

Submitter: Denise Guedon
On Behalf Of: Gabrielle Guedon
Committee: House Committee On Behavioral Health and Health Care
Measure, Appointment or Topic: HB2457

Dear Committee Members,

I am Denise Guedon, I am the parent of a daughter born with a rare metabolic disorder. I am happy to hear about and support the development of this advisory committee. My daughter Gabrielle Guedon was born critically ill and not expected to live through her childhood due to the rare genetic condition she was born with.

I'm sure you can imagine as a parent what it was like to be handed your newborn and given such news. To expect she will experience chronic illness, a slow deterioration of her central nervous system, and unlikely to live more than a few years. The prognosis was very grim at the time. I was devastated beyond words. I desperately needed some kind of support and communication with another parent that had a child with the same diagnosis. Imagine then being told that there were no other people with this condition in Oregon. In fact there weren't but a handful in the whole United States.

I eventually found NORD (National Organization for Rare Disorders). They tried to help me find other families but they were located in England. I wanted information about medical trials and as much information as I could get about her condition. There was very little available in the US to help. Other countries seemed way ahead of us in this realm. I say that because I started contacting people in other countries. There are a lot of support groups, fund raisers, and education for parents in the US if your child has a more commonly known and diagnosed condition, but if you're facing a rare condition there is little to nothing out here in the US. Hopefully this committee can start to make some change in this respect.

My little girl that wasn't suppose to live more than a few years is 35 years old now. As a very young child she voluntarily participated in a number of experimental medical trials that involved uncomfortable and invasive procedures. She said she wanted to do so, so that she could help other kids not be sick like her. She was so brave and strong, as she continues to be to this day, Some of those trials resulted in new information about medications and dosing that have helped to understand her condition better and establish better care for others with the condition.

She is an incredible human being . She lives with a disability but contues to fight for others living with disabilites as the executive director of Oregon Self Advocacy Colation. She submitted her own testimony as well. This bill could give a voice to,

and better understanding for people like my daughter, as well as support to parents and loved ones of those with rare conditions. It's a hard and lonely road.

Sincerely,

Denise Guedon