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Update

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

From the Presidents: Marion Yanovsky & Stanley Michelman

As we approach another season we can look back at last year with a tremendous feeling of pride and satisfaction. Once again our organization has exceeded all expectations in raising monies, participating in educational programs and sponsoring research projects.

The fundraising activities and generosity of our donors for the fiscal year ending in June enabled us to raise more than \$200,000. We had such great success thanks to the efforts of our Board, our members and friends. Our participation with other organizations, the JGDC, the Genetic Disease Foundation, the Genetic Alliance and many others has resulted in the growth of awareness of genetic screening. Working with these groups has enabled us to spread the word at a much reduced cost and at a much increased capacity.

We continue to advocate for research and our participation with the Genetic Disease Foundation has enabled the endowment of a research chair at the Mount Sinai School of Medicine. Our work with the JGD Consortium has contributed to the establishment of a new testing center at Jacoby Hospital. This center will enable community residents to be screened for carrier status for the available panel of diseases at a reduced cost.

We are proud of our impact on the fight to conquer genetic diseases. Our work, our creative ideas and our continued determination has been the foundation for many of these organizations to exist and to be able to accomplish so much.

The upcoming year will mark the 50th Anniversary of NTSAD. Though we wish we could "go out of business" by the elimination of all these diseases, our efforts are still needed. Our determination and dedication to helping prevent the tragedy of genetic diseases must continue until there is no more suffering and individuals and families can enjoy a full healthy life.

Genetic Alliance Conference

The Genetic Alliance increases the capacity of genetic advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions. Its goals are advocacy, education and empowerment for organizations, like NTSAD, that deal with genetic diseases.

Co-President, Marion Yanovsky and Genetic Counselor, Fran Berkwitz attended the Genetic Alliance Annual Conference in Bethesda, Maryland in July. Marion and Fran represented NTSAD and the Jewish Genetic Disease Consortium (JGDC) on a panel at a workshop focused on "the value of building coalitions". Fran gave background information about NTSAD and described how the JGDC member organizations had met initially, recognized shared goals and objectives, found that common thread that bound them, and how they determined that they could best achieve those goals if they worked together. Marion gave a Power Point presentation which showed, in full detail, a description of the JGDC activities and accomplishments over the past two years. The workshop participants (about 25), representing small rare disease organizations, were very impressed. The Q and A was active and enthusiastic. There were about 280 attendees at the conference, representing rare diseases. Participation in the workshop and our ability to network was a great opportunity to effectively get the word out about the diseases we represent.

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Research Update

Researchers Into Lysosomal Storage Find Common Ground

(Reprinted from Forward.com) Marc Tracy | Fri. Aug 25, 2006

Earlier this year, the Lysosomal Storage Disease Research Consortium awarded its first seven grants, which together total more than \$200,000, to scientists conducting research into ameliorating the effects of lysosomal-storage diseases on the central nervous system. There are more than 40 of these diseases, called LSDs, including Tay-Sachs, Gaucher disease, mucopolysaccharidosis (MPS) and Niemann-Pick disease.

The consortium maintains a collaborative relationship with the National Institute of Neurological Disorders and Stroke, a branch of the National Institutes of Health. Scientists whose grants are rejected by NINDS have the option of applying for an LSDRC grant to obtain further data, with the understanding that, after more research, they will reapply for the original NINDS grant.

“The beauty of this is that our money helps to facilitate their research, such that they have results that would allow them to apply to the NIH and get the larger money,” said Barbara Wedehase, the executive director of the National MPS Society. It and the National Tay-Sachs & Allied Diseases Association initiated the consortium, though several other LSD organizations now participate as well.

Those who suffer from LSDs lack an enzyme — which enzyme is missing depends on the disease — necessary for cellular processes to occur properly. What results is the accumulation of unwanted material in the lysosome, a part of the cell. The results can range from joint pain and anemia (in the case of Gaucher) to limited motor function and even death (in the case of infantile Tay-Sachs).

The consortium arose with the realization that “by joining funds together, we would be able to serve a greater number of people,” Wedehase said. Dr. Mark Sands, who sits on the LSDRC’s grant-review committee, noted the consortium’s utility: “The underlying biology is really very similar” among the several LSDs, he explained. “Discoveries in one field could really impact dramatically other diseases.”

The majority of LSDs sufferers have neurological symptoms. “The brain remains the most difficult challenge,” said Dr. Mark Haskins, the chair of the Grant Revi.

