

Spirit of Collaboration



Global collaboration in the fight against Niemann-Pick Disease took a great step forward with the First International Meeting of NPD Non-Profit Organizations held in Scotland in October 2009. The meeting was attended by NPD representatives from 9 countries. (See inside story for more details.)



Barb Vorpahl | NNPfD Chair

As 2009 winds to a close, we look back on the year just passed to reflect on our progress, celebrate goals achieved, and to gear up our plans for the new year. The NNPfD continues to grow and develop its capacities and programs, raising funds for essential research into treatments and a cure for Niemann-Pick Disease, and providing much-needed family support services.

October 2009 marked the 8th Annual Niemann-Pick Disease Awareness Month -- a time when we pulled out all the stops to educate our communities across the U.S. and Canada about NPD, and the challenges families who are affected by it face. We had a record number of families participating in awareness and fundraising activities this October -- see inside for photos and more information about all the exciting things our families have been doing throughout the year.

These active families, together with our determined, all-volunteer board of directors and dedicated staff, continue to

offer their hearts and souls to advance the work of the NNPfD -- raising money for research and supporting NPD families in myriad ways. Their efforts go far in alleviating the pain associated with the journey of Niemann-Pick Disease, ensuring that no family has to travel this road alone.

In this newsletter you'll read about the NNPfD's evolving global collaborations -- namely, we co-hosted the First International Meeting of NPD Organizations held recently in Scotland, and we are planning for the first international NNPfD Family Support and Medical Conference, to be co-hosted by the Canadian Chapter of the NNPfD in Toronto next summer.

The NNPfD is a vital organization, thriving on the involvement of NPD families, our membership and supporters like you, all persevering in our Quest for a Cure. Thank you for your continued support! Happy Holidays to all, and we look forward to hearing from you in 2010!

Barb Vorpahl
NNPfD Board Chair



NATIONAL NIEMANN-PICK DISEASE FOUNDATION

"In the Spirit of Collaboration"

OUR VISION "A WORLDWIDE GROUP UNITED FOR NIEMANN-PICK DISEASE"

National Niemann-Pick Disease Foundation Co-Hosts First International Meeting of Niemann-Pick Disease Organizations

Meeting Marks Advance in Global Collaboration to Fight NPD

An historic step towards increased collaboration and support for NPD families internationally was taken in October when nine Niemann-Pick Disease advocacy groups from around the world gathered together under a joint invitation and sponsorship from the NNPDF of the United States and the NPD Group United Kingdom.

International NPD representatives from Argentina, Canada, France, Germany, Italy, Netherlands, and Spain were eagerly welcomed to the Edinburgh, Scotland gathering by NPD group representatives from the US and UK. (*Support groups from Australia and Poland were not able to send attendees.*) The sixty attendees consisted of board members, parent advocates, researchers, physicians, and pharmaceutical delegates. All participants gratefully acknowledged the NNPDF and NPD Group UK for spearheading and sponsoring this event and sincere thanks were offered to Actelion Pharmaceuticals and Genzyme Corporation for their backing of this meeting.

This international meeting marked significant progress in worldwide cooperation in the fight against NPD and allowed participants to explore ways in which to share information, assist in the progress and advancement of research, as well

as to develop an overall understanding of Niemann-Pick Disease. Such global collaborations help maximize efforts and avoid duplication of work, and foster good stewardship of hard-earned resources directed toward family support



programs and urgently-needed research.

Once the group overcame language barriers and cultural differences, it became abundantly clear that the same challenges and issues are faced by families around the world as they journey through the diverse and complicated phases of NPD. Of significant importance was the unanimous vote which approved the formation of the International Niemann-Pick Disease Alliance (INPDA). It is envisioned that the INPDA will represent all NPD Groups as a unified entity to assist with the development and prioritization of NPD programs worldwide. Stay tuned for updates and announcements on this exciting new chapter for families with loved ones affected by Niemann-Pick Disease.

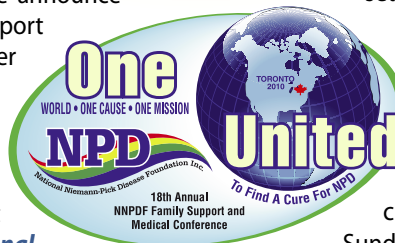


Jim Green, Board Chair of the NPD Group UK and Barb Vorpahl, Board Chair of the NNPDF, welcomed NPD support group representatives to the First International Meeting of Niemann-Pick Disease Organizations to Edinburgh, Scotland.

