

Tay-Sachs & Allied Diseases

2019



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

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

National Tay-Sachs & Allied Diseases Association

thanks

Sue and Gus Sirot

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

This Calendar-Journal is dedicated to

**The Scientists of the
Tay-Sachs Gene Therapy Consortium**

*Founded in 2007 to develop a safe and effective
gene-based treatment for the closely related
Tay-Sachs 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**.



A COMMITMENT TO RESEARCH

We have been moving ever closer to clinical trials in all our diseases. We continue to advance research in our diseases through a combination of building knowledge about the diseases through family engagement and funding innovative, high quality research. In 2018, NTSAD funded four new research grant awards directly, plus one through the Million Dollar Bike Ride. NTSAD has now awarded 67 grants exceeding \$4.0 million since the inception of the Research Initiative in 2002. NTSAD's grant dollars have been leveraged to over \$30 million in NIH and other grants. The new grants are:

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

Principal Investigator: Alessandra d'Azzo, PhD, St. Jude Children's Research Hospital

Role of microglia in Sandhoff disease pathology

Principal Investigator: Tony Futerman, PhD, Weizmann Institute of Science, Israel

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

Principal Investigator: Xuntian Jiang, PhD, Washington University

Accelerated program for CSF delivery of AAV gene therapy for Tay-Sachs and Sandhoff patients

Principal Investigator: Miguel Sena-Esteves, PhD, University of Massachusetts Medical Center

Million Dollar Bike Ride Award:

Brain MRI signatures in infants with infantile forms of GM-1 and GM-2

Principal Investigator: Igor Nestratil, MD, PhD, University of Minnesota



TAY-SACHS GENE THERAPY (TSGT) CONSORTIUM

About half of NTSAD research grant dollars since the inception of the Research Initiative have been awarded to TSGT Consortium investigators.

This important initiative was founded in 2007 specifically to advance human clinical trials in the quest for a gene therapy for Tay-Sachs and Sandhoff diseases. The Consortium has completed pre-clinical milestones, including working on FDA filings and producing vectors in preparing for a much-anticipated 2019 clinical trial.

In parallel, research is on-going to develop next generation vectors and drug delivery methods. There are also gene therapy programs in GM1 and Canavan diseases that are showing great promise.



AWARENESS

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

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



WHAT IS CARRIER SCREENING?

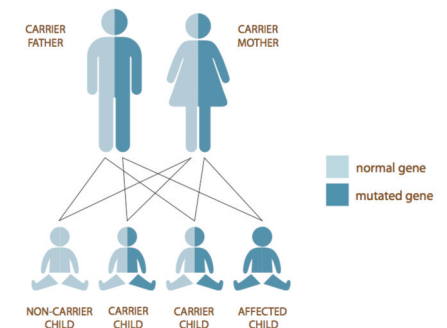
Our genes come in pairs, one from each parent. A carrier of a recessive disease is an individual who has a mutation in one copy of a particular gene that causes the gene not to function properly. Since carriers have a second working copy of the gene, they generally do not develop any symptoms of the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

Recessive Genetic Diseases

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

Special Circumstances

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



PREVENTION

Can genetic diseases be prevented?

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

How can I be screened for genetic diseases?

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

Published opinions and resources:

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

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

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

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

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

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

Carrier Screening For Tay-Sachs & Allied Diseases

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

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

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

DNA (Molecular) Screening

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

Enzyme (Biochemical) Screening

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

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

NOTE: A combination of DNA and enzyme testing is strongly recommended for Tay-Sachs screening for the most sensitive and accurate results. View the [NTSAD Position Statement on Tay-Sachs Screening](http://www.ntsad.org) at www.ntsad.org

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

Visit **www.ntsad.org** for information about the diseases, where you can be screened, and for additional resources.

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

Historical Perspective on Tay-Sachs & Allied Diseases – NTSAD Leading the Fight for more than 60 Years –

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

- 1983 - Thomas Jefferson University School of Medicine, Philadelphia, PA, Michael Reese Hospital, Chicago, IL and the Mount Sinai School of Medicine, New York, NY use chorionic villi sampled from the placenta, in utero to diagnose fetal Tay-Sachs disease in the first trimester of pregnancy.
- 1987 - Centennial of Dr. Bernard Sachs' description of first American patients with Tay-Sachs disease observed by an International Scientific Conference in New York, published as Volume 44 of "Advances in Genetics -Tay-Sachs Disease", edited by Dr. Robert J. Desnick and Dr. Michael M. Kaback.
- 1992 - NTSAD sponsors first-ever conference for individuals and families affected by Late Onset Tay-Sachs disease: a rare form of Tay-Sachs disease affecting adults.
- 1993 - Dor Yeshorim, a unique Tay-Sachs carrier screening program serving the Orthodox Jewish community, observes one decade of service; more than 40,000 people tested.
- 1995 - The American College of Obstetrics and Gynecology (ACOG) issued its first opinion statement on Tay-Sachs disease screening followed by its opinion statement three years later on screening for Canavan disease.
- 2002 - NTSAD launches the Research Initiative which disburses grants for cutting-edge research projects that can lead to treatment and cure for lysosomal or leukodystrophy diseases impacting the central nervous system.
- 2003 - NTSAD involved in lawsuit about the Canavan disease gene patent. The settlement ensures royalty free use of the gene in research to treat Canavan disease.
- 2005 - NTSAD partnered with the MPS Society to co-found the Lysosomal Storage Disease Research Consortium. With the NIH, it offered a joint grant program to support research addressing the neurological aspects of lysosomal storage disorders.
- 2007 - More than 2 million people have been screened and thousands of healthy babies have been born as a result of Tay-Sachs carrier screening.
NTSAD awards grants to the Tay-Sachs Gene Therapy Consortium Research Project (TSGT) for animal research to treat Tay-Sachs and Sandhoff diseases.
- 2009 - National Institutes of Health awards \$3.6 million four year grant to the Tay-Sachs Gene Therapy Consortium Research Project.
Discovery of naturally occurring Tay-Sachs disease in rare Jacob Sheep. Carrier sheep donated to NTSAD by sheep farmers Fred & Joan Horak for inclusion in the Tay-Sachs Gene Therapy Research Project.
NTSAD hosted a CME Conference with Brigham & Women's Hospital, "Diagnosis, Management & Treatment of Progressive Neurological Disease from Infancy to Adult using Tay-Sachs Disease as a Model."
- 2011 - The First Annual Day of Hope was held. Over 100 families and their communities have now held events each September to raise funds for research.
- 2013 - The FDA grants Orphan Drug Designation for Tay-Sachs & Sandhoff gene therapy with NTSAD as the sponsor.
"Parenting a Child with a Life Limiting Illness" video and guide were made to lessen the feelings of isolation that newly diagnosed families experience.
- 2014 - NTSAD Corporate Advisory Council formed. The CAC, through its collective industry experience, serves as a resource to NTSAD to advance research to patients.
- 2016 - First GM-1 Research Meeting held.
- 2018 - NTSAD 40th Annual Family Conference held in Jacksonville, Florida.
- 2019 - NTSAD continues to fund promising innovative research, through the NTSAD Research Initiative, for neurodegenerative diseases that affect the central nervous system. Since 2002, NTSAD has awarded 67 research grants, exceeding \$4 million. NTSAD grant dollars have been leveraged to over \$30 million in NIH and other grants.

