman at Liberty University, majoring in mechanical engineering.

"I hope to find new ways to design a lighter weight, more compact wheelchair for my sisters and others like them. I will always be thinking of them as I learn."





NTSAD ANNUAL **FAMILY** CONFERENCE

JULY 7-10, 2022



RENAISSANCE DENVER CENTRAL PARK HOTEL | DENVER, COLORADO

For the first time in more than three years, NTSAD families, researchers, clinicians, and rare allies will be gathering in person for the 44th Annual Family Conference. Whether you are a family, or an individual affected by Canavan, GMI, Sandhoff, or Tay-Sachs and coping with a diagnosis, providing care, or healing from a recent or enduring loss, the conference provides the latest updates in research, resources, and support for you. All are welcome.



join us!



National Tay-Sachs &
Allied Diseases Association

2001 Beacon Street, Suite 204, Boston, MA 02135

(617) 277-4463 | www.NTSAD.org



Day of Hope 2021

Through the extraordinary efforts of NTSAD's community members, their friends and families, the 2021 Day of Hope raised more than \$50,000 for research thus far.

This year marked the 11th Anniversary of Day of Hope and a decade of Hope! Day of Hope events unite people in our shared cause to find effective treatments. Since September 2011, our community has raised nearly **\$550,000 for the NTSAD Research Initiative.**

Thanks to families and companies participating in Day of Hope and raising rare awareness and money for research. Because of you, there are now clinical trials for Tay-Sachs, Canavan, GM1, and Sandhoff Diseases



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**.



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?

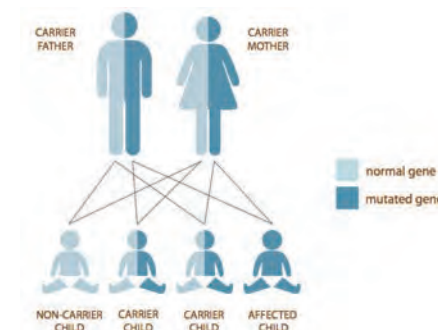
Our genes come in pairs, one from each parent. A carrier of a recessive disease is an individual who has a mutation in one copy of a particular gene that causes the gene not to function properly. Since carriers have a second working copy of the gene, they generally do not develop any symptoms of the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

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. Zeiger, 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 - 2021 – Clinical trials launched

National Tay-Sachs & Allied Diseases Association

thanks

Gus Sirot

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



My Dear Susan,

*We've shared so many wonderful moments in our lives—
We've often said how blessed we are to have traveled the
world – saw six beautiful grand and great grandchildren
brought into the world who would bring us so much joy—
Singing, dancing, laughing and look around every
moment to see if you were smiling...and you were.*

*I cherish the happiness you've brought into my life—from the
very first night we met...WE KNEW...a year later we married
and it has been a wonderful and happy 36 year journey...*

Our memories will last forever—I will talk about them to anyone who will listen.

REST IN PEACE my darling, best friend—“SCOOTER SUE”... my wonderful Susan...

You will be missed by everyone whose life you've touched....

I will love you forever...

Gus

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

Talia

Vania

In memory of
My Beloved Husband Charlie

You will always be my love.

I will always miss you.

You were the very best!

Rest in peace,

Marion

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 Memory of

Sue Sirot

*Who, with her devoted Gus, produced and funded
the printed calendar of recorded tributes,
raised huge funds for NTSAD over a multitude of years.
Let her memory be a blessing and a joyful solace in itself,
for her family and friends*

Claire & Cliff Kahn

*In loving memory of our
son & brother*

RAPHI HABERBERG

Gili, Benjamin, Ari & Karen



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 Memory of Our Parents

Barbara & Burton Salomon

Our Grandparents

**Al, Carrie, Jerry & Irma
and our Cousin Donna**

With Much Love,

Doug & Alan Salomon

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



In Memory of Fran Berkwits

*with love and great admiration
in this year which would have been
your 100th birthday*

*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.

In honor of
Marion Yanovsky

*YOUR dedication, passion and love for
the lives you touch is endless...*

YOU are the best!!!

We love you,

Susan, Alan, Jason and Bryan

In loving memory of

Charlie Yanovsky

*We are the luckiest children and grandchildren
to have been blessed with your love and
the time we spent together*

You are in our hearts forever,

Susan, Alan, Jason and Bryan

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
and in Tribute to
our mother

'A Woman of Valor'

אשת חיל

Jennie Gottlieb

Du Du Liegst Mier In Herzen



In Memory of

Lila & Daniel Jacobson

With thanks from NTSAD

for all you did in the "early years"

to get us to where we are today!

In loving memory of

Jerome Sirot

Susan Sirot

Remembered and Loved Always

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

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.

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SUNDAY

MONDAY

TUESDAY**WEDNESDAY****THURSDAY**

FRIDAY

SATURDAY

	<div>In Memoriam</div> <div>Harry Silberfarb January 3 Rose Weisfeld January 5 Herbert Gordon January 6 Samuel Eisenberg January 7 Bonnie Pastor January 7 Harold Feldman January 12 Sylvia Silberfarb January 17 Margo Isselbacher January 17 Beatrice Gecht January 28 Jane Eisenberg January 29</div>					1
2	3 <div>Rona Devane</div>	4	5	6 <div>Emily Kate Gentile Marissa Heringer Rebecca Heringer</div>	7 <div>4:25</div> <div>Peter Roimisher Rose Price Cooley</div>	8 <div>David Sirot</div>
9 <div>Noah Philip Devane</div>	10	11 <div>Geoffrey Zack Wasserman Andrew David Markinson</div>	12	13	14 <div>4:32</div> <div>Robyn Finkel Kohen</div>	15
16	17 <div>Renée Hasman Nolan Russell Wasserman MARTIN LUTHER KING, Jr BIRTHDAY OBSERVED</div>	18	19	20	21 <div>4:41</div> <div>Mia Levy</div>	22 <div>Charlie Levy</div>
23	24	25	26 <div>Barbara & Gary Feldman</div>	27	28 <div>4:49</div>	29
30	31					

