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
New York Area

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 beloved memory of

Frances Berkwits

If you were lucky enough to have spent time with Fran, then you would know how devoted she was to NTSAD, its mission and most importantly to the families. She was soft-spoken but firmly intelligent, with a mind for details that was beyond impressive.

Fran began her journey with NTSAD in the 1950s when she worked with families whose children were at Kingsbrook Jewish Medical Center in New York. With the advent of carrier testing and prenatal diagnosis in 1969, Fran's work expanded to include community and carrier testing programs in the New York area. Her work as a genetic counselor and social worker was invaluable to the NTSAD family. She attended many family conferences, board meetings and many other genetic-related organization conferences. At every opportunity and at every board meeting, Fran articulately reminded us about the need to stay vigilant in the areas of awareness and carrier screening to successfully prevent new diagnoses of our diseases. She was always a woman with a purpose.

Her time serving on the NTSAD National Board of Directors, the NTSAD Scientific Advisory Committee, the NTSAD New York Area Chapter Board, and the Jewish Genetic Disease Consortium Board will forever be appreciated.

We remember Fran with great admiration and gratitude for her tireless commitment to the prevention of Tay-Sachs and related genetic diseases.
We could not have done it without her.
With Special Thanks To

The Board of Directors NTSAD New York Area

Dedicated to the elimination of Tay-Sachs and the Allied Diseases
Raising awareness for prevention
Supporting Family Services
Funding Research
Volunteering together - a true labor of love
Always making a difference for more than 50 years!
Historical Perspective On Tay-Sachs & Allied Diseases

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 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. Larry Schneck, Bruno Volk and Carlo Valenti at Kingsbrook, Brooklyn, N.Y. use amniocentesis to diagnose Tay-Sachs disease in utero.

1970 - Drs. Larry Schneck, Bruno Volk and Carlo Valenti at Kingsbrook, Brooklyn, N.Y. use amniocentesis to diagnose Tay-Sachs disease in utero.

1971 - Michael Kaback, MD conducts mass community screenings to identify Tay-Sachs carriers took place in Baltimore and New York. Tay-Sachs disease was established as the first genetic disease meeting criteria necessary for public prevention programs.

1971 - 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 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.

1981 - NTSAD sponsors workshop session. "Tay-Sachs Disease: Progress in Testing and New Approaches" at the 32nd Annual Meeting of the American Society of Human Genetics, held in Dallas, TX.

1981 - Michael Kaback, MD creates International Quality Control Program for Tay-Sachs Disease testing and California Tay-Sachs Prevention Program.

1983 - Dor Yeshorim, a unique Tay-Sachs carrier screening program serving the Orthodox Jewish community, founded by Rabbi Josef Ekstein and 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.


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.

1998 - More than 1,331,000 young adults screened and almost 700 healthy babies born to high risk couples as a result of Tay-Sachs carrier testing.

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.

2007 - Present - NTSAD awards grants to the Tay-Sachs Gene Therapy Consortium Research Project 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.


2002 - Present - NTSAD continues to fund promising innovative research, through it’s Research Initiative, for neurodegenerative diseases that affect the central nervous system.
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.

Our Vision

- Direct, fund and promote research to develop treatments and cures
- Provide comprehensive support services to affected families and individuals
- Guide prevention, education, awareness and screening through effective grassroots collaborations with chapters and affiliates
- Lead advocacy efforts as the recognized authority for this family of genetic diseases

The related genetic diseases include over 50 lysosomal storage diseases and over 40 leukodystrophies.

Caring for Families

A big part of NTSAD’s mission is to support families in a variety of ways throughout the year to promote emotional healing, engagement and empowerment. We cultivate a strong family network as an essential component of comprehensive support services, and plan to expand our system of mentors.

NTSAD’s unparalleled family support network extends worldwide with over 750 members. Through a confidential network, new members share knowledge about home care, medical obstacles, and coping with the daily struggles caring for a loved one with a rare genetic disease.

The annual family conference held every spring brings together families, affected children and adults, healthy siblings, caregivers, and medical and research professionals. It is an invaluable resource for families who look to one another and to professionals for advice, support and community.

As a result of our current strategic planning process, we have a goal to develop a “family management system.” It will enable our Family Services team to support families as they move through their illness journey -- essentially helping families and affected individuals anticipate what is coming and what they can do to best prepare and cope.
Prevention Through Education and Carrier Screening

NTSAD receives calls every week to help couples and individuals navigate the complicated world of genetic screening. Anyone can be a carrier, regardless of background, although Ashkenazi Jews, French Canadians, Cajuns, Irish-Americans are at a higher risk for being Tay-Sachs carriers. NTSAD partners with other organizations to educate physicians and the public about Ashkenazi Jewish Genetic diseases, and is involved in the Irish Carrier Screening Rate Study.

Going forward, we plan to advocate for carrier screening, universal population screening, as well as newborn screening. We will educate our supporters about carrier screening and expanded screening for our group of diseases as new trends evolve.

Leading the Fight in Research

NTSAD launched its Research Initiative in 2002 to fund innovative research for neurodegenerative diseases that affect the central nervous system. NTSAD funds promising research and programs that may lead to major grant support and with the potential to reach clinical trials.

Forty grants, totaling $3 million have been awarded through the NTSAD Research Initiative program and an additional 13 grants through the former Lysosomal Storage Disease Research Consortium. These grants have led to NIH grants of more than $10 million toward finding a cure. These grants have supported research in a number of allied diseases including the gangliosidoses (Tay-Sachs, Sandhoff, GM1), Canavan, Batten, and Krabbe diseases. The projects funded include gene therapy, stem cells, enzyme enhancement, biomarkers and natural history studies.

The Tay-Sachs Gene Therapy Consortium continues its work toward clinical trials. They have successfully identified new vector formulations that yield increased enzyme expression in the brain with little or no evidence of neurological changes compared to controls. These vectors have successfully been tested in animals in short-term studies. The next steps will plan for production of the vectors for further toxicology studies, meetings with the FDA, and regulatory filings before initiating human clinical studies.