2018 HIGHLIGHTS OF THE YEAR

CONNECTING FAMILIES & RESEARCH

The Eighth Annual **Day of Hope** was a successful effort in engaging nearly 30 families and their communities to raise over \$70,000 for research. NTSAD, its families, their friends and community worldwide have rallied and raised funds over \$375,000 since the first Day of Hope in 2011.

The recently launched **GM2 Patient Insights Network (PIN)** is open to all families who are coping, or have coped, with the diagnosis of Tay-Sachs or Sandhoff diseases in all their forms. The PIN, managed by Invitae, securely houses and safeguards patient data with a goal to collect and share data to bring new treatments to patients faster. We hope that families can build a global community through their shared experiences through participating in the PIN. NTSAD partners with the Cure Tay-Sachs Foundation (CTSF), Cure GM1 Foundation, Canavan Foundation and Canavan Research Illinois on the PINs for Tay-Sachs, Sandhoff, GM1 and Canavan diseases.

To build **Late Onset Natural History**, adults affected with Late Onset Tay-Sachs or Sandhoff participated in assessments with the help of clinician researchers and industry partners for the fourth consecutive year at the 2018 Annual Family Conference. **This work, together with NTSAD-funded and NIH-funded natural history studies, is building the necessary data for developing clinical trial endpoints for use in future clinical trials.**

NTSAD and CTSF partnered with the **TREND Community** to get a better understanding of the patient experience regarding off-label use of a drug that has yet to be approved or proven effective for our diseases. While we are hopeful that there will soon be a clinical trial, this anecdotal information is being turned into evidence through the use of algorithms and other data mining techniques. **TREND hopes to use the data collected to share back with the patient communities.**

NTSAD's 60th ANNIVERSARY

NTSAD and Event Chair Alexis Buryk hosted **Voices of Determination**, a fundraising benefit in New York City. Special guests and speakers were Jill Abramson, journalist & former Executive Editor of the New York Times, Barbara Corcoran, Founder of the Corcoran Group and “Shark” on ABC’s “Shark Tank”, and Katie Couric, award-winning journalist. Joining them were Katie and Allie Buryk, twin daughters of Alexis who both face the daily challenges of living with LOTS. Katie and Allie capped off the evening with personal, inspirational, and determined voices. Together we raised almost \$130,000!

EXPANDED FAMILY SERVICES

The **NTSAD Care Tip Series** continues to grow with the addition of two videos filmed at the 2018 Annual Family Conference that cover the topics of The Vest and Physical Therapy pointers. This series continues to serve as an invaluable resource for parents and caregivers around the world.

NTSAD's **40th Annual Family Conference** was one of our largest conferences with nearly 300 attendees including families, children, adults living with the Late Onset forms, volunteers, caregivers, speakers and researchers. Because of all the research progress toward clinical trials, we held research breakout sessions in each of our disease areas so that families could learn and ask questions in smaller discussion groups.



An **NTSAD Mentor Committee**, comprised of several volunteer veteran members, has been re-established after several years to offer another dimension of services to families and adults in the weeks and months following a diagnosis of Tay-Sachs, Sandhoff, GM1 or Canavan diseases. The hope is that connecting families with others who have been down the same road will be a comfort and lessen the isolation they might feel.

EXCEPTIONAL SUPPORT

In 2018, NTSAD's impact on our community was demonstrated by the receipt of the two largest charitable gifts in NTSAD's history. The first was from a family who lost a child to Tay-Sachs more than 50 years ago who have been giving generously for many years in support of our family services programs. The second gift was made by a grateful family who, due to the introduction of carrier screening by NTSAD more than 40 years ago, was able to have healthy children and now healthy grandchildren. They are two different families making different gifts but in recognition of the same community, NTSAD. They are humbling and powerful examples of grateful families giving from generation to generation.



AWARENESS

Retro Report recently released their latest production, "Genetic Screening: Controlling Heredity," in partnership with PBS's American Experience. NTSAD contributed archival footage relating to the role that Tay-Sachs screening played in the advent of voluntary community-driven genetic screening.



TAY-SACHS GENE THERAPY CONSORTIUM

A Big Step Closer to Clinical Trials

The UMass Medical School issued a press release announcing that UMass Medical School and the Tay-Sachs Gene Therapy Consortium (TSGT) are beginning work to file an Investigational New Drug (IND) application to the FDA. This application is for a Phase I/II clinical trial for GM2 Gene Therapy. At the same time, they have begun the work to manufacture vectors for the clinical trial.

The Tay-Sachs Gene Therapy Consortium research team, including Drs. Miguel Sena-Esteves, Heather Gray-Edwards, and Doug Martin, has spent a great deal of time over the past two years conducting preclinical toxicology and efficacy tests (funded by NTSAD and Cure Tay-Sachs Foundation) which has brought them to filing this IND.

This announcement is something we've been preparing for since NTSAD sat at the table with the Tay-Sachs Gene Therapy Consortium team at Boston College in March 2007. Over \$2 million of Research Initiative gifts we've received from our donors have gone to funding this research since 2007. NTSAD's grants to the Consortium have included:

- animal studies from mice to cats to Jacob Sheep
- the care for the herd of Jacob Sheep
- gene therapy vector development and subsequent validation studies
- biomarker research
- natural history studies
- toxicology and efficacy studies; and
- facilitating meetings, making introductions to experts in the field of drug development, and being in constant communication with the consortium team all along the way.

