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VOLUME 1, ISSUE 40

# Niemann-Pick

SPRING NEWS 2007

National Niemann-Pick Disease Foundation

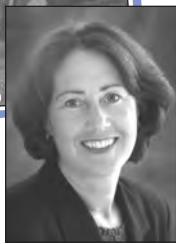
*Celebrates 15<sup>th</sup> Anniversary*  
of Support, Service, and Research!

*"How Can We Help?"*



Tinker Bell and Mini Mouse, aka, sisters Brianna (NPC ~ 4) and Bailey (NPC ~ 6) Patterson of Murrieta, California had smiles to spare as they readied themselves for Trick-or-Treat activities last year. Since its inception in 1992, the National Niemann-Pick Disease Foundation has continued to emphasize and develop its family services programs based on the ongoing needs of our family membership. The girls' parents, Tara and Jeremy, consider the services provided by the NNPDP as life-lines while they deal with the day-to-day challenges of Niemann-Pick Disease. This issue of the Niemann-Pick News highlights and focuses on the services that the NNPDP offers to our membership.

*Note: We are heartbroken to inform our families and supporters that Bailey lost her battle with NPD Type C on March 26th, 2007. Our hearts and thoughts go out to her family and friends.*



**BARBARA VORPAHL**  
NNPDF Board Chair

I'm excited to be back again as Chair of the NNPDP as we celebrate our 15th anniversary. My husband Gary and I were one of the founding families of the NNPDP. Through the years, I have served in all capacities of the foundation, residing as chair from 2000 through 2004. Our family started our battle against Niemann-Pick Disease when our daughter Stacey was diagnosed at age two. Stacey died two years ago, at the age of nineteen, after a long courageous struggle from the effects of Niemann-Pick type C disease.

We know first hand the daily challenges of this disease, and realize it was the support of the many family and friends we have met through the NNPDP that got us through. As a parent watching your child decline before our eyes, it was the NNPDP that empowered us to stand up and do something to fight this disease by raising funds to find a cure.

As we face life without Stacey, I realize even more the importance of the NNPDP and I am committed as Chair to carrying out its mission and purpose... to promote research to find treatments and a cure for NPD, and to provide support to anyone - individuals, families, communities, and organizations - affected by this disease.

This Spring issue focuses on the many services that NNPDP provides to those affected by Niemann-Pick Disease. It is these families, their stories and their

children's faces that compel us to continue moving forward to make their journeys less difficult whenever possible. We are here to provide compassionate services that reduce isolation, to offer information that helps them get through each day, and education about the broad issues and developments that can impact them over time. We help families learn about the basics of NPD and its treatments, tackle the complexities of genetic counseling, seek access to medical equipment, conduct fund raisers, or simply need to talk with other affected families. We're here to help.

We offer hope through research. We are committed to funding research to find a cure (see the Niemann-Pick Research page to learn about a major new study that NNPDP has funded in the UK). But research takes time and a cure, especially for NPC, is not readily available. That is why it is so vital that we continue to provide the financial support needed to back this work.

We are also very excited to announce the launch of our new web site [www.nnpdf.org](http://www.nnpdf.org) (yes, old address, but a very new look). We've made it easier for you to learn about Niemann-Pick disease and to access the wealth of information that is available to help those affected by NPD. Spend a few minutes surfing the site and let us know what you think.

We're grateful for your continuing support for all of the things that your foundation does. If you will join us at the Family Conference in August (see the web site under Family Services) we'll thank you personally for your generous support. And we'll continue to provide those critically important services that you have come to rely upon from NNPDP.

CHECK OUT OUR NEW WEBSITE



[www.nnpdf.org](http://www.nnpdf.org)

A publication of The National Niemann-Pick Disease Foundation

*"We're Here To Help"*



**NADINE M. HILL**  
*NNPDF Director of Family Services*

I am the first contact that a family makes with NNPDF after they receive a diagnosis. I am in the unique position to be working with families whose children and loved ones are dealing with different stages of the disease and are at different places in their NP Journey.

I coordinate NNPDF's communication, education, and community awareness initiatives. I also work with families to raise funds for treatments and a cure, and I respond to a family's needs as they deal with Niemann-Pick Disease in each of its stages. I coordinate NNPDF's annual family conference, lead the production of our newsletter, and I use other tools such as our

list-serves to provide opportunities for individuals and families to interact directly with others affected by NPD.

