Madame Chair Gossage and Members of the Senate Public Hearing Committee, my name is Elaine Belardo, and I am testifying as a proponent of SB-88 Requiring Dementia Training for the State Long Term Care Ombudsman's Office. My experience with the State Long Term Care Ombudsman's Office occurred in June 2021. My husband, Rear Admiral (Retired) Jose H. Belardo III, was diagnosed with Early Onset Alzheimer's disease at the age of fifty. It was my honor to be his caregiver, and his remarkable character was never touched by the brutality of Alzheimer's.

As a 100% permanently disabled veteran my husband was afforded benefits in accordance with his disability rating that provided emergency long term care placement in my absence. Five years into the disease, my husband was in the later stages by 2021, and was mostly nonverbal, able to feed himself, but needed help with all activities of daily living and navigating the day. In mid-June 2021, my highly active and physically able 86-year-old mother became suddenly ill. A Veterans Administration Registered Nurse and Social Worker helped plan my husband's Long Term Care placement with full understanding of his needs as a late-stage Alzheimer's patient. He was placed for ten days, and I left to tend to my mother who died two days after my arrival. While I was away, friends visited and checked on my husband every day for eight days. I returned on the ninth day to find that he was highly agitated, fearful and had a black eye, and a large hematoma in the center of his forehead. When I asked what happened, it was explained that he went to bed in stable condition and was found asleep in bed the next morning with a black eye and bruising on his face. It was further explained that it was an unwitnessed fall, and he must have fallen out of bed, and then put himself back to bed. I left written instructions that he did know how to get into a bed and had to be placed in bed and covered. For him to be found in the bed, asleep with covers after a fall would require quite a bit of help. I looked for ways to advocate for him. I spoke with the State Long Term Care Ombudsman's Office expecting a response to my concerns that he was assaulted, advocacy, and an investigation. In the end, they created a scenario that my husband did not have capacity to conduct and labeled the incident an unwitnessed fall that required no investigation. Even after I explained the improbability of the scenario based on how far the disease had progressed, and my nightly experience as his caregiver, I was told" you never know what a person with Alzheimer's will do." Lack of knowledge about late-stage Alzheimer's dementia, stigma and stereotyping people with dementia left no room for the Ombudsman to act on my husband's behalf. For so long, I have wrestled with why such a fine gentleman like Jose' had to endure painful mistreatment in a Long-Term Care facility. I am hopeful that sharing the deeply painful experience my beloved husband endured will be a catalyst for change in the State Long Term Care Ombudsman's Office. Increasing knowledge, awareness and understanding of the unique needs of people with a dementia diagnosis in Long Term Care facilities is my hope for SB-88. I urge the committee to support SB-88.

Respectfully submitted,

Elaine Belardo



To: Senator Beverly Gossage, Chair, and Members, Senate Public Health and Welfare Committee From: Kylee Childs, Director of Government Affairs, LeadingAge Kansas Date: February 11, 2025

LeadingAge Kansas is the state association for not-for-profit and mission-focused aging services. We have 150 member organizations across Kansas, which include not-for-profit nursing homes, retirement communities, hospital long-term care units, assisted living, home plus, senior housing, low-income housing, home health agencies, home and community-based service programs, PACE and Meals on Wheels. Our members serve more than 25,000 older Kansans each day and employ more than 20,000 people across the state.

Proponent Testimony for SB88

We support requiring the state Long-Term Care Ombudsman staff to receive training in memory care. The Long-Term Care Ombudsman's office is there to assist residents of nursing homes, assisted living facilities and other long-term care settings with:

- Educating residents and protecting their rights.
- Receiving and investigating complaints regarding violation of those rights.
- Facilitate discussions related to facility transfers or discharges and care planning.
- Reporting concerns without fear of retaliation.

On the flip side, the office is also there to support providers in:

- Addressing system issues and improving quality care.
- Offering guidance on residents' rights.
- Mediating disputes between residents, families, and facilities.

A lot of our providers have experienced encounters with the LTC Ombudsman's office that resulted in guidance negating the reality of a resident's condition, the legal implications when a Power of Attorney (POA) is involved in decision making on behalf of the resident, and a lack of understanding between residents' rights and regulatory requirements. We believe training on recognizing and understanding how to interact with residents with memory care diagnoses will improve these interactions and result in better outcomes for residents, their families, and providers.

