



**National Coalition for Hospice and Palliative Care
Outside Witness Testimony Prepared for the Senate Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies**

**Fiscal Year 2025 Appropriations for the National Institutes of Health,
National Institute on Aging, and Related Institutes**

Chair Baldwin, Ranking Member Capito, and members of the Subcommittee, thank you for the opportunity for the National Coalition for Hospice and Palliative Care (NCHPC) to submit testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies on the fiscal year 2025 appropriations for the National Institutes of Health (NIH). The NCHPC represents 14 leading professional organizations dedicated to advancing equitable access to quality care for serious illness. Our member organizations speak for the interdisciplinary workforce that delivers palliative care and hospice care. This includes more than 5,500 physicians, 1,000 physician associates, 11,000 nurses, 5,000 chaplains, 8,000 social workers, researchers, and pharmacists, along with over 1,800 palliative care programs and 5,300 hospices. Our coalition provides a broad, multidisciplinary perspective on serious illness care for patients across the lifespan and their families.

Funding and Report Language Requests

On behalf of the NCHPC, we urge you to include **\$12.5 million for the National Institute of Aging (NIA) for the trans-Institute, multi-disease Consortium for Palliative Care Research Across the Lifespan.**

Building on ongoing efforts of the NIH and NIA to establish the Consortium for Palliative Care Research Across the Lifespan, we offer the language below for consideration as part of the report to accompany the FY 2025 Labor, Health and Human Services, Education and Related Agencies (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.

Funding would support the comprehensive multi-Institutes and multi-Centers initiative aimed at a wide range of palliative care research, training, dissemination, and implementation projects to intensify the strategic coordination of palliative care research efforts.

Why do we need palliative care research? The purpose of palliative care research is to improve the evidence-base 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.”ⁱ Numerous studies have demonstrated that high-quality palliative care can provide significant benefits for patients,

caregivers, and the health care system itself. ⁱⁱ “Beneficial at any stage of a serious illness,” palliative care 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. Palliative care 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.” ⁱⁱⁱ

Current Challenges: There are growing populations of people 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 NCHPC thanks the leadership of the Appropriations Committee and the LHHS Subcommittee 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’24: [pp. 108-109]. [Senate Report 118-84](#), Labor/HHS FY 2024 Appropriations]

- Provides \$12.5 million for NIA to implement a trans-Institute, multi-disease strategy to focus, expand, and intensify national research programs in palliative care
- Directs NIH to 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.

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.

We greatly appreciate the Appropriations Committee’s previous support of advancing palliative care research. 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 continue to implement a trans-Institute strategy to expand and intensify national research programs in palliative care.

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

The [NCHPC](#) thanks you for this opportunity to submit Outside Witness Testimony and our funding and report language requests related to palliative care research. Our coalition welcomes the opportunity to discuss our views with you. If you have any questions, please contact Jessica Hausauer, PhD, Executive Director, at jessica@nationalcoalitionhpc.org.

Sincerely,
NCHPC Members

American Academy of Hospice and Palliative Medicine
American Cancer Society
Association of Professional Chaplains
Center to Advance Palliative Care
HealthCare Chaplaincy Network
Hospice and Palliative Nurses Association
National Association for Home Care & Hospice
National Hospice and Palliative Care Organization
National Palliative Care Research Center
National Partnership for Healthcare and Hospice Innovation
Palliative Care Quality Collaborative
Physician Assistants in Hospice and Palliative Medicine
Social Work Hospice and Palliative Care Network
Society of Pain and Palliative Care Pharmacists

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

ⁱⁱ https://aahpm.org/uploads/advocacy/The_Evidence_for_High-Quality_Palliative_Care.pdf

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