



National Niemann-Pick Disease Foundation, Inc.
P.O. Box 49; 401 Madison Ave., Suite B
Fort Atkinson, WI 53538-0049
Tele: 920-563-0930; Fax: 920-563-0931
Web: www.nnpdf.org ; Email: nnpdf@nnpdf.org



Celebrate Every Moment!

Dear Friends of the National Niemann-Pick Disease Foundation,

Here at the National Niemann-Pick Disease Foundation we are wrapping up what has been a very busy **9th Annual October Niemann-Pick Disease Awareness Month**. Families around the U.S. and 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, and making presentations to community groups, just to name a few. The NNPDF also hosted a nationwide online auction fundraiser and ran a special “10-10-10 Awareness Campaign” to spread information about Niemann-Pick Disease (NPD) and the devastating effects it has on families. During the month of October our family membership pulled out all the stops to educate the public and raise funds for NPD research and family support services.

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 family in Canada, with a “tiny but mighty” baby girl who has spent her entire life fighting and, so far, beating the odds.

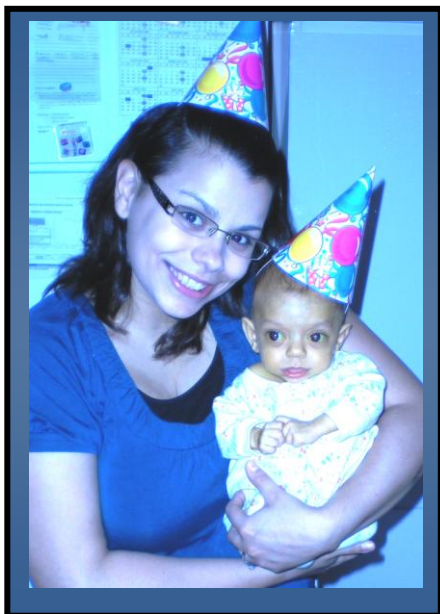


Fourteen-month-old Monica Taillefer has Niemann-Pick Disease Type C (NPC), a rare and deadly genetic disease which promises to cut her precious life short. NPC has, as yet, no approved treatment or cure.

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 the NNPDF 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 NNPfD Toronto Family Conference amongst our new NPfD family.

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

Simon and Heather, Proud Parents of a Princess

*The National Niemann-Pick Disease
Foundation (NNPDF) provides
support and hope to families such as Monica's,
and we need your help...*

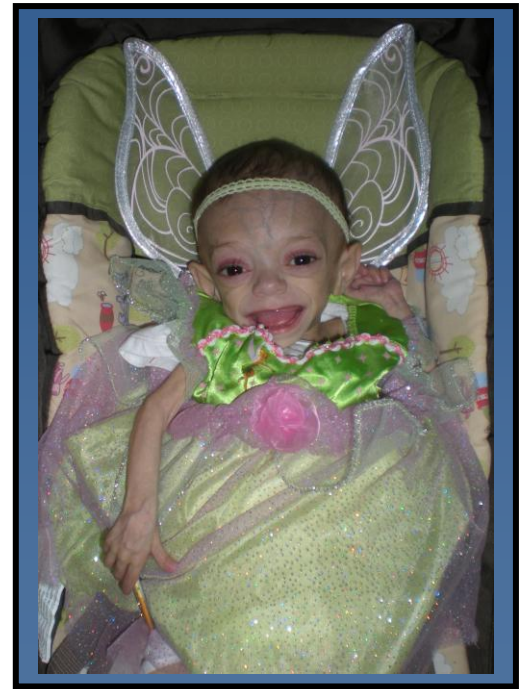
The NNPDF was founded in 1992 to provide support services to all those affected by Niemann-Pick Disease and to raise funds for research into NPD.

Our families benefit from the NNPDF's accurate, up-to-date information, referrals and resources, and the foundation provides a nurturing network of support and guidance.

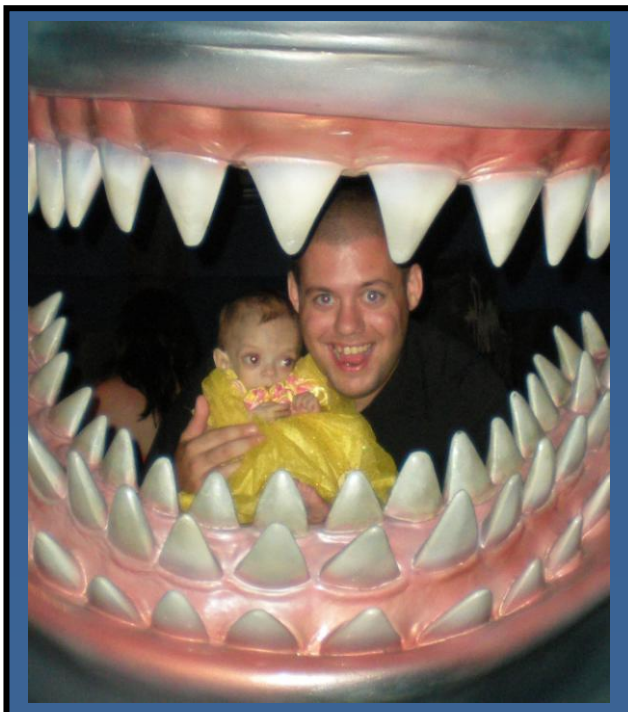
The NNPDF's Scientific Advisory Board (SAB) members, based on their expertise in the disease, provide advice about medical care, clinical research trials and experimental medications. Further, the SAB reviews research funding applications and makes recommendations on which projects to fund.

The NNPDF provides services to families throughout the U.S., and through an arrangement with the Canadian Chapter of the NNPDF (CCNNPDF), to families in Canada. The NNPDF also serves as a primary information resource for those with NPD around the world.

To date, the NNPDF has 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 NNPDF 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!

Sincerely,

Karen R. Quandt, R.N., M.S.N.

NNPDF Board Chair

P.S. Please see the other side of this page for one more way you can support the NNPDF through the purchase of 2011 wall calendars. Thank you!