



Canadian Chapter of the  
National Niemann-Pick Disease Foundation  
Tammy Vaughan, Chair  
R.R. #1  
Durham, Ontario N0G 1R0  
519-369-2837; [tammyv@butterball.ca](mailto:tammyv@butterball.ca)  
[www.nnpdf.ca](http://www.nnpdf.ca)

## Season's Greetings!

December 2011

Throughout 2011, your support of the work of the Canadian Chapter of 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 CCNNPDF provide year-round hope to the ill-fated families dealt a crushing blow by Niemann-Pick Disease (NPD).

The Canadian Chapter of the National Niemann-Pick Disease Foundation (CCNNPDF) works collaboratively with the National Niemann-Pick Disease Foundation (NNPDF) (U.S.) to offer support services to our family membership in Canada and funding of research into NPD treatments. This close CCNNPDF/NNPDF partnership helps eliminate redundancy and maximizes the impact of your generous donations in our fight against Niemann-Pick Disease. The bulk of CCNNPDF funds are directed toward Niemann-Pick Disease research through an established research strategy with guidance from an international Scientific Advisory Board of distinguished NPD researchers. As the CCNNPDF Board Chair, I serve as Secretary of the NNPDF Board of Directors.

### Your 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 CCNNPDF/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.ca](http://www.nnpdf.ca) for research updates and details of upcoming 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.)

These are just a sampling of what the CCNNPDF/NNPDF partnership has accomplished during 2011. In 2012, the CCNNPDF will help the NNPDF mark its 20<sup>th</sup> anniversary. 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.

It is probably no surprise to you that in these times of global economic crisis and rising costs, the CCNNPDF/NNPDF is working hard to stretch 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!**

**Your support of the Canadian Chapter 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 the Family Celebration Gala as NPD families gather to wrap-up the 19<sup>th</sup> Annual NNPDF Family Support and Medical Conference held in Norfolk, Virginia, this past August.*



The CCNNPDF/NNPDF, our volunteer boards of directors, and our volunteer board of scientists, researchers, and medical clinicians, all diligently serve our member families, and our families are ever so grateful to receive the many and varied services we provide.

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 there for my family in our time of need. I am also thankful that the two foundations (CCNNPDF and NNPDF) continue 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.**

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.

**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 Canadian Chapter of 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 CCNNPDF 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,

*Tammy Vaughan*

Tammy Vaughan, CCNNPDF Board Chair  
NNPDF Board Secretary  
Mom of Alex Vaughan (NPC) (1998 - 1992)  
and Laura Vaughan (NPC) (1995 – 2001)