May 20, 2022

Dear Senators Baldwin and Capito:

On behalf of the Alzheimer’s Association and the Alzheimer’s Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer’s and other dementia, and to their caregivers. The Alzheimer’s Association and AIM write today to support the Palliative Care and Hospice Education and Training Act (PCHETA), S.4260, which would expand and strengthen workforce training in palliative and hospice care, as well as improve education and awareness, among other provisions.

The burden of Alzheimer’s on individuals and families continues to grow. Today, more than 6 million Americans aged 65 and older are living with Alzheimer’s dementia and by mid-century, this number is expected to nearly double. Total payments for all individuals living with this disease are estimated at $321 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover $206 billion, or 64 percent of the total health care and long-term care payments for people with Alzheimer’s or other dementias. Total payments for health care costs, including hospice care, for people with Alzheimer’s and other dementias are projected to increase to nearly $1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

Alzheimer’s is a progressive, neurodegenerative and fatal disease for which there is currently no treatment or cure. Palliative and hospice care can improve both the quality of care and quality of life for those with advanced dementia. For nursing home residents with moderate-to-severe dementia, statistics show that those who received an initial palliative care consultation between one and six months before death had significantly fewer hospitalizations and emergency department visits in the last seven and 30 days of life, and individuals who receive an initial consultation within one month also had significantly fewer hospitalizations in the last seven days of life compared with those who did not. Individuals enrolled in hospice care are less likely to be hospitalized in the last 30 days of life and more likely to receive regular treatment for pain. Satisfaction with medical care is higher for families of individuals with dementia who are enrolled in hospice care than for families of individuals with dementia not enrolled in hospice care.

The Palliative Care and Hospice Education and Training Act would establish the Palliative Care and Hospice Education Centers to improve training in palliative care, develop and disseminate curricula, support the training and retraining of faculty, and provide students with clinical training in appropriate sites of care. It would also establish fellowship programs within the new Palliative Care and Hospice Education Centers to provide short-term intensive courses focused on palliative care, establish a program to promote career development for certain physicians, authorize grants to schools of medicine and other entities, and would provide for the establishment of a national campaign to inform patients, families and health professionals about the benefits of palliative care and the services that are available to support patients with serious or life-threatening illness. Additionally, this legislation would direct the National Institutes of Health to use existing authorities and funds to expand palliative care research.
The Alzheimer’s Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer’s and other dementia. If you have any questions about this or any other legislation, please contact Rachel Conant, Vice President of Federal Affairs, at rconant@alz-aim.org or at 202.638.7121.

Sincerely,

[Signature]

Robert Egge
Chief Public Policy Officer, Alzheimer’s Association
Executive Director, Alzheimer’s Impact Movement