

P
E
R
S
E
V
E
R
E



PERSEVERE (per•se•vere):

To persist steadily in an action or belief, usually over a long period and despite problems or difficulties.

When you look up the word **PERSEVERE** in the dictionary you will find the definition listed above; however, when you look at the team photo above featuring little Naomi Tyrrell (NPC ~ age 6), and the other photos in this edition you witness the true meaning of the word firsthand.

You see families enduring insurmountable circumstances, yet finding the courage and strength to do what needs to be done. You will find families reaching out, sharing their stories to create awareness and raise money for research into this fatal disorder. You see families joining together accomplishing goals and overcoming obstacles they never could have imagined. – **PERSEVERANCE**

Through it all we are often asked, “How do you do it?” Our answer... we have all learned from the greatest teachers, our children, as they struggle each day with every breath, fighting to take one more step or to utter one more sweet sound, with joy shining through and a smile upon their faces. They teach us how to turn a parent’s worst nightmare into something positive. They help us to face our broken dreams and unexpressed fears. They help us to bring forth strength and courage we never knew we had. They teach us to pull ourselves up and to appreciate the everyday miracles. – **PERSEVERANCE**

Barb Vorpahl ~
NNPDF Chair

VISIT OUR WEBSITE



www.nnpdf.org

NATIONAL NIEMANN-PICK DISEASE FOUNDATION

"The Spirit of Collaboration"

CANADIAN CHAPTER OF THE NATIONAL NIEMANN-PICK DISEASE FOUNDATION

All of the NPD support foundations live for the day when effective treatments and cures can be found for this group of diseases. By sharing information and awareness we can contribute to an overall strategy which will maximize the use of resources and shorten the time taken to achieve our goal.



CC-NNPDF Board of Directors
Visit their website at www.nnpdf.ca

This **Spirit of Collaboration** is truly evident through the joint efforts between the Canadian Chapter of the NNPDF (CC-NNPDF) and the National Niemann-Pick Disease Foundation (NNPDF). In January 2006, the Canadian government granted charity status to the CC-NNPDF. The Canadian Chapter is active and thriving thanks to several dedicated NPD families who were instrumental in bringing the foundation charity status to a reality. Of particular note are the Lucy and Enio Liegghio family, in memory of their son Luke (NPC), who died in 2005 at age 8, and the Tammy and Allan Vaughan family, in memory of their children Alex (NPC), who died in 1992 at age 4, and Laura (NPC), who died in 2001 at age 6.

This was an extremely important accomplishment for our "sister chapter" in Canada. Gaining the registered charity status has benefited the organization in a number of ways as it has allowed supporters of the Canadian Chapter to receive receipts for their tax-deductible donations. The chapter is also better able to approach Canadian pharmaceutical companies for research into treatments, to request that municipalities proclaim

October as Niemann-Pick Disease Awareness Month, and to lobby the Canadian federal government for grant monies designated for registered charities.

This dedicated group has also been extremely successful in raising funds. These Canadian donations are combined with funds raised in the United States for research, utilizing the NNPDF's Scientific Advisory Board (SAB) and grant funding process to ensure the funds are well spent.

The collaborative relationship between the NNPDF and CC-NNPDF extends into the area of Family Support, allowing the NNPDF to assist NPD families in Canada with the information and assistance they need to meet the challenges of this disease. Further, the chapters work in partnership to carry out administrative responsibilities such as tracking donations for tax purposes, producing and distributing newsletters, fundraising, website and research updates, as well as awareness materials.

The Canadian Chapter will host the 2010 Family Conference in Niagara Falls, New York. Tammy Vaughan, Chair of the Canadian Chapter, also serves on the NNPDF Board of Directors as secretary and is actively involved in all aspects of the NNPDF.

OUR VISION "A WORLD WIDE GROUP UNITED FOR NIEMANN-PICK DISEASE"

Collaborative efforts between Niemann-Pick Disease advocacy groups continue to grow internationally.

The first advocacy group established to assist families with NPD was the Niemann-Pick Disease Group United Kingdom (NPDG(UK)) formed in 1991, closely followed by the development of the National Niemann-Pick Disease Foundation (NNPDF) in 1992. Since that time there have been many other organizations formed (and groups that are in the process of being developed) in Argentina, Australia, Canada, France, Germany, Italy, Poland, Portugal, and Spain.

The NNPDF has worked closely with the NPDG(UK) over the years sharing and developing information, resources and funding of research. In our vision to create a **"World Wide Group United for NPD,"** plans are underway for the NNPDF and the NPDG(UK) to co-host an International Meeting for all NPD family support groups in the Fall of 2009 in Scotland.

The purpose of the meeting is to enhance communication and representation among the varied groups of organizations. We realize

the need to collaborate to avoid duplication of work and to maximize efforts in our common missions, being good stewards of our hard-earned resources.

These collaborative efforts and the cooperative development of information and awareness will be an integral factor to an overall strategy which will maximize the use of resources and shorten the time taken to achieve our vision....



