April 3, 2024

The Honorable Tammy Baldwin Chair Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Senate Committee on Appropriations Washington, DC 20510

The Honorable Shelley Moore Capito Ranking Member Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Senate Committee on Appropriations Washington, DC 20510 The Honorable Robert Aderholt Chair Subcommittee on Labor, Health and Human Services, Education, and Related Agencies House Committee on Appropriations Washington, DC 20515

The Honorable Rosa DeLauro Ranking Member Subcommittee on Labor, Health and Human Services, Education, and Related Agencies House Committee on Appropriations Washington, DC 20515

RE: FY 2025 LHHS Funding and Report Language Request to Support Palliative Care Research

Dear Chairs Baldwin and Aderholt and Ranking Members Capito and DeLauro:

The undersigned member organizations of the Patient Quality of Life Coalition (PQLC) write to thank you for including \$12.5 million for the National Institute of Aging (NIA) to implement a trans-Institute, multidisease strategy to focus, expand, and intensify a national research program in palliative care. Your ongoing bipartisan, bicameral, and steadfast leadership has been instrumental in realizing this step to strengthen the commitment to support patients facing serious illness and their families. PQLC is a group of over 40 organizations dedicated to advancing the interests of patients and families facing serious illness, with the overarching goal of providing patients with serious illness greater access to palliative care services. Our members represent patients and their caregivers, health professionals, and health care systems.

As you begin work on the FY 2025 Labor, Health and Human Services, Education, and Related Agencies (Labor/HHS) bill, we request \$12.5 million to support the newly announced consortium for palliative care research across the lifespan. Such funding will advance research, foster development of early and mid-stage researchers, and engage various healthcare systems and community partners.

FUNDING REQUEST

On behalf of our nationwide network of advocates, PQLC urges you to continue to support access to quality palliative care and appropriate, effective pain management by prioritizing palliative care research at the NIH/NIA.

We urge the Senate Appropriations Subcommittee on Labor/HHS to provide \$12.5 million in FY 2025 funding to NIA for the trans-Institute, multi-disease Consortium for Palliative Care Research Across the Lifespan.



REPORT LANGUAGE REQUEST

Building on current efforts of NIH/NIA to establish the Consortium for Palliative Care Research Across the Lifespan, we offer the language below for your consideration as part of the report to accompany the FY 2025 LHHS appropriations:

Palliative Care Research.—The Committee provides \$12,500,000 for NIA to coordinate the work of the Consortium for Palliative Care Research Across the Lifespan, including developing early and mid-stage researchers, and engaging various healthcare systems, providers, and community partners. The Committee recognizes that palliative care is a critical area of research and informs supportive care for patients of all ages with serious illness and their families focused on relief of symptoms and suffering, communication of prognosis and treatment options in the context of patient goals, and coordination of care within and across healthcare settings.

BACKGROUND

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms and stress of a serious illness. Palliative care is appropriate at any age and any stage in a serious illness (ideally made available to patients with serious illnesses upon diagnosis) and can be provided along with curative treatment. By focusing on priorities that matter most to patients and their families, palliative care has been shown to improve both quality of care and quality of life during and after treatment. Furthermore, palliative care reduces hospital utilization and results in overall cost savings. Yet, despite the demonstrated benefits of palliative care, there remain millions of Americans who are unable to access such services.

This requested FY 2025 appropriations funding would continue the valuable work started by the Appropriations Committee's FY 2024 palliative care funding. Continued funding in FY 2025 will allow NIH to continue the five-year plan set out in the NOFO to develop a specialized center called the "Consortium." The aim of the Consortium will be to provide resources, expertise, and coordination to advance innovative, high-quality research on palliative care for those living with serious illnesses across the lifespan. This research infrastructure will encompass Alzheimer's disease (AD) and AD-related dementias (ADRD), cancer, and other serious illnesses and populations relevant to the partnering ICOs.

We greatly appreciate your leadership and previous support of advancing palliative care research.

Our organizations welcome the opportunity to discuss our requested funding and report language with you. If you have any questions, please contact Daniel E. Smith, acting chair of PQLC at <u>dan.smith@advocacysmiths.com</u>.

Sincerely,

Alzheimer's Association Alzheimer's Impact Movement American Academy of Hospice and Palliative Medicine American Cancer Society Cancer Action Network

- American Heart Association
- Association for Clinical Oncology
- Association of Pediatric Hematology/Oncology Nurses
- **Cancer Support Community**
- Catholic Health Association of the United States
- Center to Advance Palliative Care
- Children's National Hospital
- Coalition for Compassionate Care of California
- The CSU Shiley Haynes Institute for Palliative Care
- Fire & Water Consulting
- GO2 for Lung Cancer
- Hospice Action Network
- Hospice and Palliative Nurses Association
- **Motion Picture & Television Fund**
- Mount Sinai Health System
- National Alliance for Caregiving
- National Coalition for Hospice and Palliative Care
- National Hospice and Palliative Care Organization
- National Palliative Care Research Center
- National Patient Advocate Foundation
- **Oncology Nursing Society**
- Pediatric Palliative Care Coalition
- Physician Associates in Hospice and Palliative Medicine
- St. Baldrick's Foundation
- Trinity Health