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
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
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,

Sue
SUE KAHN TO RECEIVE THE WORLDSYMPOSIUM™
2022 PATIENT ADVOCATE LEADER (PAL) AWARD

Each year, WORLDSymposium recognizes one individual for patient advocacy leadership in the field of lysosomal disease. The Patient Advocate Leader (PAL) award will be presented at WORLDSymposium 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 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."
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
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.
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.
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/SANDHOF (GM2)**
- Rare, autosomal recessive lysosomal storage disorders
- Tay-Sachs disease caused by mutations in the HEXA gene which result in excessive accumulation of ganglioside lipids in the brain and nerve cells
- Sanofi Genzyme researchers identified mutations in the HEXA gene

**OBJECTIVES**
- Understand the physical and emotional aspects of the patient’s journey, including symptom onset, diagnosis, and ongoing disease management.

**METHODS**
- 15 surveys and interviews with late-onset Tay-Sachs/Sandhoff (GM2) patients (n=13) and caregivers (n=2) in the US.
- 5 interviews with GM2 expert physicians in the US, UK, DE, and ES.
- Research currently ongoing; poster summaries interim findings.

**CONCLUSIONS**
- Symptoms typically emerge in childhood or early adulthood.
- Diagnosis often takes over a decade; common red flags include Ataxia, Progressive Lateral Sclerosis (ALS) and Slow Impaired Mobility (SIMA).
- Treatment aimed at symptomatic management and patients are often frustrated by healthcare providers.

**EMOTIONS**
- Sadness, frustration, anger, confusion, anxiety, and fear.

**IN THEIR OWN WORDS**
- “I was clumsy and walked funny, but thought I was normal.”
- “My friends said my walk wasn’t normal, but I thought I needed to get stronger.”
- “I fell and broke my hip at 24. My mom said, ‘This is not normal. You’re seeing a doctor about this right now.’”
- “The specialist said I had atypical ALS. It’s a death sentence.”
- “The GM2 diagnosis was a relief, but also scary.”
- “Late-onset GM2 takes everything from you. It’s a terrible disease.”

**EARLIER SYMPTOMS**

<table>
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<tr>
<th>Symptom Area</th>
<th>% Who Experience</th>
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<tbody>
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<td>Balance</td>
<td>75%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>75%</td>
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<tr>
<td>Mood changes</td>
<td>50%</td>
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</table>

**LATER SYMPTOMS**

<table>
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<tr>
<th>Symptom Area</th>
<th>% Who Experience</th>
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<tbody>
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<td>Leg weakness</td>
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<tr>
<td>Short-term memory loss</td>
<td>50%</td>
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<tr>
<td>Speech</td>
<td>50%</td>
</tr>
</tbody>
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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.
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.”

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**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.”
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, GM1, 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-today 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
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 Berkwis, 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.
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.
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.
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.


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-founded 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
Daniel
Jay
Julia
Jonah
Jacob
Samantha
Justin
Talia

Hadara
Elijah
Jill
Tyler
Sydney
Kaitlin
Brielle
Rebecca
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

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’

ишא ודיל

Jennie Gottlieb
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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**In Memoriam**
- Harry Silberfarb  January 3
- Rose Weisfeld       January 5
- Herbert Gorden      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

**MARTIN LUTHER KING, Jr BIRTHDAY OBSERVED**
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
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<td>Bernard Finkel</td>
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**In Memoriam**

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<th>Name</th>
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<td>Sydney Levy</td>
<td>February 9</td>
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<td>Charlotte Stark</td>
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<td>William Yanovsky</td>
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<td>Harrison Hoffman</td>
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<td>Ida Jacobson</td>
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<td>Burton Salomon</td>
<td>February 22</td>
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<td>Bernard Gecht</td>
<td>February 24</td>
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Visit our website: www.ntsad.org
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
With all our love to our wonderful and beautiful grandchildren

HADARA
ELIJAH
JONAH
JEREMIAH
TALIA
VANIA

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
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<tr>
<td><strong>In Memoriam</strong>&lt;br&gt;Allen Levine April 2&lt;br&gt;Alex Lifshitz April 12&lt;br&gt;Alan Thaler April 16&lt;br&gt;Albert Eisenberg April 21&lt;br&gt;Barbara Salomon April 24&lt;br&gt;Elaine Verona April 29</td>
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<td>10 PALM SUNDAY</td>
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<td>17 EASTER&lt;br&gt;PASSOVER&lt;br&gt;Hayden Skyler&lt;br&gt;Roimisher&lt;br&gt;Yocheved Thaler</td>
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<tr>
<td>For the Blessings of My Wonderful Children &amp; Grandchildren Who Fill My World With Love</td>
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<td>Ann Brandt</td>
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| 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 |
# May 2022

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<td>David Fine</td>
<td>Elise Heringer</td>
<td>Charles Yanovsky</td>
<td>Michelle Finkel</td>
<td>Jennifer Colton</td>
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**In Memoriam**

- Errol Yanovsky  May 2
- Stanley Michelman  May 7
- Jack Zimmer  May 8
- Benjamin Gecht  May 9
- Anne Yanovsky  May 19
| 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 honor of our great-granddaughter Layla Mackenzie Preiser  
| Sheila & Lee Cohen |
| In honor of our grandchildren Adam Taylor Chaitin  
| Alexandria Rae Chaitin  
| Jeremy Scott Chaitin  
| Paul Nunzio Chaitin  
| Paul & Sandra Chaitin |
| 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 |
### June 2022