...a world where Niemann-Pick disease is no longer a threat to a full and productive life for patients and their families. Medical professionals, thoroughly familiar with the disease, will promptly and accurately diagnose it early in the patient's life - perhaps prenatally - and then prescribe an appropriate therapy. Families affected by Niemann-Pick disease will not be devastated by the diagnosis or its impact on their lives.

Individuals with Niemann-Pick disease will have the same chance as their siblings and peers to run and play, to hope and achieve, and to live out their dreams.

MEMORIALS

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

Jeffrey Dean Baker (NPC) ~ 44 years

Riley May Corbitt (NPC) ~ 6 years

Kevin Matthew Eadie (NPC) ~ 14 years

Lindsay Lee Fitzgerald (NPC) ~ 16 years

Mitchell Flynn Harrower (NPC) ~ 7 years

Fred Wayne Jones (NPC) ~ 57 years

BJ Lawrence (NPC) ~ 22 years

Kimberly Rodarte (NPC) ~ 29 years

Katlyn Rose Sumbad (NPA/B) ~ 2 years

*And like a single drop of rain
That on still waters fall,
Their lives did many ripples make
and touched the lives of all.*

Making Our Voices Heard

"The NNPDF ~ Where Success Begins with You!"

Life for Brooke ~ Knights of Columbus Spaghetti Dinner
In honor of: Brooke Thomas
Omaha, Nebraska



Aikens-Sims Family & Friends Mailing
In honor of: Ashley Sims
Geneva, New York



Lafayette Elks Lodge Bingo
Knights of Columbus Tootsie Roll
In memory of: Braden Smith
In honor of: Riley and Keaton Smith
West Lafayette, Indiana



Persevere Campaign
Goals for Naomi
In honor of: Naomi Tyrrell
Shelton, Connecticut

Hope for Aadiya
In honor of: Aadiya Dasgupta
Michigan

Varela - Cisneros Family & Friends Mailing
In memory of: Malayna Varela
Yuma, Arizona



Tomorrow's Hope Walk Fest
In support of all Niemann-Pick Families
Jefferson, Wisconsin

Celebration of Barb & Gary Vorpahl's 30th Wedding Anniversary

Golf "Fore" Stacey Memorial Classic
In memory of: Stacey Vorpahl
Fort Atkinson, Wisconsin



2nd Annual Katlyn Sumbad Golf Tournament
Family & Friends Mailing
In memory of: Katlyn Sumbad
Modesto, California



Hanover 5-K Road Race & Walk
5th Annual Bryant University "Teeter-Totter" Marathon
Hosted by: Ryan Kelly
In memory of: Erin Roberts
Hanover, Massachusetts



1st Annual Kevin Eadie Golf Tournament
In memory of: Kevin Eadie
Williamsburg, Virginia



Family & Friends Mailing for October Awareness
In honor of: Mindy Fagan
Jackson, Michigan



Evening of Hope Cellphone pouch sales
In honor of: Peyton and Kayla Hadley
Medford, Oregon

Bachman and Van Dyke families Family & Friends Mailing for October Awareness
In memory of: Zoe Bachman
Kings Mountain, North Carolina



Ducks for Bucks Willow Wicks Candles
In memory of: Breann Chavez
Farmington, New Mexico



Gabrielle's Gift NPJ Awareness Events
In honor of: Gabrielle LaVerde
Deltona, Florida



Family & Friends Fundraiser Picnic Tastefully Simple Fundraiser
In memory of: Bryanna DeSouza
Naugatuck, Connecticut



Hunter's Hope Golf Tournament and Fundraiser
In memory of: Hunter Ozmer
Roanoke, Virginia



Riley Donegan Awareness Speech
In honor of: Blake Donegan
LaGrange, Illinois



1st Annual Memorial Ride/Poker Run
In memory of: Ryan Richardson
Crestview, Florida



Tyler's Diner Benefit Quilt Show Tyler's Diner Dinner and a Show Little Wings Childcare Center
In memory of: Tyler Heinze
In honor of: Katie and Faith Heinze
Elsie, Michigan



Lee King Benefit Bass Tournament
In honor of: Lee King
Eufaula, Alabama



We, the families of the children and young adults affected by Niemann-Pick Disease thank you for joining us as we PERSEVERE in our quest for a cure.

NATIONAL NIEMANN-PICK DISEASE FOUNDATION

"Family and Community Collaborations"

"A STRATEGY FOR SUCCESS"

As NPD families gather the support of family and friends around the county and in Canada they have found collaborative efforts for fund raising and awareness campaigns garner exceptional results!

