Dear Chairs DeLauro and Visclosky and Ranking Members Cole and Calvert:

We are writing to thank you for your continued strong support of the ALS Research Program (ALSRP) within the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense (DOD) and the National ALS Registry at the Centers for Disease Control and Prevention (CDC). Your support of these critical programs is helping to advance the search for a treatment for ALS, also known as Lou Gehrig’s disease.

As you know, ALS 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.

**DOD ALS Research Program**

We believe that it is important for the DOD to identify and research all diseases that may be related to service in the U.S. military, including ALS. According to numerous studies, including those funded by the DOD, VA and NIH, military veterans are approximately twice as likely to die from ALS as those who have not served in the military.

The ALSRP is explicitly designed to promote new ideas that are in the early stages of development with the potential to yield highly impactful data and new avenues of investigation. This high-risk/high-reward program fills the gap in the drug development pipeline in which limited funding has prevented promising treatments from reaching patients. ALSRP also supports the best science, funding research in the private sector on a peer-reviewed, competitive grant basis. To date, the ALSRP has supported six promising ALS drug candidates, four that...
have moved into advanced drug development, and two have advanced to early-phase clinical trials, all representing potential ALS treatments.

Building on a solid foundation of promising preclinical research, the ALSRP is uniquely positioned to make investments in early phase clinical trials. These investments will de-risk early phase trials for ALS, bridging the “valley of death” to make private investment into ALS more possible. With several promising ALSRP-funded preclinical projects with the potential to enter early phase trials, now is the time to increase investment in this critical gap in the ALS research continuum.

The Fiscal Year 2020 ALS Appropriations Request contains report language that will focus ALSRP efforts on making 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 specific report language being requested includes:

“CDMRP

ALS Research – The Committee commends the Department of Defense for the potentially promising therapies that have been made possible by the Amyotrophic Lateral Sclerosis Research Program (ALSRP). The Committee recognizes that the need to de-risk early stage ALS research funding spans beyond the pre-clinical phase and into early stage clinical trials. Drawing from the successes of the ALSRP to-date, the Committee recommends that research applications requesting ALSRP funding for early stage clinical trials, Phase 1 or Phase 2, be considered for awards, should sufficient funds be available.”

CDC National ALS Registry

The National ALS Registry at CDC, established in 2009, collects data on ALS patients in the United States to better describe the incidence and prevalence of ALS, and examine risk factors and the demographics of those living with ALS. It includes information voluntarily provided by persons with ALS and it collects and compiles data from federal agencies (such as the Centers for Medicare and Medicaid Services, NIH, and the VA). The Registry:

- Makes collected data available to researchers who are looking to identify disease patterns and risk factors.
- Connects patients directly with clinical trials and epidemiological studies
- Notifies patients when a study is available in which they are eligible to participate.
- Funds ALS research on etiology and determining risk factors for ALS.
- Conducts public health surveillance of how many people have ALS in the United States.
- Collects risk factor data through 17 surveys of patient enrollees, ranging from demographics, smoking, alcohol history, disease progression, and to environmental exposure such as pesticide use. To date, over 60,000 surveys have been completed by persons with ALS.

Conclusion
The Fiscal Year 2020 ALS Appropriations Request contains language and provisions to help leverage existing ALS research and investments to-date and strengthen the ALS Registry. Specifically, the request would:

- Increase funding of the ALSRP at DOD to provide opportunities to fund early phase (Phase 1-2) clinical trials, while continuing to fill the need for preclinical research for the disease.
- Provide level funding for the National ALS Registry at CDC to continue collecting critical data on ALS patients in the US to better describe the incidence and prevalence of ALS and examine risk factors and the demographics of those living with ALS.
- Leverage the ALSRP to de-risk early phase (Phase 1-2) clinical trials for ALS, bridging the “valley of death” to make private investment into ALS more possible.
- Accelerate the ALS research pipeline through speeding the development of new therapies and drugs.

We thank the Committee for its support of funding for ALS research and the ALS Registry. We appreciate your consideration of our FY2020 appropriations requests, including $20 million for the DOD ALSRP, a $10 million increase over FY2019, as part of the Defense Appropriations Act, and level funding of $10 million for the CDC National ALS Registry in the LHHS 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 this horrific disease.

Sincerely,

Joe Courtney
Member of Congress

Peter T. King
Member of Congress

Eliot L. Engel
Member of Congress

George Holding
Member of Congress

Seth Moulton
Member of Congress

Brian Fitzpatrick
Member of Congress
Judy Chu  
Member of Congress

Wm. Lacy Clay  
Member of Congress

Steve Cohen  
Member of Congress

Christopher H. Smith  
Member of Congress

John Garamendi  
Member of Congress

Bill Foster  
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Earl L. "Buddy" Carter  
Member of Congress

Sanford D. Bishop, Jr.  
Member of Congress

Stacey E. Plaskett  
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Paul D. Tonko  
Member of Congress

Jan Schakowsky  
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Alcee L. Hastings  
Member of Congress
Juan Vargas  
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Chris Collins  
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Henry C. "Hank" Johnson  
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Gerald E. Connolly  
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David N. Cicilline  
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Karen Bass  
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Lucy McBath
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Susan Davis  
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Dave Loebsack  
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Mark Takano
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Sean Casten
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Jody Hice
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Mike Thompson
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John Yarmuth
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Glenn "GT" Thompson  
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Anthony Brindisi  
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Chris Pappas  
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Ann McLane Kuster  
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A. Donald McEachin  
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Filemon Vela  
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Joseph P. Kennedy  
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Alexandria Ocasio-Cortez  
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Andy Levin  
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Ro Khanna  
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Thomas R. Suozzi  
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Jimmy Panetta
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Ben McAdams
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Dan Kildee
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