NNPDF is able to offer services that families have come to rely upon due in great part to the spirit and energy that ALL of our loved ones affected with NPD share ~ those who have died, those currently fighting, those yet to be diagnosed, and the families that support them ~ you all inspire us to take that ONE extra step. I benefit from so many messages of hope and inspiration that it helps to lift my spirit and encourage me as I assist our families and their extended families.

You can learn more about the NNPDF's Family Service Program in the rest of this newsletter, by contacting me at [nhill@nnpdf.org](mailto:nhill@nnpdf.org), and via the Foundation web site [www.nnpdf.org](http://www.nnpdf.org).

*Nadine Hill works out of NNPDF's office in Ft. Atkinson, WI. She resides in the small community of Jefferson, WI with her husband, Mike, and three sons - A.J. ~ 19, Evan ~ 14, and Paul ~ 12. Nadine brings a strong background in office and administrative management to NNPDF. Her goal is to maximize foundation efforts to raise awareness of NPD, to be an asset and facilitator for families and friends touched by the disease, and to raise funds to find treatments and a cure.*



**CATE WALSH VOCKLEY, MS, CGC**  
*NNPDF Coordinator of Education, Referral and Advocacy*

I am NNPDF's advocate for patients and families, whether addressing new diagnoses, obtaining appropriate health care, respite care, or insurance coverage, or working to support continuing research and educational initiatives. I am available to discuss the various aspects of Niemann-Pick Disease with families and medical professionals, providing information and referral services, assisting with correct diagnosis, genetic counseling, education, and many other needs.

I have developed a relationship with a national network of health care providers with expertise in metabolic disease diagnosis and management. This serves as an excellent resource as we strive to quickly identify experienced providers and obtain prompt diagnoses for individuals affected by NPD. The skills developed through these efforts assist me as I develop new programs and resources for individuals affected by Niemann-Pick disease and for their families and supporters.

*Cate Walsh Vockley is a board certified genetic counselor working out of Children's Hospital of Pittsburgh. She has been involved with the Niemann-Pick disease community for a number of years, beginning with her role in the Mayo Clinic project on DNA analysis of the NPC1 and NPC2 genes. Cate obtained a Master of Science degree in genetic counseling from the University of Colorado Health Sciences Center in 1986. This education provided a unique combination of knowledge about the scientific and medical aspects of hereditary disease while also emphasizing the psychological effects of such diagnoses. Her major areas of interest include inherited metabolic disorders, hereditary cancer conditions, and ethical and psychosocial aspects of human genetics. Cate has worked in Denver, at Yale University, at the Mayo Clinic, and now at Children's in Pittsburgh. She has worked in a multidisciplinary metabolic disease clinic, providing ongoing education, counseling and support for families as they have dealt with challenges of a chronic medical condition in a loved one. Cate has also been involved in the Minnesota planning grant for follow up of newborn screening across the state.*

**MEMORIALS**

*Please take a moment to remember those we have lost recently to Niemann-Pick Disease.*

- |   |  |
|---|--|
| Bryanna Scribner DeSouza (NPC) ~ age 14 years | Bailey Grace Patterson (NPC) ~ age 6 years |
| Noah Jordan Gerchick (NPA) ~ age 10 months    | Braden A. Smith (NPC) ~ age 10 years       |
| Haley Ann Hockmeyer (NPC) ~ age 16 years      | John A. Zahner, Jr. (NPC) ~ age 35 years   |
| Kristina Marie Mabe (NPA) ~ age 14 months     |  |

*Our hearts go out to their families and friends.*

*How fortunate we are that in our hearts we keep forever the memories of those we love... and the times we shared together.*

*Memorial Donations*

DIRECTED TO THE NNPDF:



**BRYANNA SCRIBNER DESOUZA**  
NPC 01/20/92 ~ 12/05/06



**HALEY ANN HOCKMEYER**  
NPC 03/22/91 ~ 02/20/07



**KRISTINA MARIE MABE**  
NPA 01/27/06 ~ 03/31/07



**BAILEY GRACE PATTERSON**  
NPC 08/12/00 ~ 03/26/07



**NOAH JORDAN GERCHICK**  
NPA ~ age 10 months



**BRADEN A. SMITH**  
NPC 09/03/96 ~ 10/31/06

# MAKING OUR VOICES HEARD

"The NNPDF ~ Where Success Begins with You!"

