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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

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Written Testimony Presented by:

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Good morning Chairman Green, Vice Chairman McClain, Ranking Minority Member Sheehy and members of the Committee. My name is Marlin Seymour and I am the Executive Director of The ALS Association Central & Southern Ohio Chapter. I am here today, not only representing our local Chapter headquartered here in Columbus, but also representing The ALS Association Northern Ohio Chapter, headquartered outside of Cleveland, who have senior staff leaders joining us here today. Between the Northern Ohio Chapter, covering 33 counties and the Central & Southern Ohio Chapter, covering 55 counties, we reach across all boundaries of the state, providing **FREE** services and support to those with ALS. We are here today representing people with ALS in Ohio in support of Senate Bill 163, to create a license plate to raise awareness of ALS and funds…for our mission…

"to discover treatments and a cure for ALS, and to serve, advocate for and empower people affected by the ALS to live their lives to the fullest."

Mr. Chairman, thank you for allowing us to testify. We would like to recognize and thank Sen. Stephanie Kunze for introducing Senate Bill 163 and for her strong desire to support the ALS community. We also thank Senate co-sponsors Antonio, Yuko, Fedor (pronounced Fedder), Schaffer, and Williams. I would also like to acknowledge the early efforts on this project back in 2006 by our Board Member and ALS patient Rob Harklau, who passed away in August of 2011 and the more recent efforts of ALS Patient Dennis Ursetti of the Northern Ohio Chapter. In addition, I'd like to thank ALS patient Shelley Few – who testified before the House

Transportation Committee in May 2019 on House Bill 227, related to the same topic and before the Senate Transportation, Commerce & Workforce Committee in November of 2019 and January this year. I'm also here today representing ALS patient Becky Rottier who testified before the Senate Transporation, Commerce & Workforce Committee in January of this year, as well. Although they would like to be here today, testifying in person as they have in the past, due to COVID-19, they are staying home in order to stay safe. These past opportunities to testify have been stepping stones toward continuing to raise awareness within the Ohio legislature and with the public at large, about this devastating and terminal illness.

Amyotrophic Lateral Sclerosis or ALS, robs people of their ability to perform the every day things that you and I take for granted, such as getting dressed, eating and sometimes even speaking or blinking an eye. Someone diagnosed with ALS will likely lose their ability to walk, move their arms, talk, and even breathe. ALS is a fatal illness and the average life expectancy for a person with ALS is two to five years from the time of diagnosis**.** The disease does not discriminate in who it strikes, and can impact anyone at anytime, regardless of their age, gender, race or ethnicity.

Did you know that those who serve in the military are twice as likely to develop ALS?? Because of this disturbing finding, the Department of Defense in 2007, created the ALS Research Program and <u>every year since that date, the U.S. Congress has appropriated money within the DOD, specifically for ALS research</u>.

Thanksgiving of 1994, my family reluctantly accepted our own **"membership"** into the ALS community when my mother was diagnosed with Lou Gehrig's disease. Nine months later, I was ecstatic to learn that there was an organization that would help provide support, education and understanding – that was The ALS Association Central & Southern Ohio Chapter. I started attending the local support group in Columbus and **then -** only three months later - my mom's journey with ALS ended - she died just 12 months after being diagnosed.

The ALS Association Central & Southern Ohio Chapter and The ALS Association Northern Ohio Chapter

The ALS Association's nationwide network of chapters - including two here in Ohio - provide patient services and support to the ALS community and all of that is done, **FREE OF CHARGE**. **We also do not bill for services nor do we receive any public support.** Simply put, through our free programs, we are able to offer a better quality of life, while those with ALS are living through this terrible illness. Our Chapters provide a wide range of services that may not otherwise be available to patients, their families, **or their** caregivers. Those services include case management by nurses and social workers, support & education groups, equipment loan programs, bereavement groups, children's programs, newsletters, home visits, and patient grants, among other services. In addition, both Chapters provide Chapter paid, credentialed healthcare professionals who help staff multidisciplinary ALS clinics at the Cleveland Clinic, the Louis Stokes VA

Medical Center – both in Cleveland -- and the OhioHealth ALS Clinic, in Columbus. These 3 clinics are the only credentialed ALS Association Certified Treatment Centers of Excellence in the state. All of these programs are **tangible** and **provide improved quality of life** at a time when they are desperately needed.

Yankees Great, Lou Gehrig – 80th Anniversary

July the 4th, 2020, will be the 81st anniversary of Yankees great Lou Gehrig's farewell speech. Gehrig was diagnosed with ALS on June 19th, 1939 – on his 36th birthday and died of ALS, two short years later, **yet there is still no known cause…, cure…. or effective treatment for this disease.**

ALS License Plate Design

If this legislation is signed into law, the design of the ALS Awareness Plate will be a Sunflower, imagined by ALS patient Shirley Schmelzle and designed by Haley Porst, in an effort to unite the ALS Community. The sunflower is a symbol of strength, grace and dignity. When in clusters, the flowers support each other, allowing for growth in a multitude of shapes, sizes and colors. This diversity represents the people fighting this disease and reminds us to always have hope. Shirley was a friend of our Chapters who received our services and passed away, still fighting for ALS, on January, 2016.

By supporting Senate Bill 163, you will be making a tangible difference in the lives of people like Dennis Ursetti, Shelly Few, Becky Rottier and so many others who are living with ALS today and whom we are here representing.

If your knowledge of ALS was anything like mine was in 1994 when my Mom was diagnosed, you may not have known much about this horrific disease, until today. I hope that our testimony will bring you and other legislators a new perspective on **how aggressive this disease really is** and the need for greater support and awareness in the state, to better serve the ALS community.

Thank you Mr. Chairman and distinguished committee members for your time and attention and I’d be happy to try to answer any questions you may have.