Read more about this news and a significant grant for this research in the following press release from UMass Medical School.

Blu Genes Foundation gives UMMS \$1.4M to bring Tay-Sachs gene therapy to clinical trial

UMass Medical School Communications

November 06, 2018

The Blu Genes Foundation, a Toronto-based foundation dedicated to the development of gene therapy treatments for rare disease, has donated \$1.4 million to UMass Medical School for the advancement of a Phase I/II clinical trial for the genetic disorder Tay-Sachs. The gift from the Blu Genes Foundation will be a catalyst in moving research from the preclinical phase to early stage human trials, according to Heather Gray-Edwards, PhD, DVM, assistant professor of radiology at UMass Medical School.

“This philanthropic investment in our Tay-Sachs research from the Blu Genes Foundation will allow us to take more than a decade of scientific discovery into the clinic, where our novel gene therapy approach will directly impact patient lives,” Dr. Gray-Edwards said.

Tay-Sachs, and a similar disease, Sandhoff disease, are inherited neurologic diseases that occur when genetic mutations prevent cells from producing enzymes needed to break down and recycle materials. Without these enzymes, the materials accumulate to toxic levels, slowly destroying the nervous system. A team of researchers from UMMS and Auburn University in Alabama have been working on a gene therapy to correct the enzyme deficiency using adeno-associated virus, or AAV, vectors.

The average life expectancy for children with infantile Tay-Sachs or Sandhoff disease is about three to five years; there is currently no treatment for either disease. The gene therapy in development has shown promise in animal models of these diseases by extending lifespans up to four times those of untreated animals.



Heather Gray-Edwards, PhD, DVM



Miguel Sena-Esteves, PhD



Terence R. Flotte, MD

In addition to Gray-Edwards, the development team includes Miguel Sena-Esteves, PhD, associate professor of neurology at UMMS and principal investigator of the program; Terence R. Flotte, MD, the Celia and Isaac Haidak Professor of Medical Education, executive deputy chancellor, provost and dean of the School of Medicine, professor of pediatrics, microbiology & physiological systems and RNA therapeutics at UMMS, and clinical principal investigator of the trial; and Douglas Martin, PhD, professor of anatomy, physiology and pharmacology at the Auburn University College of Veterinary Medicine.

“We have spent a great deal of time over the past two years conducting preclinical toxicology and efficacy tests and the results provide the supporting data to submit an Investigational New Drug (IND) application to the FDA,” said Dr. Sena-Esteves. “We now are beginning work to file an IND with the FDA for the Phase I/II trial and we hope to secure approval in early 2019. We also have initiated manufacturing of the vectors, which should take approximately five months to complete. These are important milestones in this process that demonstrate real progress toward our goal of launching a clinical trial.”

“Once we have secured the go-ahead from the FDA, we will be ready to quickly enter the clinical phase of this project, which we anticipate happening as early as March 2019,” said Dr. Flotte. “We are excited to work with the National Tay-Sachs & Allied Diseases Association (NTSAD) and the Cure Tay-Sachs Foundation (CTSF), two patient organizations that have been our partners from the beginning of this project and will continue to partner with us as we move into the upcoming trial. NTSAD and CTSF have together invested more than \$4 million in our research over the past decade to help get us to this point. Now together with this very generous and catalytic gift from the Blu Genes Foundation, we are one big step closer to making this trial a reality.”

The Blu Genes Foundation is a recently established nonprofit organization that is raising funds to advance gene therapy and find a cure for genetic disorders such as Tay-Sachs. “By strategically investing our philanthropic resources in world class research, our goal is to offer hope to patients and families where currently there is none,” said Joseph Cordiano, chairman of the Blu Genes Foundation. “We are excited to join NTSAD and CTSF in partnering with UMass Medical School and Auburn University at a critical juncture to help make this first-in-human clinical trial a successful reality.”

“The proof-of-concept studies in affected animals are compelling, and the FDA provided a clear path forward to human clinical trials,” said Dr. Martin. “Too many children with Tay-Sachs and Sandhoff have died since we started this project. The time has finally arrived to push back on these diseases. Our single-minded goal is to get a safe and effective therapy to patients and their families as quickly as possible. Thanks to the support of the Blu Genes Foundation, NTSAD and CTSF, achieving our goal is within sight.”

AN OPPORTUNITY TO ADOPT & CARE FOR JACOB SHEEP!



NTSAD hopes to further the research to find a treatment and cure for Tay-Sachs disease with our Jacob Sheep Project. Tay-Sachs disease is present in the population of a rare breed of sheep called Jacob Sheep. The genetic makeup of these sheep is very similar to humans in the way that matters most for solving the mystery of Tay-Sachs disease. Funds must be raised to help care for the Jacob Sheep. There are now carrier sheep that are part of the Tay-Sachs Gene Therapy (TSGT) Consortium research project. You can help care for these sheep or even adopt a sheep in the following ways.

- | | | |
|--------------------|---|--|
| Make a gift | ☐ \$125 to adopt a sheep | ☐ \$1,000 to name a Jacob's lamb |
| Feed the flock | ☐ \$500 for four months | ☐ \$250 for two months ☐ \$125 for one month |
| Care for the flock | ☐ \$1,500 for one year | ☐ \$750 for six months |

If you adopt or name a sheep you will receive a certificate with a photo of your Jacob sheep.

☐ Yes, I would like to support the Jacob Sheep Program. Enclosed is my donation of \$_____ to NTSAD.

Print Name: _____

Address: _____

City, State, Zip: _____

E-mail: _____

Phone: _____

Enclosed is my check payable to NTSAD for \$_____. If you prefer, we accept VISA/MASTERCARD/AMEX/DISCOVER

CARD NUMBER _____ EXP. DATE _____

SIGNATURE _____

MAIL COMPLETED FORM TO: NTSAD, 2001 BEACON STREET, SUITE 204, BOSTON, MA 02135



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

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

**Over \$400,000 has been raised since our First Annual Day of Hope on September 18, 2011
Mark Your Calendar for the Ninth Annual Day of Hope September 21, 2019!**

A FAMILY GATHERING

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

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



CONFERENCE GOALS

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

HELPING HANDS PROGRAMS

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



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.

