



Volume IV, Number 1 Fall 2005

# Update

A Publication of NTSAD New York Area  
Serving New York, New Jersey and Connecticut

## New York Area Supports NTSAD RESEARCH INITIATIVE

The mission, vision, and opportunity statement for the Research Initiative is a three-pronged strategy for growth as follows: • unprecedented levels of communication combining the successful grant program with the Lysosomal Storage Disease Research Consortium (LSDRC) • a new partnership with the National Institutes of Health (NIH) and other leading patient disease advocacy groups • leveraging the successful grant program in relationships with emerging biotech/biomedical companies that do or could share our focus.

The goals are to transition the current Research Initiative from a seven-program, \$400,000 seed-funding mechanism to a multimillion-dollar combination of exploratory technologies and mechanisms and clinical trials whose progress and understanding are shared by the scientific, medical, and patient communities.

Our focus on communication included an announcement that NTSAD has a part time employee who is working on a lay-person's summary of our 7 grants to date, including objectives and results. Our committee will also cover important topics such as the LSDRC and the NIH including imminent opportunities for awards by the patient advocacy consortium and the NIH, bio-tech companies, and clinical trials. This information will be disseminated on the website and through a newsletter format. There was a tremendous hunger for what the latest potential breakthrough is and how our children can participate in clinical trials. These materials will help our stakeholders to understand the value of supporting our initiative.

With basically all of our current funds obligated to previous grant awards, it was announced that the budgetary goal for the next 12 months for the Research Initiative was over \$200,000 in funding - comprised of \$100,000, immediately for the LSD Consortium partnership with the National Institutes of Health and other major patient advocacy groups, \$100,000 for at least two new grant awards, and \$15,000 for tissue banking managed by the National Disease Research Interchange. Through partnerships with NIH and biotech companies, our dollars will be compounded/leveraged to having multimillions of dollars focused on our priorities.

NIH is getting ready to award funds. As soon as NIH selects which grants will be funded, the LSDRC will receive the remaining grants and NINDS scoring information. NINDS was impressed with quality and quantity of the grants received so far. We will have to wait to see how many researchers get funded before we know how much funding will remain for future grants. This program announcement with set aside funding is a very good way to make sure there is funding available for future grants.

There will be an important scientific workshop at NIH at the next NTSAD Annual Conference in April 2006 in Alexandria, VA, focusing on Glycosphingolipids. This will facilitate significant collaboration among our researchers.

by Kevin Romer, Chairperson  
Research Initiative

## FROM THE PRESIDENTS

Marion Yanovsky &amp; Stanley Michelman

The New York Area Chapter had a busy spring, with three very successful walks, raising almost \$90,000 for chapter programs and research. What began as a high school project in Long Island three years ago has become one of the best fundraising activities for the chapter. This was the third year for the Long Island walk. **Allison & Kraig Fox** again did an outstanding job as the walk chairs. Delicious snacks and fabulous raffle prizes made the walk even more fun.

After four very successful golf outings, this year **Sharon & Steve Hoffman** honored the memory of their son Harry with a walk in Rockland County. The Spring Valley High School Key Club volunteered and helped to raise money. The 92 members of the East Ramapo Marching Band (which can be seen in the movie "The Manchurian Candidate") played as the walkers proceeded. It was very exciting and a tremendous financial success. The Harry Hoffman Fund supports the National Annual Family Conference and the NTSAD Research Initiative.

**The Heringer Family** decided to take our walks one step further. Thanks to the Heringers, the three 4th Grade classes at P.S. 158 in Manhattan held a fundraising walkathon in June, raising more than \$4,000 for NTSAD. (See Article)

**Shari & Jeff Ungerleider** held a successful Spring Boutique at their home, as a preview for the Annual Holiday Boutique in November at the YM-YWHA in Wayne, NJ. This was a follow-up to the ELUF Comedy Night which raised over \$50,000 for the NTSAD Research Initiative. The Evan Lee Ungerleider Fund also supports the National Annual Family Conference.

The New York Area Chapter, including the Hoffman & Ungerleider family funds, has awarded a special **research grant** of \$10,000 to the Dor Yeshorim Program for a project for a Cord Blood Registry & Bank for Stem Cell Research.

**Gus & Sue Sirot** are busy at work on the **Annual Calendar for 2006**. An ad form is enclosed. Membership dues are due for the fiscal year ending June 2006. Our members are most important to the success of the organization.

NTSAD New York Area continues to participate in the **Jewish Genetic Disease Consortium** (a committee of disease groups for the purpose of promoting education and awareness.) The Consortium will be represented at a booth at the upcoming conference of Reformed rabbis in Houston in November and at the conference of Conservative rabbis in Boston in December. As a member organization of the **Genetic Disease Foundation**, NTSAD New York Area participates in educational outreach to physicians and has a continuing relationship with the carrier testing and research programs of the Human Genetics Department of the Mount Sinai School of Medicine.

NTSAD NY Area has contributed more than \$75,000 over the past three years toward the NTSAD Research Initiative administered by our national organization. Additional funds will be allocated for the coming year. We have included a report by Kevin Romer, chairperson of the program.

The enthusiasm and participation of Board Members and the general membership in chapter activities has been truly inspiring. Be sure to look over the list of upcoming events in this newsletter. We look forward to your participation.

