**Testimony on Lou Gehrig’s Disease & H.B. 227 to create an ALS Awareness License Plate**

**(ALS-Amyotrophic Lateral Sclerosis)**

House Transportation & Public Safety Committee

The Honorable Doug Green, Chair

Ohio State House

Columbus, Ohio

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Presented by:

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Person with ALS

Resident of

Gallipolis, Ohio

My name is Shelly Few. I would first like to thank you for the opportunity to speak here today to share my story. In the fall of 2015 I started having trouble walking. My gait was off. The walking app on my phone proved to me that my mile walk was a whole 6 minutes slower than it had been just months before. By the time I got in to see my doctor I could no longer do a calf raise on my left leg. The doctor ran tests and and referred me to a neurologist. Despite my complaints of weakness, all of the doctors 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 to help correct the situation. Despite nearly two years of going to specialists and many rounds of physical therapy to figure out what was wrong with me, I was getting nowhere. In April of 2018, while accompanying a patient to a doctor 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 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. I was diagnosed with 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 but permanent. My husband has 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 was a stay at home mom most of my marriage and did not have disability insurance through my employer. I felt like a burden to my family. My husband and I worked to pay for our children’s college, that was no longer possible. Not only was I not bringing money into the household, I was costing us money for the equipment and modifications that I needed. $500 for leg braces, $1400 for a ramp, gas money for out of town doctor visits and hotel rooms. The expenses were never ending.

 Then we discovered the ALS Association and the kind knowledgeable staff. In June of 2018, my husband and I showed up unannounced at the associations office in Columbus. The staff greeted us with open arms and empathy. I hobbled in with a cane and left with a rolling walker from the loan closet. We were invited to attend the support group meeting that evening where we met fellow PALs and realized we were not alone. Finally, we were surrounded by people that understood what we were gong through.

 The license plate project is important to me for a couple of reasons. One is awareness. I’m hoping that as people see information about ALS 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 Ohio ALS Association chapters so that they may continue to provide needed services to people with ALS and their families.