## Congress of the United States Washington, DC 20515

November 22, 2010

President Barack Obama
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear President Obama,

As you consider priorities for the upcoming Fiscal Year 2012 budget proposal, we write to request that you recommend funding for the Lifespan Respite Care Act program (P.L. 109-442) at \$50 million. Given the serious fiscal constraints currently facing our country, this request has been reduced by one half below the previous fiscal year's authorized and requested amount.

On October 29, 2010, family caregivers everywhere were honored by your Presidential Proclamation designating November 2010 as National Family Caregivers Month, which accurately underscored the need to support our family caregivers. Further, your October 30, 2009 Proclamation cited the Lifespan Respite Care Act as an important resource for caregivers of children and adults, with opportunities to receive much-needed assistance and take part in support programs with other families.

Despite its widely supported enactment in 2006, the Lifespan Respite Care program received only \$2.5 million in Fiscal Years 2009 and 2010. However, we were pleased to see your commitment to increased program funding totaling \$5 million in your Fiscal Year 2011 budget submission to Congress. As the only federal program to address respite accessibility and affordability issues for families regardless of age or disability, it serves a critical and unique purpose of improving the quality of care at home while guarding against increased state and federal long-term care costs in the future.

The Lifespan Respite Care Program authorizes competitive grants to state agencies and Aging and Disability Resource Centers, in collaboration with a public or private non-profit state respite coalition or organization, to make quality respite available and accessible to family caregivers across the lifespan. It allows grantees to identify, coordinate and build on federal, state and local respite resources and funding streams, and would help support, expand and streamline planned and emergency respite, provider recruitment and training, and caregiver training.

The first twelve state grantees are making important strides with limited grant funding, but further progress will be hampered without expanded resources. While Congress prepares reauthorizing legislation for this program in FY2012, a lack of adequate funding could make it difficult to demonstrate sufficient success to warrant its continuation, despite the well-documented need.

The funding request for this proposal is extremely modest relative to the billions of dollars worth of uncompensated care provided today by the nation's 65 million family caregivers. According to the latest AARP study in 2007, the economic value of uncompensated family caregiving to the U.S. economy was estimated at \$375 billion – up from \$350 billion the previous year and more than total Medicaid spending in 2007, including both federal and state contributions for medical and long-term care, at \$311 billion. Even with the progress we made in supporting long-term services and supports in health care reform, the unanswered respite needs of these family caregivers could undermine progress made toward a successful home and community-based system.

Moreover, in these times of serious budget constraints, respite provides a valuable tool to aid in economic recovery. A recent study from the National Alliance on Caregiving and Evercare demonstrated that the economic downturn has had a particularly harsh effect on family caregivers. The study found that six in ten caregivers are workers, and in this economic climate 50 percent of them are less comfortable with taking time off from work to care for a family member or friend. According to another study by the National Alliance for Caregiving and the MetLife Institute, American businesses lose up to \$33.6 billion annually in productivity costs related to caregiving responsibilities.

Respite, the most frequently requested family support service, has been shown to provide family caregivers with the relief necessary to maintain their own health, balance work and family, bolster family stability, keep marriages intact, and avoid or delay more costly nursing home or foster care placements. Delaying nursing home, institutional or foster care placement of just one individual for several months can save Medicaid, child welfare, or other government programs tens of thousands of dollars.

For families and individuals who may not qualify for any public or private respite funding, including children with severe disabilities, teens with serious emotional and psychological conditions, and adults with Multiple Sclerosis, ALS, traumatic brain injury, spinal cord injuries, cancer, Alzheimer's and many other chronic physical and mental health conditions, these programs may be holding out the only helping hand. For our wounded veterans returning home from war 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.

The Lifespan Respite Care Act is the only federal program that stands ready to meet these goals with funds for respite start-up, training, and coordination. We strongly believe that increased investment in prevention services, like respite, will reap better outcomes and lower costs for patients, their families and the health care system. We request that you recommend \$50 million in the President's FY 2012 budget request to Congress, and we thank you for your ongoing leadership on this issue.

Sincerely,

mes R. Langevin

Member of Congress

M. Grijalva

Member of Congres

Joyd Doggett

Member of Congress

Janide D. Schakowsky

Member of Congress

**Ed Pastor** 

or r of Congress

Any Frank Member of Congress

Barney Frank

Member of Congress

Member of Congress

Gerald E. Connolly Member of Congress

Member of Congress

Jim McGovern Member of Congress

Member of Congress

Member of Congress

Kathy Greenlee, Assistant Secretary on Aging Cc:

Jeffrey Crowley, Director, Office of National AIDS Policy and Senior Advisor on

Disability Policy, the White House