State of Kansas House of Representatibes

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Eric L. Smith Representative, 76th District

February 13, 2018

Madame Chair Vickie Schmidt

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Committee:

I met my wife, Becky, when she was only 14 and I was 16. We were high school sweethearts who set a bond of friendship that age cannot erode. We were blessed to have been given this opportunity to spend our lives together, friends now for more than 34 years.

At the age of 44, my wife had an episode where she woke up blind in one eye. As she went thru the day, the condition did not improve and by noon she had contacted her optometrist. She told me, that day, that the doctor had sounded grave when he told her he was contacting an ophthalmologist. Later that day, we were told that it was most assuredly optic neuritis. The condition was most commonly associated with multiple sclerosis, a disease that had been mentioned a couple of times before, due to sensations she had experienced in previous months. Subsequent MRIs showed lesions scattered throughout her brain, spinal cord and brainstem, indicating the disease had a firm foothold on her.

This was only 4 short years ago, and my wife is on her third medicine, Aubagio. Her treatments began immediately with self-administered injections of Copaxone multiple times a day, 2 years later switching to a new pill called Tecfidera. When new lesions show up on a new MRI, she switches medication. We are usually clued in when her condition worsens and new symptoms develop. She walks with a stiff gait, now, not with the relaxed confidence she always had. She has trouble navigating stairs and narrow paths, a constant sense of vertigo. Fatigue is frequent. Most frustrating for her is what is referred to as brain fog. Her memory is unreliable for the simplest of words, names are a challenge.

When you watch someone you have known since childhood struggle with a disease you thought would never enter your life, you are hit with a sense of helplessness. That somehow, you wish you could have seen it coming so you could have been prepared, somehow. To imagine an insurance company telling us that we have to follow financial guidelines for treatment instead of actively beginning the most successful treatment option known to medical experts would have been unimaginable, but that is exactly what some people endure. Relapsing remitting multiple sclerosis is different than progressive multiple sclerosis and the medications are different, as are the dosages, times of treatment, etc. In fact, within each of those categories are different levels of disability with unique treatment requirements. Like cancer, specialists are constantly sharing information to attempt to find the most effective method of slowing the disease, a process insurance companies don't participate in. Yet, currently, insurance companies are allowed to make arbitrary decisions regarding the treatment options of this and several other diseases.

We aren't talking about simple antibiotics and painkillers. We aren't talking about old medicine. We are talking about perhaps the most important part of the fight for a cure...trusting the experts to create hope. That the antiquated practices of step therapy are causing shortened life spans and lesser quality of life, unnecessarily.

For me, we're talking about a cure for my wife and more time for people like my wife and I to have quality time with our kids and parents.

Thank you for taking the time to consider my testimony.

Eric Smith

State Representative