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NATIONAL NIEMANN-PICK DISEASE FOUNDATION

"Foundation Updates"



Karen Quandt NNPDF Board Chair

As we near the end of 2010, it's time to take stock of all the National Niemann-Pick Disease Foundation (NNPDF) has accomplished in the year past and to marshal our resources for the work of the year to come. The NNPDF has had a year of

continued growth with many successes to celebrate, raising funds for essential research into treatments and a cure for all of types of Niemann-Pick Disease (NPD) and providing much-needed support services for families grappling with NPD.

This newsletter will update you on many of the foundation's activities including research, Family Support Services, international collaborations, and the wide variety of awareness and fundraising events hosted by our member families across the continent.

2010 marked my first year as the volunteer board chair of the NNPDF, and, like all things associated with Niemann-Pick Disease, it has proven to be an opportunity for learning and growth. As parents of a child with Niemann-Pick Disease Type C (NPC), my husband, Gene, and I had to carefully consider the ramifications of taking on the chairmanship of this busy organization. Our son, Ty (age 14), is active and energetic like most teenagers. At the same time, his NPC creates changing care needs and challenges for family life.

In this first year as NNPDF board chair, I have made some observations about how a diagnosis of NPD affects a family such as ours. While the diagnosis is undeniably devastating, dropping the oppressive weight of an indescribable grief on a family, there is another aspect of how NPD "changes everything."

Learning about a disease you wish you'd never heard of and mounting the battle against it forces a family to expand its frontiers, and its definitions of "family" and "community." With a rare disease such as NPD, you must move out of your comfort zone to search for help and answers and hope, wherever they may be found. As a result, your personal universe expands from your familiar neighborhood and town to encompass all others with NPD (and those who are knowledgeable about NPD), whether they are across the country or across the globe.

Fortunately, we live in an era when communication technologies allow us to share information widely and quickly. When we recently received an announcement that medical professionals may soon be able to diagnose NPC with a simple blood test, we were able to share that news around the world in a matter of minutes.

The sharing of information was also the focus of the NNPDF's 2010 Family Support and Medical Conference held in August in Canada. Co-hosted by our sister-chapter, the Canadian Chapter of the NNPDF (CCNNPDF), and welcoming over 200 attendees including families, clinicians and researchers from around the world, it was the first international conference of its type. The meaningful graphic on the cover of this newsletter illustrates the many faces of NPD, including some of the families in attendance at the conference.

The Family Conference also marked the selection of two new postdoctoral research fellows, bringing the number of research projects currently being funded by the NNPDF to four. The National Institutes of Health (NIH) continues work on the Natural History Study and maintains an emphasis on clinical care for those with NPC. Further, the International Niemann-Pick Disease Alliance (INPDA) continues to build as a worldwide resource to facilitate collaboration and to accelerate advances in research.

In addition to the benefits realized through global sharing and support, we are ever conscious and grateful for the grassroots support shown our families in their day-to-day challenges with Niemann-Pick Disease. It is the generosity of individuals like you that allows us to maintain and broaden our services year after year in support of the families affected by NPD. We hope you enjoy reading about and seeing the photos of our families in the center of this newsletter, as they have worked hard in their communities to raise funds and awareness for NPD.

New brochures about Niemann-Pick Disease Type C (NPC) and Niemann-Pick Disease Types A and B (ASMD) were developed in 2010 and are now available, in both NNPDF and CCNNPDF versions. Families may request brochures for use at their fundraising and awareness events by emailing nnpdf@nnpdf.org.

With your love and encouragement, we have made great progress during 2010, but our job is not done. We will continue to forge ahead until we have locked down effective treatments or a cure for all with Niemann-Pick Disease.

We thank you for your dedicated support in this endeavor, now and through 2011! Together, we will

PERSEVERE in our Quest for a Cure!

With deepest gratitude, Karen R. Quandt, R.N., M.S.N. NNPDF Board Chair



The 2011 NNPDF Annual Meeting will be held in Milwaukee from Friday, February 4th through Sunday, February 6th. The Foundation's annual board meetings are open to all members of the NNPDF. Please refer to the Web site (www.nnpdf.org) for more details or contact the NNPDF Central Office if you are interested in attending.

