

Dear chair Noose and committee members

Hello, I am Gabrielle Guedon executive Director the Oregon self advocacy coalition and was born with a rare disease. The situation I have is called Glutathione synthesis deficiency . Only 70 people worldwide has survived this condition that are alive right now. It impacts my central nervous system and create acidosis every day of my life . I'm hemolytic anemia and I have chronic infections that can put me into medical crisis on a regular basis. I have difficulty focusing and processing information due to the impact. My condition has on my brain. It makes me weak, and it makes it harder for me to live my life on a daily basis without support which are very hard to find and who, and who truly understand my needs instead of assuming I should be doing more instead of truly understanding what this condition truly does to my body on a regular . Throughout the years of my life, I've experienced a lot of misunderstanding behind my disease and how it affects my daily life. Many community members don't understand the difficulty that people with rare diseases and medical conditions face on a regular basis.. we have many hidden disabilities, medical conditions, and other things that affect our daily life and that's on top of normal human life experience. We are so little in numbers throughout the state that we are a lot of times are not acknowledged for the needs we have and I feel that this advisory committee is needed to give us equal care and more opportunity in healthcare. Our bodies might be different than other people, but what we're capable of with the correct support can change our lives and can change the expectancy of our life. we deserve to have the medical supports, and a team of people advising in the true needs of people with rare diseases. Thank you for considering bill HB 2475. It will change lives and give hope back individuals who experience rare disease and their families. We are in this together!

Thank you

Gabrielle Guedon

Advocate, community partner, Ally, friend