NNPDF 18TH ANNUAL FAMILY SUPPORT AND MEDICAL CONFERENCE

ONE CAUSE. ONE CURE. ONE MISSION.

It is with great anticipation and excitement that we announce plans for the 2010 NNPDF 18th Annual Family Support and Medical Conference to be co-hosted by our sister chapter, the Canadian Chapter of the National Niemann-Pick Disease Foundation (CC ~ NNPDF). International collaborative efforts remain in the forefront as the NNPDF and the CC ~ NNPDF work hand-in-hand in planning this extraordinary event which will also be slated as the *First International Niemann-Pick Disease Family Support and Medical Conference*.



Our conference theme of, **ONE CAUSE. ONE CURE. ONE MISSION.**, sets the tone for a forum that will be filled with session topics which not only address the needs of our families caring for a loved one but also offer them the opportunity to learn the latest updates on research and treatments for NPD. The beautiful and celebrated destination of Toronto, Ontario Canada, will play host to this conference from Thursday, August 5th through Sunday, August 8th, 2010, at the historic downtown Delta Chelsea Hotel.

The 2010 Annual NNPDF Board Meeting will be held the weekend of Friday, January 29th through Sunday, January 31st, in Milwaukee, Wisconsin. 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 and updates pertaining to these meetings.

MEMORIALS

Alexandria T. Bexton (NPC) ~ 10 years Tristian Allan Norton-Rogers (NPA) ~ 17 months
Sandra James (NPC) ~ 40 years Joele Jean Ruppert (NPA/B) ~ 4 years
Israel Lujan Macareno (NPC) ~ 10 years Leonard K. Whitehead (NPC) ~ 22 years

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

*If I had a single flower
for every time
I think about you,
I could walk forever
in my garden.*

~ Attributed to Claudia Ghandi

Making Our Voices Heard

"The NNPDF ~ Where Success Begins with You!"

In the Spirit of Collaboration ~ Families Unite to Host October Niemann-Pick Disease Awareness Events and Activities Across the United States and Canada



Family & Friends Letter
In memory of: Zoe Bachman (NPA)
Kings Mountain, North Carolina



Cisneros Family & Friends Letter
In memory of: Malayna Varela (NPC)
Yuma, Arizona



Raiden's Hope Fishing Tournament
In honor of: Raiden Linkous (NPC)
Dublin, Virginia



Family & Friends Letter
Community Fund Raising Events
In honor of: Mitchell Brubaker (NPC)
Simi Valley, California

Werribee Primary School Dress-up Day
In memory of: Mitchell Harrower (NPC)
Werribee, Victoria
Australia



Ducks for Bucks
Willow Wicks Candle Sales
In memory of: Breann Chavez (NPC)
Farmington, New Mexico



Memorial Directed Donations
Family & Friends Memorial Letter
In memory of: Tristian Allen Norton-Rogers (NPA)
Salem, South Dakota



Family & Friends Letter
5th Avenue Jewelry Party
In honor of: Tehyez Minde (NPA)
Hobbema, Alberta Canada ~ CC-NNPDF



Community Fund Raising Events
Vinyl Banner Promotion
In honor of: Emily Hrbacek (NPC)
Eureka, Missouri



Third Annual Riley Walk-a-Thon
American Cruisers Poker Run
In memory of: Riley Corbitt (NPC)
Scottsboro, Alabama



Cruise for Adam
Ride for Adam ~ Poker Ride & Family Picnic
In honor of: Adam Recke (NPC)
Bethlehem, Pennsylvania



Hunter's Hope Memorial Golf Tournament
In memory of: Hunter Ozmer (NPC)
Roanoke, Virginia



Family & Friends Letter
In memory of: Belinda Robbins (NPC)
In honor of: Callie Traxler (NPC)
Mattoon, Illinois



Celebrate Family ~ Memorial Picnic
Community Fund Raising Events
In memory of: Bryanna DeSouza (NPC)
Naugatuck, Connecticut



Family & Friends Letter
In honor of: Kaiden St. Germain (NPC)
Edmonton, Alberta Canada ~ CC-NNPDF



6th Annual Erin Roberts Memorial Hanover 5K Road Race
Roberts-Jurgela Wedding Donation
In memory of: Erin Roberts (NPC)
Hanover, Massachusetts



3rd Annual Memorial Golf Tournament
Katlyn's Memorial Birthday Letter
In memory of: Katlyn Sumbad (NPD A/B)
Modesta, California



Family & Friends Letter
Community Fund Raising Events
In memory of: Damon Cardinal (NPA)
Edmonton, Alberta Canada ~ CC-NNPDF