We respectfully request the committee to pass SB88. I'm available for follow-up questions if needed.

To: Kansas Legislature

Re: SB 88 Dementia Training for Ombudsman

February 6, 2025

Dear Legislature,

I fully support Bill SB 88 for Dementia training to be passed for the Ombudsman program. I had a good experience last year with Ombudsman Hector Rodriguez. He was extremely helpful as a liaison between a Senior Facility and my parents. This particular case did not deal directly with Dementia, but it involved my father being denied access to visit my mother who was in the Memory Care unit.

I have seen first-hand how some members of the care staff in Memory Care units occasionally give improper care due to lack of training or not applying what they learned. I've seen staff yell at a patient, telling her to shut up and sit down. I've witnessed a dining staff person tell a resident that they made a mess, again, without realizing the psychological effect that might have. I've seen improper techniques for helping a resident with transfers or other mobility issues. I've witnessed care givers ignore residents who say they are not feeling well, only to have that person sent to the emergency room shortly thereafter.

The good staff members are usually very good. They're very compassionate and understanding, and you wish the whole staff would model their behavior. But the rank and file tend to be unmotivated, rude or belligerent, but yet think highly of themselves.

The required Ombudsman training would, hopefully, help raise the standards of care because the facilities would have to take more responsibility for their actions. If the Ombudsman coming into their facility was fully up to speed on all aspects of care and treatment, then the facility would have less opportunity to twist the situations or deny that they did anything wrong. It would help the Ombudsman work from a position of strength instead of any perceived weakness.

Respectfully,

Craig Fisch 13836 W 110th TER Lenexa, KS 66215 (913) 244-9150 cfischbiz@gmail.com



RE: KABC testimony for Senate Committee on Public Health & Welfare

Proponent Testimony- Senate Bill 88 (Written only)

Members of the Committee,

Thank you for the opportunity to provide testimony today. Kansas Advocates for Better Care (KABC) is a non-profit organization dedicated to improving the quality of long-term care for older adults, regardless of where they reside.

As Executive Director of KABC, I respectfully request your support for Senate Bill 88:

As of 2020, 54,500 Kansans aged 65 and older live with Alzheimer's and will likely need long-term care supports. By law, long-term care ombudsmen must prioritize residents' requests and preferences with their consent and direction, even when a legal representative is involved. Given the unique and complex needs of residents with cognitive impairments, ombudsmen must receive comprehensive training to effectively support them and speak up for their rights.

Training for Long-Term Care Ombudsman staff and volunteers is essential for effective advocacy. The Initial Certification Training Curriculum follows federal standards, requiring at least 36 hours of training, including independent study, fieldwork, and classroom instruction. Continuing education requirements mandate 18 hours annually, exceeding the requirements for CNAs in Kansas.

The curriculum already covers critical topics, including Alzheimer's and dementia care, which has been a recurring training focus. Requiring this training in statute reinforces its importance. Ombudsmen play a vital role in protecting residents' rights, ensuring their voices are heard, and supporting decision-making, including those with dementia.

KABC supports SB 88 and further advocates for dementia care training to be mandatory for all long-term care facility staff in Kansas, both initially and as part of ongoing education.

Thank you for your time and consideration of this important proposal.

Sincerely,
Daniel Goodman

Daniel Goodman Executive Director, Kansas Advocates for Better Care My name is David Herdman and I will be testifying in writing only as a proponent of SB 88 – Requiring Dementia Care training for the State Long Term Care Ombudsman office.

My testimony follows. Madame Chair Gossage, it is my privilege to testify about this issue. You and I just met last year at Alzheimer's Advocacy Day and at Union Station in Kansas City just a couple of weeks ago discussing a job training program I was representing at the "Giving Machines" in Union Station. Always a pleasure to talk and meet with you.

My testimony is on the following page.

David Herdman

Madame Chair Gossage and Members of the Senate Public Health Committee,

My name is David Herdman and I am submitting my support of SB88 -Requiring Dementia Training for the State Long Term Care Ombudsman's Office.

My family has 9 Aunts, Uncles, Cousins, and Siblings who have passed from Alzheimer's or are living with it in different stages presently.

For 8 years, I have been an Alzheimer's test patient for new treatments and life changes at the KU Alzheimer's Research facility. My genetic markers indicate I am 12 times more likely to have Alzheimer's at some point in time.