A Letter from Blyth Taylor Lord, President of NTSAD

To Our Supporters,

NTSAD is proud to be one of the first patient advocacy groups in the country and proud that for over 60 years now, our community of parents, friends, doctors, scientists, and the biotech industry has steadily pursued what matters most to our affected families: prevention through carrier screening, person-to-person support to help families cope, and research for treatments.

As a rare disease community, it can feel daunting, and at times even disheartening, to consider the amount of work and fundraising needed to achieve treatments. We need people beyond our affected families, their friends, and the researchers to care and help. Our honored guest speaker at the Imagine & believe event in Boston in November 2018, Barry Shrage, understands this better than most, and not just because of the Ashkenazi Jewish community's historical connection to Tay-Sachs disease. In his 30-year leadership of Combined Jewish Philanthropies and his new position at Brandeis, Barry has written and spoken on how it is the moral obligation of the individual alone and within their community to work to save the lives of others. This is what it means to be a connected, caring and decent human being.

No one has practiced this virtue more than Dr. Miguel Sena-Esteves. Miguel has committed his professional career to gene therapy research. For over 11 years, Miguel has looked into the eyes of adults affected by Late Onset Tay-Sachs, affected children, their parents and siblings, and felt the call to give their stories a different, better ending. With the financial support of NTSAD and others, including the NIH, and a personal reservoir of goodness and determination, Miguel and his collaborators have overcome significant setbacks in the research to arrive on the cusp of a Phase I/II trial for children affected by Tay-Sachs and Sandhoff disease.

Barry's words and Miguel's practice find their meeting point in Mandy Ronaldson's family. Two of Mandy and Jeff's four children, Madeline and Mollie, have Juvenile Sandhoff disease. Every day, the Ronaldson family goes about its business of living life to the fullest with generous hearts in the face of disease that is slowly robbing the girls of their abilities. Every day, the Ronaldsons believe in the promise of Miguel's research and the possibility of a treatment. Every year, the Ronaldson's community raises funds to make it so.

These individuals remind us of why we look beyond our individual selves to care for others and make a difference for the better. We are so very grateful to have your support of the programs of NTSAD, through your support of the 2019 NTSAD Calendar. Thank you for Imagining and Believing with us.

With appreciation,

Blyth Taylor Lord

President, NTSAD

Mother of Cameron (Infantile Tay-Sachs)

National Tay-Sachs & Allied Diseases Association

Proudly Supports

The Tay-Sachs Gene Therapy Consortium

In Driving Key Initiatives in Gene Therapy

In Memory of Our Parents

Barbara & Burton Salomon

With Much Love,

Doug & Alan Salomon

IN MEMORY OF OUR BELOVED DAUGHTER

RACHEL MEREDITH

FOREVER IN OUR HEARTS

IN HONOR OF OUR GRANDSONS

TYLER MATTHEW

ANDREW JARED

RHODA & FRED KANTER

In loving memory of

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

The Sirot Family

In 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 Loving Memory of
Great Grandma Francie Berkwits



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

Annie & Zoe Elberg

In Loving Memory of
Francie Berkwits



A shining example of a life well-lived.

Your memory is a blessing to us all.

Jake, Lacey, Annie & Zoe Elberg

IN LOVING MEMORY OF
MY PARENTS

IRVING JEROME BURGER

MICKEY H. BURGER

AND

MY BROTHER

HOWARD BURGER

Clare Burger

To all our wonderful grandchildren
who give us so much pleasure

Nicole

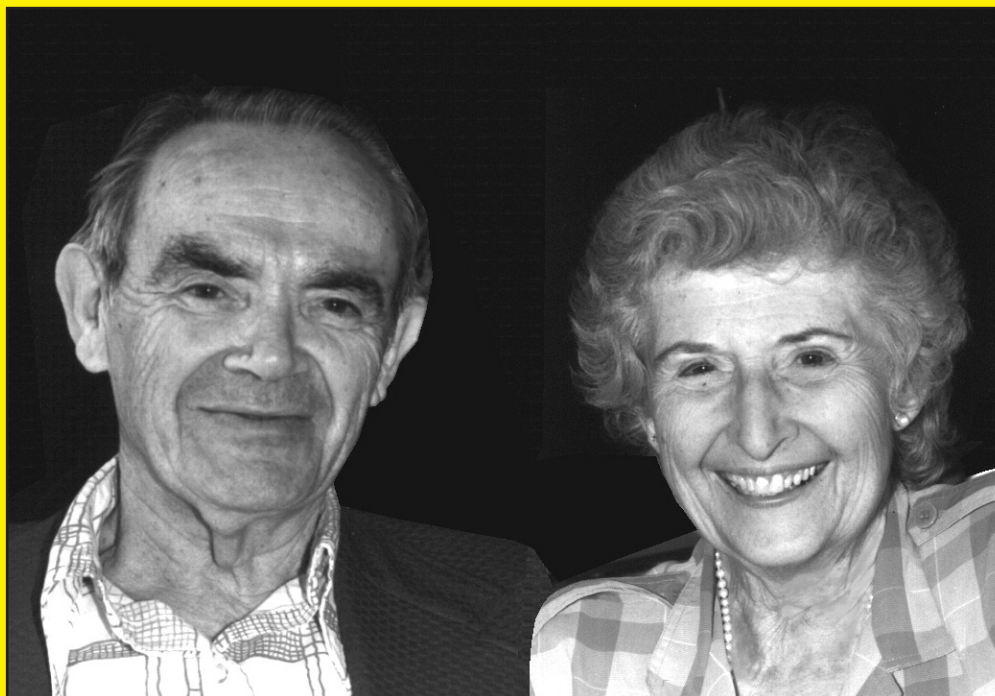
Michael

Julie

Jake

and Harry who left us too soon

All our love,
Grandma Judy & Grandpa Gerry



In Loving Memory of

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 loving memory of our
son & brother*

RAPHI HABERBERG

Gili, Benjamin, Ari & Karen

In memory of
Marcia Feinberg
and
Aaron Feinberg
Ann Hanover

Leading the fight for a cure

Judy & Corey Lev

In memory of my beloved parents

Jeanette and Seymour Thaler

and my brother

Alan Mark Thaler

Together forever in Gan Eden

Phyllis Thaler

Kudos and Gratitude

to Marion Yanovsky, the Ungerleider family &
all Board members of the NY Chapter of NTSAD
for recognizing the importance of fundraising to maintain
the Jacob Sheep colony with Tay-Sachs.

