



Canadian Chapter  
National Niemann-Pick Disease Foundation  
Tammy Vaughan, Chair  
R.R. #1  
Durham, Ontario N0G-1R0  
519-369-2837  
tammyv@butterball.ca

March 31<sup>st</sup>, 2010

**Dear Family and Friends,**

As I sat down to write the letter for this year's tournament I took a look back at the letters I had sent out over the last 7 years. When I had finished I was pretty proud at what has been accomplished in the Niemann-Pick Disease community here in Canada. The first year of the tournament – which was June of 2003 – we hadn't even considered the formation of the Canadian Chapter of the National Niemann-Pick Disease Foundation. Since that time we have been successful in our quest to have the CCNNPDF recognized as a registered charity in Canada and the best news to date was just announced earlier this month – that news being the approval of the first drug, *Zavesca (miglustat) produced by Actelion Pharmaceuticals*, for the treatment of Niemann-Pick Disease in Canada. This drug is by no means a cure for Niemann-Pick Disease, but it does give some hope, stabilization, but most importantly the gift of time to those affected as we battle on for the elusive cure!

2010 will mark the 18<sup>th</sup> year since we lost our little prince Alex - this year he should have been graduating from University, ready to make his mark in the world. 2010 will also mark the 9<sup>th</sup> year since we lost our little princess Laura - this year Laura would be finishing up her first year of high school. Sitting back and trying to visualize what these two precious children would look like and what their personalities would be like is heart wrenching – that's why the quest for a cure is so important to us – we do not want another family to have wonder what their children would have grown up to be. We do know though that Alex and Laura have made their individual mark on this earth, touching and grabbing the hearts of all that they came into contact with and we are here to honor these lives that were so short lived.

So here we are once again asking for your support as we plan the *8<sup>th</sup> Annual Alex and Laura Vaughan Memorial Golf Tournament to be held Saturday, June 19, 2010, at Stone Tree Golf Course*. Your generosity over the last 7 years has been absolutely awe inspiring and appreciated more than we can tell you – we are hoping for that support once again this year. Your continued involvement through your contribution as a hole sponsor, a gift for the silent auction, a cash donation, or by golfing in the tournament is very much appreciated.

Here's to our quest to eliminate our slogan, *"They have only their childhood to experience a lifetime"*, someday soon we will be celebrating the end of this life-stealing disease.

For the children,

*Allan, Tammy and Michael*

Allan, Tammy and Michael Vaughan

**"SAVE THE DATE"**

**Saturday, June 19<sup>th</sup>, 2010  
Stone Tree Golf Course**

**8<sup>th</sup> Annual Alex and Laura Vaughan  
Memorial Golf Tournament**