First Annual Food Fest ~ Don's Seafood Hut
In memory of: Michael Landry (NPC)
Gonzales, Louisiana

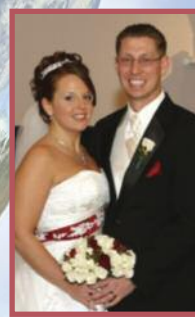


Curwood Festival Days
In memory of: Tyler Heinze (NPC)
In honor of: Katie and Faith Heinze (NPC)
Elsie, Michigan

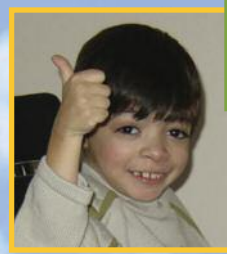


American Legion Poker Run
In memory of: Ryan Richardson (NPC)
Crestview, Florida

Alex and Laura Vaughan Memorial Golf Tournament
In memory of: Alex and Laura Vaughan (NPC)
Durham, Ontario Canada ~ CC-NNPDF



Yates-Brown Family Wedding Donation
In memory of: Jeffrey and Zachary Yates (NPC)
Rush, New York



Life for Luke Dance and Dinner Gala
In memory of: Luke Liegghio (NPC)
Vaughan, Ontario Canada ~ CC-NNPDF



Golf "FORE" Stacey Memorial Classic
Wisconsin Governor's Proclamation
In memory of: Stacey Vorpahl (NPC)
Fort Atkinson, Wisconsin

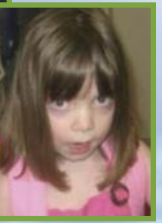
Taylor White-Richardson Family & Friends Fund Raisers



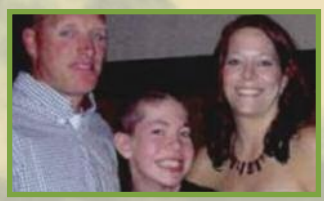
Family & Friends Letter
Hair Cut-a-Thon & Bowl-a-Thon
In honor of: Taylor White-Richardson (NPC)
Galena, Illinois ~ Ryan & Jill Richardson Family



United Way & CFC Training Event
Soda Can Tab Top Collections
In memory of: Andrew Limer (NPC)
In honor of: Katie Limer (NPC)
Arlington, Texas



Family & Friends Letter
In honor of: Lee King (NPC)
Eufaula, Alabama



Family & Friends Letter
Iowa Governor's & Dubuque Mayoral Proclamations
In honor of: Taylor White-Richardson (NPC)
Dubuque, Iowa ~ White-Simon Family

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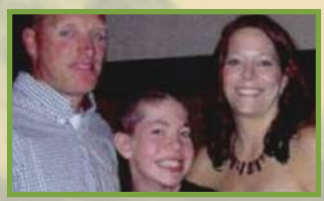
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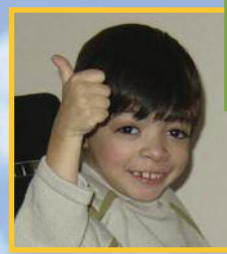
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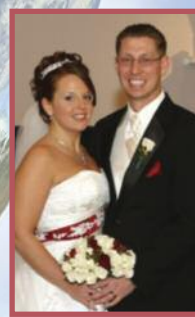


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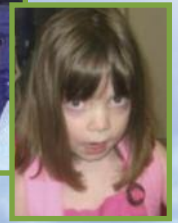
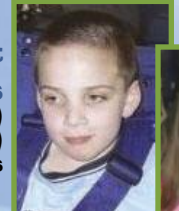


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NATIONAL NIEMANN-PICK DISEASE FOUNDATION

"Family and Community Collaborations"

OCTOBER 2009 DESIGNATED

National Niemann-Pick Disease Awareness Month

October 2009 was named the 8th Annual National Niemann-Pick Disease Awareness Month – a time to spread the word about this rare disease, the devastation it causes families, and raise funds to advance research which has already identified the gene responsible for NPD, and will in time, find treatments and a cure. An overwhelming number of our NPD families throughout the United States and Canada hosted a wide-range of awareness, educational and fund raising campaigns in honor of their loved ones affected by Niemann-Pick Disease and in support of the NNPDF. Our membership rallied the sponsorship of their families, extended support networks and community members to ask for their help and assistance as we

PERSEVERE in our Quest for a Cure.