*Never doubt that a small group  
Of thoughtful committed citizens  
Can change the world...  
Indeed that is the only way  
It is ever done.*

MARGARET MEAD



**6th Annual Life For Luke Dinner Gala Celebration & Silent Auction**

In memory of: Luke Liegghio  
Vaughan, Ontario Canada



**1st Annual "Golf For A Cure" Southmore Country Club**

In honor of: Adam Reeke  
Bethlehem, Pennsylvania



**Naomi Tyrrell Holiday Happenings**

In honor of: Naomi Tyrrell  
Shelton, Connecticut



**Persevere Wear & Wristband Project**

In honor of: Naomi Tyrrell  
Shelton, Connecticut

**Vinny VanDetta Family Awareness Day Spaghetti Dinner & Silent Auction**

In honor of: Vinny VanDetta  
Hamlin, New York



**Wisnewski Family Awareness Events Snodgrass Racing Team "Racing For A Cure"**

In memory of: Cole Allen Wisnewski  
Melbourne, Florida

**Sullivan Family Awareness Event United Way & Combined Federal Campaign**

In memory of: Karen Sullivan  
St. Louis, Missouri



**Mareena's Memory Day North Oyster School**

In memory of: Mareena McNab  
Ladysmith, British Columbia Canada



**Breann Chavez Butterfly Wings Candle Sales**

In memory of: Breann Chavez  
Farmington, New Mexico

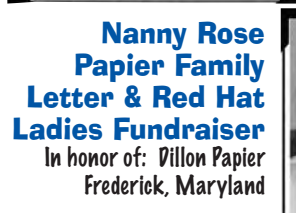


**Papier Family & Friends Fund Raisers**



**Dillon's Daycare Celebrations KinderCare ~ Westview**

In honor of: Dillon Papier  
Frederick, Maryland



**Nanny Rose Papier Family Letter & Red Hat Ladies Fundraiser**

In honor of: Dillon Papier  
Frederick, Maryland



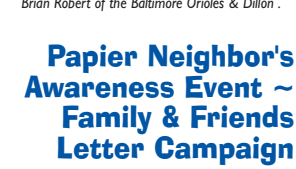
Nanny Rose & Dillon



**Baltimore Orioles Spring Training Dillon Papier Day**

In honor of: Dillon Papier  
Frederick, Maryland

Brian Robert of the Baltimore Orioles & Dillon



**Papier Neighbor's Awareness Event ~ Family & Friends Letter Campaign**

In honor of: Dillon Papier  
Frederick, Maryland



**Strong Commitment and Support of the NNPDF Continues**

*Upcoming Benefit Events*

**April 13<sup>th</sup>, 2007 TY QUANDT FAMILY COMMUNITY DANCE**

In honor of: Ty Quandt  
Mt. View Elementary School  
Edgewood, Washington

**PAPIER FAMILY & FRIENDS EVENTS**

April 29<sup>th</sup>, 2007 ~ Bowie Baysox Dillon Papier Night  
June 10<sup>th</sup>, 2007 ~ Greensborough Grasshopper's Baseball Night  
September 2007 ~ Dillons Fight FORE A Cure Golf Classic  
In honor of: Dillon Papier  
Frederick, Maryland

**May 20<sup>th</sup>, 2007 5K Run/Walk "RACE FOR THE CURE"**

In honor of: Adam Reeke  
Allentown, Pennsylvania

**May 21<sup>st</sup>, 2007 THE DIMATTEO FAMILY CHARITABLE FOUNDATION SECOND ANNUAL CHARITY GOLF TOURNAMENT**

Woodbridge Country Club  
In honor of: All members of the NNPDF  
Woodbridge, Connecticut

**June 2<sup>nd</sup>, 2007 1<sup>ST</sup> ANNUAL BREANN CHAVEZ MEMORIAL COMMUNITY DAY**

In memory of: Breann Chavez  
Farmington, New Mexico

**June 9<sup>th</sup>, 2007 2007 LEE KING BENEFIT BASS TOURNAMENT & RAFFLE**

In honor of: Lee King  
Lakepoint State Park ~ Lake Eufaula  
Eufaula, Alabama

**June 15<sup>th</sup> & 16<sup>th</sup>, 2007 TOMORROW'S HOPE WALK FEST 2007 "Walking As One"**

In honor of: All members of the NNPDF  
Jefferson, Wisconsin

**June 16<sup>th</sup>, 2007 5TH ANNUAL ALEX AND LAURA VAUGHAN MEMORIAL GOLF TOURNAMENT**

In memory of: Alex and Laura Vaughan  
Stone Tree Golf Club  
Durham, Ontario, Canada

**June 23<sup>rd</sup>, 2007 2007 GOLF "FORE" STACEY MEMORIAL GOLF CLASSIC**

In memory of: Stacey Lynn Vorpahl  
Fort Atkinson, Wisconsin  
*"A Life that touched so many echoes still..."*

