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Seasons Greetings!

Throughout 2011, your support of our work at the National Niemann-Pick Disease Foundation has made a life-changing difference to the children and adults affected by Niemann-Pick Disease, as well as their families who love and hold them so dear.

As we pause to reflect on the far-reaching impact your generosity has enabled us to have this year, **we especially want to thank you!** You have helped the NNPDF provide year-round hope to the ill-fated families dealt a crushing blow by Niemann-Pick Disease (NPD).

Your past support, among many other things, has helped us to:

- ✓ Provide information and referral services for families still reeling from a diagnosis of Niemann-Pick Disease. The NNPDF works hard to counteract the inevitable feelings of loneliness and isolation when a family receives the devastating news of a rare, fatal disease by providing a caring network of supporters and reliable, accurate information.
- ✓ Advance research into Niemann-Pick Disease as we urgently seek effective treatments and a cure to put an end to the heartbreak of NPD forever. The dedicated scientists and physicians working on Niemann-Pick Disease are making exciting advances in unlocking its mysteries, giving us distinct hope for the future. (Please see our Web site at www.nnpdf.org for research updates and details of upcoming 2012 clinical trials which offer a real sense of hope to families affected by both Niemann-Pick Disease Type B (ASMD) and Niemann-Pick Disease Type C.)
- ✓ Provide financial assistance to families to attend the NNPDF's Annual Family Support and Medical Conference, where they find a loving network of others who truly understand, and have personal access to the country's eminent medical clinicians and research experts in this ultra-rare disease.

These are just a small sampling of what the NNPDF has accomplished during 2011. The NNPDF will mark its 20th anniversary in 2012, and each year continues to build on the one before, all made possible by the hard work of our families to raise awareness and funding in their local communities, and the generous support of donors like you.

Your support of the National Niemann-Pick Disease Foundation is a critical lifeline for NPD patients and their families. You help us connect them with the resources they need and you help them find strength in the face of a horrific prognosis – in short, **YOU GIVE THEM HOPE.**

Photo: *Smiles abound at our Saturday Evening Family Celebration Gala as NPD families gather to wrap-up the 19th Annual NNPDF Family Support and Medical Conference held in Norfolk, Virginia this past August.*



It is probably no surprise to you that in these times of global economic crisis and rising costs, the NNPDF is working hard to stretch its resources and economize in every aspect possible. However, we continue to not only meet the needs of our members, but to find ways to expand and enhance what we are able to do – because we know firsthand the pain of receiving the dreaded diagnosis of Niemann-Pick Disease, and **WE CANNOT IGNORE THOSE WHO NEED US!**

The NNPDF, our volunteer board of directors, and our volunteer board of scientists, researchers, and medical clinicians are all still diligently serving our 400 NNPDF member families, and our families are ever so grateful to receive the many and varied services of the NNPDF.

During this time of year, I always take a moment to stop and count my blessings. I am appreciative of so many things - including the fact that the NNPDF was here to answer my family's call when we first received Ty's diagnosis of Niemann-Pick Disease Type C. I am also thankful that the foundation continues to grow and get stronger year after year, helping families just like mine face and live with a diagnosis of Niemann-Pick Disease.

Your generosity helps us advance our mission to beat Niemann-Pick Disease. Through your volunteerism, participation in events, and your financial and in-kind gifts, our dreams become a reality. Without this support, we would not be able to positively affect our families as they struggle with the challenges of supporting a chronically-ill child.

Today, much work remains and your assistance is essential. Like many of you, the economy has hit us hard--straining and squeezing the foundation's financial and other resources. But we cannot slow our efforts. Children's lives depend upon it.

So many families need us now more than ever. As awareness of NPD grows in the medical community, so do the number of diagnosed cases. We are contacted almost daily by families who have recently received a diagnosis of NPD, and who want and need our family services, referrals, information and research updates. As the NNPDF is the **ONLY** Niemann-Pick Disease patient advocacy group in the United States and Canada, we are their sole resource for these essential services.

But with limited resources for services and research ~ we can only do so much.

Won't you stand with us as we serve those in this rare orphan disease community? **Your gift of any amount to the National Niemann-Pick Disease Foundation would mean so much to us.** Even the most modest gifts, when added up, make a real difference in the lives of those we serve.

Today, more than ever, we must all consider carefully where we apply our resources. You can be assured your gift to the NNPDF will be greatly appreciated and faithfully stewarded to bring the greatest benefit to families dealing with NPD.

Our mission depends on people like you. Your financial assistance is essential to the important work that we do. Please, make a gift today.

With a grateful heart,

Karen R. Quandt

Karen R. Quandt, NNPDF Board Chair
Mom of Ty (Niemann-Pick Disease Type C)



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