The Darrile & Mark Papier Family

Frederick, Maryland • In honor of: Dillon (NPC ~ age 7)

3rd Annual Dillon Papier Charity Golf Tournament, Silent Auction & Dinner



Frederick Keys & Bowie Baysox Baseball Benefits



Zumbathon Urbana Dance Studio Event



Urbana Dance Troupe Show



Foster's Grille Monthly Monday Family Night



Ty's 13th Birthday Celebration

The Karen and Gene Quandt Family

Edgewood, Washington • In honor of: Ty (NPC ~ age 13)

"Surf's Up" Dance & Silent Auction



NNPDF Family Conference Hosts

Tee Time for Ty Golf Tournament



The Lorna and Leon Tyrrell Family

Shelton, Connecticut
In honor of: Naomi (NPC ~ age 7)

Naomi's Night Event



Persevere Wear & Products Campaign



Treasuring Each Day ~ 2010 Wall Calendars



RESEARCH UPDATES

The NNPDF's new Strategic Plan for Research has proved to be a key tool in our work towards improving the foundation's ability to attract quality research applications and ensure that our research funds are faithfully stewarded to bring the greatest benefit to all affected by NPD. Under the direction and support of our esteemed members of the NNPDF Scientific Advisory Board (http://www.nnpdf.org/aboutus_05.html), the foundation was able to define more specifically our role within the NPD research community. One of the main goals of this new Strategic Plan was to ensure that the foundation is working collaboratively with other organizations to maximize the impact of all research funds spent on Niemann-Pick Disease.

In August 2009, the first round of **Peter G. Pentchev Research Fellowship** grants were awarded to two promising postdoctoral fellow applicants:

Fellowship Candidate: Ian Martin Williams - Neurobiology of Purkinje Cells in NPC1; Sponsor: Frances M. Platt Department of Pharmacology, University of Oxford, UK

Fellowship Candidate: Fabrizio Vacca – Analysis of cholesterol export from purified endosomes in NPC models; Sponsor: Jean Gruenberg, Department of Biochemistry, Sciences II, University of Geneva, Switzerland.

You may learn more about these fellowship research applications and other NPD related research information via our Web site at: http://www.nnpdf.org/npdisease_14.html

RESEARCH PROJECTS AND RECRUITMENT STUDIES

An additional aspect of the foundation's new Research Strategic Plan is our support of ongoing research trials and candidate recruitment studies. The NNPDF has established specific guidelines to ensure that research projects are of good quality and will deliver genuine benefits for families living with Niemann-Pick Disease before we agree to help with recruitment of candidates for this research. Again, the foundation Research Committee turned to the expertise of the members of our Scientific Advisory Board (http://www.nnpdf.org/aboutus_05.html) to assist in the task of developing new procedures pertaining to the review of these requests.

Once a research recruitment application has been reviewed and subsequently approved, the foundation is then given the task to share this information with our family membership. You may learn more about current trial study recruitments on our web site at: http://www.nnpdf.org/npresearch_06.html



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2009 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 2009 year-end gift can significantly reduce your income taxes, while providing meaningful support for the work of the NNPDF.

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

Gifts of Cash ~

Mail Checks To:
NNPDF, PO Box 310, Fort Atkinson, WI 53538-0310

Via Credit Card at:
www.nnpdf.org

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.

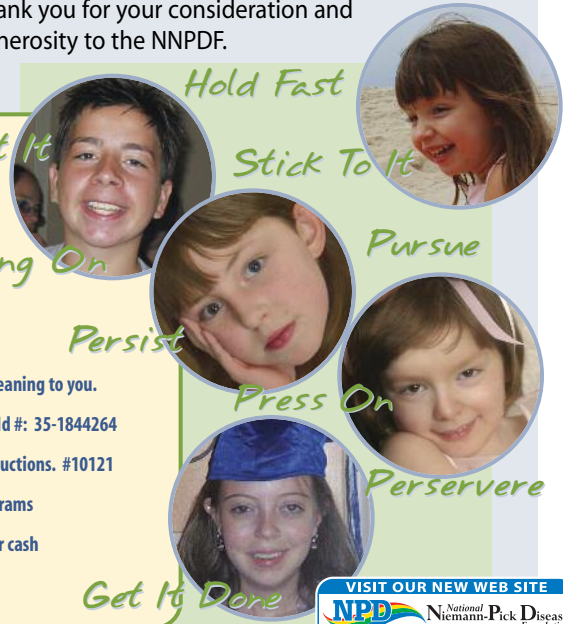
United Way Contributions ~ Via employee payroll deductions. Tax Id #: 35-1844264

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



VISIT OUR NEW WEB SITE
NNPDF National Niemann-Pick Disease Foundation
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.

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