

Rep. Dittrich: Giving voice to rare disease in WI - you are not alone

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Twenty-two years ago my husband and I learned at birth that one of our children had a rare genetic condition. We were shocked at this rare disease diagnosis – overwhelmed with sadness, helplessness in what this would mean for our child's life, our family's, the treatments and care, costs and so much more. For families who have faced this same reality, they know that crushing feeling filled with tears and desperation. We felt alone and afraid. It was heartbreaking. But in the weeks, months and now years since, we received help and direction. It has never been easy, and the struggles are constant, but our family learned something. Through God and our constant faith, all things are possible. We also found the statewide and national community of those battling rare diseases is incredibly supportive, but also needs help in making their voices heard. That's why on February 28th, I am joining other rare disease families in Wisconsin, and a supportive legislature and Governor, to declare it 2023 Rare Disease Awareness Day.

We are hoping on this day, we can reflect on the reality of the impact rare diseases have on families and individuals around our state and nation. Did you know that up to 30 million people are impacted with diseases and conditions that are chronic and debilitating and classified as rare? These brave individuals are negatively impacted daily by upwards of 7,000 rare diseases.

Thankfully there are more than 800 drugs and biologics that are FDA approved to help, but millions of patients are remain suffering without FDA approved medication. And it doesn't stop there. Individuals and families affected by rare diseases often experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to treatments or ancillary services. Rare disease efforts to raise money for research are also difficult. We've all heard about cystic fibrosis, spina bifida, muscular dystrophy or sickle cell disease, but that leaves

thousands of others in the shadows that still need public and private investment in research for medications and treatment to live their lives.

Another part of rare disease awareness is more personal. It's about kindness, compassion and respecting someone living with a rare disease. Please know the person you are seeing did not choose this way of life, but rather, they are living it in the best way they can. They are deeply loved and helped by those around them. They don't want your pity, and while you may never know their true struggle, they do want your respect. Over the years our family and many others in this community found our children to be more marginalized than included with other children. Parents, families, friends and other advocates have helped to change that, but more still needs to be done.

As for my child and our family, we have persevered and found strength in our faith. It is hard and remains a daily challenge, but knowing you are not the only one impacted by rare disease gives all of us hope and inspiration.