#### Events
- **Research Updates**
  - [www.ntsad.org](http://www.ntsad.org)

#### Calendar
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#### In Memoriam
- Harold Gottlieb June 4
- Esther Sider June 4
- Sarah Finkel June 8
- 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 Berkwits June 29

#### Observations
- **May 2022**
- **July 2022**

#### Observations
- **SUNDAY**:
  - 5th: In Memoriam
  - 12th: Lillian Sherman
  - 19th: FATHER’S DAY
  - 26th: SUMMER BEGINS

- **MONDAY**:
  - 6th: Matthew Feldman
  - 13th: Scott Harris Gentile
  - 20th: Heath Feldman

- **TUESDAY**:
  - 7th: Lior Levy
  - 14th: FLAG DAY
  - 21st: Matthew Lawrence Gentile

- **WEDNESDAY**:
  - 8th: Lee Cohen
  - 15th: Stacy Campbell
  - 22nd: Jayden Campbell

- **THURSDAY**:
  - 9th: Michael Silberfarb
  - 16th: Sharon Silberfarb
  - 23rd: Elise & Emil Heringer

- **FRIDAY**:
  - 10th: Shawn Silberfarb
  - 17th: 8:13
  - 24th: 8:14

- **SATURDAY**:
  - 11th: 8:05
  - 18th: 8:10
  - 25th: 8:14

#### Research Updates

- 1st: Brian Finkel
- 8th: Esmeralda Sirot
- 15th: Matthew Feldman
- 22nd: Lee Cohen
- 29th: Michael Silberfarb
In loving memory of

Helaine Seccia

“A lifelong friend”

Gus Sirot
### In Memoriam

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<td>Dillon Henry</td>
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<td>Sylvia Farber</td>
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<td>Leonard Chudnick</td>
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<td>Irwin Ungerleider</td>
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<td>Karl Yanovsky</td>
<td>July 31</td>
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### NTSAD

**wwwntsad.org**

617-277-4463

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**INDEPENDENCE DAY**

**Charles Gentile**

**Dennis Finkel**

**Emily Charlez Fine**

**Ava Skye Weinstock**

**Gloria Levenson**

**Jonah Dzitrie**

**Howard & Riva Levy Goldman**

**Jon Boorstein**

**Leigh Boorstein**

**Carol Handwerker**

**Marian & Charles Yanovsky**

**Joshua Andrew Devane**

**Michele & Bruce Elyssa Shapiro**

**Fern Finkel Gentile**
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
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In Memoriam
- 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
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
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In Memoriam:
- Ceil Benbasset: September 9
- Sheila Wasserman: September 10
- Leo Diamond: September 14
- Jack Finkel: September 16
- Carole Colton: September 29
- Sue Sirot: September 29

Special Days:
- Labor Day: September 5
- Erev Rosh Hashanah: September 25
- Rosh Hashanah: September 26
- Autumn Begins: September 18
- In Memoriam: September 11, 16, 27
In Loving Memory of

Harrison Hoffman

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

Love,
Mommy, Daddy & Jake
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<td>Elise Rae Gecht</td>
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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 🖤
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**Thanksgiving Day**

**In Memoriam**

- Billie Hoffman
- Adele Zimmerman
- Miriam Lifshitz
- Daniel Jacobson
- Aaron Lifshitz
- Abner Berkwits
- Robert Plotkin
- Stephen Silberfarb
- Owen Brandt
- Emma Zimmerman
- Lawrence Shapiro
- Jill Goldberg
- Helen Diamond
- Lester Pinger
- Harry Verona
- Irving Zaretsky
- Noah Jarashow
- November 1
- November 2
- November 4
- November 7
- November 9
- November 10
- November 12
- November 15
- November 17
- November 18
- November 20
- November 21
- November 23
- November 24
- November 25
- November 25
- November 30
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
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**November 2022**

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**December 2022**

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**January 2023**

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**In Memoriam**

- Jack Litt: December 3
- Lorraine Gettleman: December 4
- Estie Zausner: December 5
- 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

**Chanukah Dates**

- Chanukah - 1 Candle: December 3
- Chanukah - 2 Candles: December 4
- Chanukah - 3 Candles: December 5
- Chanukah - 4 Candles: December 6
- Chanukah - 5 Candles: December 7
- Chanukah - 6 Candles: December 8
- Chanukah - 7 Candles: December 9
- Chanukah - 8 Candles: December 10
- Chanukah - 8th Day: December 11

**Special Notes**

- Christmas Eve: December 24
- New Year’s Eve: December 31
In memory of my beloved parents

Jeanette and Seymour Thaler

and my brother

Alan Mark Thaler

Together forever in Gan Eden

Phyllis Thaler
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 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 the best grandparents

Helen & Leo Diamond

Susan Yanovsky Roden

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 | |
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 Yanovskyy**

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 Yanovskey
Karl Yanovsky
Errol Yanovskey
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 Yanovskin
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
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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<td>Beloved brother of Gus Sirot</td>
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In loving memory of

TOBY & HAROLD GOTTTLIEB
SUSAN SIROT
SAMi ELENA MANSOUR
Together Forever

Gus Sirot and Family
In Memoriam

Harry Silberfarb ......................................... January 3
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Jean McKenna ............................................. Seena Schneiderman
Bob Salomon ............................................. Lilyyan Salomon
Evelyn Sussman ........................................... Lenny Sussman
Sophie Lorito ............................................. Betty Hazan
Ted Saloman .............................................. Betty Hazan
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 (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.

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Pomona, NY 10970-0090
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