### **MATCHING GIFTS**

**DOES YOUR COMPANY HAVE  
A MATCHING GIFT PROGRAM?**

### **ANNUAL ELUF HOLIDAY BOUTIQUE**

**Wednesday, November 30, 2005**

**YM-YWHA – WAYNE, NJ**

**Call Shari Ungerleider for info**

**(973) 595-8563**

## 4<sup>th</sup> Graders Raise over \$4,200 for NTSAD

In June, the 4<sup>th</sup> graders at P.S. 158 in Manhattan held a walkathon, as a community outreach project to benefit NTSAD New York Area. Spearheaded by the **Heringer family**, the students in three 4<sup>th</sup> grade classes raised more than \$4,200 earmarked to fund new research projects examining potential treatment and cure for Tay-Sachs and related diseases of the central nervous system.

Prior to the walk, NTSAD genetic counselor, Fran Berkwits, visited each 4th grade class, educating the students with a lesson in basic genetics. The students asked friends, neighbors, and family members for donations. **Rebecca and Marissa Heringer** worked hard to encourage their classmates to participate.

The 94 students walked the Promenade at Carl Schurz Park and then walked to the ice-cream shop and adjacent bagel store for ice-cream cones and cookies, which were donated. Students worked hard to be the highest fundraiser in their class. Each class was awarded prizes to the four top fundraisers. Prizes included passes to Chelsea Piers, baseball tickets to a Brooklyn Cyclones game, Lunch with the Teacher, and Gift Certificates to a toy store. In the words of Elise Heringer, "It just took my time and all I had to do was ask in order to get things donated."

In addition to the funds raised, P. S. 158 families and the surrounding community were educated about genetic diseases. A **Community Service Award** plaque was presented to the 4<sup>th</sup> grade. We want to thank Darryl Alhadeff, Principal and the 4<sup>th</sup> grade teachers Martin Woodard, Andrea Leon, and Rachel Moramarco for their outstanding effort in teaching the students to give of themselves for the good of others.



### AD CALENDAR BLANK

CALENDAR DEADLINE OCTOBER 30, 2005

You are hereby authorized to insert attached copy in the **2006 Ad Calendar**

- Gold Page .....\$325
  - Full Page .....\$225
  - 1/2 Page .....\$125
  - 1/4 page .....\$ 65
  - 1/8 Page .....\$ 35
  - Single Name Listing ....\$ 5
  - Birthday, Anniversary, Memoriams
- (\$15 minimum donation to receive calendar)*

Return to Chairperson:

NTSAD - NY Area  
 Attn: Gus Sirot  
 1202 Lexington Avenue, #288  
 New York, N.Y. 10028  
 212-431-0431  
 Fax 888-354-4884

Please Print

Name .....

Tele. ....

Enclosed is \$ \_\_\_\_\_

Please make checks payable to NTSAD-NY

If you prefer, we accept

Visa  Mastercard  AMEX

Card Number \_\_\_\_\_

Exp. Date \_\_\_\_\_ Signature \_\_\_\_\_

All donations are tax deductible to full extent of the law.

Print Name \_\_\_\_\_

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Telephone (Day) \_\_\_\_\_ (Evening) \_\_\_\_\_

**ATTACH COPY**



National Tay-Sachs & Allied Diseases Association  
 New York Area, Inc.  
 1202 Lexington Avenue #288  
 New York, NY 10028

NON PROFIT ORG  
 US POSTAGE  
**PAID**  
 MONSEY, NY  
 10952  
 PERMIT 7090

**ADDRESS SERVICE REQUESTED**

**UPCOMING EVENTS & ACTIVITIES**

- Annual Calendar**
- Raleigh Hotel Weekend**
- Holiday Boutique**
- Stay-at-Home Event**
- Annual Membership**
- Annual NTSAD Family Conference**
- Family Fun Walks**

Notice of events and fundraising activities will be sent to you. Please feel free to choose whether or not you would like to participate. We would like to give everyone the opportunity to decide, therefore we will advise you as events occur

**CARRIER TESTING**

**If you know of couples who have not been tested and would like information please have them contact us at**

**(212) 431 0431**

**or e-mail us at [info@ntsad-ny.org](mailto:info@ntsad-ny.org)**

*If you are planning a bequest, large or small, please let us know. Your bequest will enable NTSAD to continue vital programs of research, public and professional education, carrier testing, quality control for laboratories, and referral services, with the hope that Tay-Sachs and the allied diseases will be eradicated.*

**WE ARE ON THE WEB!  
 YOU CAN DONATE ONLINE!  
 Visit: [www.ntsad-ny.org](http://www.ntsad-ny.org)**



**M E M B E R S H I P**

*Become a member of NTSAD today.*

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Does your company have a matching gift program?

yes  no If yes, please enclose form.

- \$25 Family/Individual  \$250 Sustainer
- \$50 Friend  \$500 Benefactor
- \$100 Supporter  \$1000+ Corporate

Check Enclosed

Credit Card:  Visa  MC  Amex

Card # \_\_\_\_\_

Expiration Date \_\_\_\_\_

Signature \_\_\_\_\_

All donations are tax deductible to the full extent of the law. NTSAD is a 501(c)(3) tax exempt organization. A copy of the latest annual report may be obtained, upon request, from our organization or the Office of the Attorney General, Charities Bureau, 120 Broadway, NY, NY 10271.