Dear Representatives and Senators,

We are writing representing physicians across the U.S. who provide multidisciplinary care to people living with Amyotrophic Lateral Sclerosis (ALS). We want to bring to your attention that Medicare reimbursement for multidisciplinary care is inadequate and compromises our ability to provide essential care to people living with ALS. We urge your support for the ALS Better Care Act (H.R. 5663/S.3258), which will provide a modest supplemental, facility-based payment to bridge the shortfall of Medicare reimbursement for multidisciplinary care.

ALS is a devastating, progressive neurological disease with no cure and very few treatments. It is characterized by progressive degeneration of nerve cells in the spinal cord and brain. People living with ALS lose the ability to move, are likely to fall and eventually become wheelchair-dependent and completely paralyzed. They also lose the ability to swallow, breathe, and complete activities of daily living as the disease progresses. Without multidisciplinary care, vulnerable people living with ALS are more likely to require more costly care such as emergency room visits, hospitalizations, and nursing home care.

Multidisciplinary care is comprehensive support provided by specialized ALS clinics with physicians and other health care professionals providing integrated services to patients — including physical, respiratory, and speech therapy as well as mental health providers and neurologists. Medical evidence demonstrates that ALS multidisciplinary care improves quality of life and survival, and the American Academy of Neurology deems this to be a central care measure for ALS.

At present, ALS multidisciplinary care services provided in a clinic are not adequately reimbursable under Medicare. As a result, most ALS centers are forced to either curtail multidisciplinary care, serve fewer patients, or rely on philanthropic support to provide quality care. While this is a problem for all ALS clinics, it is a particular problem for clinics in rural areas or disadvantaged urban settings where the need is great, but there are few resources.

Patients, families, and caregivers can be left hopeless as they look to their physicians and care teams to ease the effects of this fatal disease. As physicians, we know how to help, but the services we can provide are hampered by inadequate Medicare reimbursement for ALS multidisciplinary care. It is critical to the health of people living with ALS and their families that Congress pass the ALS Better Care Act.

The ALS Better Care Act would amend the Medicare statute to create a facility-based, supplemental payment, beginning in 2025, to qualified health care organizations that provide qualified multidisciplinary ALS-related services not otherwise reimbursed under Medicare. Patients, who already have a significant cost-sharing burden, would not be asked to cost share for the supplemental payment. This will allow ALS physicians to focus on care and building outstanding multidisciplinary programs rather than curtailing multidisciplinary care.

We all look forward to the day when ALS is no longer the devasting disease it is now. In the meantime, we have a responsibility to ensure that we prioritize, fund, and provide the best care possible for Medicare beneficiaries with ALS.

We applaud the work done in recent years by Congress to help meet the needs of ALS patients and their loved ones and stress the necessity of continued momentum on this front.

Thank you for your attention to this matter. Please co-sponsor the ALS Better Care Act.

Sincerely,

Alabama
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Kathleen Smith

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Sri Raghav Sista
Anne Hatch
Shafeeq Ladha
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