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June 14, 2023

The Honorable Tim Kaine
231 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Tammy Duckworth
524 Hart Senate Office Building
Washington, DC 20510

The Honorable Ed Markey
255 Dirksen Senate Office Building
Washington, DC 20510

Dear Senators Kaine, Markey, Duckworth:

The American Academy of Neurology (AAN), the world's largest association of neurologists representing 40,000 professionals, is strongly committed to improving the care and outcomes of persons with neurologic illness in a cost-effective manner. One in six people live with a brain or nervous system condition, including Alzheimer's disease, Parkinson's disease, stroke, epilepsy, traumatic brain injury, ALS, multiple sclerosis, muscular dystrophy and headache.

The AAN writes to express our support for S.801, CARE for Long COVID Act. An estimated 15% of US adults have reported ever having Long COVID symptoms.¹ Many of these patients report neurologic symptoms, including brain fog, headache, cognitive impairment, and sleep disorders among others.² We appreciate your leadership in recognizing the importance of addressing Long COVID impacting so many Americans, and AAN supports legislation like the CARE for Long COVID Act that promotes a greater understanding of this complex condition. This will allow neurologists and other physicians to provide the most appropriate patient care for impacted individuals.

Since 2020, our knowledge of COVID-19 has significantly grown. With science at the forefront of policymaking, synthesizing research to formulate the best path forward is imperative. According to one study, one-third of patients diagnosed with COVID-19 developed psychiatric or neurologic disorders within six months, including depression, anxiety, stroke, and dementia. In that same study, researchers who evaluated more than 230,000 electronic health records, which includes anonymous data from 81 million patients, primarily in the US, found that among COVID-19 patients admitted to an intensive care unit (ICU), the incidence of developing a psychiatric or neurologic disorder rose to an unprecedented 46 percent.³ Another study showed that 22% of children who were hospitalized with COVID-19 or Multisystem Inflammatory Syndrome in Children (MIS-C), a rare condition that can occur after a COVID-19 infection, had neurologic complications.⁴ A new study has shown that Long COVID

¹ <https://www.kff.org/policy-watch/long-covid-what-do-latest-data-show/>

² <https://pubmed.ncbi.nlm.nih.gov/35198136/>

³ https://journals.lww.com/neurotodayonline/Fulltext/2021/06030/6_Months_After_COVID_19_Infection,_1_in_3_Develop.4.aspx

⁴ <https://jamanetwork.com/journals/jamaneurology/fullarticle/2798383>

patients have to use more brain power for memory tasks.⁵ This complements the ongoing research that is identifying biological mechanisms into the neurological presentations of Long COVID that is paving the way for future studies on this condition⁶ We believe we must follow the science as it relates to researching and caring for people affected by Long COVID, and S. 801 will aid us in this pursuit. Our understanding of the cognitive impact of Long COVID and best clinical practices can continue to grow with the passage of this bill.

As we move towards a collective goal of better health for all Americans, we appreciate your focus on:

- Data collection and patient registries
- Health equity in Long COVID outcomes and treatment
- Provider education on Long COVID and assessment
- Dissemination of Long COVID information, including comorbid neurologic conditions

The AAN is committed to promoting brain health and given the prevalence of neurologic symptoms in patients with Long COVID, a greater understanding of this condition is an important step forward in advancing brain health for impacted patients.

The AAN thanks you for working diligently addressing the needs of patients suffering from Long COVID and the physicians providing their care. If you have any questions or requests for additional information, please contact Kelly McCone, Senior Congressional Affairs Manager, at kmcccone@aan.com, or Madeline Turbes, Health Policy Manager at mturbes@aan.com. We look forward to working with you as we all strive to address the toll of Long COVID on the American public.

Sincerely,



Carlyne E. Jackson, MD, FAAN
President, American Academy of Neurology

⁵ <https://n.neurology.org/content/early/2023/04/26/WNL.0000000000207309>

⁶ <https://nn.neurology.org/content/10/4/e200097>