



CANADIAN CHAPTER OF THE NATIONAL
NIEMANN-PICK
DISEASE FOUNDATION INC.

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Celebrate Every Moment!

Dear Friends of the Canadian Chapter of the National Niemann-Pick Disease Foundation,

The Canadian Chapter of the National Niemann-Pick Disease Foundation (CCNNPDF) is wrapping up what has been a very busy year. Families around Canada have been holding awareness and fundraising events from the simple to the complex – selling “Persevere” wristbands, sending letters to families and friends, asking government officials to sign proclamations, hosting golf outings, producing awareness videos, developing Facebook pages on the Web, and making presentations to community groups, just to name a few. (Visit www.nnpdf.ca for photos and recaps of these fun family events, and for notices of upcoming events.)

During 2010, the CCNNPDF developed new brochures, launched a new Web site, and distributed posters to educate about the devastating effects Niemann-Pick Disease (NPD) and to raise funds for NPD research. Further, the CCNNPDF served as co-host for the 18th Annual NNPDF Family Support and Medical Conference in August, the first international conference of its kind. We thank you for your generous support as donors, volunteers, and loving friends throughout the year, and we wish you all the best for 2011!

Though a diagnosis of Niemann-Pick Disease is nothing short of soul-shattering, we are writing to you today with the inspiring story of a young Quebec family, with a “tiny but mighty” baby girl who has spent her entire life fighting and, so far, beating the odds.



Sixteen-month-old Monica Taillefer has Niemann-Pick Disease Type C (NPC), a rare and deadly genetic disease which promises to cut her precious life short.

Though they received this heartbreaking diagnosis when their daughter was just two months old, Monica’s parents, Simon and Heather (Patenaude) Taillefer, live every day to the fullest, celebrating each and every moment they have together with their special little “Princess.”

Simon and Heather recognize each new day as a cherished gift, focusing on the time they do have with their only child, even knowing full well that in the end, NPC will likely steal their beloved baby from their arms.

Their determination and positive attitude embody our motto of “Persevere.”



With the love of parents such as these, it's no wonder Monica is such a tough little fighter. Her doctors, seeing the ravages of NPC on her small body, have told Simon and Heather to prepare themselves for the worst; however, Monica has beaten everyone's expectations and has even grown stronger after several close brushes with death!

In spite of her difficulties, Monica is a "smiling machine" who babbles happily and loves to get dolled up in her princess dresses. Thanks to a generous gift the family recently enjoyed a trip to Disney World, and Monica "lit up" with joy at the interactions with her favorites -- the Disney princesses, Mickey Mouse, and Piglet.

"Princess Monica," as we are fond of calling her, loves her bath time play, and her rides in the stroller or car. She gets so excited when her parents stir up her baby cereal, and, like many little ones her age, Monica is truly a Cookie Monster!

The Taillefer family celebrates the 5th of every month as a birthday, complete with decorated cakes lovingly made by mom, Heather. This family, faced with the heartbreaking knowledge that Monica's days are numbered, chooses to celebrate the miracle of each new month and each milestone of this precious baby's life.

When you know your time with your child is limited, you worry less about spoiling her and more about lavishing her with love and attention while you can. If you are like Heather and Simon, you treasure every moment, every giggle, every cuddle, every kiss, and make memories you will hold forever close in your heart.



Simon and Heather write...

When Monica was diagnosed back in October 2009, we were told we only had months due to how severely affected her liver was. We didn't think we'd get to celebrate a first birthday, or many other firsts, or see our baby without jaundice.

In January 2010, the doctors said we only had weeks left, then in March 2010, Monica fell ill with the flu and we didn't think she would make it through the night.

But that night she demonstrated her incredible perseverance and strength. She woke up being herself again, wanting the arms of her mommy and daddy.

Her jaundice eventually went away and then came her big day – her first birthday – which she celebrated **twice**: once with 175 friends and family, and then again on her actual birthday, August 5th, as a surprise at the NNPDF/CCNNPDF Toronto Family Conference amongst our new NPD family.

Thank you for your generous support of the CCNNPDF and essential research that will find the treatments and cure we so desperately need!

Simon and Heather, Proud Parents of a Princess

For more photos from Monica's monthly birthdays, visit our special Web page at www.nnpdf.ca/MonicaTaillefer.html .

Please see page 7 of the enclosed NNPDF newsletter for more information about the activities of the CCNNPDF.

The Canadian Chapter of the National Niemann-Pick Disease Foundation (CCNNPDF) provides support and hope to families such as Monica's, and we need your help...

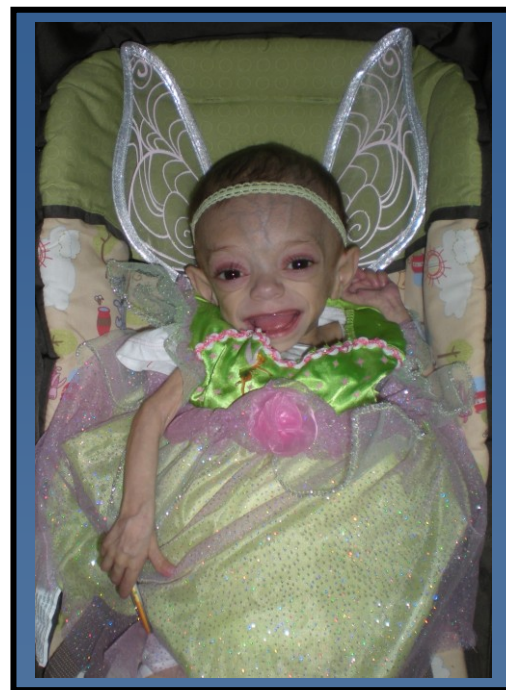
The CCNNPDF was founded in 2005 as a sister chapter to the NNPDF (U.S.) to provide support services to families in Canada affected by Niemann-Pick Disease and to raise funds for research into NPD. Our families benefit from receiving accurate, up-to-date information, referrals and resources, and the foundation provides a nurturing network of support and guidance.

Money raised through the CCNNPDF is invested in Niemann-Pick Disease research through the NNPDF's research program with guidance from the NNPDF's Scientific Advisory Board (SAB), Board of Directors, and Research Committee.

The SAB members, based on their expertise in the disease, provide advice about care, research trials and medications. Further, the SAB reviews research funding applications and makes recommendations on which projects to fund.

This partnership helps eliminate redundancy and maximizes the impact of research dollars. (Tammy Vaughan, chair of the CCNNPDF, serves as secretary of the NNPDF board, and is on the NNPDF's Research Committee.)

To date, the combined efforts of the NNPDF/CCNNPDF have raised over \$4.8 million for NPD research, and significant progress is being made. The genes responsible for NPD have been identified, and experimental drugs are being evaluated and used with some positive results. We need to maintain and increase this momentum in our race against time for children such as precious Baby Monica.



Baby Monica enjoying a magical day as Tinkerbell.



**Please, will you join us as we
PERSEVERE in our Quest for a Cure?**

Supporting the CCNNPDF is a powerful way to fight back against Niemann-Pick Disease as we help families and drive research which will unlock the mysteries of NPD.

The very lives of children such as sweet Monica depend on it, and we are immensely grateful for your generosity and support in this battle!

Thank you, and Happy Holidays to you and yours!

Sincerely,

Tammy Vaughan

CCNNPDF Board Chair