

Testimony by Sharon Radtke regarding Rare Disease Advisory Council

Hello, I am Sharon Radtke, I live at 205 Everest Road in Milton.

In 2015, I was diagnosed with a rare disease that is called Pemphigus Vulgaris, a blistering skin disease which affects my mouth, nose, throat and esophagus although some people experience blisters all over their body. Only 3 people in a million are diagnosed with this disease.

For ten years, I have been treated with Prednisone, Cellcept (an immunosuppressant) and Rituximab infusions which cost \$25,000 each time I have an infusion. However, I just received the latest invoice for my December infusion and the charge was actually \$30,000! Even after 10 years of treatments, I had a surprise flare in my esophagus last May and had to be hospitalized and almost lost my life. That hospitalization alone cost \$106,000! How do people deal with all these overwhelming medical costs?

These are some of the issues Vermonters with rare diseases face every day. That is why a Rare Disease Advisory Council is so important to Vermonters. Right now, a small group of us with rare diseases have been meeting once a month. We know firsthand all the obstacles one faces with a rare disease and believe that a Vermont Rare Disease Advisory Council could be a central place where people with all kinds of medical conditions could go for assistance. Some of the issues we face include:

- How do we seek a correct diagnosis? It typically takes two years for people with rare diseases to be diagnosed.
- Once we know what it is, how do we access treatment without having to drive hundreds of miles to see a specialist?
- Are medical televisits with specialists possible?
- Are there any support groups for my specific disease in Vermont?
- Are there any programs to assist us with paying out-of-pocket expenses for medications?
- How do we deal with unnecessary testing, only because it is required by our insurers?
- Are there pain management programs available in Vermont?
- How do we find affordable transportation if we cannot drive ourselves to medical appointments?

A Rare Disease Advisory Council would be a great resource for all of us with rare conditions, but also for Vermonters who have multiple medical conditions, like my husband who is being treated for Parkinson's Disease and Renal Cancer.

I hope you will consider creating a Rare Disease Advisory Council in Vermont. Thank you.

Sharon Radtke