Throughout this family saga, my cousins and I have surveyed many different facilities in different states to see if they were a good fit for our relatives.

It is simple for a facility to say "yes we can handle patients who need memory care", but not so simple to provide the service. This can be a profitable move for a facility, but it may not end up being best for the patient.

Having an "educated and aware" ombudsman may be the best protection for the patients. And those at the Alzheimer's association will provide that training at no charge.

Thanks for your consideration.

David Herdman

February 6, 2025

Public.health.welfare@senate.ks.gov

Dear Madame Chair Gossage and Members of the Senate Public Health Committee,

I am testifying as a proponent of SB 88 - Requiring Dementia Training for the State Long Term Care Ombudsman's office.

Thank you for your time and consideration as I share a recent experience working with a family whose loved one was diagnosed with Alzheimer's Disease and residing in an assisted living memory care unit in Kansas. It highlighted the critical need for an ombudsperson to be trained in dementia care.

The resident was experiencing significant communication challenges that were not being adequately addressed by the staff despite several care planning sessions and meetings with the Director of Nursing. The family was frustrated and felt helpless as their loved one's health and well-being was at risk so we turned to the LTC ombudsperson for assistance.

While the ombudsperson was committed to advocating on behalf of the dementia resident, it became clear that a deeper understanding of dementia care—hence more confidence-- would have significantly improved their ability to assess the situation and provide meaningful recommendations to the staff. The ombudsperson struggled to interpret the resident's behaviors through the lens of dementia, missing key opportunities to suggest person-centered approaches that could have improved the resident's quality of life.

If the ombudsperson had been trained in dementia care, they could have played a more effective role in ensuring that the facility was implementing best practices. They could have also helped the family better understand the unique needs of their loved one and supported them with greater advocacy and empathy.

Dementia-specific training is not just beneficial, it is essential. This is especially true for the advocates who are expected to protect our vulnerable Kansans experiencing dementia. When our advocates are equipped with knowledge about person-centered care and best practices in dementia care, they can ensure that residents receive the dignified and compassionate care they deserve.

When a family or resident requires a Kansas Ombudsperson, they should feel confident their advocate is thoroughly prepared to understand the complexities of dementia care and will appropriately address the situation that leads to a solution.

I strongly urge your support for SB 88 and thank you for your time today.

Valerie Blanco Johnson, CSA®

Calcris Banco Shuson

Certified Senior Advisor

February 6, 2025

Madame Chair Gossage and Members of the Senate Public Health Committee. My name is Terry Roberts and I am testifying as a proponent of SB 88 – Requiring Dementia Training for the State Long Term Care Ombudsman's office.

Thank you for your service and the impact you have on the quality of care for all of our families.

I am writing this to share our experience with our mother.

Our mother was a math and English teacher. She created and conducted seminars on caring for the chronically ill and also grief recovery.

Mom was widowed at the age of 44 and moved back to TX to take care of her parents. She continued to teach, serve in her church, and in her community.

Mom started showing signs of diminished capacity in her late 50s, but managed fairly well until her mid-70s. She was able to stay at home for a couple of years with 24 hour care and then moved to an assisted living facility.

She did quite well at the assisted living facility. Her room was always nice and neat, her clothes were clean, and she enjoyed visiting her friends. The time came when she was not able to stay in the assisted living area and was moved to memory care. While in memory care she would walk around and check on people and try to be helpful in her own way.

When my brother and I visited we could tell if she was having a bad day or if something was more seriously wrong. There were several times we had to request that she be checked for a UTI. Sometimes she did have a UTI, other times, it was just the progression of the disease. She lost her capacity for speech and also lost the sense of pain. She fell and broke her nose, but did not feel the pain. After that she developed a UTI. My brother requested that she be tested and see a doctor and it did not happen. Finally, my brother took her to an ER on a Thursday evening. On

Friday the doctor told us that the infection had spread throughout her body, to treat her would only prolong her suffering. She had a living will and by following her wishes a palliative care plan was put into place and she was admitted to hospice. She died 5 days later.

I cannot help but wonder if the staff had been better *trained* and if there had been *more* staff if mom would have lived longer. She did not have a great quality of life, yet she found joy each day.

Anyone caring for our loved ones when they are not capable of caring for themselves needs to be trained properly. Regardless if that is direct care or in an oversight capacity.