As a result of the strategic planning process, the Research Initiative will still encompass basic and translational research, although it will now prioritize “Clinical Trial Readiness” with the increased possibility of new therapies. Therefore, in addition to soliciting proposals for novel research projects, we will strongly encourage proposals that address disease progression and natural history, development of patient registries, biomarkers, clinically meaningful efficacy endpoints for clinical trials and newborn screening.
This Annual “Day of Hope” Event to Fund Research brings NTSAD families and their communities together for one day every September. From California to England, hope is shared through pancakes, glasses of lemonade, plates of spaghetti and many miles walked.

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 $120,000 has been raised since our First Annual Day of Hope on September 18, 2011.

Mark Your Calendar for the Fifth Annual Day of Hope on September 19, 2015!
A FAMILY GATHERING

The NTSAD Annual Family Conference is the cornerstone of our exceptional Family Support Services. It provides over 200 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.
NTSAD 2014 Highlights

- NTSAD awarded a Research Initiative Grant to BioStrategies, LC with David Radin, PhD as Principal Investigator for the project, "Lectin-assisted transnasal delivery of corrective enzyme for GM1 gangliosidosis."

- NTSAD’s Board of Directors developed a five-year Strategic Plan. This plan outlines how NTSAD will advance research for treatments, better serve our families, and promote accurate and effective carrier screening.

- NTSAD formed a Corporate Advisory Council (CAC). The CAC, through its collective industry expertise, serves as a resource to NTSAD to advance its research agenda and help to position NTSAD as an attractive partner to industry.

- The NTSAD New York Area Chapter transferred its administration to the national office of NTSAD. The chapter’s focus on education, awareness and research will remain in the Tri-State Area. Marion Yanovsky and the work of the chapter was celebrated in May.

- In July, members of NTSAD’s Science Advisory Committee (SAC) and clinicians from industry gathered at a GM2 Clinical Research Meeting. Their goal is to collaborate to expedite clinical trials for GM2 and related diseases.

- Dr. Douglas Martin and his colleagues at Auburn University completed a three year study on sheep with Tay-Sachs disease (TSD). They conducted safety and efficacy studies of AAV gene therapy in the sheep and will continue to optimize gene therapy in the sheep model of TSD.

NTSAD 2015 Initiatives

- Research
  - Plan and drive next steps in achieving Clinical Trial Readiness
  - Organize and host Scientific Symposium & Workshop in April, 2015
  - Support and help to identify the options for a path forward to clinical trials for the Tay-Sachs Gene Therapy Consortium

- Family Services
  - Launch Rare Siblings Project
  - Complete roadmap document for NTSAD’s major diseases
  - Support families as they move through their child’s illness journey

- Education/Prevention
  - Participate in pan-ethnic carrier screening initiatives as new guidelines are introduced
Research Update

What is the NTSAD Research Initiative?

NTSAD has funded research since its beginnings in the 1950s. It led to the discovery of the Tay-Sachs gene and the subsequent advent of carrier screening. In 2002, the Research Initiative was formalized and began funding cutting-edge research and collaborating with other rare disease groups to make the most of the grants. **Over $3 million has been raised cumulatively for research since the Research Initiative began in 2002.** The onset of advancing technologies took research to a new level and the formation of the Tay-Sachs Gene Therapy Consortium in 2007 changed the landscape of NTSAD's research portfolio.

Now, the future of the Research Initiative will encompass not only basic and translational research, but it will also focus on clinical trial readiness as the possibility of new therapies shine on the horizon. One component of clinical trial readiness are natural history studies. A natural history study gives researchers a clear picture of how a disease advances and how to measure the effectiveness of a therapy. The article below summarizes the natural history studies of our family of diseases conducted to date, much of which has been funded by NTSAD.

**Natural History Studies: An Important Part of Getting Ready for Clinical Trials**

by Allison Bradbury, PhD and Staci Kallish, DO

NTSAD, to date, has made over $354,000 in grants for natural history studies and has helped in gathering essential data for the studies. Data collected from natural history studies is garnering importance as success in research moves us closer to initiating clinical trials. It is vital to have a baseline knowledge of the disease progression from which to measure the success of therapy. Researchers are conducting these vital natural history studies and collecting fundamental data to inform clinical trials. Furthermore, natural history studies provide valuable information to families and clinicians to help manage these difficult diseases. Natural history work is ongoing for many of our diseases with the aim of preparing to fund and conduct more natural history studies in preparation for future clinical trials.
In 2011, Dr. Florian Eichler’s group, at Massachusetts General Hospital in Boston, published an unprecedented natural history study on infantile GM2 gangliosidosis.

- The study included data on symptom onset and disease progression of 92 patients with infantile GM2 (Sandhoff and Tay-Sachs disease) that were surveyed through NTSAD.

- The mean age at onset of earliest symptom was 5.0 ± 3.3 months and the average age at diagnosis was 13.3 ± 5.3 months. The most common initial symptoms were developmental arrest (83%), abnormal startle response (65%), and low muscle tone (60%).

- 98% of patients had seizures and the majority required multiple seizure medications, 75% of patients were partially or completely fed by G tube, and 88% required regular suctioning.

- Based on this study the researchers were able to develop a clinical severity scoring system based on the time at which milestones are lost and new symptoms arise.

Dr. Eichler’s group also completed a natural history study further characterizing juvenile and adult-onset types of Late Onset Tay-Sachs (LOTS).

- Retrospective data on symptom onset and progression was acquired from 55 patients that were surveyed through NTSAD.

- The most common initial symptoms were the same in juvenile and adult LOTS and included difficulty running, speech abnormalities, impaired gross motor skills, inability to climb stairs, and impaired fine motor skills.

- The median time of onset of symptoms to becoming wheelchair-bound was 4 years in juvenile patients and 26 years in adult patients. Similarly, juvenile patients lost the ability to climb the stairs in the 1st decade of life, while adult patients lost this ability in the 3rd or 4th decade of life.

- Further defining the disease progression between juvenile and adult-onset LOTS will provide important information for patients, their families, and clinicians in managing and tracking this disease.
Dr. Cynthia Tifft, at NIH, has conducted a natural history study on patients with GM1 gangliosidosis.

- Repeated MRI scans of 5 late infantile GM1 patients showed rapid and similar progression from the first scan (median 6.5 months from onset of symptoms) to the second scan (median 43 months from onset of symptoms).

