

Testimony by Sharon Radtke regarding H. 573-An act related to the Vermont Rare Disease Council- Thursday, April 25, 2024.

- Hello, I am Sharon Radtke and I live in Milton, VT. Thank you for meeting with us today.
- I have been advocating for Vermonters with Rare Diseases for the past few years with Vermont's Federal Representatives (Senators Sanders and Welch and Congresswoman Ballint, so when I heard that there was a possibility for a Vermont Rare Disease Council, I was thrilled and jumped at the chance to participate in the planning committee.
- I was diagnosed with Pemphigus Vulgaris in 2015. Pemphigus is a blistering skin disease in which you get sores in your mouth, nose, throat and in some cases all over your body. Only 3 in one million people are diagnosed with Pemphigus.
- There are no blistering disease specialists in Vermont, therefore, I was fortunate that when my oral surgeon suspected that I had Pemphigus he sent me to a dermatologist at UVM who knew how to treat Pemphigus because she had done her residency at the Pemphigus clinic at Johns Hopkins.
- I spent 5 years receiving painful treatment including Prednisone, Cellcept and Rituximab infusions.
- I often had to fight with for insurance coverage because they insisted I stay on Prednisone, which was physically making me lame- I had to use a cane to walk.
- Rituximab infusions had yet to be approved for Pemphigus by the FDA so that took months to be approved.
- During the pandemic my dermatologist referred me to a blistering skin disease specialist at the University of Pennsylvania via telemedicine and the doctor there helped me to reach remission.
- However, after the pandemic passed, I could no longer see the doctor at University of Pennsylvania via telemedicine, I was required to go to Philadelphia in person.
- Therefore, I am back seeing a dermatologist at UVM. I am no longer in remission but I treat my sores topically and just take it one day at a time.
- When you have a rare disease you feel all alone -invisible-and have no idea where to turn for support. I was able to find support from the folks at the Pemphigus and Pemphigoid Foundation and through a support group for people with Pemphigus on Facebook. But otherwise, I was alone. and there are no supports in place here in Vermont to help me.
- My infusions cost \$25,000 each- and I had 8! Thank goodness I have good insurance. However there was no where to go for help in Vermont!
- Having a support structure for people with rare diseases in our state would make all of the difference to people like me.
- A Rare Disease Advisory Council would give the Rare Disease community a voice in our state government.

Respectfully submitted by,  
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