

National Coalition for Hospice and Palliative Care Jessica Hausauer, PhD, Chief Executive Officer

Written Public Testimony Prepared for the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Fiscal Year 2026 Appropriations for the National Institutes of Health, National Institute on Aging, and Related Institutes April 9, 2025

Chair Aderholt, Ranking Member DeLauro, and members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of the National Coalition for Hospice and Palliative Care (NCHPC) to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on the fiscal year 2026 appropriations for the National Institutes of Health (NIH). NCHPC requests \$12.5 million for the National Institutes of Health (NIH) and National Institute on Aging (NIA) to continue the multi-Institute, multi-disease Consortium for Palliative Care Research Across the Lifespan.

We greatly appreciate your leadership in investing in palliative care research, including the \$12.5 million provided in FY 2024 and FY 2025 for the National Institute on Aging to implement a multi-Institute, multi-disease research strategy. We stand ready to work with the Subcommittee to advance policies that improve care and quality of life for people facing serious illness, as well as their families and caregivers.

The NCHPC represents 14 leading professional organizations dedicated to advancing equitable access to quality care for serious illness. Our member organizations represent the interdisciplinary workforce that delivers palliative and hospice care and patient and family advocates. Collectively, our members represent 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

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 2026 Labor, Health and Human Services, Education and Related Agencies (LHHS) appropriations: **Palliative Care Research.** —The Committee continues \$12,500,000 for NIA to coordinate the work of the Consortium for Palliative Care Research Across the Lifespan, including developing early- and mid-career researchers and engaging a range of 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-Institute and multi-Center 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? Palliative care is patient- and family-centered – it focuses on aligning treatment with achievable patient goals and supporting individuals and caregivers during and after treatment to maximize quality of life. It can be delivered alongside curative treatments and across care settings including hospitals, clinics, homes, and long-term care facilities. Hospice care is palliative care tailored to individuals near the end of life. The purpose of palliative care research is to improve the evidence base to relieve suffering and improve quality of life for people 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. Research shows that palliative care improves quality of life, enhances satisfaction with care, and reduces unnecessary hospitalizations and health care costs—often resulting in longer survival. These benefits are achieved through better symptom management, care coordination, and alignment of treatment with patient goals.

Current Challenges: As more people live longer with serious illness across the lifespan, the demand for high-quality palliative care continues to grow. Yet many individuals still lack access to this essential care, due to geographic, economic, or systemic barriers. Even when palliative care is available, the current evidence base remains insufficient to guide effective symptom management, support family caregivers, and meaningfully improve quality of life. To ensure research reflects the needs of all who are affected, it must include individuals with limited access to care and explore how social factors—such as poverty, social isolation, food insecurity, and unsafe housing—shape care delivery and outcomes.

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 support the multi-Institute strategy due to the growing health care demands for increased access to quality evidence-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.

<u>FY'23:</u> Explanatory Statement to Accompany the Consolidated Appropriations Act, 2023, Palliative Care [p. S8887, <u>Division H</u> – 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. On behalf of all of those we serve, the NCHPC requests the Subcommittee to continue its support for a NIH strategy for palliative care research by providing \$12.5 million for the National Institute on Aging to continue leading the implementation of the Consortium for Palliative Care Research Across the Lifespan. We also urge the Subcommittee to ensure NIH grants include sufficient support for indirect costs—covering essential infrastructure such as labs, data storage, and research administration—so that investigators and institutions can continue advancing critical research in serious illness care.

The NCHPC thanks you for this opportunity to submit Written Public Testimony and our funding and report language requests related to palliative care research. We welcome the opportunity to discuss our views with you. If you have any questions, please contact Jessica Hausauer, PhD, Chief Executive Officer, at jessica@nationalcoalitionhpc.org.

Sincerely,

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Jessica Hausauer, PhD Chief Executive Officer