March 16, 2018

The Honorable Tom Cole, Chairman
Appropriations Subcommittee on Labor
Health and Human Services, and Education
2358-B Rayburn House Office Bldg.
Washington, DC 20515

The Honorable Rosa DeLauro, Ranking Member
Appropriations Subcommittee on Labor
Health and Human Services, and Education
1016 Longworth House Office Bldg.
Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

As you prepare the Fiscal Year 2019 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, we respectfully request that you include $5 million for the Lifespan Respite Care Act (P.L. 109-442) programs.

Respite care provides temporary relief for family members engaged in the full-time task of caring for their aging or disabled loved ones with special needs. Whether they are tending to a mother with Alzheimer’s disease, a husband injured in Afghanistan, or a child with autism, family caregivers provide approximately 80 percent of long term care to the chronically ill in the U.S. In fact, there are over 43 million family caregivers in the U.S., and reports estimate the annual economic value of uncompensated family caregiving to be about $470 billion, more than total Medicaid spending in 2013.

Although the benefits of family caregiving are plentiful, it can take an emotional, mental and physical toll. Respite is the most frequently requested support service among family caregivers; however, the vast majority of family caregivers still go without respite care. Access to respite services has been shown to improve caregiver health and well-being, promote family stability, reduce the likelihood of abuse and neglect, and avoid or delay the need for admission to costlier institutional settings, resulting in significant savings for the health care system and taxpayers. According to a study from the Archives of Pediatrics and Adolescent Medicine, every $1,000 states spent on respite services in the preceding 60 days resulted in an 8 percent drop in the odds of hospitalization.

The Lifespan Respite Care Program was authorized in 2006 as the only federal program to address respite issues for families regardless of age or disability. While some respite services are offered to certain populations through initiatives under the Department of Veterans Affairs and Medicaid, the lack of coordination and resources continues to impede access to these crucial supports. This program has already provided grants to 37 states and the District of Columbia to help coordinate federal, state and local resources and streamline the delivery of planned and emergency respite services, provide services for unserved groups, recruit and train respite workers, as well as train caregivers themselves.
For families and individuals who don’t qualify for any public or private respite funding, these programs may be holding out the only helping hand. For our wounded service members and veterans returning with traumatic brain injuries and other polytraumas, Lifespan Respite systems could be the lifeline their families must turn to in their new roles as life-long family caregivers. Further, Lifespan Respite is often the only open door for families affected by conditions and diseases like multiple sclerosis with earlier onset—since many existing respite programs have age restrictions and are targeted towards children or the aging.

With proper community supports like respite services, we can prevent the dramatic shift of these costs onto our health care system. The Lifespan Respite Care program is the only federal program that stands ready to meet these goals with funds for respite start-up, training, and coordination.

We urge you to include $5 million for Lifespan Respite Care Act programs in the FY19 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, and we look forward to working with you on cost-effective and proven ways to support our nation’s family caregivers.

Sincerely,

Jim Langevin
Ann M. Donley
Bill Foster
Debbie Dingell

Gregg Harper
Brooke Lee
Hoyt D. Drench
John S.
Members of Congress
Adriano Espaillat
Ann McLane Kuster
Barbara Lee
Bill Foster
Bradley S. Schneider
Carol Shea-Porter
Chellie Pingree
Daniel W. Lipinski
Danny K. Davis
David Scott
Debbie Dingell
G. K. Butterfield
Gerald E. Connolly
Gregg Harper
Jamie Raskin
Jan Schakowsky
John Garamendi
John Yarmuth
Lloyd Doggett
Mark DeSaulnier
Michelle Lujan Grisham
Nanette Diaz Barragán
Raúl M. Grijalva
Sean Patrick Maloney
Steve Cohen
Ted Deutch
Terri A. Sewell
Tulsi Gabbard