In loving memory

**Estelle Krakaur
Lauri Jill Adelsberg
Gertrude Adelsberg
George Corn
Lilly Corn**

In Memory of
Gertrude Bertinthal
and

Seth Kupperman

*Elyse & Matt Chaifetz
Piper & Ethan
Mili and Harris Kupperman*

In Support of Research

Sandy Levine

In Loving Memory of
Susan Sirot
*A dear friend who has touched
so many hearts.
The world has lost a true gem.
May she rest in everlasting peace.*

*Love,
Judi, Jason, Elyssa &
Corie Shapiro & Family*

January 2022

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March 2022

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February 2022

SUNDAY

MONDAY










TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

		1	2	3	4  4:58	5
			GROUNDHOG DAY	 Bernard Finkel	 Alyson Lifshitz	
6	7	8	9  Nicole Mansour Dzitire	10	11  5:07  Brayden Harris Greenhut  Binyamin Naftalowitz	12  Bobby Handwerker  Tzvi Naftalowitz  Caroline Zamel
13	14  Bryan Zachery Roden VALENTINE'S DAY	15	16	17  Dave & Esmeralda Sirof	18  5:15  Anaelle Bedziner	19
20	21  Reese Goldstein PRESIDENT'S DAY	22  Bryan Markinson	23  Steven Yanovsky	24  Sheila Cohen	25  5:24	26  Adam Davis
27	28	<div> <div>In Memoriam</div> <div> <div>Sydney Levy</div> <div>February 9</div> </div> <div> <div>Charlotte Stark</div> <div>February 11</div> </div> <div> <div>William Yanovsky</div> <div>February 15</div> </div> <div> <div>Harrison Hoffman</div> <div>February 17</div> </div> <div> <div>Ida Jacobson</div> <div>February 19</div> </div> <div> <div>Burton Salomon</div> <div>February 22</div> </div> <div> <div>Bernard Gecht</div> <div>February 24</div> </div> </div>				<div>Visit our website: www.ntsad.org</div>

In Memory of My Dad and My Grandpa

Charles Yanovsky

Your forever charm, humor and magic tricks are missed.

*Santana will always play, while we drink pina coladas,
swim and take in your beautiful roses.*

You lived life on life's terms.

We miss you and love you so much!

Steven and Asher

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SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
		1 ♡ Caroline & Hasan Zamel	2 🍰 Jason Ross Roden	3	4 🕯️ 5:32 🍰 Eva Frances Gentile	5
6	7 🍰 Sophie Levy	8	9 🍰 Benjamin Matthew Wasserman	10	11 🕯️ 5:40	12 🍰 Jacob Benjamin Fine
13 DAYLIGHT SAVINGS MOVE CLOCK AHEAD	14 🍰 Ashley Feldman	15	16 🍰 Nicholas Troncoso	17 🍰 Shulamis Naftalowitz ST. PATRICK'S DAY	18 🕯️ 6:47 🍰 Jaden Shapiro	19
20 SPRING BEGINS	21 🍰 Eli Goldstein Jessica Lynn Wasserman 🍰 Mara Page Markinson	22	23	24	25 🕯️ 6:55	26
27 🍰 Zachary Kohen	28	29 🍰 Ann Brandt	30	31 🍰 Wayne Roimisher	<div>In Memoriam<div>Estelle GoldsteinMarch 3Lila JacobsonMarch 6Matthew Forbes RomerMarch 8Nathan SiderMarch 10Alan BergMarch 12Joel ChavisMarch 17Marcia FeinbergMarch 24Toby GottliebMarch 25Mary K. UsckyMarch 25</div></div>	

With all our love to our wonderful
and beautiful grandchildren

HADARA

ELIJAH

JONAH

JEREMIAH

TALIA

VANIA

POPPI GUS & GRANDMA SUE

In Memory of
Adam Davis
2/26/99 - 8/28/01

Deep thanks to
Sue Kahn's
amazing leadership!
– Ruth Feldman

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

In honor of our grandchildren
Sydney, Ben, Esther, Anna & Zoe
Lynda & Mel Schriever

March 2022

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May 2022

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April 2022

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

<div> <div>In Memoriam</div> <div> <div>Allen Levine</div> <div>April 2</div> </div> <div> <div>Alex Lifshitz</div> <div>April 12</div> </div> <div> <div>Alan Thaler</div> <div>April 16</div> </div> <div> <div>Albert Eisenberg</div> <div>April 21</div> </div> <div> <div>Barbara Salomon</div> <div>April 24</div> </div> <div> <div>Elaine Verona</div> <div>April 29</div> </div> </div>					1 <div> 7:03 </div> APRIL FOOL'S DAY	2 <div> Lee Finkel </div>
3	4	5 <div> Roberta Meyers David Goldstein </div>	6 <div> Hadara Abdul-Ghani </div>	7	8 <div> 7:10 </div>	9
10 PALM SUNDAY	11 <div> Chaim Thaler </div>	12	13	14	15 <div> 7:18 </div> GOOD FRIDAY TAX DAY 1ST SEDER EREV PASSOVER	16 <div> Gregory Hasman </div> PASSOVER
17 <div> Hayden Skyler Roimisher Yocheved Thaler </div> EASTER PASSOVER	18 PASSOVER	19 <div> Ross Silberfarb </div> PASSOVER	20 <div> Ethan Cantor </div> PASSOVER	21 PASSOVER	22 <div> 7:25 </div> <div> Hal Lifshitz </div> EARTH DAY PASSOVER	23 PASSOVER
24	25 <div> Susan & Alan Roden Amanda Megan Gecht </div>	26 <div> Talia Abdul-Ghani Vania Abdul-Ghani Easton Benbasset </div>	27 <div> Diane Toner Gentile </div>	28	29 <div> 7:32 </div> <div> Taylor Ceil Benbasset </div> ARBOR DAY	30