**Summer 2007 MARCELLO & MATTHEW PERUGINI MEMORIAL WALK**

In memory of: Marcello & Matthew Perugini  
Waterbury, Connecticut

**August 16<sup>th</sup> ~ 19<sup>th</sup>, 2007 15TH ANNUAL NNPDF FAMILY CONFERENCE**

All NNPDF Families and Supporters!  
Milwaukee, Wisconsin

**September 2007 1<sup>ST</sup> ANNUAL RYAN RICHARDSON MEMORIAL RIDE**

In memory of: Ryan Richardson  
Crestview, Florida

**October 2007 ~ CELEBRATE! 6TH ANNUAL NIEMANN-PICK DISEASE AWARENESS MONTH**

All NNPDF Families & Supporters Nationwide!

*"We, the families of the children affected by Niemann-Pick Disease thank you for joining us as we persevere in our quest to find a cure!"*



For more information on these events visit our website

# Family Services

*NNPDF's goal is to provide services that anticipate and respond to the needs of those dealing with Niemann-Pick disease, so as to reduce the impact of the disease on immediate and extended families.*

For 15 years, NNPDF has assisted families as they face the challenges of living with Niemann-Pick Disease. Our Family Services Program has grown during this period to include facilitation of family connections, education, counseling services and referral, and assistance with awareness campaigns and fund raising. We encourage anyone affected by Niemann-Pick Disease to access NNPDF's services.



## Facilitation of Family Connections

NNPDF offers help in easing the emotional burden imposed by Niemann-Pick Disease by fostering and facilitating networking and other connections among individuals and families. These connections can reduce feelings of isolation and despair as families experience the different phases of NPD.

Since 1992, NNPDF's annual Family Conference has brought together families, scientists, and medical professionals to share medical and research information, and to provide support to individuals and families. This year's conference is a do-not-miss event (see the back page of this issue for more information on our 15th annual conference to be held August 16th ~ 19th in Milwaukee, Wisconsin.)

*"I now consider Niemann-Pick News ~ my newsletter. It is my link to the families, support, medical world, and research updates that I need to meet NPD head-on."*

NNPDF also fosters networking through electronic list-servs for each type of the disease (NPA, NPB, and NPC). These electronic mailing lists provide opportunities for discussion and sharing of concerns, problems, and solutions. NNPDF also sponsors a special list-serv for families whose child has died, as well as a sibling list-serv. Each of the list-servs can be accessed and joined through the NNPDF web site.

The NNPDF website itself contains information about the Foundation, but more important, it contains a wealth of information about Niemann-Pick Disease, its diagnosis and treatments, and myriad educational tools for individuals and families dealing with the disease. The web site can also help with fund raising initiatives and acquisition of books, promotional items, and other resources to address NPD.

*"I used to feel so lost, waiting for someone to notice, to offer us a hand, to reach out and help, then I found the NNPDF."*



## Education

NNPDF provides medical and educational information to schools, doctors, and other health-care professionals. These materials can assist with the diagnosis and treatment of NPD, and they provide referral information to those affected by the disease.

NNPDF also promotes and assists with continuing education and community awareness campaigns through informational brochures, educational videos, a public relations media guide, and many other materials.



## Support, Counseling, Referral Services, and Advocacy

NNPDF provides genetic and supportive counseling and referral services through its Coordinator for Education, Referral, and Advocacy. We provide families access to the emotional support they need while dealing with all types of NPD. We also offer information about working with doctors, clinics, insurance companies, and other health and human service programs. NNPDF programs have been developed to assist families during a crisis and to offer practical suggestions about day-to-day care of those affected by NPD. Most importantly, we work to support enduring relationships with other NPD parents.



## Support of Fundraising and Awareness

NNPDF receives financial support for its Family Services and Research Programs from individuals, families, and private organizations. We are grateful for this support. We encourage families to develop and conduct fund raising initiatives on behalf of NNPDF and we have developed a specialized Fund Raising Manual, which is available to families on-line at [www.nnpdf.org](http://www.nnpdf.org) or from the NNPDF office. The manual offers guidance and recommendations for hosting community fund raising as well as NPD awareness events, which assist in "getting the word out" about this rare disease - to doctors, families, government leaders, and the general public.