The Canadian Chapter of the National Niemann-Pick Disease Foundation



Tammy & Allan Vaughn Family Golf Outing
In memory of: Alex (NPC) & Laura (NPC)
Durham, Ontario



Lucy and Enio Liegghio Family Gala
In memory of: Luke (NPC)
Vaughan, Ontario



COORDINATOR CHAPTER OF THE NATIONAL NIEMANN-PICK DISEASE FOUNDATION INC.
www.nnpdf.ca



Cardinal-Hudson Family Events
In memory of: Damon Cardinal (NPA)
Edmonton, Alberta

The Karen and Gene Quandt Family

Edgewood, Washington • In honor of: Ty (NPC ~ age 12)



Ty's 12th Birthday Celebration Dinner

Race "4" Ty



Ty's School Disco Fever Family Dance



The Amy and Sean Recke Family

In honor of: Adam (NPC ~ age 9)



5K Run/Walk Race for The Cure

Third Annual Golf for a Cure



Ride for Adam



Adam's Day with the Philadelphia Phillies



The Darrile and Mark Papier Family

Frederick, Maryland
In honor of: Dillon (NPC ~ age 6)



Frederick Keys Benefit for Dillon Papier

2nd Annual Dillon Papier Charity Golf Tournament



William Irwin's 5th Birthday Party



Bowie Baysox Benefit



Kindercare Coin Race



Foster's Grille Monthly Monday Event



SUPPORT OF THE NNPDF CONTINUES

Our annual campaign continues on in earnest! This year is proving to be a challenge for many in such uncertain economic times. We would like to thank anyone and everyone who has the courage and conviction to continue their support of the NNPDF through your giving efforts.

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

Thank you for your generosity.

There are many ways to support the NNPDF. Visit our website or contact the NNPDF office for more detailed information.

SECURED DONATIONS VIA CREDIT CARD
at: www.nnpdf.org (DonateNow)

TRIBUTE GIFTS ~ In honor or in memory of a loved one or a special celebration

UNITED WAY CONTRIBUTIONS
(NNPDF Tax Exempt ID#: 35-1844264)

COMBINED FEDERAL CAMPAIGN
(CFC ~ ID#: 10121)

GIFTS OF CASH ~ Payable to the NNPDF
IRA CHARITABLE ROLLOVER OPTIONS
MONTHLY BANK DRAFTS & PLEDGES
GIFTS-IN-KIND
GIFTS OF STOCK
PLANNED GIVING
MATCHING GIFTS
UNDERWRITING GIFTS



**NNPDF OFFICE
CONTACT INFORMATION:**

NADINE M. HILL,
Director of Family Services
E-mail: nhill@nnpdf.org

PHONE: 1-920-563-0930
TOLL FREE: 1-877-287-3672
401 Madison Avenue, Suite B
Post Office Box 49
Fort Atkinson, WI 53538-0049
Web site: www.nnpdf.org

CATE WALSH-VOCKLEY,
Coordinator of Education,
Referral, and Advocacy
E-mail: Catherine.walshvockley@chp.edu
Phone: 412-692-7349
Children's Hospital of Pittsburgh ~
Medical Genetics

CONTRIBUTIONS & MEMBERSHIPS TO:
NNPDF, Inc.
Post Office Box 310
Fort Atkinson, WI 53538-0310

NNPDF BOARD OF DIRECTORS:
Barb Vorpahl, Chair
Fort Atkinson, Wisconsin
Doug Pease, Vice Chair
New Orleans, Louisiana
Carl Wayne Moore, Treasurer
Fort Worth, Texas
Tammy Vaughan, Secretary
Durham, Ontario Canada

DIRECTORS-AT-LARGE:
Rhonda Brown-Kehoe Karen Quandt
Susan Green Holly Roberts
Melissa King Nancy Sullivan
Darrile Papier

MARK YOUR CALENDARS ~ 2009

**NNPDF 17th ANNUAL
Family Support
& Medical
Conference**



**Seattle, Washington
Doubletree Guest Suites**
(www.seattle.doubletree.com)

**Thursday, July 30th ~
Sunday, August 2nd, 2009**

**Conference Theme:
It's Raining Hope in Seattle**



Family Hosts: Karen and Gene Quandt,
along with their sons Tim and Ty (NPC ~ age 12).

Sometimes the difference between ordinary and amazing is where it happens. Seattle, Washington, is ANYTHING but ordinary. You've all heard about these special attractions for years... you just didn't realize it was all in one place!

Visitors will have an opportunity to see all that Seattle has to offer from high a-top the world-famous Space Needle, discover the beauty and majesty of the Puget Sound Region, and explore the stony shores and Cascade volcanoes of Mount Rainier.

Our Family Conference hosts and team members have begun planning an event that will address the needs of our families while offering them the opportunity to learn the latest on research and treatments. Watch the web site for more details.

VISIT OUR WEBSITE
 
www.nnpdf.org

2009 NNPDF ANNUAL BOARD MEETING ANNOUNCEMENT

The 2009 Annual NNPDF Board Meeting will be held the weekend of February 6th, 7th and 8th, in Milwaukee, Wisconsin. The Foundation's annual board meetings are open to all members

of the NNPDF. Please contact the NNPDF Central Office if you are not a board member but would like to receive more information pertaining to this meeting.

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.

National Niemann-Pick Disease Foundation
P.O. Box 49
Fort Atkinson, WI 53538-0049



NON-PROFIT
U.S. POSTAGE
PAID
BETHESDA LUTHERAN
HOMES & SERVICES