Drs. Ed & Roz Kolodny

In loving memory

Estelle Krakaur

Lauri Jill Adelsberg

Gertrude Adelsberg

George Corn

Lilly Corn

In loving memory of
Helen Greenblatt

A wonderful friend

Sue & Gus Sirot

For Audrey

You will always be remembered

Much love,

Doug

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SUNDAY

MONDAY**TUESDAY**

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

		1	2	3	4	5
		NEW YEAR'S DAY		Rona Devane	4:22	
6	7	8	9	10	11	12
Marissa Heringer Rebecca Heringer	Rose Price Cooley	David Sirot	Noah Philip Devane		Geoffrey Zack Wasserman Andrew David Markinson	Sue & Gus Sirot
13	14	15	16	17	18	19
	Robyn Finkel Kohen			Renée Hasman Nolan Russell Wasserman	4:37	
20	21	22	23	24	25	26
	Mia Levy MARTIN LUTHER KING, Jr BIRTHDAY OBSERVED	Charlie Levy			4:46	Barbara & Gary Feldman
27	28	29	30	31	In Memoriam Harry Silberfarb January 3 Rose Weisfeld January 5 Herbert Gordon January 6 Samuel Eisenberg January 7 Harold Feldman January 12 Sylvia Silberfarb January 17 Margo Isselbacher January 17 Beatrice Gecht January 28 Jane Eisenberg January 29	
Olivia Vairo						

In Memory of

Stanley B. Michelman

“A True Leader”

Bruce H. Nagel, Esq.

Nagel Rice

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SUNDAY

MONDAY

TUESDAY**WEDNESDAY**

THURSDAY

FRIDAY

SATURDAY

In Memoriam Sydney Levy Charlotte Stark William Yanovsky Harrison Hoffman Burton Salomon Bernard Gecht February 9 February 11 February 15 February 17 February 22 February 24					1 4:55	2
						GROUNDHOG DAY
3	4	5	6	7	8 5:03	9
Bernard Finkel	Alyson Lifshitz					Nicole Mansour Dzitire
10	11	12	13	14	15 5:12	16
	Brayden Harris Greenhut Binyamin Naftalowitz	Bobby Handwerker Tzvi Naftalowitz Caroline Zamel		Bryan Zachery Roden VALENTINE'S DAY		
17	18	19	20	21	22 5:20	23
Dave & Esmeralda Sirot	Anaelle Bedziner PRESIDENT'S DAY		EREV PURIM	Reese Goldstein PURIM	Bryan Markinson	Steven Yanovsky
24	25	26	27	28	Visit our website: www.ntsad.org	
Sheila Cohen		Adam Davis				

*In honor of
our dear friends*

Marion & Charlie

Sheila & Lee Cohen

In memory of

Meryl Robin Krasnow

Born Sept. 7, 1960

Phyllis & Stan Krasnow

In memory of

Karen Todd

*Rest in Peace
Love you always,*

Cidni

In memory of my aunt

Marcia Feinberg

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

Susan Z. Cohen

February 2019

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April 2019

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March 2019

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

In Memoriam Estelle Goldstein March 3 Matthew Forbes Romer March 8 Nathan Sider March 10 Alan Berg March 12 Joel Chavis March 17 Marcia Feinberg March 24 Toby Gottlieb March 25 Mary K. Uscky March 25					1 5:30 Caroline & Hasan Zamel	2 Jason Ross Roden
3	4 Eva Frances Gentile	5	6	7 Sophie Levy	8 5:38	9 Benjamin Matthew Wasserman
10 DAYLIGHT SAVINGS MOVE CLOCK AHEAD	11	12 Jacob Benjamin Fine	13	14 Ashley Feldman	15 6:46	16 Nicholas Troncoso
17 Shulamis Naftalowicz ST. PATRICK'S DAY	18 Jaden Shapiro	19	20 SPRING BEGINS	21 Eli Goldstein Jessica Lynn Wasserman Mara Page Markinson	22 6:53	23
24	25	26	27 Zachary Kohen	28	29 7:01 Ann Brandt	30
31						

In celebration of our precious grandchildren

Asher, Jason & Bryan

Marion & Charles Yanovsky

In loving memory of

Jeanette & Seymour Thaler

Alan Thaler

Martin Thaler & Family

March 2019

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April 2019

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

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

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!*

May 2019

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SATURDAY

	In Memoriam Errol Yanovsky May 2 Stanley Michelman May 7 Jack Zimmer May 8 Benjamin Gecht May 9 Anne Yanovsky May 19		1	2 Cake Corie Shapiro	3 Candles 7:37	4
5	6	7	8	9 Cake Richard David Chudnick	10 Candles 7:44 Cake Alice Finkel Markinson	11
12 Cake Samira Zamel Troncoso MOTHER'S DAY	13	14	15	16	17 Candles 7:51 Cake Noa Levy	18 Heart David & Heather Levy Cake Nadia Zamel
19 Cake Gary Gecht	20	21 Cake Matthew Forbes Romer	22	23	24 Candles 7:57 Cake Michele Goldman	25
26	27MEMORIAL DAY	28 Heart Rona & Michael Devane	29	30 Cake David Fine Cake Elise Heringer Cake Charles Yanovsky	31 Candles 8:03 Cake Michelle Finkel Cake Jennifer Colton	

In loving memory of

**Barbara & Burt
Salomon**

In memory of

Jerry Sirot

Beloved brother of Gus Sirot

Marion & Charlie Yanovsky

*In loving memory of
NTSAD Super Volunteers*

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

May 2019

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July 2019

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28	29	30	31				

June 2019

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

**Research Updates
at
www.ntsad.org**

In Memoriam

Harold Gottlieb	June 4	William Romer	June 21
Esther Sider	June 4	Gita Katz	June 24
Sarah Finkel	June 8	Nathan Zimmer	June 25
Charles Goldstein	June 8	Sidney Finkel	June 26
Harold Goldstein	June 13	Sheila Donner	June 27
Sami Elena Mansour	June 13	Frances Berkwits	June 29

