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, 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 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
David L. White
Diane C. Tucker
Elizabeth Wylie
Kathleen Smith
Mia Davis
Sherry Kolodziejczak

Arizona

Minnesota
Amber Erickson
David Walk
Georgios Manousakis
Jaimin S. Shah
Katherine Teigen
Nathan Staff

Anne Hatch
Holli Horak
Iryna Muzyka
Shafeeq Ladha
Sri Raghav Sista
Stephen Johnson

California
Catherine Lomen-Hoerth
Dominic Ferrey
Jill Ann Goslinga
Jonathan Katz
Laura Rosow
Leila Darki
Liat Rabizadeh
Liberty Jenkins
Martina Wiedau
Maxwell Greene
Namita A. Goyal
Nanette C Joyce
Priya Dhawan
Said R Beydoun
Swathy Chandrashekhar
Viktoriya Irodenko

Connecticut
Uzma Usman

District of Columbia
Elham Bayat

Florida
Amparo "Amy" Gutierrez
Bjorn Oskarsson
Cecilia T. Deidan
Gabriela Lopes
I-Hweii Amy Chen
Jennifer Barber Winkler
Jim Wymer
Michael Benatar
Michael Benatur
Michael Pulley
Patricia Graese
Tuan H. Vu
Whitney McNeely

Georgia

Missouri
Andee Glick
Erik Ensrud
Jaime Basnett
Robert Bucelli
Vovanti Jones
William Arnold

Nebraska
David Franco
Elizabeth Hartman
Joseph A. Fernandes
Michael Pichler
Gary Pattee

Nevada
Geri Lynn Grossan

New Hampshire
Elijah W. Stommel

New Jersey
Alfonso Preciado
Dora Leung
Ellen Anne Morse
Florian P Thomas
Jonathan Tiu
Joseph Campellone
Lori Rehling
Mary Sedarous

New Mexico
Cynthia Olivas
Jonathan Cauchi

New York
Erin Manning
Eufrosina Young
Hiroshi Mitsumoto
Marinella Gallea
Matthew Harms
Monique A. Pimontel
Neil Shneider
Noam Harel
Peter Creigh
Simona Treidler

Michael H. Rivner

Hawaii
Jeffrey Liu

Idaho
Jackie Whitesell

Illinois
Alexander Garreau
Alix Jampol
April Szymanski
Ashley Kochman
Bella Bauman
Brittany Hitson
Candace James
Charles K Abrams
Claire Heneghan
Colin Franz
Dominique Kosk
Emma Schmidt
Glenn Harris
John M Coleman III
Jori Fleisher
Joseph Apostol Burroughs
Kellie Reynolds
Kourosh Rezania
Kristin Gustashaw
Kristin Larsen
Laura Freveletti
Lisa Wolfe
Madhu Soni
Meghan Deplaris
Neha M. Cramer
Rabia Malik
Raymond Roos
Senda Ajroud-Driss
Sharon Veis
Caroline Lipic

Indiana
Robert Pascuzzi

Kentucky
Debra Suiter
Edward J. Kasarskis
Keri McKenney
Stephen N Scelsa

North Carolina
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James B. Caress
Jim Caress
Jorge Almodovar
Richard Bedlack
Leo McCluskey

Ohio
Komal Sawlani
Lisa Barnes
Rebecca M. Kuenzler
Tracy Frazee

Oregon
Nicholas T. Olney
Lauren Brown

Pennsylvania
Alison Walsh
Alissa Romano
Anahita Deboo
Colin Quinn
Daniel Kelly
Daniel Kramer
Elizabeth Fletman
Gema Giler
Hristellina Iilieva
James Grogan
Lauren Elman
Lyle W. Ostrow
Mansoureh Mamarabadi
Rebecca Hsu
Sandeep Rana
Stephanie Dobak
Tawfiq Al-Lahham
Terry Heiman-Patterson
Tom Noff
Xiaowei Su
Zachary Simmons

Rhode Island
Vincent LaBarbera

Martin E. Brown

Louisiana
David Darragh
Ehtesham Khalid
Emilee Gautreaux

Maine
John A. Taylor

Maryland
Brent T. Harris

Massachusetts
Donna Jordan
Dorean Ho
James D. Berry
Jennifer Morganroth
Mark Garret
Sabrina Paganoni
Merit Cudkowicz

Michigan
Abbas Jowkar
Anaka DeVries
Kara Steijlan
Karyn Kuzniar
Matthew J. Ebright
Paul Twydell
Stephen Goutman
Ximena Arcila-Londono

South Carolina
Jerry Kurent
Katherine Ruzhansky
Sarah Breevoort

South Dakota
Nicholas Purcell

Tennessee
Chelsea A. Shugars

Texas
Carlayne Jackson
Daragh Heitzman
Ericka Portley Greene
Himabindu Iyyapu
Karen Toennis
Stanley H. Appel
Tonya Hitschmann

Utah
Mark B. Bromberg

Virginia
Andrew Galbreath
Beth Whittington
Gordon Smith
Kelly Gwathmey
Lydia Sharp
Matthew Elliott
Melani Grieff
Neel Dixit
Qihua Fan
Rebecca Fannin
Thomas Chelimsky
Xinli Du

Washington
"Silver" E. Denton
B. Jane Distad
Greg Carter
Ileana Howard
Leo H. Wang
Michael Weiss
Morgan Chojnacki
Oscar Hernandez

West Virgina
Sara M. Hoten

Wisconsin
Daniel Anderson
Dominic Fee
Nassima N Baba-Ahmed Fertikh
Paul E. Barkhaus
Sarah Oppelt
Doris Lozano