- In contrast, serial MRI evaluation of 10 juvenile GM1 patients did not show significant changes in the severity of the MRI score over the course of the study.

- Dr. Tifft is also conducting magnetic resonance spectroscopy (MRS), which uses another type of imaging. She has found alterations of brain metabolites such as NAA, a molecule present in neurons, in GM1 patients.

- Alterations of MRI and brain metabolites determined by MRS could provide a non-invasive manner to track disease progression in affected children and measure therapeutic efficacy in clinical trials.

A natural history study for the gangliosidoses is also currently underway at the University of Minnesota led by Dr. Chester Whitley. It is a natural history study in which researchers hope to collect multiple sets of information from patients over time. They hope to include 15 Tay-Sachs disease/Sandhoff disease and 15 LOTS disease patients. This study will help researchers to better understand disease progression and continue to develop objective measures of disease severity.

Dr. Paola Leone was a principal author on a 2006 Canavan Disease natural history publication (Neuropediatrics 2006; 37: 209-221). This study was designed to model the natural history of Canavan disease using MRI and proton magnetic resonance spectroscopy (1H-MRS - another type of imaging). Researchers were able to demonstrate elevation of nerve specific brain metabolite, NAA, and glial cell (another important type of cell in the brain), specific metabolite, myoinostitol. This study also used MRI to quantify changes in myelin formation and brain atrophy in specific regions of the brain. There is interest in building on this research to be able to monitor future studies involving drug, gene therapy, or stem cell treatments.
Dr. Douglas Martin and his team of researchers at Auburn University have recently completed a three year study on sheep with Tay-Sachs disease (TSD). In addition to further characterizing this disease model, Martin's group conducted safety and efficacy studies of AAV gene therapy in the TSD sheep. Since the sheep have a mutation in the HEXA gene (and subsequent deficiency of Hexosaminidase A (HexA) protein), this is an authentic model of Tay-Sachs disease. Furthermore, the large brain size of the sheep allows researchers to confront certain challenges of gene therapy, including brain targeting and distribution.

The Details
- TSD sheep were treated by direct brain injection of AAV vectors encoding Hex.
- There were three different AAV vector designs and two different doses tested in the TSD sheep.
- TSD sheep were treated after the onset of symptoms in the mild to moderate disease stage.
- Both short and long-term AAV gene therapy studies were conducted.

The Results
Survival
- Untreated TSD sheep had a disease onset of less than two months of age and lived an average of 9.1 months.
- When all AAV treated TSD sheep were combined (all vector designs and doses), average lifespan was 13 months of age, a 43% increase.
- The most successful AAV treatment group had a mean lifespan of 14.3 months, a 57% increase.

MRI and brain pathology
- MRIs were conducted on normal, untreated TSD sheep, and AAV treated sheep with a very high magnetic field (7 Tesla), allowing for superior quality brain images.
- MRIs showed that many changes caused by disease, including loss of myelin, were improved after AAV gene therapy.
- Untreated TSD sheep brains showed pronounced neuroinflammation upon histological examination (inflammation of brain tissue seen when looking at the brain with a microscope). AAV gene therapy was found to decrease but not fully prevent this response.
**Enzyme activity/storage reduction**

- As expected, levels of therapeutic enzyme were highest at the injection site and decreased with distance from the injection.
- With both dosages of the most promising vector design, all areas of the brain near the injection site had levels of enzyme above normal. In the more distal cerebellum (part of the brain that controls movement), enzyme levels were near normal with higher dose but substantially lower with the lower dose.
- Only the cervical region (closest to the brain) of the spinal cord showed Hex levels above background, and only the higher dose vector reached normal levels in this region. Complementary studies in Sandhoff disease cats produced much better distribution of enzyme to the spinal cord, which could be one factor in improved survival seen in cats.
- Ganglioside storage product was reduced in all areas of the brain near the injection site, but not significantly reduced in distant brain regions (i.e. cerebellum) or spinal cord. This was not surprising since the therapeutic Hex enzyme did not sufficiently reach these areas.
- Enzyme activity was low in all tissues analyzed outside the central nervous system (liver, heart, spleen, small intestine, and kidney). This is also different from AAV treated Sandhoff cats, in which enzyme activity can reach >50% of normal activity in some tissues and may account for longer survival in the cats.

**Going Forward**

- One gene therapy treated sheep is still alive and doing well at almost 1.5 years of age and continues to be monitored regularly.
- The flock was moved from Texas to Auburn University in May of 2013, which will allow the project to grow.
- The veterinarians at Auburn University had a very successful first breeding season with 13 lambs already born and two more expected in the near future.
- Dr. Martin and his team of researchers will continue to optimize gene therapy in the sheep model of TSD, primarily focusing on better distribution of the enzyme to more distal brain regions (cerebellum) and the spinal cord.

**NTSAD** has provided grants of more than $300,000 to nurture the flock that has made enormous contributions to the gene therapy research project.
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 30 carrier sheep that are part of the Tay-Sachs Gene Therapy (TSGT) Consortium research project. The sheep have been transported to Auburn University where the research is being carried out. 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
Carrier Screening For Tay-Sachs & Allied Diseases

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.

There are 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 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
Are you of Irish descent?
Are you aware you may be a carrier for Tay-Sachs Disease?

There is a higher carrier rate for Tay-Sachs disease in people with Irish ancestry, but no exact risk number has been determined. Researchers in Philadelphia at Einstein Medical Center’s Genetics Division are conducting a study to determine an accurate carrier rate for Tay-Sachs disease in the Irish population and to also identify the most common gene changes within this group.

Participation in this study will help protect future generations of Irish families from the tragedy of Tay-Sachs disease. Your participation will also provide you with valuable information about your own carrier status so that you can make informed decisions for a healthy family. If you have at least 3 Irish grandparents and are 18 years or older, you may be eligible to receive FREE carrier screening for Tay-Sachs disease.

At no cost to you, this study will provide you with your carrier status for Tay-Sachs disease and genetic counseling to explain your results and answer your questions. One simple blood test is all that is needed to participate!

To participate in the study contact
Amybeth Weaver, MS, CGC at irish@tay-sachs.org or call 215-887-0877.