*"The list-serv is such a wonderful way to stay in touch and in contact with other families. It is a place one can have support without judgment and yet offers suggestions on how to face this new world ~ the world of NPD."*

October has been designated National Niemann-Pick Disease Awareness month and is a special time to raise awareness about NPD nationwide. NNPDF's "A Guide to Getting Media Coverage," provides directions to enhance newspaper and television coverage of an event. An NPD Awareness Ad is a powerful statement of why Niemann-Pick research is so important, and can be printed for use as awareness flyers. Our National Spokesperson, Sportscaster James Brown, has recorded a television public service announcement to promote NNPDF community events (you can view this announcement on NNPDF's web site at [www.nnpdf.org](http://www.nnpdf.org)).

NNPDF is a foundation that provides services to all individuals affected by Niemann-Pick Disease. We do not charge for our services; rather, our funds come from family fund raising events, private donors, and other foundations. We invite all interested individuals and organizations to join NNPDF in support of our efforts to raise awareness of NPD, to support individuals and families affected by the disease, and to support research toward finding treatments and a cure for Niemann-Pick Disease. You can learn more about NNPDF's programs by visiting our web site at [www.nnpdf.org](http://www.nnpdf.org), or by contacting the NNPDF office at [nnpdf@nnpdf.org](mailto:nnpdf@nnpdf.org).



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# Yesterday, Today, Tomorrow

2007 NNPDF Family Conference - Milwaukee, Wisconsin

The **15th Annual NNPDF Family Support and Medical Conference** will begin on Thursday, August 16th and run through Sunday, August 19th, 2007 in Milwaukee, Wisconsin. NNPDF's newly elected Board Chair, Barb Vorpahl, her family, and the NNPDF Office will co-host the conference.

"Yesterday ~ Today ~ Tomorrow!" is our conference theme and this Sanskrit Proverb our inspiration.

*"Everything was so wonderful. We left the conference empowered with information and a network of support."*

We are excited to invite all past and present NNPDF members and friends for a weekend filled with opportunities to obtain urgent medical and research updates and the family support and networking that is so vital to all.

This year's conference will feature special sessions on the multi-disciplinary approaches to treating the entire child; Identifying initial symptoms for NPD (all types) and how symptoms change as the disease progresses; Puberty, pregnancy, and late onset for all types of NPD; An historical perspective on NPD, including scientific research to find treatments and a cure; and sessions in stress management for care givers.

*Look to this day  
For yesterday is but a dream,  
And tomorrow merely a vision.  
But today, we lived,  
Makes every yesterday  
a dream of happiness  
And every tomorrow  
a vision of hope.  
Look well,  
therefore,  
to this  
day.*

Research, medical, and clinical updates for NPA, NPB, and NPC will also be presented by some of the world's most prominent NPD scientists and physicians.

Summer in Milwaukee is fabulous and there will be so much to see and do ~ you won't know where to start!! The conference will be held at the historic Hilton ~ Milwaukee City Center ([www.hiltonmilwaukee.com](http://www.hiltonmilwaukee.com)) just one mile from the lakefront! Lake Michigan that is!! If

you don't find the time to get to the lake, there is an indoor water park at the Hilton - A beachfront right outside your door!

All registration and travel information is on the NNPDF web site at [www.nnpdf.org](http://www.nnpdf.org). The NNPDF Office will also be mailing registration, hotel, and travel information to families. You can link to the many attractions available in this great city ~ known as the Jewel of the Great Lakes, via the NNPDF web site.



*"You can connect with people who truly understand you."*

## Our "First Time" Fund Raiser Contest continues for the 2007 Conference.

### The rules are simple:

- ♥ This must be your "first" fund raising event for NNPDF
- ♥ Only events held after June 30, 2006 will be counted
- ♥ Results and receipts must be turned into the Foundation by July 1, 2007
- ♥ NNPDF Board members, officers, and their relatives are not eligible

You can hold more than one fund raiser during the year if you wish. *Be sure to notify Nadine Hill at the NNPDF Office that you are participating in the "First Time" Fund Raiser Contest so she can track your results.*

### The rewards of participating are great

(even if you aren't the prize winner):

- ♥ A sense of accomplishment at doing something you may have thought impossible
- ♥ Moving the fight against NPD forward
- ♥ The top fund raiser will be recognized at the Family Conference
- ♥ The top fund raiser will receive three nights deluxe lodging accommodations at the 15th Annual NNPDF Family Support and Medical Conference to be held August 2007.

Everyone participating will be "First Timers" - so everyone has an equal chance at being the top fund raiser. Whether you raise \$50 or \$5,000, it all helps in the fight against Niemann-Pick.

CHECK OUT OUR NEW WEBSITE



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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