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

April 2022

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June 2022

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May 2022

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

1	2  Corie Shapiro	3	4	5	6  7:40	7
8 MOTHER'S DAY	9  Richard David Chudnick	10  Alice Finkel Markinson	11	12  Samira Zamel Troncoso	13  7:47	14
15	16	17  Julie Feldman  Noa Levy	18  David & Heather Levy  Nadia Zamel	19  Gary Gecht	20  7:54	21  Matthew Forbes Romer
22	23	24  Michele Goldman	25	26	27  8:00	28  Rona & Michael Devane
29	30  David Fine  Elise Heringer  Charles Yanovsky MEMORIAL DAY	31  Michelle Finkel  Jennifer Colton	<div> <div>In Memoriam</div> <div> <div>Errol Yanovsky</div> <div>May 2</div> </div> <div> <div>Stanley Michelman</div> <div>May 7</div> </div> <div> <div>Jack Zimmer</div> <div>May 8</div> </div> <div> <div>Benjamin Gecht</div> <div>May 9</div> </div> <div> <div>Anne Yanovsky</div> <div>May 19</div> </div> </div>			

Happy 80th Birthday to
Marion Yanovsky
“One of a Kind”
Love,
Maddy & Herb Roimisher

Happy High School Graduation
June 2022

Riley Page Roimisher
& William Jacobs

In memory of
Sue Sirot
Sandi Plotkin & Family

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

In honor of
our great-granddaughter
Layla Mackenzie Preiser
Sheila & Lee Cohen

In Loving Memory of
Bonnie Pastor

"Eric's Mom" and founder of the
Late Onset Tay-Sachs Research
& Education Foundation
to raise money for research

With appreciation from
your NTSAD family

In honor of our grandchildren
Adam Taylor Chaitin
Alexandria Rae Chaitin
Jeremy Scott Chaitin
Paul Nunzio Chaitin
Paul & Sandra Chaitin

May 2022

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July 2022

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24 25 26 27 28 29 30
31

June 2022

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

<div>Research Updates at www.ntsad.org</div>			1 <div><div> Brian Finkel</div><div> Esmeralda Sirot</div></div>	2	3 <div><div> 8:05</div></div>	4
5	6	7 <div><div> Matthew Feldman</div><div> Lior Levy</div></div>	8 <div><div> Lee Cohen</div></div>	9	10 <div><div> 8:10</div></div> <div><div> Michael Silberfarb</div></div>	11 <div><div> Shawn Silberfarb</div></div>
12 <div><div> Lillian Sherman</div><div> Natan Thaler</div><div> Lisa & Griffith Holland</div></div>	13 <div><div> Scott Harris Gentile</div></div>	14 FLAG DAY	15 <div><div> Stacy Campbell</div></div>	16	17 <div><div> 8:13</div></div>	18
19 FATHER'S DAY	20 <div><div> Heath Feldman</div></div>	21 <div><div> Matthew Lawrence Gentile</div></div> SUMMER BEGINS	22 <div><div> Jayden Campbell</div></div>	23 <div><div> Sharon Silberfarb</div><div> Elise & Emil Heringer</div></div>	24 <div><div> 8:14</div></div> <div><div> Jason Shapiro</div></div>	25
26	27 <div><div> Miriam Thaler</div><div> Mitchell Gordon</div></div>	28 <div><div> Susan & Bill Boorstein</div></div>	29	30 <div><div><div>In Memoriam</div><div><div><div>Harold Gottlieb</div><div>June 4</div><div>Gita Katz</div><div>June 24</div></div><div><div>Sarah Finkel</div><div>June 8</div><div>Sidney Finkel</div><div>June 26</div></div><div><div>Charles Goldstein</div><div>June 8</div><div>Sheila Donner</div><div>June 27</div></div><div><div>Harold Goldstein</div><div>June 13</div><div>Matthew Feldman</div><div>June 27</div></div><div><div>Sami Elena Mansour</div><div>June 13</div><div>Frances Berkwits</div><div>June 29</div></div><div><div>William Romer</div><div>June 21</div><div></div><div></div></div></div></div></div>		

In loving memory of

Helaine Seccia

“A lifelong friend”

Gus Sirot

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SUNDAY**MONDAY****TUESDAY**

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

<div><div>In Memoriam</div><div><div>Leon Finkel</div><div>July 3</div></div><div><div>Dillon Henry</div><div>July 6</div></div><div><div>Sylvia Farber</div><div>July 18</div></div><div><div>Leonard Chudnick</div><div>July 20</div></div><div><div>Irwin Ungerleider</div><div>July 21</div></div><div><div>Karl Yanovsky</div><div>July 31</div></div></div>		<div>NTSAD</div> <div>www.ntsad.org</div> <div>617-277-4463</div>			1 <div><div></div><div>8:14</div></div>	2 <div><div></div><div>Jon Boorstein</div></div>
3	4 <div>INDEPENDENCE DAY</div>	5 <div><div></div><div>Charles Gentile</div></div>	6 <div><div></div><div>Leigh Boorstein</div></div>	7 <div><div><div></div><div>Joshua Andrew Devane</div></div><div><div></div><div>Carol Handwerker</div></div></div>	8 <div><div></div><div>8:12</div></div> <div><div><div></div><div>Marion & Charles</div><div>Janoosky</div></div></div>	9
10	11 <div><div></div><div>Emily Charlez Fine</div></div>	12 <div><div><div></div><div>Dennis Finkel</div></div><div><div></div><div>Bruce Goldman</div></div></div>	13	14	15 <div><div></div><div>8:09</div></div>	16 <div><div></div><div>Jared Craig Sakolsky</div></div>
17	18 <div><div></div><div>Gloria Levenson</div></div>	19 <div><div><div></div><div>Ava Skye Weinstock</div></div><div><div></div><div>Taylor Jenna Weinstock</div></div><div><div></div><div>Lori R. Goldman</div></div></div>	20	21 <div><div></div><div>Scott J. Goldman</div></div>	22 <div><div></div><div>8:04</div></div> <div><div><div></div><div>Kourtney Brooke Lavin</div></div></div>	23
24	25 <div><div></div><div>Jonah Dzitrie</div></div>	26 <div><div><div></div><div>Howard & Riva Levy</div></div></div>	27 <div><div><div></div><div>Michele & Bruce</div><div>Goldman</div></div></div>	28 <div><div></div><div>Elyssa Shapiro</div></div>	29 <div><div></div><div>7:57</div></div>	30 <div><div></div><div>Fern Finkel Gentile</div></div>
31						

In Loving Memory of
Emma Faith Zimmerman

An angel in the book of life,
Wrote down my baby's birth.
Then whispered as she closed the book,
"Too beautiful for Earth."

