



In the Spirit of Collaboration



Tammy Vaughan | CC-NNPDF Chair

A word from our Board Chair

Hello everyone, and welcome to the first edition of the Canadian Chapter of the National Niemann-Pick Disease Foundation newsletter supplement page!

We have joined forces with the NNPDF in the U.S. and will be using this format to update our Canadian members and constituents on all that is new and exciting. Please let us know if you would like to see an article on a specific topic – we will do our best to accommodate your request.

In addition to the information contained in the enclosed Niemann-Pick News document from the NNPDF, we will use this space to recognize specific events and activities occurring in Canada. This supplement page will allow us the opportunity to highlight our generous corporate and individual sponsors, as well

as bring you updates from our top fundraisers. We will be recapping all awareness and fundraising activities large or small, so be sure to let us know what you've been up to in helping advance our Quest for a Cure.

Stay up to date with details pertaining to the work of the CC~NNPDF via our foundation Web site at: www.nnpdf.ca. Please feel free to contact us anytime with your ideas, suggestions, or concerns at: nnpdf@nnpdf.org

As the year 2009 comes to a close, the board of directors of the Canadian Chapter wish everyone a blessed Christmas and all the best in 2010.

Tammy Vaughan,
CC-NNPDF Chair



Pictured are Lucy Liegghio and Tammy Vaughan at the First International Meeting of NPD organizations held in Scotland in October 2009.

Global Collaboration

NPD family associations from around the world met in Edinburgh, Scotland, during October to brainstorm. It was Jim Green and his group from the U.K. who had this vision and organized this meeting.

The international meeting was a huge success on so many levels. It was inspiring to meet and hear all the other individuals working toward the same goal throughout the world.

The meeting was extremely well organized. It provided all representatives with the opportunity to get to know each other and to share with everyone their efforts and work to date on public awareness, fundraising and their desire to eradicate NPD. The discussion groups were very informative and everyone

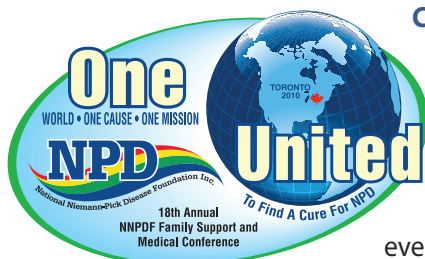


was able to express their interests and to give their opinions on where we wanted to go from here.

The consensus of the group was to form a global NPD alliance. We believe that in order to achieve our common goals more quickly we must combine our efforts, work together and share our ideas and research. Jim Green has agreed to head this International NPD Alliance (INPDA) for the first two years and each country will have a representative participate.

This decision has given us a new lease on our role in Canada and has provided us with a boost of energy and determination to work even harder to achieve our goal. We are excited at what is ahead for all of us. We look forward to working together toward our common goal.

One World. One Cause. One Mission.



CC ~ NNPDF to co-host First International NNPDF conference in Toronto, Ontario Canada.

It is with great excitement and anticipation that we announce that the Canadian Chapter of the NNPDF will act as co-hosts for the 18th Annual NNPDF Family Support and Medical Conference to be held in Toronto, Canada, the weekend of August 5th through the 8th, 2010, at the Delta Chelsea Hotel. It will also be slated as the **First International Niemann-Pick Disease Family Conference** and is sponsored by our sister chapter in the United States ~ the NNPDF. Please refer to the enclosed newsletter for more details pertaining to this event and watch our Web site for additional updates.



Making Our Voices Heard

"The CC-NNPDF ~ Where Success Begins with You!"

CC-NNPDF Fundraising Highlights:

7th Annual Alex and Laura Vaughan Memorial Golf Tournament

Thanks to our many friends, family and the generous businesses and sponsors throughout Canada and the US, the 7th Annual Alex and Laura Vaughan Memorial Golf Tournament was a resounding success.

The tournament is held annually at the Stone Tree Golf Club in Owen Sound in memory of our precious children, Alex and Laura who died from Niemann-Pick Disease Type C2, Alex in 1992 at the age of 4 and Laura in 2001 at the age of 6.

Each year we are literally overwhelmed by the amazing support that we continue to receive. Once again thank you from the bottom of our hearts for your support and charitable contributions to this cause that is so important to us. It is this support, now and in the future, that will ensure that one day we hold a celebration announcing "we have prevailed in our quest for a cure!"

See you June 19, 2010 as we celebrate these precious little lives at our 8th annual tournament.

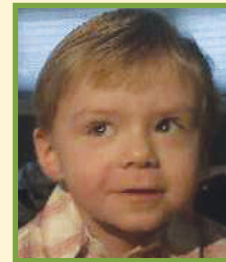
Tammy, Allan and Michael Vaughan



Family & Friends Letter

A Sister's Love ~ Persevere Campaign

In memory of:
Damon Cardinal (NPA)
Edmonton,
Alberta Canada



Family & Friends Letter

In honor of:
Kaiden St. Germain (NPC)
Edmonton, Alberta Canada

Family & Friends Letter 5th Avenue Jewelry Party

In honor of:
Tehyez Minde (NPA)
Hobbema,
Alberta Canada



Life for Luke Foundation In memory of: Luke Liegghio (NPC)

Life for Luke 8th Annual Dinner Gala and Silent Auction In memory of: Luke Liegghio (NPC) Vaughan, Ontario Canada



It was another memorable night! The room looked spectacular, the guests were arriving and the atmosphere was warm and inviting. Family, friends and the community gathered to celebrate Luke Liegghio's life and to support the Life for Luke Foundation's efforts to eradicate Niemann-Pick Disease.

Our family continues to be incredibly grateful to the inspirational and loving fundraising committee who worked incredible hours on end to create an event that was truly a masterpiece!

Thanks to our corporate sponsors and all our individual donors almost everything seen and experienced was completely donated. In spite of a year full of economic strife around the world, the gala, along with other smaller events held throughout the year, we had yet another banner year!

Saturday, March 6th, 2010, family and friends of Luke's family will be uniting for the 9th Annual event to be hosted at the Riviera Parquet Banquet Hall and Conference Centre in Vaughan, Ontario. We hope to see you there!

Lucy, Enio and Vanessa Liegghio



Father Bressani Catholic High School 25th Annual Fashion Show In memory of: Luke Liegghio (NPC) Woodbridge, Ontario



Mom to Mom Sale In memory of: Luke Liegghio (NPC) Woodbridge, Ontario



Please refer to the Canadian Chapter of the NNPDF Web Site for more information and updates on these and other events to be held in support of foundation efforts.

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