

2/25/19

Senator Gene Sullentrop, Chair
Senate Public Health and Welfare Committee
Re: SB 93 Proponent

Chair Sullentrop and Committee Members:

In July 2015, I lost sight in my left eye while on vacation with my extended family in Florida. It happened gradually, and honestly, I did not really understand what was going on as I was a very fit and healthy woman. When we arrived back in Overland Park, my husband and I were very surprised when my doctor sent me to the ER expecting I had a stroke. After many tests and a 3 day hospital stay my spinal fluid was tested for MS. MS is difficult to diagnose and they use many tests to so, one of these tests is if protein is present in your spinal fluid. It was not until August 2015 that it was concluded that I had Multiple Sclerosis.

As a healthy wife and mother of 3 in her 40s, I wanted to take the most aggressive approach against the disease so that I would not lose my sight or my ability to walk. My husband and I wanted to tackle the disease head on. We did lots of research and meet with several neurologists before deciding on Dr. Kaplan and Amy Dix at the MS Center for Kansas City. It was what happened next that was the most surprising. Huge strides have been made in MS medications in the past 10 years. Until 18 years ago there were no MS therapies and now there are over 15. The therapies that were offered 10 years ago are MUCH less effective than newer therapies. **I wanted the best therapy for my best chance to continue to see and walk.** However, my insurance dictated that I start with a MUCH less effective medicine. In fact, the medicine is only effective 20% of the time. **I had to try and fail on two of these "less effective" medications before my insurance would even consider letting me try one of the newer medicines. It was during these three months of "trial and error" that I developed new MS symptoms that I did not have before. Currently, there is not a medication that changes your MS symptoms, meaning once you have a symptom, you will always have it.** In addition to my loss of sight, I also developed a lesion in my spine and additional lesions in my brain affecting both of my shoulders, legs and feet. I truly believe if I would have had the ability to start a more aggressive treatment right away, I would have better use of my legs. **This is my personal story of why I hope you will support SB 93 and vote to move it to the full consideration of the entire senate.**

Thank you for all you do to represent us. This is the third year MS Activists and more than two dozen other patient organizations have advocated for common sense reforms in step therapy. I hope you will vote "do pass" upon conclusion of today's meeting.

Sincerely,

Meg Godderz
Member,
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