Compassion without Competency is Neglect.

Your actions or inactions while serving on this committee impact the quality of life and the quantity of life for countless Kansans. As you conduct your business each day, I ask that you look at what you are doing as though you are developing a plan of care for your mother, your father, your spouse, your children, and yes, yourself.

Your decisions will determine the level of competent compassionate care you will receive someday.

We owe so much to our loved ones who have raised us and cared for us.

"This debt demands a result, not an appeasement." From, Guy Ritchie's

The Covenant

Respectfully,



Signed by: Terry Roberts

Senate Committee on Public Health and Welfare Proponent Testimony SB88 February 11, 2025

Dear Senator Gossage and Members of the Committee,

Thank you for this opportunity to provide written testimony as a proponent of SB88;

I am Camille Russell and have personal experience as a family member of a loved one whose final time, living with Alzheimer's, was in a nursing home. I also spent 9 years as a regional and state long-term care ombudsman in Kansas, communicating with and advocating for thousands of residents; a large amount of them with Alzheimer's disease and related dementias.

Training for Ombudsman staff and volunteers is critical for maintaining an effective long-term care Ombudsman program.

The Initial Certification Training Curriculum for Long-Term Care Ombudsman Programs is a basic curriculum for initial certification training based on the requirements included in the Administration for Community Living (ACL) Long-Term Care Ombudsman Program Training Standards. https://ltcombudsman.org/omb_support/training/norc-curriculum

Per ACL's training standards, each state is required to provide a <u>minimum of 36 hours</u> of initial certification training that includes:

- up to 7 hours of independent study;
- at least 10 hours in the field; and
- a range of 16-20 hours of classroom style training (can be provided in-person, virtual, or by phone).

The current National Long-Term Care Ombudsman Resource Center curriculum provides approximately 30 hours of training time. However, the training time is customizable and will depend on a variety of factors, such as the number of trainees; amount of time used for discussion, questions, and activities; state-specific information; etc. There are ten online training modules that take approximately 10 hours to complete. They are used in coordination with the original training materials and those hours can be incorporated into the total training time.

A vast amount of required subject matter is covered and the initial certification already includes an introduction to common health issues the residents may experience, including Alzheimer's and other dementias.

It is important to note that long-term care ombudsmen are also required to complete a minimum of 18 hours of continuing education annually. This is 6 more hours of continuing education annually than is currently required of CNA's in Kansas, who work with residents daily. Person-centered care: specifically including residents living with dementia has been an annual training provided to long-term care ombudsmen for several years as it has been deemed an immensely important topic.

Making this specific addition to the Kansas Long-Term Care Ombudsman statute will serve to ensure this important topic remains a priority ongoing.

Both initial and ongoing training in ALL the required topic areas is essential to long-term care ombudsmen fulling their primary role and core duty as *resident directed* advocates. Long-Term Care Ombudsman are resident directed and play a crucial role in protecting the rights and well-being of all residents. For residents with Alzheimer's disease and related dementias, long-term care ombudsman work to ensure that their capacity to make decisions is respected and that they are empowered to participate in their own care to the full extent possible. This is done using active listening and observation to ensure residents understand their rights, choices and potential outcomes, and can express their wishes. Ombudsmen are required to work with residents first and foremost to gain their consent and direction, even when a resident has a legal representative.

This is a topic of training that would be important to be required for ALL people working in all long-term care facilities; both as initial training and as an annual continuing education.

Long-term care ombudsmen often are called upon to set an example for others, in that I support SB88 and furthermore encourage this to be added as required training for staff working in all adult care homes in Kansas.

Respectfully,

Camille Russell

PO BOX 276

Chanute, Kansas 66720

Camille Russell

iam4accountability@yahoo.com

Madame Chair Gossage and Members of the Senate Public Health Committee

I am providing written testimony in support of SB88.

Unfortunately my wife died due to Alzheimer's disease. She was in a care facility for 2.5 years. Staff at the facility were required to take a training course. All of the caregivers were trained in the care of dementia patients.

The director at the facility where my wife was a resident suggested I take their training course. I did take the training course. Taking the course I became aware of a number of things I was doing that wasn't appropriate. For example, approaching the patient, feeding the patient and overall expectations.

Having this knowledge helped me understand what my wife was experiencing and what I could do to support her life the best I could.

Lee Wages