 8:04

1

 Brian Finkel
 Esmeralda Sirot

2

3

4

5

6

7

 8:09

8

 Matthew Feldman
 Lior Levy

 Lee Cohen

9

10

11

12

13

14

 8:12

15

 Lillian Sherman
 Natan Thaler
♥ Lisa & Griffith Kolland

 Scott Harris Gentile

FLAG DAY

 Stacy Campbell

16

FATHER'S DAY

17

 Michael Silberfarb

18

 Shawn Silberfarb

19

20

 Heath Feldman

21

 8:14

 Matthew Lawrence
Gentile

SUMMER BEGINS

22

 Jayden Campbell

23

 Sharon Silberfarb
♥ Elise & Emil Keringer

30

24

 Jason Shapiro

25

26

27

 Miriam Thaler
 Mitchell Gordon

28

 8:14

♥ Susan & Bill Boorstein

29

In loving memory of

Helaine Seccia

“A lifelong friend”

Gus Sirot

June 2018

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3	4	5	6	7	8	9
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August 2018

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July 2019

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

	1	2  Jon Boorstein	3	4 INDEPENDENCE DAY	5  8:13  Charles Gentile	6  Leigh Boorstein
7  Joshua Andrew Devane  Carol Handwerker	8 ♥ Marion & Charles Yanovsky	9	10	11  Emily Charlez Fine	12  8:10  Dennis Finkel  Bruce Goldman	13
14	15	16  Jared Craig Sakolsky	17	18  Gloria Levenson	19  8:06  Ava Skye Weinstock  Taylor Jenna Weinstock  Lori R. Goldman	20
21  Scott J. Goldman	22  Kourtney Brooke Lavin	23	24	25  Jonah Dzitrie	26  8:00 ♥ Howard & Riva Levy	27 ♥ Michele & Bruce Goldman
28  Elyssa Shapiro	29	30  Fern Finkel Gentile	31	In Memoriam Leon Finkel July 3 Dillon Henry July 6 Sylvia Farber July 18 Leonard Chudnick July 20 Irwin Ungerleider July 21 Karl Yanovsky July 31		

*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 memory of our loving uncle

Jerry Sirot

We love you and wish you to Rest in Peace Forever

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

July 2019

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September 2019

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August 2018

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

In Memoriam Sarah Pinger Phyllis Chavis Shirley Leib Wendy Gordon Scott Peter Colton Jerry Sirot Ray Colton Saul Donner Adam Davis August 7 August 9 August 10 August 16 August 16 August 20 August 22 August 26 August 28				1	2  7:53	3
4  Samantha Gordon	5  Charlie Gecht	6	7  Steven Greg Chudnick	8	9  7:44	10
11	12	13	14  Scott Finkel  Alyse Gordon	15	16  7:35  Elaine Levy	17
18  Scott Brian Fine  Daniel Silberfrab  Avraham Thaler	19	20	21  Marc Robinson	22	23  7:24	24
25  Stacy & Noah Cantor  James Colton	26  Joan Kantz	27  Jill Feldman	28  Layla Campbell	29	30  7:13	31

**For
Honeydew and Gus**

*Love,
Angus*

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

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

In memory of
Gertrude Bertinthal

*Deborah, Arthur, Harris,
& Seth Kupperman
Elyse & Matt Chaifetz*

GEM ADJUSTERS, LTD.
LICENSED PUBLIC ADJUSTERS

HAROLD GREENBLATT
PRESIDENT

TEL: 718-352-7400
FAX: 516-441-5094
E-Fax: 484-918-2604
E-MAIL: GEMADJUSTERS@AOL.COM

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

August 2019

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October 2019

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September 2019

SUNDAY

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WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

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

Grandma Betty

and

Papoo Louis S. Hazan

“Forever In Our Hearts”

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

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

Compliments of

Leslie & Steve Schwarz

In loving memory of

Gerry Goldberg

A Special Man

Marion & Charlie Yanovsky

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

Norman Wasserman

September 2019						
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November 2019						
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October 2019

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY																												
		1 ROSH HASHANAH II	2  <i>Spencer Shawn Markinson</i>	3  <i>Riley Paige Roimisher</i>	4  6:14  <i>Elise Rae Gecht</i>	5  <i>William Gentile</i>																												
6	7	8  <i>Daniel Ian D'Amato</i> EREV YOM KIPPUR	9  <i>Meryl Gordon</i> YOM KIPPUR	10	11  6:03  <i>Michael Devane</i>  <i>Joe Rattien</i>  <i>Michael Gary Chudnick</i>	12																												
13  <i>Barbara Hasman</i>	14  <i>Susan Roden</i> COLUMBUS DAY	15	16  <i>Maya Jade Benbasset</i>	17  <i>Matthew Gordon</i>	18  5:52  <i>Elijah Dzitrie</i>	19																												
20  <i>Erin Finkel</i>	21  <i>Jack Zimmerman</i>  <i>Jerimah T.C. Snyder</i>  <i>Anthony Gentile</i>  <i>Jack Zimmerman</i>	22  <i>Arlene Gecht Koral</i>	23  <i>Davie Benbasset</i>	24	25  5:42  <i>Caroline Wager Chudnick</i>  <i>Brittany Sari Zimmer</i>	26  <i>David Silberfarb</i>																												
27  <i>Robert Nathan Wasserman</i>  <i>Eric Jason Fine</i>	28  <i>Pasquale Vairo</i>	29  <i>Adam Brian Gecht</i>	30	31  <i>Zachary Cantor</i>  <i>Marion Yanovsky</i> HALLOWEEN	In Memoriam <table><tr><td>Geraldine Finkel</td><td>October 3</td><td>Steven Berg</td><td>October 19</td></tr><tr><td>Roberta Meyers</td><td>October 3</td><td>Joseph Gentile</td><td>October 26</td></tr><tr><td>Alex Pinger</td><td>October 4</td><td>Stella Zimmer</td><td>October 27</td></tr><tr><td>Harriet Lurie</td><td>October 5</td><td>Dorothy Zaretsky</td><td>October 28</td></tr><tr><td>Anna Finkel</td><td>October 8</td><td>Leon Jacobson</td><td>October 29</td></tr><tr><td>Henry Sirot</td><td>October 9</td><td>Miriam Finkel</td><td>October 30</td></tr><tr><td>Sophie Gecht</td><td>October 12</td><td></td><td></td></tr></table>		Geraldine Finkel	October 3	Steven Berg	October 19	Roberta Meyers	October 3	Joseph Gentile	October 26	Alex Pinger	October 4	Stella Zimmer	October 27	Harriet Lurie	October 5	Dorothy Zaretsky	October 28	Anna Finkel	October 8	Leon Jacobson	October 29	Henry Sirot	October 9	Miriam Finkel	October 30	Sophie Gecht	October 12		
Geraldine Finkel	October 3	Steven Berg	October 19																															
Roberta Meyers	October 3	Joseph Gentile	October 26																															
Alex Pinger	October 4	Stella Zimmer	October 27																															
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Anna Finkel	October 8	Leon Jacobson	October 29																															
Henry Sirot	October 9	Miriam Finkel	October 30																															
Sophie Gecht	October 12																																	

