



## **The Canadian Chapter of the National Niemann-Pick Disease Foundation**

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I would like to take this opportunity to introduce myself to you as the Chairperson of the Canadian Chapter of the National Niemann Pick Disease Foundation.

My name is Tammy Vaughan and along with my husband Allan and our son Michael we as well as Lucy, Enio and Vanessa Liegghio have made it our mission in life to raise awareness and money to find a cure for Niemann Pick Disease. Our two families have experienced the heart wrenching pain of watching three of our five children struggle and ultimately succumb to this horrific disease. We are doing everything in our power to make sure that we do not have to share this experience with any one else.

In the past five years both our families have worked diligently to creating both awareness for this rare disease and money for research into a cure or treatment for Niemann Pick Disease.

As of January, 2006 the Canadian Government has approved and granted us charity status. This is an extremely important accomplishment. Being a registered charity will benefit our organization in a number of ways. Number one, it will give us the opportunity to distribute income tax receipts for any monies that are contributed to our organization. Other benefits will be the ability to approach Canadian pharmaceutical companies for research into treatments, have municipalities proclaim October "Niemann-Pick Disease" awareness month as is done in the United States and lobby the Canadian Federal Government for any grant monies that they distribute to registered charities.

Together with some dedicated individuals and the assistance of Dr. Joe Clarke, the Head of the Genetic Metabolic Department from the Hospital for Sick Kids we will be able to work more effectively in fulfilling our mission.

In February, 2006 I was invited to attend the National Niemann Pick Disease Foundation's board of directors meeting in St. Louis Missouri. At that time I was voted on as a member of the board and as a representative from Canada.

Starting a Chapter in Canada is very important to us not only for the research and awareness benefits but we feel it is just as important to offer family support to those families that are struggling with the day to day challenges of raising children with this deadly disease. Our hopes are that we may direct families through the proper federal and/or provincial government channels so that all families can benefit 100% from any financial aid that is available, be a sounding board for any questions that may arise from individual families, and give

suggestions or first hand accounts of experiences that any one of us has had.

We want to be able to assist all families with the information needed to meet as many of their growing needs as necessary. We know first hand, how difficult it is to deal with this disease on a day-to-day basis and how alone one feels when dealing with something like this particularly as this disease is so rare and we feel the more support a family has financially, physically and emotionally the better. We know how comforting it is to know there are others “out there” dealing with the same horrible situation and that we can lean on them for strength and support.

We are very interested in knowing about all of the families in Canada that are dealing with Niemann-Pick Disease so that we may offer any help that we can. Please get in touch with us to let us know that you are out there! Even if you don't require any assistance at this point it would be great to have you on our mailing list so that we may send you newsletters etc.

Tammy Vaughan  
Chairperson  
519-369-2837

Lucy Liegghio  
Vice-Chair  
905-850-1870  
[casaliegghio@sympatico.ca](mailto:casaliegghio@sympatico.ca)