

April 16, 2025

### **Continued Support for (RDAC) Bill H.46 in Vermont**

Good morning and thank you so much for the invitation and opportunity to be here again today. My name is Sarah Elliott, and I am a constituent from Glover, VT. I appreciate your time to talk more about the establishment of the Rare Disease Advisory Council, bill H.46, and what it means for patients like myself.

When I was here last, I stated that dwarfism- the rare disorder I have-is not something to be cured or fixed, but that treatments are necessary in many cases. There currently are some medical interventions- growth hormone therapy and surgical procedures, that can influence growth in individuals with dwarfism, if the family chooses that as an option. There are people who advocate on both sides of this- meaning some are for treatments, which can reduce certain medical complications that can occur immediately in childhood or later on in adulthood, and some believe it is unnecessary, or for cosmetic purpose and treating is taking away from self-acceptance and the bigger issues like inaccessibility of spaces, and society's view- including discrimination against individuals with dwarfism. Either way, quality information should be available for anyone who wants it.

I was born with a milder form of diastrophic dysplasia and was not correctly diagnosed until adulthood. Once again- children with dwarfism are often born to average height parents, meaning you might have no family history and then the gene presents itself. Often skeletal dysplasia is detected in utero, but sometimes it is not present until birth or even later into childhood. There is nothing for me personally that could have been done differently had I had a correct diagnosis earlier on, but for some this information could be vital. With the termination of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), having a state-level committee to support rare disease patients in both identification and management of their disorder- is a tremendous public health and human services related need. The RDAC's influence would not just end with medical care either—quality of life could be addressed, including housing, transportation, access to community resources and more.

It is quite difficult to find resources in Vermont simply because there is not a large population of individuals with dwarfism here, so the information is just not available. We are also small, rural and secluded which makes living with a rare disorder much more difficult. Combined with the stigma that people with dwarfism face- being mocked and humiliated in public, just for being in spaces you are visiting or shopping in, it can be a very isolating experience, often leading to depression or even suicide. I was once called an "Oompa Loompa" by a student when I was an educator, and it comes down to people not knowing any better and there being a need for advocates like myself to continue to educate our communities whenever we have the opportunity. The RDAC could further support these efforts, and lead to better outcomes in life for people with dwarfism and other rare disorders.

Once again, I respectfully ask for your support and that you vote in favor- either yes or aye- when it comes time to cast your vote, ensuring the voices of rare patients are heard in state policy decisions for generations to come. Thank you for your time, and for your service to our beautiful State of Vermont.