Focusing research on the brain would appear to favor Tay-Sachs, which is largely neurological, as opposed to Gaucher, whose sufferers exhibit no neurological symptoms. Both diseases disproportionately afflict Ashkenazic Jews. One grant recipient is Dr. Synthia H. Mellon, of the University of California, San Francisco. She is investigating whether neurosteroids, a class of compounds derived from cholesterol, can be used to replace the product that would otherwise be created by the missing enzyme in an LSD patient — in this case, a Tay-Sachs patient. NINDS turned her down; she’s currently using her LSDRC grant to obtain further data from animal models.

“This consortium was willing to take the chance, to see, Will it work or not?” Mellon said. “And if it does work, there will hopefully be a bigger payoff.”

Haskins said that the LSDRC was a step in the right direction, but not a panacea. “It’s not the one-bullet theory, where if you solve one LSD you solve them all,” he said. “But any insights we can gather on how to improve function in LSDs will spill over into other LSDs.”



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Return this form to NTSAD, 1202 Lexington Avenue, #288, New York, NY 10028

Genetic Package Deal

(Reprinted from *The Jewish Week* 10/24/2006)

Francesca Lunzer Kritz - Health Writer

By joining forces, groups addressing Jewish hereditary diseases are able to increase awareness and prevention.

With too many charitable organizations chasing too few charitable dollars, a newly formed organization stands out as an example of what people can do if they join hands instead of gnashing teeth.

Recently, a group of small organizations representing serious and often fatal Jewish genetic disease came together to form a collective — the Jewish Genetic Disease Consortium — that allows each group to retain its individual mission and character but together helps educate Jews about preventing these diseases.

The consortium was founded about a year ago and is made up of a variety of groups including patient organizations, genetic counselors, educators, advocates and medical professionals dedicated to helping families avoid the tragedy of genetic diseases, says Lois Neufeld, co-chair of the New York-based consortium.

“Unfortunately,” says Neufeld, “many people still believe that Tay-Sachs disease is the only Jewish genetic disease of concern and that it has been all but eradicated. The fact is, until scientists learn how to correct inherited genetic mutations, every generation of Ashkenazi Jews is at risk of passing on a gene for one of at least 11 diseases — such as Canavan disease, Bloom’s Syndrome and Familial Dysautonomia — that occur more frequently in the Ashkenazi population.”

The good news, says Neufeld, “is that individuals can now be tested for all of these diseases with one simple blood test. Knowing your carrier status can help you to prevent tragedies in future generations.” Educating young Jews about the need for testing is the consortium’s mission.

When asked why there’s a need for the consortium, Neufeld has a ready answer: “Each of the member patient organizations already provides information about a particular disease through their own Web sites and outreach programs. But through the consortium, these groups have joined together with medical professionals, genetic counselors and educators to speak with one voice about the importance of genetic testing for all of the diseases.

“Each of the patient organizations recognizes that they advocate for very small populations,” she continues, “but as a group, the JGDC advocates for all people at risk. This gives the consortium greater political power and an economy of scale that none of the individual groups could achieve on their own.”

Experts who work in the field of Jewish genetic diseases are extremely proud of the new effort. “Historically, the various support groups have always worked independently. And, to a certain extent, this is reasonable and important. The research for Gaucher, for example, is not same as for [other diseases],” says Dr. Sue Gross, medical adviser to the consortium and associate professor and co-director of the Division of Reproductive Genetics at Montefiore Medical Center and the Albert Einstein College of Medicine in the Bronx.

However, says Gross, from the outside looking in, if you don’t have an immediate connection with these disorders, they seem like rare diseases and one seems like the next. That all changed with the consortium. While individually rare, as a group they are not.

“The collective energy, the collective voice which is now communal and the overwhelming chesed that you feel at the consortium meetings is indescribable,” says Gross. “I sit there overwhelmed by people who have had their lives completely turned upside down by tragedy, and in between running to take care of their own families, handling phone calls from newly diagnosed families, running in and out of hospitals, they spend every waking hour making sure that this tragedy will never befall another family. I don’t think I have ever felt as Jewish as when I have spent time with these amazing people.”

