

Vermont Senate Speech
April 8, 2026

Hello, my name is Sharon Radtke and I live in Milton. I am here to support H.46 to establish a Rare Disease Advisory Council in Vermont. My rare disease is called Pemphigus Vulgaris, an autoimmune blistering skin disease, which I have in my mouth, nose, throat and esophagus. Some people with Pemphigus have it all over their scalp and skin. One in 3 million people are affected by Pemphigus and I have only met one other person in Vermont. There are no blistering skin disease doctors in Vermont, however, I was lucky to find a dermatologist who had experience in diagnosing the disease in 2015. Most rare disease patients take two years or more to be diagnosed. Most Pemphigus patients have the most success with Rituximab infusions, which is a biologic. I have had 14 Rituximab infusions since 2015, and each infusion costs \$25,000...\$13,000 for just the medicine. Yes, since 2015, my infusions have totaled \$350,000! I thank my lucky stars that I have a good medical coverage! However what do others do who have no insurance coverage? Even paying for a % of these treatments can lead to bankruptcy.

One in 10 Vermonters have a rare disease. People of all ages and walks of life face medical obstacles with a disease name that most people cannot even pronounce. We often feel very isolated.

That is why I have been working on H46 to establish a Rare Disease Advisory Coalition in Vermont. People with rare diseases really need a place to go for advice and support, especially when they are first diagnosed.

Just remember when you walk into any room with ten or more people, at least one of those people has a rare disease they are dealing with! I hope you will consider establishing a Rare Disease Advisory Council in Vermont. It will definitely make a difference in our lives.

Submitted by
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