



Jennifer and Meghan all dressed up!



How infectious!

Dear Epilepsy Parents,

My name is Jennifer Bertram a mom of a child with Epilepsy. This is my daughter Meghan and is the reason for how I have come to be part of this care notebook. I was asked to be part of a project to give my ideas as a parent to improve care for children with Epilepsy. I was among 8 other states that had a parent on their team. It was very flattering to all of us to be part of improvement of how our children are treated by Epilepsy specialists. What we found is that all of the states were encountering some of the same problems and that parents wanted many of the same things. This is one of many improvements that we have implemented and we hope that it will help you manage your child with Epilepsy.

It has been a journey of 8 years this month that we got our initial diagnosis at Children's Hospital of Wisconsin. I remember it like it was yesterday when the doctor told us she had Epilepsy. So many thoughts were going through our head. What does this mean for the future and how am I going to do this? You don't learn or expect this when you are a parent.

I know if I would had ways in the very beginning to talk with other parents and put my thoughts in one place it would have helped me stay organized and allow me to make clearer decisions throughout the years. This will not change your diagnosis but it will help you to get the details to your professionals and it will help you cope.

Remember you are the center of your child's care and your child's voice on your team. Whether it be the school, community groups, Pediatrician or your Epileptologist, you are your child's advocate and know your child the best. Allow your professionals to guide you to make the best decisions for your child and your family. I know with this care notebook it will help you to keep your information organized so you can communicate better with all your child's professionals.

Sincerely

Jennifer Bertram