This study is funded through the generous support of
The Albert Einstein Society
National Tay-Sachs & Allied Diseases Association of Delaware Valley (NTSAD-DV)
National Tay-Sachs & Allied Diseases Association New York Area
## January 2015

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**Holiday Observations:**
- **NEW YEAR'S DAY**: January 1
- **MARTIN LUTHER KING, Jr BIRTHDAY OBSERVED**: January 18
- **Noah Philip Devane**: January 10
- **Mia Levy**: January 22
In Loving Memory of
Harrison Hoffman

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

Love,
Mommy, Daddy & Jake
In honor of our daughters, Felissa and Stephanie and our grandsons, Benjamin and Nicholas and

In memory of our children, Geoffrey and Janna

With deep gratitude and fondness, we will always keep Fran Berkwits in our hearts for her compassion and unending support.

Sandra and Howard Benjamin
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**In Memoriam**

- Estelle Goldstein March 3
- Matthew Forbes Romer March 8
- Nathan Sider March 10
- Alan Berg March 12
- Toby Gottlieb March 25
- Mary K. Uscky March 25

**Daylight Savings**

- Move clock ahead

**Special Dates**

- Palm Sunday
- St. Patrick’s Day

**Additional Notes**

- February 2015
- April 2015
In loving memory of

LARRY KESSLER

In honor of your beautiful daughter
Bonnie Susan Kessler - 1967-1971

In honor of your beloved grandchildren
Sophia Bonnie Kessler - born 2006
Emma Jaclyn Kessler - born 2010

With all our love,

Anita Kessler
Marc & Michelle Kessler
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In Memoriam:
- Alex Lifshitz
- Alan Thaler
- Albert Eisenberg
In loving memory of

TOBY & HAROLD GOTTLIEB

SAMI ELENA MANSOUR

Together Forever

Sue & Gus Sirot and Family
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STUART OKIN, M.D.
BOARD CERTIFIED IN INTERNAL MEDICINE & CARDIOLOGY

Affiliated with:
St. Francis Hospital, North Shore University Hospital
and New York Hospital Queens

DIABETES AND HYPERTENSION TREATMENT

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So many gave their lives for the country they love.

Let us not forget, everyday, their dedication to our way of life.

God bless our heroes and our country.

In memory of

Ricki Beth Sussman
1953-1957

Barbara Salomon & Family
# June 2015

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<td>Frances Berkwits</td>
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*June 7: Matthew Feldman, Lior Levy  
June 8: Lee Cohen  
June 9: Michael Silberfarb  
June 10: Shawn Silberfarb  
June 11: Lillian Sherman, Natan Thaler, Lisa & Griffith Holland  
June 12: Scott Harris Gentile  
June 13: Esmeralda Sirot, Brian Finkel  
June 14: Matthew Lawrence Gentile  
June 15: Stacy Campbell  
June 16: Sharon Silberfarb, Elsie & Emil Heringer  
June 17: Jason Shapiro  
June 18: Heath Feldman  
June 19: Miriam Thaler, Mitchell Gordon  
June 21: Matthew Lawrence Gentile  
June 22: Jayden Campbell  
June 23: Sharon Silberfarb, Elsie & Emil Heringer  
June 24: Jason Shapiro  
June 25: Heath Feldman  
June 26: Miriam Thaler, Mitchell Gordon  
June 28: Sean & Bill Boorstein  
June 29: Lee Cohen  
June 30: Matthew Lawrence Gentile  

**Fathers Day**

**Flag Day**

**SUMMER BEGINS**
In loving memory of

Helaine Seccia

“A lifelong friend”

Gus Sirot
### In Memoriam

- **Leon Finkel**  July 3
- **Dillon Henry**  July 6
- **Sylvia Farber**  July 18
- **Leonard Chudnick**  July 20
- **Irwin Ungerleider**  July 21

### July 2015

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### Independence Day

#### August 2015

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In Memory of Frannie

We shared our love of working for NTSAD and also our love of knitting.
Each time I knit something from "our stash"
I will think of you with great affection.
I am proud to have had you in my life!
You are missed.

Phyllis Chudnick

Congratulations to
Susan & Alan Roden
in honor of
Bryan's Bar Mitzvah
Merri & Murray Benbasset

In Memory of
Fran Berkwits
in appreciation of
her support of NTSAD
Marcia Feinberg
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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
MYTH: Only one partner needs to be tested for Tay-Sachs and Allied Diseases.

FACT: Both partners should be tested.
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
Fran Berkwits
Sheila & Lee Cohen

Emil K. Heringer, O.D.
Independent Optometrist

In Loving Memory
of
Jean Maniscalco
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In Memory of
and in Tribute to
our mother

'A Woman of Valor'

אשה חיה

Jennie Gottlieb
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**In Memoriam**

- Adele Zimmer: November 2
- Miriam Lifshitz: November 4
- Daniel Jacobson: November 7
- Aaron Lifshitz: November 9
- Abner Berkwits: November 10
- Stephen Silberfarb: November 15
- Owen Brandt: November 17
- Emma Zimmerman: November 18
- Helen Diamond: November 23
- Lester Pinger: November 24
- Irving Zaretsky: November 25
- Noah Jarashow: November 30

**Daylight Savings Ends**

- Move clock back

**November 2015**

- **Thanksgiving Day**: November 26

**Events**

- **Election Day**: November 3
- **Veterans Day**: November 11
- **In Memoriam**: November 2, 4, 9, 10, 14, 15, 17, 18, 24, 25, 29, 30
In loving memory of

Jerome Sirot

Remembered and Loved Always

Saul, Gloria, Sandy, Debbie, Jeff, Kaitlin, Samantha and Rebecca
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In Loving Memory of
SCOTT PETER COLTON
&
CAROLE & RAY COLTON
Love,
Gerri Colton & James Colton

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

For
Honeydew and Gus

Love,
Angus

In Loving Memory of Fran
who made helping the families of NTSAD
her life’s work and passion.

We are forever in her debt.

Much love,
Sharon, Steven, Jake and
“Angel” Harry Hoffman
In loving memory of

Emma Zimmerman

There are wounds time does not heal, though it can reduce them to a manageable size.

