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(CAPC)

HealthCare
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(HPNA)

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National Hospice and
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(NHPCO)

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Care Research Center
(NPCRC)

Palliative Care Quality
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Physician Assistants in Hospice
and Palliative Medicine
(PAHPM)

Social Work Hospice &
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(SWHPN)

Society of Pain & Palliative
Care Pharmacists
(SPPCP)

Statement by Amy Melnick, MPA, Executive Director, 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 House Appropriations Subcommittee on Labor, Health and Human Services, and Education and Related Agencies March 24, 2023

The National Coalition for Hospice and Palliative Care (Coalition) appreciates the opportunity to submit testimony to the House 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 \$20 million to implement the strategy as outlined in NIH’s most recent [Congressional Justification](#) to Congress for the NIH to advance a trans-NIH effort to expand and intensify the strategic coordination of palliative care research efforts. 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. Recent research in communication and caregiving science is leading to improved communication techniques that are beginning to truly deliver on the promise of patient-centered care yet more work is needed.

The Coalition thanks the leadership of the Appropriations Committee in prior years for including consistent report language and requests to NIH to establish a trans-institute strategy

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

² 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

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 a Coordinating Center at the National Institutes on Aging at \$20 million based on NIH's recent Congressional Justification and the commitment from NIA to take on this leadership role.

The Coalition is pleased to see in the [NIH FY 24 Budget Justification](#) that the NIH affirms and reiterates the need for NIH to develop and implement a trans-Institute strategy to expand and intensify national research programs in palliative care. 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. NIH currently supports a large research cooperative that work to benefit the entire field of palliative care.⁵ The Palliative Care Research Cooperative (PCRC), funded by NINR through FY 2022, supports researchers who are developing an evidence base to ensure high quality care and optimal well-being for persons with serious illness and their care partners. We request Congress recommend the continuation of this critical element of research infrastructure.

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

⁵ palliativecareresearch.org/

New Opportunities in Palliative Care Research: NIH/NIA Commitment

With the recently released [NIH FY 24 Budget Justification](#), multiple and additional ICO's have pledged to work together 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. Recently, it was announced that NIA is leading efforts to convene subject matter experts from the ICOs listed above to expand and intensify the strategic coordination of palliative care research efforts as well as identify future research topics and questions that pertain to palliative care.

Coalition Recommendation: In FY 2024, the Coalition requests \$20 million for the National Institutes of Health to advance the above trans-NIH effort to expand and intensify the strategic coordination of palliative care research efforts as well as identify future research topics and questions that pertain to palliative care. This level of funding would supplement existing funding and support a coordinating center to convene subject matter experts from relevant Institutes, Centers, and Offices (ICOs); provide career development grants for early-stage investigators; and facilitate various NIH-supported core facilities that help connect scientists with needed tools and expertise.

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.