



## NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Four

### Your Child: Expectations vs Diagnosis

BY JESSICA LINDQVIST, MOM TO HAMPUS, JULIA, AND ISABELLA

Finding out all three of our children have Juvenile GM1 left us heartbroken. Initially, we kept asking ourselves, what could we have done to deserve this?

Everyone has their own individual reaction to dealing with trauma. Niclas and I were so tired and every night we fell asleep easier than ever, slept heavily throughout the night, and had a hard time waking up in the morning. Each morning it felt as though I was waking up into a nightmare that I just couldn't get away from, no matter what I tried. It felt like whatever purpose we had in our lives before, had just disappeared.

Hampus was the first to be diagnosed. Everything we imagined he would do, like jumping and running around, riding a bike, starting soccer practice, playing with friends, was gone. Every expectation we had about who our little Hampus would grow up to be, all of that just vanished right in front of us.

We would see how other children his age played together and were developing over time. We saw all the milestones he was supposed to reach. We felt excluded, and I felt so alone.

I started to imagine everything that would happen to him as his disease progresses. I started taking walks every day to clear my jumbled thoughts. I cried in the shower to myself every day, just so the kids wouldn't see their mother cry.

During a visit with our neurologist, we shared our worries about Julia and Isabella and decided to have them tested also. Six months after Hampus' diagnosis, we also received theirs. Both of our girls are also affected by GM1.

I couldn't believe it was true. I cursed out loud; then it was like I couldn't breathe. It was one of the worst moments of my life. Before we got the girls' diagnosis, we had some solace that although Hampus would eventually leave us, we would still have Julia and Isabella. But now, we will be left without any children - and we will have to watch them lose each other, one

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"Hope can be a powerful force"

- Laini Taylor

### Resources:

#### Benton's Family Assistance Fund

"The purpose of this fund is to provide financial assistance to families and affected individuals to purchase items and services that promote comfort, ease, and quality of life for their loved ones." Learn more and apply for assistance [here](#).

#### Welcome to Holland

[Welcome to Holland](#) is a poem written by a rare parent and addresses the loss of expectations one may feel when faced with the diagnosis of their child. While all the feelings of grief and sadness you may be feeling are absolutely valid, and deserve to be acknowledged, the idea behind this poem is to encourage the reader to still find meaning and beauty in the journey they're now on.

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by one. This is still our biggest fear, to one day see them leave each other, and for one of them to be the last one left.

Back then I didn't know how to carry on. How do you live with three death sentences? The grief is indescribable. It's like a scream, like a force of nature that aches in the deepest corner of your soul. I'm not even sure how it happened, but time passed and we kept putting one foot in front of the other. We eventually decided we needed to get in contact with other families in similar situations. We reached out to the communities we had found online and suddenly, we didn't feel so alone anymore.

In spring 2019, we attended our first NTSAD conference in Raleigh, NC. The conference was amazing, informative and inspiring. We did meet a lot of amazing people. We found in them an understanding. A connection to, and reprieve from our grief. Grief is still a part of our everyday lives. It's always in the background; behind every smile, every laugh and every tear. Some days it's overwhelming. Sometimes, I can only take an hour at a time, and sometimes I'm counting the minutes.

Despite all the stress and anxiety that we have been through these last years, we still have hope; hope that we have a chance for a future. We still have so much laughter and happiness in our lives, mixed with a lot of grief. Hampus, Julia and Isabella have taught me so much about myself, about relationships and about love.

## The Fight of Our Lives

BY NIKKI MCINTOSH, RAREMAMAS.COM

On her [Rare Mamas blog](#), Nikki McIntosh explains to readers that she, "probably much like you, didn't see the role of rare disease mom coming." She writes to "empower rare disease moms to shift from distress to prowess". In *The Fight of Our Lives* she discusses feeling exhausted, vulnerable, scattered and shaken while giving encouragement for other rare parents in their journey.

She continues, "I know the soul ache and heartbreak that comes with a child's rare-disease diagnosis, and I want no other mother to brave this journey alone. My mission is to provide the type of help and hope that I so desperately craved when my son was newly diagnosed. I am compelled to help other mothers feel empowered to support their exceptional children."

As she says in her blog post, "Let me help you identify why you are exhausted, vulnerable, scattered, and shaken: We are in the fight of our lives." You can view Nikki's article, *The Fight of Our Lives*, [here](#).

"Hope means so much more [when] it's all you have." - Nicole Vallier