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

(ALS-Amyotrophic Lateral Sclerosis)

House Transportation and Public Safety Committee

The Honorable Doug Green, Chair

Columbus, Ohio

June 2, 2020

Writtten Testimony By:

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pALS or Person with ALS

Resident of Gallipolis, Ohio

**** This testimony was last given in person by Shelly Few 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. ****

Thank you Chairman McColley and Committee Members for providing the opportunity to speak about ALS today and explain to you why Senate Bill 163 is so important to the ALS Community. I was fortunate to have the opportunity to testify in May 2019, on similar legislation before the House Transportation Committee – House Bill 227.

In the fall of 2015 I started having trouble walking. An app on my phone proved that my mile walk was a whole six minutes slower than it had been just months before. By the time I got in to see my physician, I could no longer do a calf raise on my left leg. The doctor ran tests and referred me to a neurologist. Despite my complaints of weakness, the healthcare team all agreed that I was quite strong and that my problem was a bulging disk in my lumbar region. I questioned how such a problem could cause so much weakness, but no pain. Yet, I agreed to physical therapy, hoping it would help. Despite nearly two years of going to specialists and many rounds of physical therapy, I was getting nowhere. I am a nurse by profession and in April 2018, while accompanying a patient to a doctor's appointment, I fell in the parking lot and could not get up. I had to crawl to a tree to get off the ground. I knew it was no longer safe for me to work as a home health nurse. At the end of April, I had to take a leave of absence from work. On May 22, 2018, my husband and I sat in a small hospital room as the doctor stammered through the words that would change our lives forever - - "You have ALS."

As my family and I struggled emotionally with this diagnosis, the reality of the financial impact soon set in. My leave from work would not be temporary – it would be permanent. My husband has a good job but with two sons in college and us in our mid-forties, we were not prepared for the expenses. I immediately applied and was approved for social security disability. The 5-month waiting period for payments to begin seemed like years. I felt like a burden to my family. Not only was I not contributing to the household budget, I was costing us money for the equipment and modifications that I needed. $500 for leg braces, $1,400 for a ramp, gas money and hotel charges for out-of-town doctor's visits. The expenses were and are, never ending. We didn't know how we would cope.

Then we discovered the ALS Association. In June 2018, my husband and I showed up unannounced at the Association's Central & Southern Ohio Chapter office in Columbus. The kind, knowledgeable staff greeted us with open arms and empathy. I hobbled in with a cane and left with a rolling walker from the loan program. We were invited to attend the support group meeting that evening where we met fellow pALS - or person(s) with ALS - and realized we were not alone. Finally, we were surrounded by people that understood what we were going through.

The license plate project is important to me for a couple of reasons. One is awareness. I am hoping that as people see the ALS plates they will become curious enough to find out more about the disease. The second reason is funding. The license plate project will help fund the two Ohio ALS Association chapters so that they may continue to provide needed services to people with ALS and their families.

I speak not only on my own behalf, but on behalf of The ALS Association Central & Southern Ohio Chapter and Northern Ohio Chapter and all people living with ALS in the great state of Ohio when I say how much we wish to personally thank Sen. Stephanie Kunze for giving time to the cause and concerns of people with ALS and facilitating the introduction of this important bill.

And thank you Mr. Chairman and Committee Members - - I appreciate your attention to my testimony and would be grateful for your positive consideration of Senate Bill 163.