Hello,

I am Katie Paquette from Essex, Vermont. I am here today both as a patient and an advocate, and to ask your help for H. 46, which would establish a Rare Disease Advisory Council in the state of Vermont.

I am both a rare and complex patient with Ehlers Danlos, Sjogren's Syndrome, and Fibromyalsia. If you look up Sjogrens, it might say it only causes dry eyes and mouth, but it is important for people to understand the complications that can come with this disease, and that it can vary for each person. Mine has progressed and the symptoms can be so scary. I am speaking out today because I'm someone who has always been afraid to speak up, but after living with rare and chronic illnesses, I need to make sure I can be a voice for those who are too afraid to speak up because not only can it be terrifying, but it can also be incredibly lonely. I never imagined my life would be filled with Dr. appointments, physical therapy and procedures, but it is. I know I look healthy, but I live in constant pain, with flare ups, and added anxiety.

When I mention the loneliness of living with rare diseases, I am speaking for thousands of Vermonters who feel the same way. Many of us have conditions so rare that we might be the only person in our community with that diagnosis. A Rare Disease Advisory Council would create a dedicated place where our voices can come together and our collective experiences can inform policy, and build a true community for those who often feel invisible in the healthcare system. This is not only about having a voice in government – it's about creating connections between patients, families, healthcare providers and researchers who are otherwise disconnected across our state. A Rare Disease Advisory Council would provide a way for patients like me to have a voice in state government and inform state leaders about these challenges to create potential solutions.

The timing of this bill is especially critical now. The recent termination of the Federal Advisory Committee on Heritable Disorders in Newborns and Children has created a serious gap in oversight for early detection programs that identify approximately 14,000 babies with serious conditions each year. Here in Vermont, we need our own Council to help fill this void and ensure our state's newborn screening program continues to advance.

H.46 explicitly tasks the Council with developing policy recommendations to improve Vermont's newborn screening program. As someone who knows firsthand how life-changing an earlier diagnosis could have been, I see this as one of the most vital functions of the proposed council.

I am asking you to please support H.46. To help ensure that people living with rare diseases in Vermont have a voice in state health policy. Thank you for your time and dedication to this issue. Together we are stronger!

Thank you!

Katie