Miss you muchly,
Daddy, Mommy & Jack

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

Ann Brandt

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

In Honor of My Amazing Sister,
Marion Yanovsky
With Love, Ann

In loving memory of
Owen Brandt
Your love is always with us

Ann, Lisa, Skip, Rona, Michael
Nathan, Noah & Joshua
IN MEMORY OF

EVELYN and LEONARD SUSSMAN
(1918-2000) (1916-2001)

and

RICKY BETH SUSSMAN
(1953-1957)

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

PETER and MICHAEL SUSSMAN
In Memory of

Melanie & Randi Shames
Continued Success in Eradicating Tay-Sachs

Phyllis & Julius Shames
Eric J. Shames
Ronni, Tony & Gabby Muia

In memory of

Gertrude Bertinthal

Deborah, Arthur, Harris, Seth & Elyse Kupperman

In Loving Memory of

Lawrence Krause
&
Arthur Krause

Always, Linda

In memory of

our beloved brother

Mark Howard
1968-1971

Bruce & Linda Feingold
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

and

Jonah - July 25, 2000

Sue & Gus Sirot
In loving memory of

Uncle Stanley & Aunt Joyce
You are missed!
Rest in peace

Love,
Sue & Gus
Nicole, Hadara, Elijah & Jonah

Thank you to the Pearl River Walk Committee

Catherine Duplessis, Christine Ippolito, Darlene McDonagh, Vera Schragenheim,
Kathy Whitney & family, Marcy Michelman, Sharon Hoffman,
Dale & Andy Verebes, Daryl Marx, Shari & Jeff Ungerleider & family, Moria Balseca,
Kerriann Koppel, Adrienne Eckert, Kathleen Maier, Joyce Kent, Lisa Amato,
Julie Feldman, Linda Hoffman, Elise Heringer and Marion Yanovsky

Your hard work before and during the event made it a huge success!
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 Yanovskiy
In memory of

Francie Berkwits

Loving wife, mother, grandmother and great-grandmother.

The Berkwits and Elberg Families
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 and Caleb Greenhut

In Loving Memory of

Sylvia and Harry Silberfarb

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

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Barry and Carol Silberfarb
Daniel, Anna, Zoe and Jake Silberfarb
Sharon, Will, Brayden and Caleb Greenhut
In Beloved Memory of

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
In Loving Memory of

Jerry Sirot

There is a loving bond that only twins can share - built on cherished memories of special times together and a closeness that will always mean so much.

Though words fall short at a time like this,
It brings me comfort knowing that my brother, Jerry will always be part of me, through this bond that will live in my heart.

I will remember all the good times we've shared as a gift that I will cherish forever. It's the kind of gift that makes me smile and feel so lucky to have had such a great brother and friend.

Rest in Peace Dear Brother

Love ya,
Gus
In Loving Memory Of

ALLEN & MARGIE FEIN
JOE & CEIL BENBASSET
EVELYN & LENNY SUSSMAN
LIBBY MOSBERG
JOE ROSEN
ROSE WEISFELD

Merri & Murray Benbasset
Jason & Melissa, Maya & Taylor
Corey & Hope, Easton & Harlow
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

Daniel Jacobson

A long-time NTSAD Supporter and Contributor
You Made a Difference in Many Lives

We Miss You and Your Humor

The Jacobson & Zeiger Families
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
My Parents
Irving Jerome Burger
Mickey H. Burger
and
My Brother
Howard Burger

Clare Burger
In Loving Memory of

SAMİ  ELENA MANSOUR

“A Moment of Joy”

Sue & Gus Sirot and Nicole
In Honor of all the Beautiful Sirot & Levenson Grandchildren

Sarah
Daniel
Jay
Julia
Jonah
Jacob
Samantha
Justin

Hadara
Elijah
Jill
Tyler
Sydney
Kaitlin
Brielle
Rebecca
With Loving Memories That Will Never Fade

Jean McKenna
Sheila Mirchin
Ann Mariotti
Seena Schneiderman
Yvette Sadoff
Edith Hirshhorn

Barbara Salomon
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 Beloved Memory Of

Fran Berkwits

We are honored to have had Fran so profoundly affect our lives.

Not only was Fran the gentle, caring, gifted genetic counselor, but also the quietly determined person who engendered the trust and respect that brought the Dor Yeshorim Program to life. Fran gave The Tay-Sachs Carrier Screening Program years of her voluntary presence in the New York Tri-State area.

Fran has made an indelible impression on our hearts and an invaluable contribution to the National Tay-Sachs and Allied Diseases Association for almost sixty years.

Claire and Cliff Kahn
In Celebration 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 on the NTSAD New York Area Board.
We will continue the work you started - you showed us how.

We miss you,

Members of the Board of Directors
NTSAD New York Area Chapter
In loving memory of

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

The Sirot Family
In Honor of
My Precious Grandchildren

Chani, Miriam, Rachel, Devorah,
Chaim, Rivka, Tzvi Yakov,
Yocheved, Natan, Avraham, Binyamin

and Great-Grandchildren

Rivka Bracha, Schraga Feivel
Aaron Simcha, Meir Simcha
Rivka Tamar, Eliyahu Menashe
Nisan Yakov, Temimah, Mendy
Adina Tova, Leeba, Esti, Yisroel, Anaelle

In Memory of
my beloved husband, Seymour

Jeanette Thaler
The traits of our genetic counselor, Fran Berkwits, with her brilliance and kindness were consistently expressed as she worked steadfastly for NTSAD.

Fran was always Devoted, Noble, and expertly Adept – in a manner that can never quite be replicated.

With great appreciation,

Carol S. Handwerker

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

Norman Wasserman

Two Sisters With Love for 92 Years!
In loving memory of Burt Salomon
A true philanthropist

In memory of
Henry-Hilda-Harry-Helga

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

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 Honor of Marion & Charlie Yanovsky
We are the luckiest children and grandchildren.
You are the best!
We love you,
Susan, Alan, Jason & Bryan

We are the luckiest children and grandchildren.
You are the best!
We love you,
Susan, Alan, Jason & Bryan
In loving memory of

Frances Berkwits, MS, CSW
and
Abner Berkwits, MD

Ronald A. Mermer, C.P.A.
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Fishkill, NY 12524
(845) 897-5108
Fax (845) 897-5183

Email: info@mermcpas.com
www.mermcpas.com
In loving memory of
Dakota Bihn
Marion & Charlie Yanovsky

In loving memory of
the best grandparents
Helen & Leo Diamond
Susan Yanovskya Roden

In Memory of
Fran Berkwits
Adele Schneider

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55 Northern Blvd., Suite 303
Great Neck, New York 11021
In memory of

Jerry Sirot

Joyce Erwin
In Loving Memory of

Bea Gecht

Dear friend and dedicated volunteer in the NTSAD Brooklyn Chapter

whose tireless commitment and hard work to raise funds

in the support of research and prevention

helped make a difference.