MEMORIALS

Richard Joseph Carpenter (NPC) ~ 40 years Joseph James Colton (NPA/B) ~ 5 years Aaditya Michael Dasgupta (NPC) ~ 9 years Christopher Lee Fox (NPC) ~ 21 years Sarah Elisabeth Glassman (NPA/B) ~ 3 years Caileen Harley Harrison (NPA/B) ~ 23 months Emily Jane Hrbacek (NPC) ~ 10 years
Karlyne Ann Jones (NPC) ~ 11 years
Brianna Michele Patterson (NPC) ~ 6 years
Cassandra Phillipa Stallard (NPC) ~ 21 years
Brooke Lynn Thomas (NPC) ~ 9 years
Deborah Pleasant Williford (NPD type unknown) ~ 61 years

When someone you love becomes a memory, the memory becomes a treasure.

~ Author Unknown

Please take a moment to remember those we have lost recently to Niemann-Pick Disease. Our hearts go out to their families and friends.

NATIONAL NIEMANN-PICK DISEASE FOUNDATION

"Our Quest for a Cure"

2010 NNPDF Family Support and Medical Conference

The 18th Annual NNPDF Family Support and Medical Conference was held August 5 - 8, at the beautiful Delta Chelsea Hotel in downtown Toronto. With the largest attendance at any Family Conference to date, the conference was a great success! Families in attendance benefited from an array of sessions with physicians, researchers, support professionals, and other families affected by NPD.

This conference was the first international conference of its kind, and was co-hosted by the Canadian Chapter of the National Niemann-Pick Disease Foundation (CCNNPDF), and the families of Sandra Cowie, Tammy and Allan Vaughan, and Lucy and Enio Liegghio, all of Canada.

One goal of the Family Conference is to maximize the opportunity to engage and educate the local medical community by sharing the expertise of the members of the NNPDF's Scientific Advisory Board. This year, Drs. Marc Patterson and Ed Schuchman, with the assistance of Dr. Julian Raiman of The Hospital for Sick Children in Toronto, were able to offer Grand Rounds lectures in their area of expertise - Niemann-Pick Disease Type C and

Niemann-Pick Disease Types A/B, respectively.

Conference attendees enjoyed the many amenities of the diverse city of Toronto. Friday evening the group was treated to a Toronto Blue Jays baseball game, and on



Saturday evening, a family celebration banquet and dance, complete with a magician to entertain the kiddies. The photo collage on the newsletter cover depicts many of the activities that the families enjoyed while in Toronto.

Families traveled home in high spirits and with a new sense of energy to take on the challenges of NPD armed with information and support garnered from the conference. Visit the NNPDF Web site (www.nnpdf.org) for a recap of the meeting and photos highlighting the event.

Many thanks to our Family Conference sponsors - Genzyme, Actelion Canada, and Ducks for Bucks!

First-Time Fundraiser Winner



The winner of the 2010 First-Time Fundraiser contest was the marathon team "Running4Kelly," formed in honor of Kelly Thompson (NPC) of Bristol, Connecticut. The team competed in the Country Music Marathon in Nashville, Tennessee, on a very rainy day in April, raising \$10,000 for research and family support services!

The team included Kelly's cousin Rebecca McGuire and her husband, Brad McGuire; Kelly's brother, Jim Thompson; another cousin, Kate Carpenter; and good friends Kerry Benoit and Corey Kozuch.

The foundation is ever grateful for the fundraising efforts of the Thompsons and all the other families who work so hard to raise awareness and funding to advance our Quest for a Cure for Niemann-Pick Disease!



Kelly and Rebecca



PERSINER

Karen and Gene paint D.C.