With Love
Dad, Mom and Jackson

In loving memory of
Charlie Yanovsky
Cherished "brother" and uncle
Forever in our hearts

Ann, Rona, Michael, Lisa, Skip,
Nathan, Noah, Joshua, and Aria

July 2022

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September 2022

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August 2022

SUNDAY

MONDAY


TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

	1	2	3	4  Samantha Gordon	5  7:49  Charlie Gecht	6
7  Steven Greg Chudnick	8	9	10	11	12  7:40	13
14  Scott Finkel  Alyse Gordon	15	16  Elaine Levy	17	18  Scott Brian Fine  Daniel Silberfrab  Avraham Thaler	19  7:30	20
21  Marc Robinson	22	23	24	25  Racy & Noah Cantor  James Colton	26  7:20  Joan Kantz	27  Jill Feldman
28  Layla Campbell	29	30	31	<div> <div>In Memoriam</div> <div> <div>Sarah Pinger</div> <div>August 7</div> </div> <div> <div>Phyllis Chavis</div> <div>August 9</div> </div> <div> <div>Shirley Leib</div> <div>August 10</div> </div> <div> <div>Wendy Gordon</div> <div>August 16</div> </div> <div> <div>Scott Peter Colton</div> <div>August 16</div> </div> <div> <div>Jerry Sirot</div> <div>August 20</div> </div> <div> <div>Ray Colton</div> <div>August 22</div> </div> <div> <div>Saul Donner</div> <div>August 26</div> </div> <div> <div>Adam Davis</div> <div>August 28</div> </div> </div>		

In Honor of Sue Kahn

NTSAD flourished under your leadership.

Thank you for your commitment, dedication and passion.

*It was a pleasure and honor to work with you through
my different roles on the Board.*

Shari Ungerleider

SHAPIRO LAW OFFICES

JASON S. SHAPIRO
ATTORNEY AT LAW

3205 GRAND CONCOURSE, SUITE 1
BRONX, NEW YORK 10468
TEL: (718) 295-7000 • FAX: (718) 295-7575

WWW.SHAPIROLAWOFFICES.COM
JS@SHAPIROLAWOFFICES.COM

August 2022

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October 2022

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September 2022

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

<div> <div>In Memoriam</div> <div> <div>Ceil Benbasset</div> <div>September 9</div> </div> <div> <div>Sheila Wasserman</div> <div>September 10</div> </div> <div> <div>Leo Diamond</div> <div>September 14</div> </div> <div> <div>Jack Finkel</div> <div>September 16</div> </div> <div> <div>Carole Colton</div> <div>September 29</div> </div> <div> <div>Sue Sirot</div> <div>September 29</div> </div> </div>				1	2 <div> <div>7:08</div> <div>Jonah Goldstein</div> </div>	3
4	5 <div> <div>Ryan Andrew Silberfarb</div> <div>LABOR DAY</div> </div>	6	7	8 <div> <div>Jacob Silberfarb</div> <div>Ellen Fine</div> <div>Alia Zamel</div> </div>	9 <div> <div>6:57</div> </div>	10 <div> <div>Jadyn Kohen</div> </div>
11 <div> <div>Griffith (Skip) Holland</div> <div>Michael Gary Chudnick</div> </div>	12 <div> <div>Cody Miles Gecht</div> </div>	13 <div> <div>Brandon Spencer Gecht</div> <div>Dayna Lynn Gecht</div> </div>	14	15	16 <div> <div>6:45</div> </div>	17 <div> <div>Gerri Colton</div> </div>
18 <div> <div>Emma Zimmerman</div> </div>	19 <div> <div>Samuel Wager Chudnick</div> </div>	20 <div> <div>Miriam Anna Gentile</div> </div>	21 <div> <div>Sophie Goldstein</div> </div>	22 <div> <div>Katherine Gentile Vairo</div> <div>AUTUMN BEGINS</div> </div>	23 <div> <div>6:33</div> </div>	24 <div> <div>Andrew Militscher</div> </div>
25 <div> <div>Caroline Wager Chudnick</div> <div>EREV ROSH HASHANAH</div> </div>	26 <div> <div>Leah Paige Wasserman</div> <div>ROSH HASHANAH</div> </div>	27 <div> <div>ROSH HASHANAH</div> </div>	28 <div> <div>Michael S. Goldman</div> </div>	29 <div> <div>Mitchell Ray Jacobs</div> </div>	30 <div> <div>6:21</div> <div>Evelyn Goldman</div> <div>Justin Frank Zimmer</div> <div>Matthew Neil Zimmer</div> </div>	

In Loving Memory of
Harrison Hoffman

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

Love,
Mommy, Daddy & Jake

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SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

