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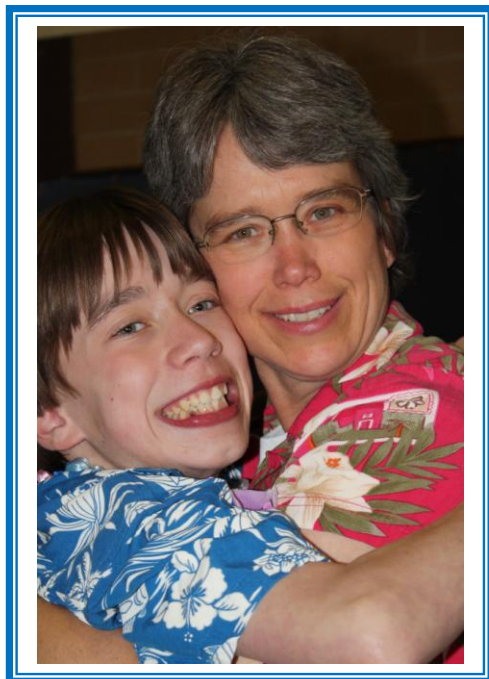
Greetings to you from the National Niemann-Pick Disease Foundation!

We thank you for all your past support of the NNPDP, and for the support we hope you will continue as we **PERSEVERE** in our battle against this formidable foe, Niemann-Pick Disease.

Please allow me to introduce myself. I am Karen Quandt, the NNPDP's new board chair, and a parent of a child affected by Niemann-Pick Disease (NPD).

Our youngest son, Ty, was diagnosed with Niemann-Pick Disease Type C (NPC) in 2005, at the age of eight. My husband Gene and I found the NNPDP Web site after Ty's neurologist said he would be tested for NPC. We were devastated when the diagnosis of this rare, genetic, neurological, terminal disease was confirmed.

The National Niemann-Pick Disease Foundation and their Web site ([www.nnpdf.org](http://www.nnpdf.org)) gave us information about the disease and resources where we could get help as we embarked on this most unwelcome journey. We began to educate ourselves and to arm ourselves for the fight of our lives against this disease which threatens to steal our now-13-year-old son from us.



Through the NNPDP we have learned a great deal about this disease and how to cope on a daily basis. Like every family affected by NPD, we face daily challenges and heartbreak with this progressive neurodegenerative killer.

We turn to other families of the NNPDP for support and guidance as many of them have experienced the same issues with their children or family members and can share their knowledge of what has helped their family cope. We have developed and benefit from this nurturing network of support thanks to the NNPDP.

We also turn to the doctors and researchers of the NNPDP's Scientific Advisory Board (SAB) for advice about medical care, clinical research trials, experimental medications, and to help explain what research is currently being conducted around the world concerning Acid Sphingomyelinase Deficiency (ASMD, also known as NPD Type A and Type B) and Niemann-Pick Disease Type C.



**Every Life is a Promise....  
So Full of Hope and Wonder....**

In addition to these much-needed Family Support Services, the NNPDF raises money for research – research essential to unlocking the mysteries of NPD and to finding effective treatments and a cure.

To date, the NNPDF has raised and directed over \$4.8 million for research, and **SIGNIFICANT PROGRESS** is being made. The genes responsible for NPD have been identified, and experimental drugs are being evaluated and used with some positive results. We need to maintain and increase this momentum in our race against time for children such as our Ty.

As I take over the responsibilities of the Chair of the NNPDF, I am well aware that I begin this journey standing on the shoulders of giants. Since the foundation was formed in 1992, many resources have been established and much has been accomplished by those founding families to help others with a Niemann-Pick Disease diagnosis find hope and answers through the NNPDF.

## **The NNPDF is here to help!**



### **RESEARCH IS TY'S ONLY HOPE!**

*“Since Ty’s diagnosis of NPC, each birthday milestone at our home is marked with a true sense of love, celebration and thankfulness that he is still with us.”*

The foundation provides compassionate services that reduce isolation, offers information that helps us get through each day, and provides education about the broad issues and developments that can impact affected individuals and families.

Through the Web site, listservs, newsletters, and knowledgeable staff, we help families learn about NPD, tackle the complexities of a genetic diagnosis, seek access to medical equipment, and conduct fundraisers. We also offer healing opportunities to simply talk with others who understand the devastation and heartache NPD wreaks on a family.

The NNPDF provides accurate, up-to-date information about all types of Niemann-Pick Disease, and is committed to continuing the fight against all types of NPD until the battle is won. Further, the NNPDF plays a global role in its support of the Canadian Chapter of the National Niemann-Pick Disease Foundation ([www.nnpdf.ca](http://www.nnpdf.ca)), and in serving as a primary information resource for those with NPD around the world.

**Supporting the NNPDF is the best way to fight back against Niemann-Pick Disease.** Because all types of NPD are rare, it is important that all of us touched by these diseases continue to support the NNPDF so that the foundation can support our families and advance the quest for treatments or cures.

**Please, will you help us PERSEVERE in our battle against Niemann-Pick Disease? The very lives of our children depend on it, and we are forever grateful for your continued support.**

**Thank you!**

Sincerely,

***Karen Quandt***

Karen Quandt, RN, MSN

NNPDF Board Chair

Mother of Ty (Niemann-Pick Disease Type C)



**Karen, Ty (NPC), Gene and Tim Quandt**