She will be missed
In memory of

Fran Berkwits

• Extraordinary wisdom
• Pioneer and pathfinder
• A very special friend and colleague
• Glowing smile and never a complaint

A true role-model and inspiration for us all.

Her legacy lives on in the entire NTSAD community.

Kevin Romer & Family

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 honor of our children

Judy & Rob, Samuel & Nicole and Maury

and our grandchildren

Daniel, Isabel Aaron and Adam

Al (י”ת) & Miriam Storch

In Memory of

Fran Berkwits

We are remembering you with love always.

Audrey & Peter Kastan
In memory of
Sue Ungerleider
A loving mother and grandmother who will be greatly missed.
You are forever in our hearts.
Jeff, Shari, Justin, Leigh & Sydney

In Loving Memory of
Toby & Harold Gottlieb
Eliana & Avi Mordekovich and Family
In honor of
Marcia Feinberg

In memory of Fran Berkwits

Words cannot capture what we all have shared in knowing Fran.

Her determination, dedication, interest and grace stand as life-lessons to us all.

We can only thank her for all she did for so many and for the exemplary teacher she was.

Jayne Gershkovitz
In honor of my wonderful children

Dr. & Mrs. Martin Thaler and Phyllis Naftalowitz
and

In memory of my beloved husband

Seymour Thaler

Jeanette Thaler

In Loving Memory of Fran Berkwits

Always caring and dedicated.
We are so grateful for all that she did to raise awareness
and for all of her work on behalf of the families.
She is and will be truly missed by all of us.
She was a very special lady.

Sandy & Allen Levine
In memory of Fran Berkwits

I don't know that anyone has worked as hard as Fran, and for as many years as Fran, to make a difference in the lives of our children and families.

She was definitely a grand dame, whose grace and gentle, but determined manner will be sorely missed.

Dan Greenberg

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

Fran Berkwits

For more than 50 years she set a standard that few could approach

She will be missed.

The Sussmans

Remembering Fran Berkwits

Fran was a true medical social worker.

She understood the problems our parents and patients faced but also the science involved.

As a result, she could not only interact with physicians and laboratory staffs but could explain the complexities of Tay-Sachs enzyme and gene testing to our families better than anyone.

She really cared about the person and what mattered most to her was that everyone be treated with courtesy and respect.

Dr. Edwin H. Kolodny
The Jewish Genetic Disease Consortium

is thankful for the opportunity to have worked with

Fran Berkwits

A valued Board Member and friend.

An advocate for carrier screening from its very beginnings

whose expertise and steady resolve to raise awareness helped lead to prevention.

With love and great admiration,

The Members of the Board of Directors

In Loving Memory of Fran Berkwits

Fran was an incredible woman who has impacted so many lives.

NTSAD was her heart and soul.

She loved being a part of the families.

She will truly be missed.

Shari & Jeff Ungerleider and Family
With Special Thanks to our Supporters

*Your generosity is making a difference in the quest for treatment and cure of Tay-Sachs and the Allied Diseases.*

---

**In honor of Danny Kenny**

*a special little boy*

Your smile warms us on even the darkest days.
We love knowing that we have an Angel right here on Earth looking out for us.
We love you.

**Aunt Kathy & Uncle Neil**

Meghan, Jimmy and Danny
In Memory of Fran Berkwits

Your love, wisdom and dedication will live on in the hearts of the many families you have guided. You have been our mentor and dear friend. You were always the smartest person in the room!

With all of our love and respect,

Elise, Emil, Rebecca and Marissa Heringer

Thank you to our

National Board of Directors
Staff & Volunteers
Scientific Advisory Committee
Corporate Advisory Council

for their dedication to the mission of NTSAD
In Memory of Our Beloved Niece & Nephew

**Rae Arlene**
and
**Michael Lee Goldstein**

Barbara & Edwin Simon

---

In Memory of Fran Berkwits

**An Extraordinary Woman**

Ann Brandt

---

I’ll never forget when you were a little bit pink.

With love always.
In Loving Memory of
William Yanovsky
Karl Yanovsky
Errol Yanovsky

In Loving Memory of
Stanley Michelman
We miss your kind and loving ways
We miss your friendship
We are sad you left us so soon
Marion & Charlie Yanovsky

In loving memory of
Helen & Leo Diamond
wonderful parents & grandparents
Marion & Charlie Yanovksy
Fran, a truly dedicated professional who committed her life to helping our cause, NTSAD. She was unrelenting when it came time to educate young adults. She was involved until the day she died.

Fran will be missed.

Lynda Schriever
Past President, Brooklyn Chapter

Hope Is On The Horizon For Treatment & Cure!

We Honor The Researchers of the Tay-Sachs Gene Therapy Consortium

With all our love to our wonderful and beautiful grandchildren

HADARA ELIJAH
and
JONAH

POPPI GUS & GRANDMA SUE
In Memory of

Stanley B. Michelman
“A True Leader”

Bruce H. Nagel, Esq.
IN MEMORY OF OUR BELOVED DAUGHTER

RACHEL MEREDITH
FOREVER IN OUR HEARTS

IN HONOR OF OUR PRECIOUS GRANDSONS

TYLER MATTHEW
ANDREW JARED

RHODA & FRED KANTER
In Loving Memory of

Sheila Wasserman

A dedicated NTSAD volunteer
always supportive and willing to help.
Her efforts over many decades made a difference.
She will be missed.
In celebration of our precious grandchildren

Asher, Jason & Bryan

Marion & Charles Yanovsky

In memory of our sweet, caring friend

Fran Berkwits

Myrna & Jerome Karp
In honor of our beloved nephew and niece

GEOFFREY & JANNA BENJAMIN

We send lots of kisses to our great nephews

NICHOLAS & BENJAMIN

who have put loads of smiles on all the family’s faces

Aunt Lele and Uncle Jerry

---

In Loving Memory of Sheila Wasserman

A kind and caring friend

We celebrate her life

Marion & Charlie Yanovsky
In loving memory of

Fran Berkwits

THANK YOU FOR ALWAYS BEING THERE!