Stan Michelman, co-chair with Neufeld of the consortium, knows the tragedy firsthand. Evan, his grandson, who died of Tay-Sachs at 4 1/2, would have had his bar mitzvah next summer. He and Neufeld are very proud of the consortium’s accomplishments, on a shoestring budget of under \$100,000, including: a “grand rounds” curriculum that teaches physicians across the country about the importance of genetic screening, increased awareness among religious groups and rabbinical students, a growing effort on college campuses and “It’s Not Just Tay-Sachs,” a presentation about Jewish genetic diseases slated for the United Jewish Communities General Assembly in Los Angeles next month.

Genetic Package Deal *(continued)*

One key goal of the consortium, however, is targeted education that explains what testing can find and offers descriptions of the diseases and the options available if a genetic disease is detected. "This is not just about sticking your arm out," says Dr. Adele Schneider, director of clinical genetics at the Albert Einstein Medical Center in Philadelphia and a board member of the consortium.

Schneider, who also heads the screening program at Einstein's Victor Center for Jewish Genetic Diseases, says that while many people still think the diseases have been eradicated, "we are picking up carriers in every four to five people we screen." (Carrier status is crucial, which is why screening on campuses is so important. People who know their carrier status are more likely to ask potential spouses their status as well and can make informed decisions if they are carriers of the same genetic diseases.)

Sue Gross says the very existence of the consortium changes the conversation about Jewish genetic diseases. "The consortium has redirected our focus from illness to health and from isolation to community building. They are initiating, essentially, the most important public health project in Jewish history."

Planned Giving

by Ivan Taback, Attorney at Law

Planned giving to the National Tay-Sachs & Allied Diseases Association NY Area (NTSAD) may benefit you, your loved ones and provide funds for researching cures for genetic diseases. Planned giving can enable charitable donation at a level that you might not have thought possible, while maximizing the tax benefits for you and your family. You'll contribute to finding a cure for genetic diseases while enhancing your present and future financial security-as well as that of your loved ones.

To notify us of your intention to make a planned gift, please contact us. In all cases, it is advisable to consult your attorney to ensure that your wishes are apparent. There are a variety of planned giving techniques. For example:

Property can be gifted to the NTSAD through your will. Property so gifted is exempt from estate taxes, which currently reaches a maximum federal tax rate of 46%. A gift may consist of a specific dollar amount, a percentage of your estate or specific assets such as marketable securities, stocks or retirement accounts. An outright bequest can be stated in a new will, or added as a codicil to an existing will, as simply as follows:

"I give and bequeath to National Tay-Sachs & Allied Diseases Association NY Area (NTSAD), a not-for-profit corporation located in New York, New York, [the sum of ___ dollars] or [all or ___% of the rest, residue and remainder of my estate] for its general purpose."

You can make gifts through more sophisticated estate planning techniques – for example, a charitable remainder trust or a charitable lead trust.

In addition to making gifts in your will, some assets are transferred outside of a will (commonly referred to as non-probate assets). These include assets in IRAs, 401(k)'s and certain other retirement plans. Often, these assets have not been taxed and when ultimately received by a beneficiary will be subject to income tax as well as estate tax. Naming the NTSAD as the beneficiary of these types of assets may be advantageous from a tax perspective. Usually, to name the NTSAD as the beneficiary of these assets, all you would have to do would be to write in *NTSAD* on the beneficiary line when you register for your retirement plan, or to modify your current election by notifying your plan administrator and signing a new beneficiary designation form.

For more information or to notify NTSAD of your intentions for planned giving, contact us at:

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Jewish Genetic Disease Consortium (JGDC)

NTSAD NY Area was one of the founding members of the Jewish Genetic Disease Consortium. Stan, Marion and Fran are members of its Board of Directors. The following is a report of its formation and accomplishments, thus far. It has been and continues to be an exciting and inspiring relationship for NTSAD.

The Jewish Genetic Disease Consortium (JGDC) was created as a means by which a number of smaller, individual organizations could join together to heighten awareness of Jewish genetic diseases, with a strong and unified voice. The goal of the JGDC is to educate and raise awareness by combining resources and experience to best reach the target audience – the Ashkenazi Jewish population, medical professionals, rabbis and cantors.

The consortium idea began in April 2003 with a meeting with Dr. Adele Schneider, Director of the Victor Center for Jewish Genetic Diseases, in Philadelphia. The FD Hope Conference on Jewish Genetic Diseases in November 2004 brought many of the groups together. Several groups decided to jointly man a booth at a Health Fair at Grand Central Station in NYC in January 2005. The seeds were planted and on January 31, 2005, seven Jewish genetic disease groups met and informally joined forces for the purpose of education and awareness for carrier screening for Jewish genetic diseases. On March 14, 2005, the Jewish Genetic Disease Consortium (JGDC) was formalized, requiring \$1,500 membership dues per organization. The JGDC does not fundraise. It is funded by dues of member organizations and grants. As of September 2006, there were 15 member organizations working together to accomplish a common goal.

