



**Parent to Parent support offers families the opportunity to not be alone.**

**To find answers and support from others who have been**



## The Importance of Parent to Parent

My name is Jennifer and my husband and I are the proud parents of three wonderful little boys, ages 5, 4 and 2. Our oldest son, Reier, has the diagnosis of spastic quadriplegic cerebral palsy and epilepsy.

Reier was born 6 1/2 weeks early, but after a three-week hospital stay in the special care nursery we went home with what we thought was a healthy little boy. When Reier was 5 months old we took him to the pediatrician due to continued issues with constipation. It was at that point this journey really began for us.

From the age of 5 months to 10 months, we were told there wasn't a diagnosis they could give us. His eyes were still crossing and his MRI revealed a somewhat abnormal picture. It was something we would need to wait and see what happened with his development. The local school district's birth-to-three program began coming to our home weekly and a private physical therapist came to our home every other week to assist Reier in developing his skills.

Each time a therapist came to our home, we tried to prod them for answers. Initially, it was more concern about what to call this thing, but after several months of seeing our baby not develop as other typical children, we wanted to know more specifics. Will he walk? Will he talk? How will this impact his life? There were

no concrete answers.

We were finally given the label of cerebral palsy at 10 months of age. With the diagnosis in hand, we began searching the internet for answers. Unfortunately, there were none. The degrees and areas of impact can vary dramatically for cerebral palsy and there was no known "cure".

The first couple of years were the most difficult. There were the feelings of guilt, (could we have done something differently), the feelings of fear, (I don't know what this means. How will it impact Reier and our family?), and the feelings of loneliness (No one understands this. We don't know anyone in this situation.)

We had never dealt with disabilities in our families. Friends & family would tell us, "It will be okay", "God only gives you what you can handle", "Don't worry", "Special babies are given to special people", but they had no idea what this really meant. It was just something to say that made them feel better. Some were fearful, some were concerned, and some just stopped coming around. A few jumped in to help.

Having a child with special needs, there are many situations that happen I don't think parents of typical kids

understand. From the simple things, such as increased appointments, paperwork, and the need to always plan and prepare for any adventures outside of the home. To more complex issues, such as the increased physical demands to care for your child, the emotional toll of ongoing surgeries, missed milestones, and dealing with the stares in the community.

The first time I felt less scared in this new world of special needs was when our son's physical therapist connected us with another family who had a child with a similar diagnosis and demographics. When I first spoke with her, it was so reassuring to hear her story and to share similar experiences. I finally felt like someone understood me.

Parent to Parent support offers families the opportunity to not be alone. To find answers and support from others who have been there ahead of them.

There is empathy but not sympathy.

There is understanding but not pity.

Parental support offers less judgment, less fear, and more comprehension. It offers parents a place to belong in an unusual circumstance.