You will be greatly missed.

Sue & Gus Sirot
In memory of our parents

Florence & Irving Turetsky

and our sister

Susan Barbara

Elaine & Barry Heimowitz

Linda & Steve Selip

In memory of

The Pingers

Sarah & Alex Pinger

Lester Pinger

Beatrice Gecht

Sylvia Farber

Stella Zimmer

Miriam Finkel
In loving memory of our beloved daughter

Lisa Cheryl Kravet

Rhoda & Stan Kravet

In honor of

Fran Berkwits

Abe Rutkovsky
In memory of
Morton & Aaron Feinberg
Hilda & Arthur Brodsky
Bernie Brooks
Murray Kubersky
from
Marcia Feinberg

In memory of
Jerry Sirot
Judy and Corey Lev
With much thanks to

Karen Haberberg

for her beautiful photography at the

“Honoring New York” event

Karen’s Website: karenhaberberg.com

Shapiro Law Offices

Jason S. Shapiro
Attorney At Law

3205 Grand Concourse, Suite 1
Bronx, New York 10468
Tel: (718) 295-7000 • Fax: (718) 295-7575

www.shapirolawoffices.com
js@shapirolawoffices.com
In memory of a wonderful woman & friend.
Thank You Fran Berkwits for your care & support throughout the years.

Vera Schragenheim

In memory of

Anita Amerio

Sue & Gus Sirot
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<td><strong>Rita Joyce Abramson</strong></td>
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<td>Sue &amp; Gus Sirot</td>
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<td><strong>Aaron Feinberg</strong></td>
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<td>Ann Hanover</td>
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<td>Marion Yanovskys</td>
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<td>Nat and Hannah Natko</td>
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<td>Custom Dry Cleaning &amp; Friendly Service with a “Touch of Class”</td>
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<td>Touch of Class Cleaners of Pomona</td>
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<td>In Honor of Our Grandchildren, Reese Leah Finkel, Grant Zachary Finkel, Dean Harrison Finkel, With Love, Robin &amp; Harvey Finkel</td>
</tr>
<tr>
<td>In Honor of Marion Yanovskys, Sheila &amp; Lee Cohen</td>
</tr>
</tbody>
</table>
In Memory of
Fran Berkwits

So loved by all the families
to whom she gave care and courage...

So missed by all the friends
with whom she created community...

So treasured by all of us whose lives
she touched in so many special ways.

Thank you, Fran
for showing us how to care, how to share,
and how to value every minute of every life.

With admiration and appreciation,
Jayne Mackta & Family

Keep up the good work!

PROforma
Corporate Systems

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NEW CITY, NY 10956
TEL. (845) 634-0500 • FAX (845) 634-0300
<table>
<thead>
<tr>
<th>In loving memory of</th>
<th>In loving memory of</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fran Berkwits</strong></td>
<td><strong>Aaron Feinberg</strong></td>
</tr>
<tr>
<td><strong>Gerri Colton</strong></td>
<td><strong>and in honor of</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Marcia Feinberg</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Ellen &amp; Susan Cohen &amp; Families</strong></td>
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<tr>
<td></td>
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</tr>
<tr>
<td>In honor of our grandchildren</td>
<td>In memory of</td>
</tr>
<tr>
<td>Adam Taylor Chaitin</td>
<td><strong>Seymour Thaler</strong></td>
</tr>
<tr>
<td>Alexandria Rae Chaitin</td>
<td>The Storch &amp; Sherrell Families</td>
</tr>
<tr>
<td>Jeremy Scott Chaitin</td>
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<td>Paul Nunzio Chaitin</td>
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<tr>
<td>Paul &amp; Sandra Chaitin</td>
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<td></td>
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<tr>
<td>In loving memory of</td>
<td>Touch of Class Cleaners</td>
</tr>
<tr>
<td><strong>Sue Ungerleider</strong></td>
<td>1017 MacArthur Blvd.</td>
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<tr>
<td>Marion &amp; Charlie Yanovisky</td>
<td>Mahwah, New Jersey 07430</td>
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<tr>
<td></td>
<td>Proprietor: Michael Weisfelner</td>
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<td></td>
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<tr>
<td>With love to the beautiful &amp; special children</td>
<td>In memory of</td>
</tr>
<tr>
<td><strong>Sami Elena Mansour</strong></td>
<td><strong>Jerry Sirot</strong></td>
</tr>
<tr>
<td>Love,</td>
<td>Beloved brother of Gus Sirot</td>
</tr>
<tr>
<td>Karen &amp; Jerry Jacobs</td>
<td>Marion &amp; Charlie Yanovisky</td>
</tr>
</tbody>
</table>
We proudly support the achievements of NTSAD

• Research for Treatment & Cure
  • Education for Prevention
  • Support for Affected Families

Georgetown Flea Market
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In loving memory of
Seymour Thaler
Beloved husband, father, grandfather & great-grandfather
and
In loving memory of
Alan Mark Thaler
Dr. & Mrs. Martin Thaler & Family
Best Wishes Always
To Our Dear Friends
Sue & Gus
Gloria & Phil Darvin

Keep up the good work
The Sacks Family

In Memory of
Sylvia Farber
The Lifshitz Family

In Memory of
Suzanne Labocetta
Sandi & Bob Plotkin & Family

Compliments of
Leslie & Steve Schwarz

Compliments of
Grandma Betty
and
Papoo Louis S. Hazan
“Forever In Our Hearts”
Elyssa, Billy, Jason, Natalie, Corie, Jaden & Devin

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Compliments of
The Rattien Family
In loving memory of

