

February 27, 2024

The Honorable Jan Schakowsky
U.S. House of Representatives
2408 Rayburn HOB
Washington, DC 20515

The Honorable Brian Fitzpatrick
U.S. House of Representatives
271 Cannon HOB
Washington, DC 20515

Dear Congresswoman Schakowsky and Congressman Fitzpatrick,

On behalf of the approximately 30,000 people currently living with amyotrophic lateral sclerosis (ALS), their friends and families, and everyone who has been touched by this disease, The ALS Association is pleased to endorse H.R.5663 the ALS Better Care Act, which will increase access to multidisciplinary care clinics for people living with ALS.

ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord. Over the course of the disease, people lose the ability to move, speak, and eventually breathe. On average, it takes about a year before an ALS diagnosis is made. The disease is always fatal, usually within five years of diagnosis. There currently is no cure.

Multidisciplinary care is considered the optimal standard for ALS care, it extends and improves the lives of people living with ALS. These clinics provide an array of healthcare services in one visit which reduces the physical, emotional, and financial stress of visiting numerous healthcare providers, and allows individuals living with ALS to spend more of their limited time with loved ones. Care at ALS clinics also addresses the needs of the family members, many who are primary caregivers.

The ALS Better Care Act is urgently needed to increase access to multidisciplinary care clinics. Right now, where a person lives and what financial resources they have determines whether they will be able to receive this life extending and life improving care. Unfortunately, current Medicare reimbursement rates make it nearly impossible to open new clinics and increase existing clinic capacity. This is because the current reimbursement does not cover the cost of the specialized multidisciplinary ALS care that people living with ALS need. In fact, many ALS clinics rely on donations to cover their costs. The ALS Better Care Act would create a \$800 supplemental payment to cover costs that Medicare does not pay for at ALS clinics.

The ALS Association is committed to doing everything we can to increase equitable access to our network of certified multidisciplinary ALS clinics across the country. We are hopeful that Congress will partner with us and the entire ALS community to achieve this goal. We look forward to working with you on this and any future legislation that extends and improves the quality of life for people living with ALS and helps make ALS livable until we cure it.

Thank you for your time and consideration of this critical piece of legislation. If you have any questions, please contact our Director of Congressional Affairs, Denise Bailin at denise.bailin@als.org.

Sincerely,



Calaneet Balas
President and Chief Executive Officer



OUR VISION: Create a world without ALS.

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

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