Annually, October is a placed bids to benefit the NNPDE and placed see

Annually, October is a time when the NNPDF and member families pull out all the stops to educate community members about NPD and to raise funds for

essential research and valued family support services. As part of October Awareness Month, the foundation

held a nationwide online auction, and we thank all those who donated items to the auction and those who



October Marked 9th Annual

Together we can make a difference!

placed bids to benefit the NNPDF. Please see pages 4 and 5 of this newsletter for highlights of the many families who held fundraising and awareness events

throughout the year. We are forever grateful. You inspire us all to



PERSEVERING in Canada





inumbs up for a cure



We are family

I got all
my sisters 'n me



"The NNPDF ~ Where Success Begins with You!

Our Ouest for a Cure ~ Families Unite to Host

Niemann-Pick Disease Awareness Events and Activities

Across the United States and Canada

Ryan's Ride Poker Run In memory of Ryan Richardson (NPC) Crestview, Florida

Memorial Walk

Waterbury, Connecticut

In memory of



Ducks for Bucks Willowwicks **Candle Sales** In memory of Breann Chavez (NPC) Farmington, New Mexico

October Awareness

Evening of Jazz

In memory of Luke Liegghio (NPC)

Vaughan, Ontario Canada

Family Fun Event

Wristband Sales

Salem, South Dakota

In memory of

Governor's Proclamation

Tristian Norton-Rogers (NPA)



Awareness Video St. Teresa's School Memorial Event Scentsy Candle Fundraiser Facebook Awareness Page In memory of Damon Cardinal (NPA) Edmonton, Alberta Canada

Rilev's Run Poker Run **Woodville Student Government Walk-a-Thon** In memory of

Scottsboro, Alabama



Hometown

Heroes Parade

Popcorn Sale

Vinyl Banners

In memory of

Sales Donations

Emily Hrbacek (NPC)

ureka, Missouri

Support the Cause **Sales Promotion** Harvest of Hope Dinner In honor of Peyton and Kayla Hadley (NPC) Medford, Oregon

Don's Seafood

Michael Landry (NPC)

Gonzales, Louisiana

Restaurants

Fundraiser

In memory of



Mad Hatter's Tea Party

Night of Musical Theater

March Gladness Project

In honor of Ty Quandt (NPC)

Edgewood, Washington

Katlyn Sumbad

Katlyn Sumbad (NPA)

Modesto, California

Memorial Golf

Tournament

In memory of

LoganFest Basketball Tournament

Johnathan Spencer (NPC) Gilroy, California **Bowl for a Cure** In honor of Andy Wood (NPC) Windham

Causes on Facebook

In honor of

Living Hope Baptist Church Dinner

In honor of Rachel Palmiter (NPC)

Portland, Oregon



Cruise for Adam

Ride for Adam

Race for Adam

Marcello and Matthew Perugini

Marcello and Matthew Perugini (NPC)

Hanover 5K Road Race In memory of Erin Roberts (NPC)

In memory of Danny and Lisa Clark (NPC) Mount Pleasant, Iowa

Community Group Talks





Niemann-Pick Walk-a-Thon In honor of Gregorio Martinez. III (NPA) Temple, Texas

In honor of

Ford IronMan Triathlon

Anne Marie OConnor-Smith (NPB)



Vericrest Financial Popcorn,

Sailey and Brianna Patterson (NPC)

Bake Sale and Penny War



Fishin' for the Mission Fishing In honor of Raiden Linkous (NPC) **Dublin, Virginia**

Facebook

In honor of

Awareness Page

Tehyez Minde (NPA)

Hobbema, Alberta Canada

In memory of

El Centro, California



Ride4Tylor RAGBRAI Team **Dubuque Bruisers Football** Hair Cut-a-Thon Governor's and Mayor's **Proclamations** In honor of Tylor White-Richardson (NPC) Dubuque, Iowa and Galena, Illinois



In memory of John B. and Kathryn Taft (NPA) Monroe, Michigan





Big House Big Heart









Hunter's Hope Memorial

Golf Tournament

and Auction

In memory of

Frederick Keys and Bowie Baysox Foster's Grille Monthly Family Night **Massanutten Resort Raffle**

In honor of Dillon Papier (NPC) Frederick, Maryland

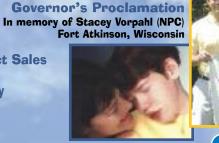




Persevere Wear and Product Sales 2011 Wall Calendars **Oravec Twins Birthday Party Bowl-a-Thon**