	<div><div><div><div><div></div><div>In Memoriam</div><div></div></div><div><div><div><div><div>Geraldine Finkel</div><div>October 3</div></div><div><div>Robert Meyers</div><div>October 3</div></div><div><div>Alex Pinger</div><div>October 4</div></div><div><div>Harriet Lurie</div><div>October 5</div></div><div><div>Anna Finkel</div><div>October 8</div></div><div><div>Henry Sirot</div><div>October 9</div></div><div><div>Sophie Gecht</div><div>October 12</div></div></div><div><div><div><div><div>Steven Berg</div><div>October 19</div></div><div><div>Joseph Gentile</div><div>October 26</div></div><div><div>Stella Zimmer</div><div>October 27</div></div><div><div>Dorothy Zaretsky</div><div>October 28</div></div><div><div>Leon Jacobson</div><div>October 29</div></div><div><div>Miriam Finkel</div><div>October 30</div></div></div></div></div></div></div></div></div></div>					1
2 <div><div><div></div><div>Spencer Markinson</div></div></div>	3 <div><div><div></div><div>Riley Paige Roimisher</div></div></div>	4 <div><div><div><div><div></div><div>Elise Rae Gecht</div></div></div><div>EREV YOM KIPPUR</div></div></div>	5 <div><div><div><div><div></div><div>William Gentile</div></div></div><div>YOM KIPPUR</div></div></div>	6	7 <div><div><div><div></div><div>6:09</div></div></div></div>	8 <div><div><div><div></div><div>Daniel Ian D'Amato</div></div></div></div>
9 <div><div><div></div><div>Meryl Gordon</div></div></div>	10 <div><div><div>COLUMBUS DAY</div></div></div>	11 <div><div><div><div><div></div><div>Michael Devane</div></div><div><div></div><div>Joe Rattien</div></div><div><div></div><div>Michael Gary Chudnick</div></div></div></div></div>	12	13 <div><div><div><div></div><div>Barbara Hasman</div></div></div></div>	14 <div><div><div><div></div><div>5:58</div></div></div></div>	15
16 <div><div><div></div><div>Maya Jade Benbasset</div></div></div>	17 <div><div><div></div><div>Matthew Gordon</div></div></div>	18 <div><div><div><div></div><div>Elijah Dzitrie</div></div></div></div>	19	20 <div><div><div><div></div><div>Erin Finkel</div></div></div></div>	21 <div><div><div><div><div></div><div>Jack Zimmerman</div></div><div><div></div><div>Jerimah T.C. Snyder</div></div><div><div></div><div>Anthony Gentile</div></div><div><div></div><div>Jack Zimmerman</div></div></div></div></div>	22 <div><div><div><div></div><div>Arlene Gecht Koral</div></div></div></div>
23 <div><div><div></div><div>Davie Benbasset</div></div></div>	24	25 <div><div><div><div><div></div><div>Caroline Wager Chudnick</div></div><div><div></div><div>Brittany Sari Zimmer</div></div></div></div></div>	26 <div><div><div><div></div><div>David Silberfarb</div></div></div></div>	27 <div><div><div><div><div></div><div>Robert Nathan Wasserman</div></div><div><div></div><div>Eric Jason Fine</div></div></div></div></div>	28 <div><div><div><div></div><div>5:38</div></div></div></div>	29 <div><div><div><div></div><div>Adam Brian Gecht</div></div></div></div>
30	31 <div><div><div><div><div></div><div>Zachary Cantor</div></div><div><div></div><div>Marion Yanovsky</div></div></div></div><div>HALLOWEEN</div></div>				<div><div><div></div><div>Pasquale Vairo</div></div></div>	

In Loving Memory of Sue Sirot

*We extend our deepest sympathy for the loss of our beloved Sue Sirot to
her loving Gus, her family, and all her loved ones.*

We are so grateful for her lifelong dedication and support for NTSAD.

*Her big heart, and lust for life will “cruise”
on with everyone that knew her.*

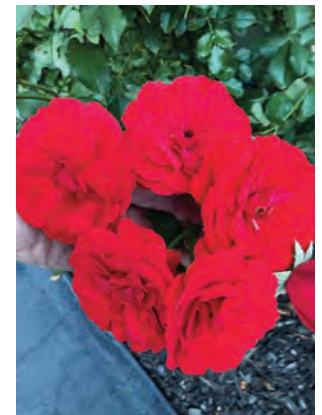
**Your American Idols,
The Heringer Family**



**C - CHARMING
H - HILARIOUS
A - ADORED
R - ROSES
L - LAUGHTER
I - INGENIOUS
E - EASYGOING**

He will be missed by all

*Love,
Inez ♡*



October 2022

2	3	4	5	6	7	8
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December 2022

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November 2022

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

		1	2	3	4 <div><div></div>5:28</div>	5 <div><div></div><div>Brian Craig Koral</div><div>Hasan Zamel</div></div>																																				
6 <div><div>DAYLIGHT SAVINGS ENDS</div><div>MOVE CLOCK BACK</div></div>	7 <div><div></div>Lisa Holland</div>	8 <div><div></div>Rivka Naftalowitz</div> <div>ELECTION DAY</div>	9 <div><div></div>Hailey Silberfarb</div>	10	11 <div><div></div>4:21</div> <div><div></div>Lew Kantz</div> <div><div></div>Nathan Edward Devane</div> <div>VETERANS DAY</div>	12																																				
13 <div><div></div><div>Myron & Joshua Kurvit</div></div>	14 <div><div></div>Cyrus Jude Benbasset</div> <div><div></div>Mitchell Ira Fine</div>	15	16 <div><div></div>Alan Finkel</div>	17	18 <div><div></div>4:15</div> <div><div></div>William Scott Jacobs</div> <div><div></div>Serena Hope Markinson</div>	19																																				
20	21 <div><div></div>Cameron Troncoso</div>	22	23 <div><div></div><div>Maddie & Herb Roimisher</div><div><div></div>Edith Berg</div></div>	24 <div><div></div><div>Sheila & Lee Gohen</div><div><div></div>Alisa Lifshitz</div><div>THANKSGIVING DAY</div></div>	25 <div><div></div>4:11</div>	26 <div><div></div>Brenna Finkel</div>																																				
27 <div><div></div>William Romer</div>	28	29 <div><div></div>Rachel Thaler</div>	30	<div><div>In Memoriam</div><table><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>Robert Plotkin</td><td>November 12</td><td>Irving Zaretsky</td><td>November 25</td></tr><tr><td>Stephen Silberfarb</td><td>November 15</td><td>Noah Jarashow</td><td>November 30</td></tr><tr><td>Owen Brandt</td><td>November 17</td><td></td><td></td></tr></table></div>			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	Robert Plotkin	November 12	Irving Zaretsky	November 25	Stephen Silberfarb	November 15	Noah Jarashow	November 30	Owen Brandt	November 17		
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Stephen Silberfarb	November 15	Noah Jarashow	November 30																																							
Owen Brandt	November 17																																									

