



NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Three

The Value of Connection

BY RYAN MILLER, JAMES' DAD

If you're like me, you probably spend far too much time scrolling on your phone and perusing social media apps. But often when it may seem that I'm wasting time on my phone, I am actually connecting with other NTSAD families.

I am certain that if it hadn't been for my virtual friends I wouldn't have made it through the last three years of my life.

Dads often have a tough role to fill in navigating the unknown that is the life of a special needs child, and then, the loss of our child. Without the love, support, and guidance of a few NTSAD families, it would have been very difficult for me to maintain the courage to continue to advocate and care for my son.

NTSAD has created an amazing network of information, knowledge, and support to help us all navigate life as a rare disease parent. I urge you to take full advantage of the resources available. Everyone processes these diagnoses at their own pace, and as soon as you are ready to discuss anything regarding these diseases, please know there is a whole community of people who have walked in your shoes, and are more than prepared to assist in any way possible, myself included! Whether it be a phone call, text message, or a Facebook friend request, NTSAD will always be there for you.

What I Wish I Had Known

BY NATE CHAPMAN, OLLY BELLE'S DAD

There are lots of things I wish I had known when my daughter, Olly Belle, was diagnosed with Tay-Sachs Disease. Like, what in the world is Tay-Sachs Disease? It turns out that was the easy thing, the doctors would explain that. Here are the things I wish I had known then, things that others might not tell you, broken down into four game-changing categories.

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"Hope can be a powerful force."

- Laini Taylor

Resources:

Obtaining a Medicaid Waiver

Medicaid Waivers help provide services for your medically fragile child regardless of income or primary insurance. Follow [this link](#) to help find resources and information about obtaining a Medicaid Waiver in your state.

Emma's Fund for Families

Emma's Fund for Families is established to enable families to have memory making opportunities in honor of Emma. To apply for a memory making grant for your family, please click [here](#).

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Get a Support Team:

I can't stress this one enough. You need people in your life that will help, not just say they will help, but actually help. We found this in our family and in our church. We would have been lost without them. When people say, "let me know if I can help", take them up on their offer. If your yard needs to be mowed, say something, if your house needs to be cleaned, or you need a meal, ask. You would be amazed at what people will actually do for you and how much stress is relieved. Another aspect of this is having people to talk to. Yes people, plural. People who will listen and not pity you, but hear you and support you in that moment. It's important to surround yourself with people who aren't going to try and be an expert, people who won't try to fix what's unfixable. The most supportive people are those who will help you make decisions and process your feelings. This may not even be family members. Remember they are processing all of this, too.

Apply for Assistance Now:

Seriously, do it now. It takes time to get approved and you will want everything in place so you can get the help you need, when you need it. The process varies by state, and even by county. I recommend starting with a county social worker to begin this process. Talk with the social worker at the hospital you will likely be visiting. Ask them what resources are available to families, such as parking and meals as those expenses add up quickly and quietly.

Make Memories:

When Olly was diagnosed we made the decision to go to Disney World and Daytona Beach, FL. Was it harder traveling with her and her supplies? It was, but if I had to do it over again the only thing I would change is that we would have stayed longer. Don't wait because you don't know what next year, month, week or even tomorrow will bring. We almost waited too long to go. We originally talked about going three months later than we did. Had we delayed our travel, we never would have taken the trip, and that I would have regretted.

You Are Your Child's Best Advocate:

Your medical team is there to guide you in making the best health care decisions for your child, not to make them for you. You know your child better than anyone else in the world. Trust your gut. If something seems off, tell the doctors. If they don't listen, tell a different doctor. Personally, this one was hard. We were overwhelmed dealing with a disease we had never heard of. How do we take charge? It is important to find a great team of doctors, nurses and other medical professionals to help you through this process. At the end of the day, you know what your goals are and what is important to you, so trust yourself. Let me close with this: you are awesome and you are doing great. This isn't an easy journey, and one no parent would choose, but it is the one we are on. Know that even if we never meet, I am standing with you.

"A dream is the bearer of a new possibility, the enlarged horizon, the great hope." - Howard Thurman