In honor of Naomi Tyrrell (NPC) Shelton, Connecticut







www.nnpdf.org









NNPDF Direct **Mail Appea** Family and **Friends Letter** In honor of Monica Taillefer (NPC) Herouxville, **Quebec Canada**













ADVANCING KNOWLEDGE ~ TRANSFORMING LIVES

"Research Updates"

2010 Peter G. Pentchev Research Fellowships Awarded ~ NNPDF Funds Two Postdoctoral Research Projects

One of the key programs of the NNPDF is the continued funding of research into NPD. We are pleased to announce the recipients of the 2010 Peter G. Pentchev Postdoctoral Research Fellowships!

The research projects of Dr. Nicholas Cianciola of Case Western Reserve University, and Dr. Dorothea Maetzel of the Whitehead Institute for Biomedical Research, were selected through an application process which included

reviews by the members of the NNPDF's Scientific Advisory Board (SAB).

Dr. Dan Ory, Chair of the NNPDF's Scientific Advisory Board summarized the two selected projects:

1. Nicholas Cianciola - "Activation of an alternative cholesterol homeostatic mechanism in NPC"

Dr. Cianciola's project builds upon an exciting observation he made while a graduate student and will explore the role of a viral protein in facilitating movement of cholesterol from lysosomes. The research has the potential to identify new therapeutic targets to stimulate release of cholesterol from lysosomes in the absence of a functional NPC1 protein.

Promising Therapies for Niemann-Pick Type C Disease

National Institute of Neurological Disorders and Stroke Meeting ~ June 2010

Representatives from the NNPDF attended the "Promising Therapies for Niemann-Pick Type C Disease" meeting sponsored by the National Institute of Neurological Disorders and Stroke (a division of the U.S. National Institutes of Health) in Rockville, Maryland, June 3-4.

Detailed discussion and presentations surrounding new and promising therapies for NPD type C were offered to 150 attendees of this conference. Organizers Dr. Danilo A. Tagle and Dr. Steven U. Walkley gathered the leading experts and researchers from around the world to take part in this "first of its kind" meeting on NPC.

The NNPDF has compiled a summary of the presentation abstracts from the meeting, available on the NNPDF Web site "The Latest Research" page at: http://www.nnpdf.org/npdisease_14.html

2. Dorothea Maetzel - "In Vitro modelling of Niemann-Pick type C Disease Using Patient-Specific Induced Pluripotent Stem Cells"

Dr. Maetzel's project will lead to development of pluripotent stem cells from human NPC mutant fibroblasts. The stem cells will then be used for high throughput assays to identify small molecules that can correct the cholesterol accumulation in the NPC

cells. Development of these cell lines will allow testing of whether the genetic defect can be corrected in the stem cells, which could have therapeutic potential.

The NNPDF also continues to support the research projects of the 2009 Peter G. Pentchev Fellows, Dr. Ian Williams ("Neurobiology of Purkinje Cells in NPC1"), and Dr. Fabrizio Vacca ("Analysis of cholesterol export from purified endosomes in NPC cellular models").

For more details, including links to all four researchers' Lay Summaries, please visit the NNPDF Web site's "The Latest Research" page at: http://www.nnpdf.org/npdisease_14.html

Gordon Conference on Lysosomal Diseases

The Gordon Research Conference on Lysosomal Diseases will take place in Galveston, Texas, January 23-28, 2011. This scientific conference, being organized by Drs. Fran Platt, Steve Walkley and Tony Futerman, will offer sessions on topics such as the basic science of lysosomal biology and function, relationships of lysosomal diseases to other neurological diseases, pathogenic cascades, biomarkers, recent advances in therapy, clinical trials and design, and much more. Niemann-Pick Disease is one of over 40 Lysosomal Storage Diseases.

The Gordon Research Conferences promote discussions and the free exchange of ideas at the research frontiers of the biological, chemical and physical sciences. Scientists with common professional interests come together for a full week of intense discussion and examination of the most advanced aspects of their field. The NNPDF is proud to be a sponsor of this conference. For more information, visit www.grc.org.

