

COALITION MEMBERS

American Academy of Hospice
and Palliative Medicine
(AAHPM)

Association of
Professional Chaplains
(APC)

Center to Advance
Palliative Care
(CAPC)

HealthCare
Chaplaincy Network
(HCCN)

Hospice & Palliative
Nurses Association
(HPNA)

National Association for
Home Care & Hospice
(NAHC)

National Hospice and
Palliative Care Organization
(NHPCO)

National Palliative
Care Research Center
(NPCRC)

National Partnership for
Healthcare and Hospice
Innovation
(NPHI)

Palliative Care
Quality Collaborative
(PCQC)

Physician Assistants in Hospice
and Palliative Medicine
(PAHPM)

Social Work Hospice &
Palliative Care Network
(SWHPN)

Society of Pain and Palliative
Care Pharmacists
(SPPCP)

**Statement by the National Coalition for Hospice and Palliative Care on
Fiscal Year 2024 Appropriations for the National Institutes of Health, the
National Institute on Aging and Related Institutes**

**Submitted for the record to the Senate Appropriations Subcommittee on
Labor, Health and Human Services, and Education and Related Agencies
May 18, 2023**

The National Coalition for Hospice and Palliative Care (Coalition) appreciates the opportunity to submit testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education and Related Agencies on the appropriations for the National Institutes of Health. In FY 2024, **the Coalition requests \$12.5 million to implement the strategy as outlined in NIH’s most recent [Congressional Justification](#) to Congress for the NIH to advance a multi-institute NIH effort to expand and intensify the strategic coordination of palliative care research efforts.**

Request: The Coalition requests that the Committee provides \$12,500,000 for the National Institute on Aging (NIA), as identified by NIH, as the lead agency 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-Institutes and multi-Centers 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. The Coalition supports funding to establish an extramural-based palliative care consortium with multiple sites to provide technical assistance, pilot and exploratory grant funding, research dissemination, data repositories, data analytics, and career development support for interdisciplinary palliative care.

The Coalition recommends this funding be inclusive of \$3,000,000 for several multi-year, early-career development grants modeled after NIA’s GEMSTAR program. This level of funding would supplement current existing funding at multiple Institutes, Centers, and Offices (ICOs) and support a coordinating center within the National Institute on Aging (NIA) to convene subject matter experts from relevant ICOs; provide career development grants for early-stage investigators; and facilitate NIH-supported core facilities that help connect scientists with needed tools and expertise.

Why do we need palliative care research? The purpose of palliative care research is to improve the evidence-base in order to relieve suffering and improve quality of life for persons and families living with serious illness. “Serious illness” is a health condition that carries a high risk of mortality AND either negatively

impacts a person's daily function or quality of life, or excessively strains their caregivers.”¹ Numerous studies have demonstrated that high-quality palliative care can provide significant benefits for patients, caregivers, and to the health care system itself. ² Palliative care is “beneficial at any stage of a serious illness, is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. It can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.” ³

Current Challenges: There are growing populations of persons living with serious illness for longer periods of time across the lifespan that would benefit from palliative care but for various reasons do not have access. Even when identified, the current evidence base is inadequate to ensure appropriate symptom management, reduce strains on family caregivers, and meaningfully improve quality of life. Research has also uncovered marked inequities in access to palliative care that need to be addressed. Black Americans suffer disproportionately in the face of serious illness and experience worse pain management, ineffective communication from providers, and an outsized burden on family caregivers.

The Coalition thanks the leadership of the Appropriations Committee in multiple prior years for including consistent report language and requests to NIH to establish a trans-Institute strategy due to the growing health care demands for increased access to quality evidenced based palliative care and the inadequate sustainable research infrastructure.

Prior Congressional Appropriations Report Language

FY’ 23: Explanatory Statement to Accompany the Consolidated Appropriations Act, 2023, Palliative Care [p. S8887, [Division H](#) – *Departments of Labor, Health, and Human Services, and Education, and Related Agencies Appropriations Act, 2023*]

- Reiterates need for NIH to develop and implement a trans-Institute strategy to expand and intensify national research programs in palliative care.
- Urges NIH to ensure palliative care is integrated into all areas of research across NIH
- Requests update in FY’24 Congressional Justification

FY’19 [p. 121, [Senate Report 115-289](#), Labor/HHS FY 2019 Appropriations]

- Strongly urges NIH to develop and implement a trans-Institute strategy to expand and intensify national research programs in palliative care to address quality of care and quality of life for the rapidly growing population of individuals in the U.S. with serious or life-threatening illnesses.

FY’11 [pp. 125-126, [Senate Report 111–243](#), Labor/HHS FY 2011 Appropriations]

- Strongly urges the NIH to develop a trans-Institute strategy for increasing funded research in palliative care for persons living with chronic and advanced illness.

On behalf of all of those we serve, the Coalition urges Congress to continue its support for a trans-NIH strategy for palliative care/serious illness research by funding the National Institutes on Aging \$12.5 million based on its recent commitment NIA to take on this leadership role.

According to NIH, “Palliative care has the potential to improve patient care, patient- clinician communication, and patient-centered outcomes while decreasing unwanted burdensome treatments and enhancing quality of life for people with serious illness, their loved ones, and their care partners. NIH recognizes the importance of palliative care, with several NIH Institutes, Centers, and Offices (ICOs) supporting a diverse set of research projects and initiatives focused on this essential area”.⁴

NIA is the leading funder of palliative care research at NIH and currently funds more than a dozen clinical trials on palliative care, including those on dementia-specific palliative care and trials using telehealth to deliver palliative care. Additionally, the National Cancer Institute (NCI), National Institute of Child Health and Human Development (NICHD), National Institute of Nursing Research (NINR), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) have specific palliative care research and clinical trials underway.

New Opportunities in Palliative Care Research: NIH/NIA Commitment

Multiple and additional ICO’s have pledged to work together, under NIA’s leadership, to implement this trans-Institute palliative care/serious illness research strategy including NIA, NCI, NICHD, NIDDK, NINR, National Institute of Mental Health (NIMH), National Health, Lung and Blood Institute (NHLBI), the National Institute of Minority Health and Health Disparities (NIMHD), National Institute of Neurological Disorders and Stroke (NINDS) and the Office of Women’s Health.

Coalition Recommendation: In FY 2024, to summarize, the Coalition requests \$12.5 million for NIH/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. An extramural-based palliative care consortium should be established with multiple sites to provide technical assistance, provide 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 should be provided for several multi-year, early-career development grants modeled after NIA’s GEMSSTAR program.

The [Coalition](#) thanks you for this opportunity to submit recommendations for the record.

The mission of the Coalition is to convene the field, advocate for equitable health care policies, improved health outcomes and establish best practices.

1 (Kelley AS, Bollens-Lund E. J Palliat Med, 2018)

2 [https://aahpm.org/uploads/advocacy/The Evidence for High-Quality Palliative Care.pdf](https://aahpm.org/uploads/advocacy/The_Evidence_for_High-Quality_Palliative_Care.pdf)

3 National Consensus Project, Clinical Practice [Guidelines](#) for Quality Palliative Care, 4th edition, 2018

4 <https://officeofbudget.od.nih.gov/pdfs/FY24/br/NIH%20FY%202024%20CJ%20Significant%20Items%20Volume%20final.pdf>