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“ ‘I’ll bet you wish your daughter had cancer, don’t you?’ a doctor asked me once. Of course, it was true.”

“Certainly, a diagnosis of cancer is devastating for an individual and their family but with the billions of dollars poured into cancer research there are now many treatment options and therapies which offer HOPE to families affected by this diagnosis. Tragically, this isn’t the case with Niemann-Pick Disease.” These are the words of Lorna Tyrrell, mother of little Naomi Tyrrell, the baby of the family, who just turned six years old this August. Naomi suffers from Niemann-Pick Disease Type C (NPC), a disease which will, inevitably, take sweet Naomi’s life.

The day of Naomi’s diagnosis was “...the worst day of my life,” Lorna recalls, her voice shaking even now, four years later. “They said there was no medicine. There’s nothing we can do. They said to take our baby home and act like nothing had gone wrong. What parent today, with all of our advanced research and medical technologies, could ever fathom they would hear those words from their physician...no treatment...no cure...take your child home and love her?”

Of course, pretending nothing is wrong is impossible when you learn that Niemann-Pick Disease is going to steal your child from you, bit-by-bit. Niemann-Pick Disease (NPD) is a lysosomal storage disease, causing accumulation of fats in the cells of the liver, spleen and brain. When brain cell function is blocked, the child loses coordination, stumbles, falls, and eventually requires a wheelchair, hospital bed, and other adaptive equipment. Over time, more dire symptoms develop, including the loss of the ability to speak and swallow, and eventually even to breathe. Health declines until, ultimately, NPD claims another life.

The Journey to a Diagnosis

Naomi was a smiling two-month-old baby when it was discovered she had an enlarged liver and spleen and doctors began testing for a list of possible causes. For 20 frustrating months, the Tyrrells took their baby from one specialist to the next. Lorna, sensing it was something serious, approached each new day and doctor’s appointment with a growing sense of fear and apprehension - all while working to keep up a semblance of family life for husband, Leon, and daughters Olivia, Rebekah, Mary, and an ill baby.



A “New Normal”



After the initial shock, grief and depression, life as the Tyrrell family knew it was forever changed. They adapted to a “new normal” which included the battle for Naomi’s life. Lorna and her family made the decision to stand up and fight back. They, like many families hit with Niemann-Pick Disease, began to work feverishly to raise funds for research, but they found it wasn’t easy.

“When I would try to raise support for the disease that was killing my daughter I was told that it didn’t affect enough people. She wasn’t as ‘important’ as someone with, say, multiple sclerosis, muscular dystrophy, or cerebral palsy.” Lorna continues, “This little-known disease (NPD) didn’t bring the attention and interest which garners the support and funding dollars necessary for research. Suddenly, I became keenly aware of the multitudes of yellow wristbands, pink ribbons and national walk-fests promoting awareness and raising funds for other worthy causes.”

Persevere ~ Persist. Quest. Cure.

To raise awareness of NPD and the challenges faced by affected families, Lorna eventually hatched the “Persevere” campaign. All those affected by NPD “hope” for treatments and a cure, but, as Lorna notes, “hope” implies sitting back and waiting for something good to happen. Rather, she chose “PERSEVERE” as the message and motto, because, as she knows all too well, there will be disappointments, setbacks and losses during a family’s journey through Niemann-Pick Disease, but in time....*a cure for NPD WILL be found, if we PERSEVERE in our Quest for a Cure.*

Lorna’s burgeoning Persevere campaign started with an order of the popular rubber sport wristbands embossed with the word Persevere, and quickly grew into a complete line of Persevere t-shirts, sweatshirts, water bottles, etc. “Persevere” is a message meaningful not just to families affected by NPD, but to anyone going through illness, life struggles and hardships. Athletes have made a strong connection and expressed an appreciation for the motto, saying they find it motivating as they train and push through challenging events. As a result, the Persevere message has caught on and been carried far and wide, raising awareness and invaluable dollars for research and NNPDF family support services, including education, advocacy and referrals.

October Designated National Niemann-Pick Disease Awareness Month

October 2009 has been named the 8th Annual National Niemann-Pick Disease Awareness Month – a time to spread the word about this rare disease, the devastation it causes families, and raise funds to advance research which has already identified the gene responsible for NPD, and will in time, find treatments and a cure.



