Testimony on Lou Gehrig's Disease & S.B. 163, to create an ALS Awareness License Plate

(ALS-Amyotrophic Lateral Sclerosis)

House Transportation & Public Safety Committee

The Honorable Doug Green, Chair

Columbus, Ohio

June 2, 2020

Written Testimony By:

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pALS or Person with ALS

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**** This testimony was last given in person by Becky Rottier to the Senate Transportation, Commerce & Workforce Committee on January 29, 2020. Today, she is unable to be here in person due to participating in The ALS Association Advocacy Day taking place at exactly the same time. At the time of this hearing, we have virtual appointments set up with all our Members of Congress and their health legislative aids throughout the entire day – Tuesday, June 2nd - to advocate on behalf of more research dollars for ALS within the DOD, the CDC and the NIH and to advocate for a waiving of the 5 month waiting period for SSDI. We are so very sorry we can not be with you in person at this important hearing. ****

Good morning. My name is Becky Rottier. First, I would like to thank you for the opportunity to share my story. I never thought I would be standing here telling you about ALS. Those who know me know that public speaking is totally out of my comfort zone. But when you are facing a disease like ALS you realize you can do things that you never thought you could.

The first time I had ever heard of ALS or Lou Gehrig 's disease is when I helped my son and his friends do a video for the Ice Bucket Challenge in 2014. They were sophomores in high school and probably were doing it more for fun and to be part of the fad than anything else. I do remember learning what the disease was thru this challenge and thinking to myself: "Wow, how horrible, that would be the absolute worst thing to happen to somebody!" Little did I know that about a year later, I would start having my first symptoms. In the fall of 2015, I noticed I couldn't do a calf raise on my left side when reaching for something high in my kitchen cupboard. I also noticed that I couldn't curl my toes very well on the left

side either. I thought how strange. But I didn't think much of it. I was just overweight and getting old. This obviously didn't go away but I continued to live with it for a year or so. Until about a year later when I was in a walking group and I just couldn't keep up. One of my friends told me I walked funny. I got my son off to college and decided I better go to a doctor. This was the fall of 2016.

Like most ALS patients a diagnosis took forever. 2 years. I was also told I had a bulging disc in my back and needed surgery. I had no pain in my back so I wasn't so sure, so I decided to get another opinion. I bounced around from neurologist to neurologist to spinal surgeon to spinal surgeon. No one in Columbus could figure me out, mostly because all my EMG tests only showed nerve damage to my left leg. My other limbs and exams were completely normal. That is until October 17, 2018. The day that changed my life. I had been referred to Cleveland Clinic and had been going there for about 9 months. Like everyone else, they were struggling to diagnosis me. I had done enough research on my own, thanks to the

internet, to know I had many ALS symptoms. Every neurologist I saw I would ask them point blank if they thought I had ALS. They all said no. So on October 17, 2018, I headed to Cleveland, alone, to yet another appointment with a new doctor and yet another EMG test. Since I had done this so many times I wasn't expecting anything different than to make a follow-up appointment in a few months. I did not know that my new doctor was the Clinic's ALS specialist.

After my physical exam and EMG test, my new doctor came to talk to me. At first, she started talking about upper motor neurons and lower motor neurons. And I knew what she was going to say before she even said it. I remember saying, "This is really bad, isn't it?" and she said "Yes, it is. I'm so sorry". This new EMG showed damage to other limbs, which meant it had spread. Everything else had been ruled out at this point. Therefore, she was confident that I had ALS. She gave me more information, but to me it sounded like Charlie Brown's teacher. She left me alone to gather myself and to be honest I can't really say I didn't see it coming. I was numb. I felt like I was floating above my body. I always knew there was

something really, really wrong. I was able to drive myself back to Columbus. I know that God was watching over me on that drive to get me home safely.

I decided to keep this news to myself for 2 months. Only a few close friends knew. My family didn't know. I struggled greatly with how and when to tell them. When I finally had to tell them I went in person. It was heartbreaking and just so sad that I can't even put it into words. My family all lives in Michigan, about a 6 hour drive from Columbus, but even with the distance we are extremely close. I have a college age son who goes to school in Canton. I lived alone and still do. I rely on close friends and my faith to get me thru each day. I believe God really does give me the strength for one day at a time. I know He will continue to do so, not just for myself but also for those that love me. I truly believe when I was diagnosed with ALS, so was my family. In ways, this is just as hard on them. They will have to take care of me eventually. One of my biggest fears is being a burden to them. Emotionally and financially.

Since I have a slow progression, I am still able to live a somewhat normal life. That is for now. I still work full time since I have a job in an office setting. I can still drive and take care of myself. But I do notice my lower body is getting weaker. I now have to wear leg braces so I don't trip over my own feet and I just started using a walking stick for balance. My left leg is very weak and gives out without notice. I have drop foot where I can no longer move my left ankle and foot at all. I tire easily and cannot walk long distances anymore. I know a wheelchair is in my near future. I know retiring from the job I have had for 22 years is coming one day. I am only 43 years old. I had lost 90 pounds the year before my diagnosis (on purpose). I have raised my son. I thought it was finally time to travel and take advantage of having some freedom in my life. Unfortunately, that was not meant to be. How am I going to pay for a handicap accessible van? How am I going to be able to afford not to work, when I am the sole provider in my household? Who is going to help me get dressed? What if I can't take care of my personal hygiene? How will I afford to make expensive modifications to where I am living? How will

I deal with my body being trapped? How in the world am I going to do this? All these questions spiral in my head daily.

In March of 2019, I attended my first ALS Association Support Group meeting hosted by the ALS Association of Central and Southern Ohio. At first, I was really hesitant to attend, fearing it would be a cry fest. To my surprise, I found a room full of people just like me, they cared, they laughed, they told their stories, and the big one: they shared advice and valuable information on how to deal with this disease both mentally and physically. I realized I wasn't alone. This was huge for me. No one really knows what ALS is like unless they have ALS. It is difficult for the average person to understand and relate to. At these meetings, there were other people in the same boat, fighting the same battle, and having the same worries. I met my dear friends Shelly and Travis that evening and what a help they have been! For me in the stage I am in, these meetings have been the support that I needed. Not only do I meet other ALS patients, but I learn a ton. The educational

part of the meetings have helped me tremendously. Like for example, the info session on feeding tubes made them much less scary.

Besides support groups, the Association helps with financial needs thru grants to help with equipment and supplies. They have a great loan program that I have borrowed a manual wheelchair from. They have equipment that I will need to borrow down the road. They are a resource for any question I have and I appreciate the warmth and kindness they have shown me. I know whatever comes up, I have a place to call and people to help me.

Thru the license plate project, I believe we can raise more awareness to this disease that effects so many more people than the general public realizes. It will be a noticeable visual reminder every day that ALS is a real thing. We do not want to be forgotten, and this project will help make sure that ALS is never forgotten about.

Not only do the patients suffer, but their family and friends do as well. I once heard someone say: "Not only have I been diagnosed with ALS, but my family has too". This is so true. Just this past weekend, I went to get a massage and I was telling my new therapist I had ALS. She had never heard of it. I was surprised! Everyone in our state could have an opportunity to learn about ALS thru the license plate project. It would be visible on our roadways every day. The hope is for people to see it and be curious enough to learn more about the disease. The more people that know what ALS is, the more support we have, the more funds can be raised, the more push for access to new treatments that are showing success, and ultimately the more hope for a cure for us and those that come after us.

Thank you very much for your time today.