In loving memory of

Sue Sirot

*She loved her family and her friends.
She was always a caring and giving person.*

**We Will Miss You,
Nadine, Gene & Joe Rattien**

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

November 2022

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January 2023

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December 2022

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

<div> <div>In Memoriam</div> <div> <div>Jack Litt</div> <div>December 3</div> </div> <div> <div>Lorraine Gettleman</div> <div>December 4</div> </div> <div> <div>Estie Zausner</div> <div>December 5</div> </div> <div> <div>Jeanette Thaler</div> <div>December 7</div> </div> <div> <div>Estelle Gordon</div> <div>December 8</div> </div> <div> <div>Seymour Thaler</div> <div>December 16</div> </div> <div> <div>Charles Yanovsky</div> <div>December 16</div> </div> <div> <div>Hayden Lord</div> <div>December 22</div> </div> <div> <div>Evan Ungerleider</div> <div>December 23</div> </div> <div> <div>Fred Goldberg</div> <div>December 23</div> </div> </div>				1	2 <div> <div>4:09</div> <div>Isabella Tori Zahl</div> </div>	3 <div> <div>Elena Vairo</div> </div>
4	5	6	7	8	9 <div> <div>4:09</div> <div>Adam Scott Koral</div> </div>	10
11 <div> <div>Kimberley Blake Lavin</div> <div>Chani Thaler</div> </div>	12	13 <div> <div>Vienna Lily Greenhut</div> </div>	14	15 <div> <div>Jennifer Chudnick</div> <div>Aliya Levy</div> <div>Asher Diamond Yanovsky</div> </div>	16 <div> <div>4:10</div> <div>Jordyan Lavin</div> </div>	17 <div> <div>Russell Matthew Jacobs</div> </div>
18 <div> <div>Harlow Benbasset</div> <div>CHANUKAH - 1 CANDLE</div> </div>	19 <div> <div>Marcia & Harvey Jacobson</div> <div>CHANUKAH - 2 CANDLES</div> </div>	20 <div> <div>CHANUKAH - 3 CANDLES</div> </div>	21 <div> <div>Aria Holland</div> <div>WINTER BEGINS</div> <div>CHANUKAH - 4 CANDLES</div> </div>	22 <div> <div>Alan Roden</div> <div>CHANUKAH - 5 CANDLES</div> </div>	23 <div> <div>4:13</div> <div>Jordan Conrad Gecht</div> <div>CHANUKAH - 6 CANDLES</div> </div>	24 <div> <div>CHRISTMAS EVE</div> <div>CHANUKAH - 7 CANDLES</div> </div>
25 <div> <div>Gus Sirot</div> <div>CHRISTMAS DAY</div> <div>CHANUKAH - 8 CANDLES</div> </div>	26 <div> <div>CHANUKAH - 8TH DAY</div> </div>	27 <div> <div>Olivia Vairo</div> <div>Jay David Sirot</div> </div>	28 <div> <div>Heather Lara Sakolsky</div> </div>	29	30 <div> <div>4:18</div> </div>	31 <div> <div>Emil Heringer</div> <div>NEW YEAR'S EVE</div> </div>

In memory of my beloved parents

Jeanette and Seymour Thaler

and my brother

Alan Mark Thaler

Together forever in Gan Eden

Phyllis Thaler

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SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	
1 NEW YEAR'S DAY	2	3 Rona Devane	4	5	6 4:24 Emily Kate Gentile Marissa Heringer Rebecca Heringer	7	Peter Roimisher Rose Price Cooley
8 David Sirot	9 Noah Philip Devane	10	11 Geoffrey Zack Wasserman Andrew David Markinson	12	13 4:31	14 Robyn Finkel Kohen	
15	16 MARTIN LUTHER KING, Jr BIRTHDAY OBSERVED	17 Renée Hasman Nolan Russell Wasserman	18	19	20 4:39	21 Mia Levy	
22 Charlie Levy	23	24	25	26 Barbara & Gary Feldman	27 4:48	28	
29	30	31			<div>In Memoriam<div>Harry SilberfarbJanuary 3</div><div>Rose WeisfeldJanuary 5</div><div>Herbert GordonJanuary 6</div><div>Samuel EisenbergJanuary 7</div><div>Bonnie PastorJanuary 7</div><div>Harold FeldmanJanuary 12</div><div>Sylvia SilberfarbJanuary 17</div><div>Margo IsselbacherJanuary 17</div><div>Beatrice GechtJanuary 28</div><div>Jane EisenbergJanuary 29</div></div>		

<u>In Memoriam</u>		
Harry Silberfarb	January	3
Rose Weisfeld	January	5
Herbert Gordon	January	6
Samuel Eisenberg	January	7
Bonnie Pastor	January	7
Harold Feldman	January	12
Sylvia Silberfarb	January	17
Margo Isselbacher	January	17
Beatrice Gecht	January	28
Jane Eisenberg	January	29

In loving memory of

Stephen and Toby Silberfarb

Barry & Carol Silberfarb & Family

*I am forever inspired by the strength, determination, openness,
generosity, and beauty of our NTSAD families.*

It is an honor working with you.