There have been joint ads in *The Forward*, *The Jewish News*, *The New York Observer* (free), *About Our Children*, development of a JGDC brochure and 10' x 10' booth for display at conferences and conventions. A website, www.jewishgeneticdisease.org, was launched in May, 2006. A Public Service Announcement (PSA) was developed and has been distributed around the country.

Outreach has been far and wide. Each member organization has contributed its skills and its contacts to get the word out. With the help of the Canavan Foundation, a grant was received to develop and launch a Grand Rounds Seminar for OB/GYNs at teaching hospitals in the NY metropolitan area. With great reviews coming in, a proposal is being presented for a national roll-out of the seminar. Communication is underway with the American College of Obstetricians and Gynecologists (ACOG) to increase the number of recommended tests, as standard of practice, for the Ashkenazi panel of diseases. The Hebrew Union College-Jewish Institute of Religion has approved the development of a JGD education module for 4th & 5th year rabbinic students and alumni. There is a commitment by the Union of Reform Judaism (URJ) to give the JGDC a meaningful role at the 2007 Biennial Convention, including a seminar on JGD's, better booth position at no charge, a JGD resolution commensurate with the resolution by the Central Conference of American Rabbis (CCAR.) In addition, the JGDC has been given the opportunity to revise the URJ's Study Guide that is distributed to all URJ members.

The JGDC has partnered with the Gift of Life (a blood donor transplant organization) to distribute educational materials. It has also found novel ways to get the message out to the public. JGDC had an exhibit at a Kosher Bridal Shower in NYC, in July 2006, distributed 1400 JGDC brochures at the International Conference on Jewish Genealogy in August 2006, and had an exhibit at "Jewzapalooza", a day of Jewish music performances in Riverside Park in NYC in September 2006.

The JGDC has displayed its booth at the following conferences and conventions: the Union of Reform Judaism Biennial Convention in Houston - Nov. 2005, the Philadelphia Screening Program at Hillel at U Penn - April 2006, the Central Conference of American Rabbis in San Diego - June 2006, and the United Jewish Communities General Assembly Convention in LA - Nov. 2006.

Looking to the future, the JGDC will build on the foundation that has been created. In addition to the active role to educate and create awareness by each individual member organization, the JGDC plans a national roll-out of the Grand Rounds Seminar Program, expansion of outreach to medical providers and genetic counseling centers, the expansion of carrier screening programs in communities and at universities, continuation of outreach to rabbinical programs and continuing education of the Ashkenazi Jewish population.



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UPCOMING EVENTS

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NTSAD Annual Family Conference

May 2007

NTSAD Family Fun Walk

Harry Hoffman Fund

Rockland County, NY

June 2007

NTSAD Family Fun Walk/Picnic

Evan Lee Ungerleider Fund

Wayne, NJ

NTSAD Will Celebrate 50 Years of Service

National Tay-Sachs & Allied Diseases Association (NTSAD) was founded in 1957 by a small group of concerned parents with children affected by Tay-Sachs or a related genetic disorder. NTSAD funded the research that brought about the discovery of the missing enzyme that causes Tay-Sachs disease and developed a carrier screening program that became a model for all genetic testing. As science yields discoveries in the arena of the allied diseases, NTSAD is committed to a leadership role in the application of this knowledge. Although disease is nothing to celebrate, there is much worth applauding: the decrease in occurrence, the increase in awareness, and the foundation of scientific breakthroughs leading us closer toward better treatments and our ultimate goal – a cure.

Today, NTSAD encompasses more than 40 allied genetic diseases, the majority of which are fatal in childhood or severely debilitating and serves thousands of families around the globe. Fueled by a partnership of dedicated volunteers, gifted professionals, and a distinguished Scientific Advisory Committee, NTSAD programs serve a diverse constituency.

With your help, we can continue to provide funding for Research, Education, and Prevention for this unique group of diseases.

NTSAD (National in Boston) is planning a gala event in New York City in the fall of 2007 to celebrate the 50th anniversary. Watch for details in our upcoming newsletters.