

"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](mailto: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](http://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.