Testimony for Public hearing House Health and Human Services Committee

February 7, 2017

James Covel Public Policy Specialist Alzheimer's Association

Strong Support of HB 2031

Dear Chair Hawkins and members of the House Health and Human Services Committee,

My name is James Covel I'm the Public Policy Lead for the Alzheimer's Association in Kansas. Over the last several months, I've had the honor and privilege of working with persons with dementia and their families. Caring for people with dementia is an incredibly challenging task, not only for family caregivers but even for trained professionals. Palliative care addresses chronic illnesses such as Alzheimer's and other forms of dementia and provides a certain level of symptom management, communication, and care coordination that other medical specialties cannot. For this reason, the Alzheimer's Association supports HB 2031, as it will help to improve the quality of availability of palliative care in Kansas through the creation of an advisory council within KDHE as was as a program to educate state officials and the public on the benefits and practices of palliative care.

Alzheimer's disease is one of the most devastating illnesses known to man. It does not discriminate and it does not leave survivors, the disease has a 100% mortality rate. This is a disease that gets progressively worse over time, robbing people of the very fabric of their being, taking their memories, their identity, and eventually their lives. Palliative care helps ease symptoms and increase quality of life for people facing Alzheimer's disease and their families.

Nearly half of all people with Alzheimer's and other dementias are in hospice care at the time of their death. Less than half of he surveyed nursing homes nationwide have some sort of palliative care program. For people with advanced dementia, such care — which focuses on managing and easing symptoms, reducing pain and stress, and increasing comfort — improves quality of life, controls cost, and enhances patient and family satisfaction.

A recent study shows that nursing home residents with dementia who receive palliative care at the end of life, compared to those who do not receive such care are up to 15 times less likely to die in a hospital, nearly 2.5 times less likely to have a hospitalization in the last 30 days of life and up to 4.6 times less likely to visit the emergency room in the last week of life.

Of all people living with dementia, 18.6 percent are currently in hospice care – a higher percentage than other chronic condition – and one in every six seniors in hospice care has a primary hospice diagnosis of Alzheimer's or another dementia.

Nearly half of all people with dementia die in hospice care. However, the availability and quality of palliative and hospice care is a concern. Less than half of surveyed nursing homes have a palliative care program. Of those with a program, only 42 percent include consultation by a physician certified in hospice/palliative care, and only 28 percent had a designated director of palliative care.

This advisory council would seek ways to provide support and extend services of current palliative care programs in Kansas while also addressing the challenges associated with palliative care delivery. It will also create a public education program to teach the broader public about the benefits of palliative care. As such programs have grown and spread across the country, it is critical for Kansas to support and educate people about palliative care, not only for the betterment of dementia care, but also for the betterment of all end of life care giving.

Thank you,

James Covel