ROSE WEISFELD

for her tireless commitment to the mission of NTSAD
With thanks and admiration

In Loving Memory of Bea Gecht

A Super Volunteer & True Friend
She will be missed

Marion & Charlie Yanovsky
<table>
<thead>
<tr>
<th>Dear Grandma Sylvia,</th>
<th>In Memory of Ahny</th>
</tr>
</thead>
<tbody>
<tr>
<td>We continue to love and</td>
<td>Her love of children lives</td>
</tr>
<tr>
<td>miss you as the years go</td>
<td>on</td>
</tr>
<tr>
<td>by.</td>
<td>May there soon be no need</td>
</tr>
<tr>
<td>What a legacy you have</td>
<td>for fund drives such as this.</td>
</tr>
<tr>
<td>left behind!</td>
<td>Phyllis Pullman</td>
</tr>
<tr>
<td>Your values live on</td>
<td></td>
</tr>
<tr>
<td>within us and your great</td>
<td></td>
</tr>
<tr>
<td>grandchildren.</td>
<td></td>
</tr>
<tr>
<td>Love, Sharon, Will,</td>
<td>In Memory of Brooke Chase</td>
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<tr>
<td>Brayden &amp; Caleb</td>
<td>Gettleman</td>
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<td></td>
<td>In loving memory of</td>
</tr>
<tr>
<td></td>
<td>Our Beloved Sister &amp; Brother</td>
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<tr>
<td></td>
<td>Sharyn Snyderman</td>
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<td></td>
<td>Fred Schriever</td>
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<td>Lynda &amp; Mel Schriever &amp;</td>
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<td></td>
<td>Family</td>
</tr>
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<td></td>
<td>Nam Myoho Renge Kyo</td>
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<td></td>
<td>Bruce Singleton</td>
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<tr>
<td>Compliments of A Friend of</td>
<td></td>
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<tr>
<td>Hadara</td>
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<tr>
<td>In Loving Memory of</td>
<td></td>
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<tr>
<td>Our beloved Sister &amp;</td>
<td></td>
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<tr>
<td>Brother</td>
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<tr>
<td>Friends of Gus &amp; Sue Sirot</td>
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</table>
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 Francie Berkwits

Caring sister-in-law • Concerned aunt

• Consummate traveler • Compassionate counselor

Who, for over 50 years (and multiple “retirements”),
never lost her drive and passion for the cause.

Gloria, Leland, Jeffrey & Michael Berkwits
In Memory of Fran Berkwits

Dedicated to helping families
Committed to education and carrier screening
She really made a difference!

Merri & Murray Benbasset

In loving memory of

Alan Mark Thaler

Aunt Miriam and Uncle Al
Judy, Rob, Daniel & Isabel Sherrell
Samuel, Nicole, Aaron & Adam Storch
Maury Storch
In honor of

Marion Yanovsky

Thank you for the love and friendship you gave to Francie Berkwits and the comfort you have brought to our families.

The Berkwits and Elberg Families
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.

Thank you to

Renée & Michael Sussman

for their generous support in advancing the vital programs of NTSAD
<table>
<thead>
<tr>
<th>In Honor of</th>
<th>Not only was Fran a dear Flying Club friend, but also a very special, wonderful, caring person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elyse &amp; Matt Chaifetz</td>
<td>Shirley Hartman</td>
</tr>
<tr>
<td>Sue &amp; Gus Sirot</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>In memory of</th>
<th>Congratulations to Debbie &amp; Arthur Kupperman on the marriage of their daughter Elyse to Matt Chaifetz.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owen Brandt</td>
<td>Sue &amp; Gus Sirot</td>
</tr>
<tr>
<td>Beloved Brother-In-Law &amp; Uncle</td>
<td></td>
</tr>
<tr>
<td>Marion &amp; Charlie</td>
<td></td>
</tr>
<tr>
<td>Susan, Alan, Jason &amp; Bryan</td>
<td></td>
</tr>
<tr>
<td>Steven &amp; Asher</td>
<td></td>
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</tbody>
</table>
In Memory of Daniel Jacobson

With great admiration for his many years of dedication in the quest to raise awareness for prevention and fund research to find a cure for Tay-Sachs disease.

NTSAD celebrates his life!
It is with great sadness and respect that the NTSAD Family had to say goodbye to a woman who embodied the NTSAD mission.

Frances Berkwits, MS, CSW
August 19, 1922 - June 29, 2014

Our deepest condolences to her family and close friends. We know she cherished her roles as mother, grandmother, great-grandmother, and friend.

She will be missed and may comfort be found in her legacy which will be felt for generations.

With deep affection and respect,

The NTSAD Staff
Sue, Joan, Diana and Ingrid

An accomplished woman, who can find? Her value is far beyond pearls.

~ Eshet Chayil, Book of Proverbs 31
In Memoriam

Harry Silberfarb ............................................. January 3
Rose Weisfled ................................................. January 5
Herbert Gordon ................................................ January 6
Samuel Eisenberg ............................................. January 7
Harold Feldman ................................................. January 12
Sylvia Silberfarb ............................................... January 17
Pearl Sirot ......................................................... January 19
Jane Eisenberg ................................................. January 29
Sydney Levy ...................................................... February 9
Charlotte Stark .................................................. February 11
Harrison Hoffman ............................................. February 17
Bernard Gecht .................................................. February 24
Estelle Goldstein .............................................. March 3
Matthew Forbes Romer ....................................... March 8
Nathan Sider .................................................... March 10
Alan Berg ......................................................... March 12
Mary K. Uscky .................................................. March 25
Toby Gottlieb .................................................... March 25
Alex Lifshitz ..................................................... April 12
Alan Thaler ....................................................... April 16
Albert Eisenberg ............................................... April 21
Stanley Michelman ........................................... May 7
Jack Zimmer ..................................................... May 8
Benjamin Gecht ................................................. May 9
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
Sarah Pinger .................................................... August 7
Phyllis Chavis .................................................. August 9
Shirley Leib ...................................................... August 10
Scott Peter Colton .............................................. August 16
Wendy Gordon .................................................. August 16
Jerry Sirot ........................................................ August 21
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
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
Helen Diamond ............................................... November 23
Lester Pinger ..................................................... November 24
Irving Zaretsky ............................................... November 25
Lorraine Gettleman ........................................ December 4
Noah Jarashow ............................................... November 30
Estelle Gordon ................................................ December 8
Seymour Thaler ............................................... December 16
Hayden Lord ................................................... December 22
Evan Ungerleider ........................................... 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
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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