



May 18, 2023

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 Robert Aderholt  
Chair  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
House Committee on Appropriations  
Washington, DC 20515

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

**RE: Palliative Care Research Fiscal Year 2024 Request; National Institutes of Health**

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

Thank you for your ongoing bipartisan, bicameral, and steadfast leadership in support of patients and families facing serious illness. The Patient Quality of Life Coalition (PQLC) was established to advance their unique interests and includes more than 40 organizations dedicated to improving quality of care and quality of life for all patients, from pediatrics to geriatrics, as well as supporting public policies that improve and expand access to quality palliative care and appropriate pain management. PQLC members represent patients, caregivers, health professionals, and health care systems.

**REQUEST**

On behalf of our nationwide network of advocates, we urge you to support access to quality palliative care and appropriate, effective pain management by prioritizing a *Palliative Care, Trans-Institute Strategy* led by the National Institute of Aging (NIA) in the Fiscal Year 2024 Labor, Health and Human Services, Education, and Related Agencies appropriations bill. We offer the language below for your consideration:

***Palliative Care, Trans-Institute Strategy.***— Palliative care is specialized medical care for people living with a serious illness and is focused on treating the discomfort, symptoms, and stress of such illness. Palliative care has the potential to improve patient care, patient-clinician communication, and patient-centered outcomes while decreasing unwanted and/or burdensome treatments and enhancing quality of life for people with serious illness, their loved ones, and their care partners. The Committee provides \$12,500,000 for NIA to implement a trans-Institute, multi-disease strategy to focus, expand, and intensify national research programs in palliative care. Funding would establish a comprehensive multi-Institute and multi-Center initiative aimed at a wide variety of palliative care research, training, dissemination, and implementation of projects to intensify the strategic coordination of palliative care research efforts. Funding is provided to establish an extramural-based palliative care consortium with no less than three sites to provide technical assistance, pilot and exploratory grant funding,

research dissemination, data repositories, data analytics, and career development support for interdisciplinary palliative care. Of this amount, at least \$3,000,000 is provided for several multi-year, early-career development grants modeled after NIA's GEMSSTAR program. Appropriations provided in fiscal year 2024 for training is expected to cover 2 years of funding for career development awards. The Committee requests a briefing within 120 days after enactment of this Act on how this strategy will be established and implemented, including timelines on when funding opportunities will be issued and when funding will be awarded.

We greatly appreciate the Appropriations Committees' previous support of advancing palliative care research, especially the report language included in the fiscal years (FY) 2011, 2019, and 2023 LHHS reports. As you may know, the FY 2024 Congressional Justification for National Institutes of Health's (NIH) summarized the ongoing activities related to palliative care research and responded to the Subcommittees' request to "ensure that palliative care is integrated into all areas of research across NIH" and to provide an update on plans to coordinate such research. The requested funding will support the need for NIH to develop and implement a trans-Institute strategy to expand and intensify national research programs in palliative care.

Our organizations welcome the opportunity to discuss our views with you. If you have any questions, please contact Daniel E. Smith, acting chair of PQLC at [dan.smith@advocacysmiths.com](mailto:dan.smith@advocacysmiths.com).

Sincerely,

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 (CAPC)  
Children's National Hospital  
The CSU Shiley Haynes Institute for Palliative Care  
Fire & Water Consulting  
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  
PAs in Hospice and Palliative Medicine  
St. Baldrick's Foundation