Diagnosis of NPC May Soon be Possible via Blood Test

Niemann-Pick Disease Type C (NPC) may soon be diagnosed with a simple blood test, according to a report from the Washington University School of Medicine, St. Louis, Missouri, published recently in Science Translational Medicine.

Dr. Dan Ory of Washington University, and the chair of the NNPDF's Scientific Advisory Board (SAB), is one of the report's authors, along with Dr. Forbes "Denny" Porter, of the National Institutes of Health (NIH), also

on the NNPDF's SAB; and Nicole Yanjanin, R.N., NIH, and on the NNPDF's Board of Directors; and others.

Visit the NNPDF's Web site NewsLine page for a link to the complete story and

a video clip, featuring Dr. Ory, along with Nancy and Art Sullivan, parents of Karen Sullivan, who passed away from NPC in 2004, at the age of 33.



Update from Genzyme on Enzyme Therapy Trial

Genzyme completed a Phase 1 clinical trial in 2009 that was designed to evaluate the safety of single-dose administration of recombinant human acid sphingomyelinase (rhASM) as a potential treatment for ASMD (also known as Niemann-Pick Disease Types A and B). We are conducting further preclinical research and engaging regulatory agencies in discussion about the available preclinical and clinical data, as well as preliminary plans for the Phase 2 trial.

The Phase 1 clinical trial results were presented publicly at two

scientific meetings last year and are being prepared for publication. We are also planning to publish results from an international, retrospective natural history study of ASMD.

We want to once again thank the participants of the Phase 1 trial for their contribution to our understanding of rhASM and acknowledge the ongoing support of the patient community. We will keep the community updated as our development plan continues.

Genzyme Corporation



ADVANCING KNOWLEDGE ~ TRANSFORMING LIVES

"Research Updates"

Niemann-Pick Disease Research – History and Future Directions

Niemann-Pick Disease (NPD) was first documented in 1914. Since then, much has been learned about the disease, including the fact that NPD can be categorized into three general types - Types A and B (also known as Acid Sphingomyelinase Deficiency or ASMD), and Type C.

Today's research has broadened to include the development of treatments for NPD. Clinical trials of miglustat (Zavesca) suggest that it may slow the progression of NPD Type C and may help maintain neurological function. Cyclodextrin is currently being studied to develop an understanding of the mechanisms behind the proposed therapeutic effect on NPC, as well as long-term safety and side effects. Enzyme therapy is being tested for use in patients with NPD ASMD. http://www.nnpdf.org/npdisease 14.html

Research at the National Institutes of Health

The National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH) began conducting research on Niemann-Pick Disease Type C (NPC) in the early 1970's. Currently, the National Institute of Child Health and Human Development (NICHD) at NIH is conducting an observational study of the natural progression of NPC under the direction of Dr. Forbes D. Porter.

The observational trial or "natural history study" began in August 2006, designed to describe the progression of the disease and to form a clinical picture of the "typical" NPC patient, as well as to identify clinical and biological markers of the disease process. Currently, the natural history study has enrolled 53 NPC patients from around the world, and their participation has contributed to presentations at the national and international level.

In collaboration with Dr. Dan Ory of Washington University, Dr. Porter proposed the use of an over-the-counter drug known as NAC for NPC. The NAC trial was begun in September 2009, and finished in August 2010. Quality of life, fatigue, liver enzymes, vitamin A and E levels, and Co-enzyme Q10 levels were evaluated. Information about the drug's effectiveness will be available following complete review and analysis of the data. Data from this trial are also being analyzed to validate potential blood markers in NPC patients, as well as to evaluate whether NAC could be useful in treating oxidative stress in NPC.

Though research takes time, the study of NPD has made remarkable progress over the years. Researchers continue to work to expand the understanding of this devastating disease and to find means of early identification and treatment.

Canadian Chapter Update

The Canadian Chapter of the National Niemann-Pick Disease Foundation (CCNNPDF) has had a busy year, with many members

conducting events to raise awareness of Niemann-Pick Disease and funds for research.