Staci Kallish

President

NTSAD Board of Directors, 2019-2022

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 Loving Memory of

Matthew Feldman

Beloved son of Sylvia Farber

In loving memory of

Jeanette & Seymour Thaler

and

Alan Thaler

Martin Thaler & Family

*In loving memory
of the best grandparents*

Helen & Leo Diamond

Susan Yanovsky Roden

GEM ADJUSTERS, LTD.
LICENSED PUBLIC ADJUSTERS

TEL: 718-352-7400
E-Fax: 484-918-2604
E-MAIL: HAROLD@GEMPUBLICADJUSTERS.COM

HAROLD GREENBLATT
PRESIDENT

55 NORTHERN BLVD., SUITE 303
GREAT NECK, NEW YORK 11021

In memory of my aunt

Marcia Feinberg

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

Susan Z. Cohen

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 LOVING MEMORY OF SUE SIROT

An infectious smile and outgoing personality
brought happiness to all who knew you.

Devotion to Gus and your family always came shining through.
Your friendship always warmed my heart.

We give thanks for your commitment and dedication
to raising funds for NTSAD to find a treatment and cure.

It has always been fun to work with you on the Annual Calendar.
You and Gus made it the success it has been for so many decades.

May your memory live on in the successes you have made possible.
You are greatly missed, but always remembered.

Rest in Peace.

With love,

Marion

NAM MYOHO RENGE KYO

BRUCE SINGLETON

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

Phyllis Pullman

In memory of

Sue Sirot

Janet Goodman

Gratitude for

***Sue Sirot's*
Years of Service!**

– Ruth Feldman

In memory of

Sylvia Farber

The Lifshitz Family

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

Sharyn Snyderman

Fred Schriever

Lynda & Mel Schriever & Family



RABBI DR. RONALD L. ANDROPHY
EAST MEADOW BETH-EL JEWISH CENTER

rabbiandrophy@yahoo.com
1400 Prospect Ave.
East Meadow, NY 11554

Office (516) 483-4205
Study (516) 489-4618
Fax (516) 489-3354

Wishing us all,
PEACE to bring comfort,
COURAGE to face the days ahead, and
LOVING MEMORIES of Charlie to forever
hold in our hearts.

Charlie's "Baby" Sister Barbara

In Loving Memory of Charlie Yanovsky

*As I look back over time, I find myself wondering....
if I ever thanked you for the very best times we had together –
like laughter, smiles and times we shared?
If I have forgotten to show gratitude enough for all the time we spent together,
I am thanking you now.
And I am hoping you knew all along how much you mean to my family and me.*

Sam

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 MEMORY OF OUR BELOVED DAUGHTER

RACHEL MEREDITH

FOREVER IN OUR HEARTS

IN HONOR OF OUR GRANDSONS

TYLER MATTHEW

ANDREW JARED

RHODA & FRED KANTER

In Memory of

Charlie Yanovsky

*This special, truly heroic man was the
beloved husband of Marion*

Together for over sixty years

*Adored by his children and grandchildren,
as well as life-long friends*

*May his memory serve as the greatest gift throughout
their lives and be their greatest comfort*

Claire & Cliff Kahn

In memory of

The Pingers

Sarah & Alex Pinger

Lester Pinger

Beatrice Gecht

Sylvia Farber

Stella Zimmer

Miriam Finkel

In Loving Memory of

Michael Alan Zeiger

and

Lila and Daniel Jacobson

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

We Miss You!

Karen & Robert Zeiger

In memory of
Anita Amerio
Susan Sirot
and
Jerry Sirot
Joyce Erwin

In loving memory of

Pearl Sirot

Henry Sirot

Jerry Sirot

Toby Gottlieb

Harold H. Gottlieb

Susan Sirot

and

Sami Elena Mansour

With thanks for the joy of

Hadara - April 6, 1994

Elijah - October 18, 1996

Jonah - July 25, 2000

Jeremiah - October 21, 2015

and

Talia - April 26, 2020

Vania - April 26, 2020

Gus Sirot

In Loving Memory of

SUSAN SIROT

SAMI ELENA MANSOUR

“A Moment of Joy”

United Forever

Gus Sirot and Nicole & Family

In loving memory of

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

The Sirot Family

In Loving Memory of

Sue Sirot

The NTSAD Community

*is grateful for your commitment and support
for research and family services
over many decades.*

We could not have come this far without you.

Rest in peace

Leading the fight for a cure

Judy & Corey Lev

In memory of our parents

Florence & Irving Turetsky

and our sister

Susan Barbara

1953-1955

Elaine & Barry Heimowitz

Linda & Steve Selip

In Loving Memory of Our Dear Friend

Sue Sirot

We will always miss you,

Craig & Caren Hirsch

In loving memory of

Helen & Leo Diamond

wonderful parents & grandparents

Marion Yanovsky

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 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

Anne & William Yanovsky

Karl Yanovsky

Errol Yanovsky

In memory of our beloved brother

Mark Howard

1968-1971

Bruce & Linda Feingold

*In Loving Memory of
My Dear Friend*

Sue Sirot

There is a hole in my heart 

Leslie Schwarz

In Honor of
Marion Yanovsky
&

In Memory of
Charlie Yanovsky

*Thank you both for being such wonderful
in-laws to Alan and loving grandparents to
Jason and Bryan*

With Love,
Charles and Leslie Roden

In Memory of
Cousin Susan Sirot

Love,
Cousins Deborah & Arthur Kupperman

In memory of our wonderful friend

Charlie Yanovsky

We think about you and miss you

Sheila & Lee Cohen

For Audrey

You will always be remembered

Much love,

Doug

In Recognition of
Sue Kahn

*Always welcoming smile
Dignified, optimistic, energetic
Empathetic, loving, giving
Supportive of families, caregivers
researchers and donors
Perpetually reaching out
Collaborating, not competing
Uncanny ability to bring all
stakeholders into the fold*

***In admiration for all you have
accomplished for NTSAD
Drs. Edwin & Roselyn Kolodny***

***Dedicated to
The Memory of
Charles Yanovsky***

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Thank You

Because of your donations, you have helped to bring about new and exciting FDA clinical trials for treatments for all those suffering each and every day from Tay-Sachs - including late-onset.