In honor of the Tay-Sachs Gene Therapy Consortium

*Thank you Drs. Miguel Sena-Esteves, Doug Martin
and your entire team for working so hard and never giving up.
Reaching Clinical Trials is a dream come true for our family.*

The Ungerleider Family
Shari, Jeff, Justin, Leigh & Sydney

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 will be missed.*

Marion Yanovsky

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SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

Billie Hoffman Adele Zimmer Miriam Lifshitz Daniel Jacobson Aaron Lifshitz Abner Berkwits Stephen Silberfarb Owen Brandt November 1 November 2 November 4 November 7 November 9 November 10 November 15 November 17 Emma Zimmerman Lawrence Shapiro Jill Goldberg Helen Diamond Lester Pinger Harry Verona Irving Zaretsky Noah Jarashow November 18 November 20 November 21 November 23 November 24 November 25 November 25 November 30 In Memoriam					1 5:33	2
3	4	5 Brian Craig Koral Hasan Zamel ELECTION DAY	6	7 Lisa Holland	8 4:25 Rivka Naftalowitz	9 Hailey Silberfarb
10	11 Lew Kantz Nathan Edward Devane VETERANS DAY	12	13 Miyon & Joshua Karwitt	14 Cyrus Jude Benbasset Mitchell Ira Fine	15 4:18	16 Alan Finkel
17	18 William Scott Jacobs Serena Hope Markinson	19	20	21 Cameron Troncoso	22 4:13	23 Maddie & Herb Roimisher Edith Berg
24 Sheila & Lee Cohen Alisa Lifshitz	25	26 Brenna Finkel	27 William Romer	28 THANKSGIVING DAY	29 4:10 Rachel Thaler	30

In loving memory of
Uncle Stanley & Aunt Joyce

You are missed!

Rest in peace

Love,

Sue & Gus

Nicole, Hadara, Elijah, Jonah & Jeremiah

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

Billie & Harold Hoffman

November 2019

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January 2020

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December 2019

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

1	2  Isabella Tori Zahl	3  Elena Vairo	4	5	6  4:09	7
8	9  Adam Scott Koral	10	11  Kimberley Blake Lavin  Chani Thaler	12	13  4:09	14
15  Jennifer Chudnick  Aliya Levy  Asher Diamond Yanovsky	16  Jordyan Lavin	17  Russell Matthew Jacobs	18  Harlow Benbasset	19	20  4:12	21  Aria Holland WINTER BEGINS
22  Alan Roden CHANUKAH - 1 CANDLE	23  Jordan Conrad Gecht CHANUKAH - 2 CANDLES	24 CHRISTMAS EVE CHANUKAH - 3 CANDLES	25  Gus Sirot CHRISTMAS DAY CHANUKAH - 4 CANDLES	26 CHANUKAH - 5 CANDLES	27  4:16  Olivia Vairo  Jay David Sirot CHANUKAH - 6 CANDLES	28  Heather Lara Sakolsky CHANUKAH - 7 CANDLES
29 CHANUKAH - 8 CANDLES	30	31  Emil Heringer NEW YEAR'S EVE			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 Hayden Lord December 22 Evan Ungerleider December 23 Fred Goldberg December 23	

In memory of
Sylvia Farber
The Lifshitz Family

Compliments of
The Rattien Family

*In Loving Memory
of*
Nat and Hannah Natko

**Friends of
Gus & Sue Sirot**

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

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

SUNDAY

MONDAY

TUESDAY**WEDNESDAY****THURSDAY**

FRIDAY

SATURDAY

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In Memory of
and in Tribute to
our mother

'A Woman of Valor'

אשת חיל

Jennie Gottlieb

Du Du Liegst Mier In Herzen



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

With much thanks,

The Heringers

In Loving Memory of
Stanley Michelman

We miss your kind and loving ways
We miss your friendship
We are sad you left us so soon

Marion & Charlie Yanovsky

With all our love to our wonderful
and beautiful grandchildren

**HADARA
ELIJAH
JONAH
and
JEREMIAH**

POPPI GUS & GRANDMA SUE

Keep up the good work
The Sacks Family

With love to the beautiful
& special children

Sami Elena Mansour

*Love,
Esther & Alan Fleishman*

In Memory of

Myrna Asch Sayles

&

Barbara Militscher Brenner

*Marilyn Asch Militscher
& Alan Militscher*

In honor of our grandchildren

Sydney, Ben, Esther & Anna

Lynda & Mel Schriever

*In Loving Memory of
Our Beloved Sister & Brother*

**Sharyn Snyderman
Fred Schriever**

Lynda & Mel Schriever & Family

The Mathew Forbes Romer Foundation

salutes

NTSAD

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

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

In Honor of

Marion & Charlie Yanovsky

We are the luckiest children and grandchildren.

You are the best!

We love you,

Susan, Alan, Jason & Bryan

In Loving Memory of

Gerry Goldberg

“Harry’s Grandpa”

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

Members of NTSAD New York Area

In loving memory of

Frances Berkwits, MS, CSW

and

Abner Berkwits, MD

Hope Is On The Horizon

For Treatment & Cure!

We Honor The Researchers of the

**The Tay-Sachs
Gene Therapy Consortium**

Marion & Charlie Yanovsky

Thank You

Dr. Samuel Dunkell

*You and Ruth were there at the beginning
to make the research happen.*

*Now we await clinical trials
for a treatment and cure.*

In honor of our grandchildren

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

Paul & Sandra Chaitin

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

Phyllis Pullman

Compliments of
Gary Gecht

In memory of
Ricki Beth Sussman

1953-1957

Dear

**Grandma Sylvia &
Grandpa Harry**

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

We miss you very much.

