April 12, 2019

The Honorable Richard Shelby  
Chairman  
Defense Subcommittee  
Committee on Appropriations  
Washington, D.C. 20515

The Honorable Richard Durbin  
Ranking Member  
Defense Subcommittee  
Committee on Appropriations  
Washington, D.C. 20515

The Honorable Roy Blunt  
Chairman  
LHHS Subcommittee  
Committee on Appropriations  
Washington, D.C. 20515

The Honorable Patty Murray  
Ranking Member  
LHHS Subcommittee  
Committee on Appropriations  
Washington, D.C. 20515

Dear Chairmen Shelby and Blunt and Ranking Members Durbin and Murray:

We are writing to thank you for your continued strong support of funding for ALS (amyotrophic lateral sclerosis) research. In particular, your support of the ALS Research Program at the Department of Defense (DOD) and the National ALS Registry at the Centers for Disease Control and Prevention (CDC) is helping scientists learn the causes of ALS and how it can be treated, cured, or even prevented.

As you know, ALS, also known as Lou Gehrig’s disease, is a fatal neurodegenerative disease that destroys a person’s ability to control muscle movement. As the disease progresses, people become trapped inside a body they can no longer control – aware of the world around them, but powerless to do anything about it. The average life expectancy for a person with ALS is just two to five years after diagnosis. **There is no effective treatment for the disease, no known cause, and no cure.**

According to numerous studies, including those funded by the DOD, Department of Veterans Affairs, and National Institutes of Health, military veterans are approximately twice as likely to die from ALS as those who have not served in the military. The DOD’s ALS Research Program (ALSRP) promotes new, encouraging research that is in the early stages of development and has the potential to yield highly impactful results. Congress has recognized the critical role of the ALSRP by appropriating funding for the program every year since FY2007, including $10 million in FY2019. Increased funding for FY2020 is needed to take advantage of that research. **To date, the ALSRP has supported six ALS drug candidates, including four that have moved into advanced drug development, and two that have advanced to early-phase clinical trials, all representing potential ALS treatments.** We hope you will join us in supporting a $20 million appropriation in FY2020 for the ALSRP to continue and increase its vital work.
In addition to supporting investment in early-stage pre-clinical research, the ALSRP is uniquely positioned to expand support for investments in early-phase clinical trials. With several promising ALSRP-funded preclinical research with the potential to enter early-phase trials, now is the time to increase investment in this critical gap in the ALS research continuum. We encourage the committee to find ways to expand the ALSRP by supporting investments in early-phase clinical trials that will hopefully accelerate the development of therapies and treatments to improve life for all patients impacted by this disease.

The CDC ALS Registry is another program critical to ALS research. In 2008, Congress passed, and President Bush signed into law, the ALS Registry Act (P.L. 110-373), which authorized the CDC to establish the National ALS Registry. Congress has maintained funding for the Registry, and we hope that the committee will support level funding of $10 million in FY2020 for the CDC to continue this vital project. Thanks to previous Congressional support, the Registry is fully operational, collecting critical information about potential causes of ALS, connecting patients to clinical trials, and strengthening ALS research. Funding in FY 2020 is needed to continue the coordination of federal efforts and to conduct outreach activities to identify cases across the country. Funding is also needed to strengthen the Registry’s biorepository, which collects blood and tissue samples that will significantly advance epidemiologic studies and research into biomarkers, risk factors, and clinical studies necessary to identify new treatments.

We thank the Committee for its support of funding for ALS research. We appreciate your consideration of our FY2020 appropriations requests, including $20 million for the DOD ALSRP, as part of the Defense Appropriations Act, including expanding investments in early-phase clinical trials for ALS. We also ask that you support level funding of $10 million for the CDC National ALS Registry in the LHHHS Appropriations Act. By strongly funding the ALSRP and the National ALS Registry, we will be able to continue taking advantage of vital research opportunities that move us closer to finding a cure for this horrific disease.

Sincerely,

Christopher A. Coons
United States Senator

Bill Cassidy, M.D.
United States Senator

Jacky Rosen
United States Senator

John Kennedy
United States Senator
Kirsten Gillibrand  
United States Senator

Kevin Cramer  
United States Senator

Richard Blumenthal  
United States Senator

Susan M. Collins  
United States Senator

Elizabeth Warren  
United States Senator

Angus S. King, Jr.  
United States Senator

Edward J. Markey  
United States Senator

Sherrod Brown  
United States Senator

Sheldon Whitehouse  
United States Senator

Chris Van Hollen  
United States Senator

Jack Reed  
United States Senator

Tammy Duckworth  
United States Senator

Dianne Feinstein  
United States Senator

Debbie Stabenow  
United States Senator
Kyrsten Sinema
United States Senator

Doug Jones
United States Senator

Catherine Cortez Masto
United States Senator

Kamala D. Harris
United States Senator

Ron Wyden
United States Senator

Jeffrey A. Merkley
United States Senator

Tom Carper
United States Senator

Cory A. Booker
United States Senator