Scientific Research is the Key

Unfortunately, these treatments may not come in time to save little Naomi, who has now lost the ability to swallow, is suffering seizures, and is confined to her wheelchair or bed. Nevertheless, the scientists who have dedicated their careers to NPD research press on, striving for the day they will joyfully announce that our persistence has paid off – that no more families will have to suffer the pain and loss of NPD.



October, as National Niemann-Pick Disease Awareness Month, is a time when we turn to you, our donors and supporters, and ask you to help us in our Quest for a Cure. In today's economy, we all must consider carefully how we allocate our charitable dollars. Your gift will fund essential research and sustain support services for families addressing the challenges of NPD. Any amount will be appreciated and will help us attain our goal of a cure for Niemann-Pick Disease.

Please say you'll help today.

Refer to our Web site or feel free to contact us for more information regarding our services and resources for families.

www.nnpdf.org

You can be assured your gift to the NNPDF will be deeply appreciated and faithfully stewarded to bring the greatest benefit to families such as the Tyrrells, who are struggling with NPD.

*October 2009 named
National Niemann-Pick Disease
Awareness Month*

NEW For 2009~NNPDF Online Auction

Isn't it better to give... AND to receive ... AND...
... support the work of the NNPDF?

▶ That's what the National Niemann-Pick Disease Foundation believes, which is why we're extending you and your family an invitation to join in on the fun! Our first NNPDF Online Auction is slated to open on October 1st, 2009. **Browse to:**

www.nnpdf.cmarket.com

▶ Place your bids, refer your friends, make a donation, or windowshop our catalog. You never know what you may find....

See back of page for hot auction items ~ deals & steals!



Thank you in advance for your help in our quest for a cure!

The NNPDF is a non-profit 501(c)(3). Federal tax exempt id #: 35-1844264. Your donations are fully tax-deductible.

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... support the work of the NNPFD?

www.nnpdf.cmarket.com

Starting on October 1, 2009, the National Niemann-Pick Disease Foundation (NNPDF) will be hosting an online auction featuring a number of fun and unique items in support of our organization and in celebration of October 2009 as the 8th Annual National Niemann-Pick Disease Awareness Month.

NPD families and community support teams will be hosting awareness and educational events, as well as local fundraisers across the nation and in Canada ~ all in honor of their loved ones diagnosed with Niemann-Pick Disease and in support of the NNPFD.

The NNPFD is kicking off a new way that our supporters can become involved during October as NPD Awareness Month ~ an Online Auction! Won't you consider joining in on the fun by bidding on an auction item beginning October 1st and ending October 31st, 2009 ~ in support of the NNPFD and our families?

Here is just a sampling of the items and products available..... **www.nnpdf.cmarket.com**

Trips ~

Key West, Florida: Hyatt Key West Resort and Marina; 4 Days/3 Nights

Cancun Mexico: Beach Extravaganza; 5 Days/4 Nights

Orlando, Florida: Enchanted Disney World Vacation; 2 Adults/2Children; 7 Days/6 Nights

Las Vegas, Nevada: Bed & Breakfast Getaway & Tour

Bingham, Maine: Whitewater Rafting in "the Forks"

Savannah, Georgia: Golf Package for Two; 6 Nights



Autographed Memorabilia ~

Coach and Congressman Tom Osborne Football

Jim Lambright Football - University of Washington

Bobby Orr Framed & Signed Photo "The Goal"

Carlton Fish Framed & Signed Photo "1975 Homerun"

Jon Lester Framed & Signed "8X10" Photograph

John F. Kennedy Limited Edition "Inauguration Speech"

Michael Phelps Framed & Signed Photo Sports Illustrated



Tickets ~

Super Bowl XLIV Mania - Tickets & Memorabilia, Miami, Florida

Gift Certificates ~

PinkCalyx Luxury Jewelry - uniquely designed jewelry pieces

MySpaShop - Holistic beauty, fitness, health & skin care items

Dancing Bear Baking Company - Brownie, Cake & Cookie Tower