Love always,

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

In Memory of

Ahny

Her love of children lives on

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 Loving Memory Of

ALLEN & MARGIE FEIN

JOE & CEIL BENBASSET

EVELYN & LENNY SUSSMAN

LIBBY & NORMAN MOSBERG

JOE ROSEN

ROSE & MIKE WEISFELD

Merri & Murray Benbasset

Jason & Melissa, Maya & Taylor

Corey & Hope, Easton, Harlow, Cyrus & Davie

In loving memory of

Pearl Sirot

Henry Sirot

Jerry Sirot

Toby Gottlieb

Harold H. Gottlieb

and

Sami Elena Mansour

With thanks for the joy of

Hadara - April 6, 1994

Elijah - October 18, 1996

Jonah - July 25, 2000

and

Jeremiah - October 21, 2015

Sue & Gus Sirot

In memory of

The Pingers

Sarah & Alex Pinger

Lester Pinger

Beatrice Gecht

Sylvia Farber

Stella Zimmer

Miriam Finkel

In Beloved Memory of

Barbara Salomon

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

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

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

In memory of

Anita Amerio

and

Jerry Sirot

Joyce Erwin

In Loving Memory of

SAMI ELENA MANSOUR

“A Moment of Joy”

Sue & Gus Sirot and Nicole

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 Honor of all the Beautiful
Sirot, Damato & Levenson Grandchildren

Sarah

Hadara

Daniel

Elijah

Jay

Jill

Julia

Tyler

Jonah

Sydney

Jacob

Kaitlin

Samantha

Brielle

Justin

Rebecca

Jeremiah

In Memory Of
Audrey Schwartz

*Beloved to Douglas, Claire and Cliff,
Ronni and Josh,
Andy, Monique and Sophie*

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

In Loving Memory of

Michael Alan Zeiger

and

Daniel Jacobson

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

We Miss You Both!

The Zeiger & Jacobson Families

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

Ann Brandt

In loving memory of my parents
Helen & Leo Diamond

Ann Brandt

In Honor of My Amazing Sister,

Marion Yanovsky

With Love, Ann

In loving memory of

Owen Brandt

Your love is always with us

Ann, Lisa, Skip, Rona, Michael
Nathan, Noah & Joshua

In loving memory of

Tessie Weinblatt

Sue & Gus



In Memory of Lawrence R. Shapiro, MD

Valued Board Member and Friend

Extraordinary Clinical Geneticist

An Advocate for Carrier Screening from its Very Beginnings

The NTSAD New York Area Chapter

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

We thank him for all he did for so many

*In support of focusing attention on
Late On-Set Tay-Sachs, so we can see our way
to treat, cure & prevent its effects*

**Optimistically,
Carol S. Handwerker**

In loving memory of
**Anita & Larry
Kessler**

In Support of Research
**Sandy & Allen
Levine**

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**In loving memory of
Harold & Toby Gottlieb**

Henry & Sylvia Kleiner

Wishing our friends

Sue & Gus Sirot

a Healthy and Happy New Year!

Caren & Craig Hirsch

**In Loving Memory of
Scott Peter Colton
&**

Carole & Ray Colton

*Love,
Gerri Colton & James Colton*

In Loving Memory of
Bea Gecht

In loving memory of
Rose & Mike Weisfeld

In memory of our beautiful

Brooke Chase Gettleman

Robin & Harvey Finkel

Congratulations to my grandson

Eli

On becoming a Bar Mitzvah

*Love always,
Grandma Arlene*

In loving memory of an incredible woman

Fran Berkwits

A Special & Dear Friend Never to be Forgotten

Always in our Hearts

We miss you very much,

Marion & Charlie Yanovsky

In Memory of

Stanley Kravet

*In loving memory
of the best grandparents*

Helen & Leo Diamond

Susan Yanovsky Roden

In loving memory of

TOBY & HAROLD GOTTLIEB

SAMI ELENA MANSOUR

Together Forever

Sue & Gus Sirot and Family

With Dear & Lasting Memories of

Frances Berkwits

*At the rising sun and its going down - We remember her
At the beginning of the year and when it ends - We remember her
For her dedication to making a better world - We remember her*

Gloria Berkwits and three nephews

In memory of our parents

Florence & Irving Turetsky

and our sister

Susan Barbara

1953-1955

Elaine & Barry Heimowitz

Linda & Steve Selip



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

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

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

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

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

*Thank you for all the years you served NTSAD.
We will continue the work you started - you showed us how.*

We miss you.

Thank you to the

Jewish Genetic Disease Consortium

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

www.jewishgeneticdiseases.org

In Loving Memory of

Marcia Feinberg

Marion & Charlie Yanovsky

In Loving Memory of

Anne & William Yanovsky

Karl Yanovsky

Errol Yanovsky

**In Loving Memory of
Sheila Wasserman**

*A kind and caring friend
We celebrate her life*

Marion & Charlie Yanovsky

In memory of

Henry-Hilda-Margo

Harry-Helga

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

In loving memory of
Jerome Sirot

Remembered and Loved Always

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

In loving memory of

Leslie Gluck

Hilda Cooperman

Sam Newman

Sue & Gus Sirot

In loving memory of

Helen & Leo Diamond

wonderful parents & grandparents

Marion & Charlie Yanovsky

In memory of

**Jeanette & Seymour
Thaler**

In Memory of a Special Woman

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

We love you and miss you.

Susan and Alan Roden

Jason and Bryan

In Loving Memory of

Billie Hoffman

“Harry’s Grandma”

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

Members of NTSAD New York Area

In loving memory of Emma Faith Zimmerman

*Find a place inside where there is joy,
and the joy will burn out the pain*

-Joseph Campbell

*Love,
Mom, Dad and Jackson*

In Loving Memory of

Sheila Wasserman

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

Always there to help everyone and anyone

Never wanting anything in return

She will always be missed

With much love,

Norman, Stuart & Kathy, Paul & Andrea Wasserman

Lisa & Lonnie Jacobs

Herb & Madeline Roimisher

In Loving Memory of
Harrison Hoffman

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

Love,
Mommy, Daddy & Jake

*In memory of
our beloved brother*

Mark Howard
1968-1971

Bruce & Linda Feingold

In Loving Memory of

Toby & Harold Gottlieb

Eliana & Avi Mordekovich and Family



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

– Ruth & Ed Feldman

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Sandi & Bob Plotkin
and Family

Compliments of
Philip & Gloria Darvin

Compliments of
A Friend of Hadara

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

Rhoda Kravet

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In Memoriam

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

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



NATIONAL TAY-SACHS & ALLIED DISEASES ASSOCIATION

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

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

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