

March 18, 2024

Dear Chairman and members of the House Insurance Committee,

My name is Mason Lough, and I am from Wellington. Today I have a question and a request.

I am 22 years old and I am graduating with honors from Oklahoma State University in May with a degree in zoology. I am 22 years old and I am the first person in my entire family to graduate college, and in two years, I'll be the first person to ever get my Master's degree. I have full-ride scholarships to both my undergraduate and graduate programs. I was named a National Merit Scholar, a Kansas Governor's Scholar, and I serve as the Vice President of the largest and oldest organization on my college campus. I am nearly to the publication process of a research paper concerning the nutritional ecology of carnivorous plants, and my Master's thesis will consist of research on isopod defense mechanisms. All of this is to illustrate the point that despite my accomplishments, I am 22 years old and sometimes I still can't handle getting my hands dirty, and sometimes I can't help but count everything I see in multiples of 4 until my head hurts, and sometimes my face will contort into angles that make my friends think I'm having an aneurysm. I want to stress that this is all very mild compared to how it once was. When I was 11 I couldn't stop myself from throwing back my head so hard it would bruise my neck, and when I was 7 I had vocal tics so loud that my elementary school music teacher made me cover my mouth or leave the classroom. I am 22, I was 11, and I was 7, and every age in between and in all that time I have never been able to focus on a test for long enough to feel confident in it. Whether it is someone clicking their pen too loud, or breathing in a funny way, or the clock ticking too loud, or my chair being uncomfortable, it all becomes too much and I find myself giving up and accepting whatever grade I have earned from taking half of an exam.

As for my question, could you do what I've done given the same circumstances? With all due respect I assume not.

The biggest challenge I have ever overcome is one that will never go away. I have Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus bacteria (PANDAS) and some days it truly drives me insane. Its symptoms include tics, anxiety, OCD, sleep issues, and a host of other problems. As I alluded to before, my worst symptoms were tics and OCD. In fact, my OCD was so debilitating that for years I could not function unless I did everything in groups

of four. If I ever tapped on anything with my hands, it had to be 4 times. I required the TV and radio volumes at multiples of four at all times, and I even had to count the syllables in my sentences and add words until they added up to a multiple of four. My tics were also very debilitating at one point. In elementary school, I had so many tics that my peers were actually wary of befriending me, including the vocal tic and the head thrashing tics I mentioned earlier, on top of many others that I can't even begin to list.

I still suffer from some tics, mostly facial contortions, due to long-term damage from being misdiagnosed and mistreated with various other disorders. My entire childhood consisted of visits to doctors all over Kansas, and none had the correct answer. Even in Kansas City at KU Medical Center, talking with some of the most highly educated doctors in the country still resulted dead ends and frustration. I am sure that one could imagine the feeling of hopelessness that seeps in when even the most widely respected people in the state do not have an answer. In another instance, I can vividly recall the moment when a doctor suggested, in my presence, that I may simply be possessed, and should seek out God. I was 8 years old. I did not receive the correct diagnosis of PANDAS until I was nearly 15. I need every reader to understand that my entire struggle with this disease comes from a very simple lack of awareness that this disease existed in the 2000s and early 2010s. In 2024, we have a much better understanding of the disease, a day dedicated to PANS/PANDAS awareness, and most importantly, we have effective treatment options.

I was lucky enough to receive one of those treatment options, as a participant of a study on intravenous immunoglobulin (IVIG) treatment and PANDAS in Omaha, Nebraska during my sophomore year of high school. This treatment was life changing and dramatically helped my condition, alleviating the large majority of my severe tics and lowering my OCD symptoms to a very manageable degree. It consisted of receiving several rounds of IVIG, which is essentially a pool of IgG antibodies in plasma from healthy individuals, over a span of about six months. To put it bluntly, this boiled down to sitting in a room for six hours with an IV in my arm, every three weeks. I honestly believe that this simple series of transfusions is the reason I am able to speak to you all today. I come to you all with the hope that individuals in Kansas may be able to receive this treatment without having to carry the financial burden of doing so. While I was fortunate enough to be a part of this study, that is certainly not the case for the vast majority of kids with this condition.

In light of that, I am asking you to vote for HB 2824. Although I believe that this disease has made me stronger than the average person, and has taught me the real meaning of perseverance by forcing me to work my way through whatever is put in front of me, I would not wish anyone the same path it has forced me to walk. Though I have gone far beyond what is expected of me to reach all of the things I've just described, I don't think any other children in Kansas suffering from this disease should have to persevere as much as I have had to. I want to absolutely stress that this struggle is so much more than a "bad spot" in my childhood. This disease has tried to take nearly everything from my family and myself- at its worst, it is all-consuming, all day long. By voting for this bill, you are voting to ensure that thousands of kids in our great state are able to overcome this disease without the unnecessary obstacles that I once faced.

Sincerely,

Mason Lough