The CCNNPDF is a sister chapter to the National Niemann-Pick Disease Foundation (NNPDF) (U.S.) and through a collaborative relationship participates with the NNPDF in the funding of NPD research and provision of family support services to members.

Money raised through the CCNNPDF is invested in Niemann-Pick Disease research via the NNPDF's research program with guidance from the NNPDF's Scientific Advisory Board (SAB), Board of Directors, and Research Committee. This partnership helps eliminate redundancy and maximizes the impact of research dollars. In 2010, the CCNNPDF contributed \$85,000 CAN toward Niemann-Pick Disease research initiatives.

Tammy Vaughan and Sandra Cowie serve as representatives of the CCNNPDF on the

NNPDF Board of Directors and are both active members of the foundation's Research Committee.

As part of the implementation of program services for families in Canada, the CCNNPDF rolled out its redesigned Web site earlier this year and it has quickly become a valuable resource for Canadian families affected by NPD. www.nnpdf.ca

Also during 2010, Health Canada announced approval of the drug

Zavesca® (miglustat) as the first authorized treatment for neurological symptoms of Niemann-Pick Disease Type C (NPC). Zavesca® is not a

> cure for NPC, but it has shown promise in treating symptoms related to NPC and in slowing the progression of the disease for some patients.

> In addition to Canada, Zavesca® has been approved for use in NPC in the European Union, South Korea, Brazil, Russia and Australia. Currently, in the United States, Zavesca® can only be prescribed "off-label" for use in NPC. Produced by Actelion Pharmaceuticals, Zavesca® is also used for treatment of patients with Type 1 Gaucher Disease, another Lysosomal Storage Disease.

> Even more recently, Zavesca® received approval for reimbursement under the Ontario Public Drug Program. Reimbursement will be considered under Canada's Exceptional Access Program, according to specific clinical criteria.

Tammy Vaughan, Chair of the CCNNPDF,

commented, "Including Zavesca® within the remit of Ontario's governmental reimbursement policy is a tremendous step forward in helping NPC patients and families who are desperate to increase life

of their lives. ...we hope other provinces might come to the same decision."





Liegghio, Tammy Vaughan and Sandra Cowie (respectively),

of the CCNNPDF Board of Directors, along with their families,

were key players in the overall success of the conference!

expectancy and improve the quality VISIT OUR NEW WEB SITE

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2010 YEAR-END GIFT IDEAS

Each year, hundreds of families around the world depend on the NNPDF for medical information, research updates and emotional support as they struggle to care for a terminally ill child or young adult. We, in turn, depend on those with compassion and the financial resources to make a difference in the lives of those who are suffering.

As you consider your year-end tax planning, we at the NNPDF hope you will consider making good use of the income tax charitable deduction. Your 2010 year-end gift can significantly reduce your income taxes, while providing meaningful support for the work of the NNPDF.

Hold Fast

Keep At

Hang

NNPDF, PO Box 310, Fort Atkinson, WI 53538-0310

Via Credit Card at: www.nnpdf.org

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Mail Checks To:

Tribute Gifts ~ Memorials, Anniversaries, Birthday Celebrations

Matching Gifts ~ Employee Business and Corporate Matching

Underwriting Gifts ~ Support a program or service that has special meaning to you

United Way Contributions ~ Via employee payroll deductions ~ Tax Id #: 35-1844264

Combined Federal Campaign (CFC) ~ Via employee payroll deductions ~ #10121

Gifts-In-Kind ~ Donations of product and services in support of our programs

Gifts of Stock ~ A transfer of stock is a strong tax-wise contribution over cash

Planned Giving ~ Bequests through wills, trusts and estate planning

Your charitable gifts make an important difference in what we are able to accomplish. Thank you for your consideration and generosity to the NNPDF.

Stick To It Pursue ersevere Get It Done

> VISIT OUR NEW WEB SITE National Pick Disease www.nnpdf.org

Information that appears in this newsletter is for the purpose of providing information and awareness and does not necessarily reflect the views of the foundation.



Fort Atkinson, WI 53538-0049 National Niemann-Pick Disease Foundation



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