And now - with these treatments and a possible cure so very, very close at hand, we ask for your help to finally turn these hopes and promises into a beautiful reality.

Gratefully,

Aunt Carol Handwerker

I am forever inspired by the strength, determination, openness, generosity, and beauty of our NTSAD families.

It is an honor working with you.

Staci Kallish

President

NTSAD Board of Directors, 2019-2022

In Honor of Sue Kahn

During the time I have volunteered with NTSAD, I have worked
with many special people who have become special friends.
Sue, you are a special friend.

It has been an honor to work with you all these years. I celebrate you for
all you have accomplished over the past 14 years to transform NTSAD into
the strong organization it is today. Your many talents are evident in all you have
done to support families and advance research toward clinical trials.

Though I will miss you, I know you are ready for the next chapter in your life.
I wish you much happiness in the years ahead.

With Love,
Marion

In Loving Memory of

Stanley Michelman

I miss your kind and loving ways

I miss your friendship

I am sad you left us so soon

Marion 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

Thank you to the

Jewish Genetic Disease Consortium

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

www.jewishgeneticdiseases.org

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

In loving memory of
Allen Levine
beloved husband of Sandy Levine

Marion Yanovsky

In Loving Memory Of My Dear Friend

Sue Sirot

Phyllis Pullman

In loving memory of an incredible woman

Fran Berkwits

A Special & Dear Friend Never to be Forgotten

Always in my Heart

I miss you very much,

Marion Yanovsky

In loving memory of

Frances Berkwits, MS, CSW

and

Abner Berkwits, MD

*To Our Precious Son Evan
& Amazing Father/Grandpa Stan,*



We love and miss you so much.

If you could have lived on alone...you would have lived forever.

You made us see what's most important in life.

You are always in our hearts.

Love, Shari, Jeff, Justin, Leigh & Sydney

In loving memory of Charlie

*who will be remembered for his zest for life, and for his dedication
and love for his family and friends. He will be dearly missed by
everyone who knew him, and by the NTSAD families for all the
years of his generous support.*

With love,

Elise, Emil, Rebecca and Marissa

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 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

In loving memory of
Uncle Stanley & Aunt Joyce

You are missed!

Rest in peace

Love,

Gus Sirot & Family

Nicole, Hadara, Elijah, Jonah, Jeremiah, Talia & Vania

In memory of
Steve Schwarz
Helen Greenblatt
Neil Blatt
Brad Goldstein

Rest in Peace,

Gus Sirot

In loving memory of

Robert Plotkin

With love,

Gus Sirot

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**

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 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

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

Billie & Harold Hoffman

In memory of

Steve Kaye

You are missed.

*Rest in peace,
Marion Yanovsky*

In loving memory

Estelle Krakaur

Lauri Jill Adelsberg

Gertrude Adelsberg

George Corn

Lilly Corn

Frances Berkwits

For her special devotion to the Tay-Sachs Community

We remember her,

Gloria Berkwits

Leland, Jeffrey and Michael Berkwits

In Memory of

Stanley B. Michelman

“A True Leader”

Bruce H. Nagel, Esq.

Nagel Rice LLP • 103 Eisenhower Parkway • Roseland, NJ

In Loving Memory of

Toby & Harold Gottlieb

Eliana & Avi Mordekovich and Family

In loving memory of

Seth Kupperman

Rest in peace,

Gus

With special thanks to

Ed Venezia

*for your extraordinary work
in the production of this annual
NTSAD calendar-journal*



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21B Branford Place • Newark, NJ 07102
Tel.: (973) 600-2451
Owner & RPh Gary Gecht



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

In Honor of Sue Kahn

Dear Sue,

Heartfelt appreciation for your 14 years of leadership, dedication, inspiration, and knowhow building a strong foundation for NTSAD to continue your legacy. Your commitment to furthering research has met accomplishments beyond our expectations. Everyone will miss working together with you. We wish you the best in your future endeavors, and hope to stay closely in touch.

All The Best,
The Heringer Family

Grandma Betty
and
Papoo Louis S. Hazan
“Forever In Our Hearts”

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

In Memory of

Ahny

Her love of children lives on

In Loving Memory of
“Honeydew”

Susan Gottlieb Sirot

Love,
Angus

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

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In loving memory of

**Barbara & Burt
Salomon**

In memory of

Jerry Sirot

Beloved brother of Gus Sirot

Marion 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

TOBY & HAROLD GOTTLIEB

SUSAN SIROT

SAMI ELENA MANSOUR

Together Forever

Gus Sirot and Family

In Memoriam

Harry Silberfarb	January 3
Rose Weisfeld	January 5
Herbert Gordon	January 6
Samuel Eisenberg	January 7
Bonnie Pastor	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
Lila Jacobson	March 6
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
Matthew Feldman	June 27
Frances Berkwitz	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
Sue Sirot	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
Aaron Lifshitz	November 9
Abner Berkwitz	November 10
Robert Plotkin	November 12
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
Charles Yanovsky	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	Allen Levine
Stanley Kravet	Anita Kessler
Estelle Krakaur	Margo Isselbacher



NATIONAL TAY-SACHS & ALLIED DISEASES ASSOCIATION

National Tay-Sachs & Allied Diseases Association (NTSAD) leads the worldwide fight to treat and cure Tay-Sachs, Canavan, GM1, and Sandhoff diseases by driving research, forging collaboration, and fostering community. Supporting families is the center of everything we do.

NTSAD is one of the oldest patient advocacy groups in the country. NTSAD focuses on funding research, supporting over 500 families and individuals worldwide, and raising awareness to prevent disease.

Supporting NTSAD makes a difference!
Thank you to all who donated to this calendar.

NTSAD

2001 Beacon St. #204

Boston, MA 02135

(617) 277-4463

www.ntsad.org

Email: info@ntsad.org

Annual Calendar Address

NTSAD

1515 Route 202 #90

Pomona, NY 10970-0090

Email: marionyanov@aol.com

(914) 672-7712