



March 10, 2025

The Honorable Shelley Moore Capito
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 Tammy Baldwin
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: Prioritization of robust funding for NIH and palliative care research in FY25

Dear Chair Capito, Ranking Member Baldwin, Chair Aderholt, and Ranking Member DeLauro,

The undersigned organizations of the Patient Quality of Life Coalition (PQLC) are writing to request that you prioritize robust funding for the National Institutes of Health (NIH) and palliative care research in fiscal year (FY) 2025 appropriations and reassert the role of Congress in directing research appropriations levels and policies. We are deeply concerned by the recent attempts by the administration to drastically alter funding policies, withholding grants and reducing indirect payments contrary to Congressional intent. While courts have paused implementation of many of the proposed policy changes, if implemented these policies would have a negative impact on palliative care research.

Palliative care is the relief of pain and suffering for individuals living with serious illness. It's a team-based approach, providing an extra layer of support at any age or stage of illness, often together with curative treatment. The scope of serious illness is vast and includes conditions such as cancer, Alzheimer's Disease and Related Dementias (ADRD), advanced organ diseases (including heart, lung, liver, and kidney disease), stroke, neuromuscular degenerative diseases, infectious diseases, and childhood cancer and other pediatric illnesses.

The Patient Quality of Life Coalition represents patients living with serious illnesses and their families, as well as survivors, hospitals, health systems, hospices, physicians, nurses, physician associates, chaplains, pharmacists, social workers, and scientists. Our goal is to ensure that every individual has access to high-quality palliative care, all healthcare providers and institutions have the capacity to deliver high-quality palliative care, and a robust knowledge base exists to support the delivery of this care.

The Impact of NIH-Funded Research

Reports from the National Academy of Medicine, NIH, and multiple scientific studies have documented the high prevalence of physical, psychosocial, and financial suffering associated with serious illness; mismatches between patients' goals for care and the treatments they receive; and

systemic healthcare failures in providing appropriate care for individuals with serious illnesses and their caregivers, leading to low-value healthcare—especially in rural America.

NIH-supported scientists across the United States have conducted ground-breaking research to improve quality of life for individuals with serious illnesses. Their work has led to significant advancements, including reducing patient symptoms such as pain, nausea, and breathlessness; enhancing patient and family quality of life; and improving survival rates.

Additionally, NIH-funded research has transformed care delivery by expanding access to palliative care, particularly in rural areas; improving the Medicare hospice benefit by identifying quality gaps and opportunities for greater efficiency; and reducing overall healthcare costs.

Consequences of NIH Funding Cuts

The growth and success of serious illness research over the past 20 years has been a major achievement, and reductions in NIH funding and the NIH workforce would be catastrophic for patients and their families. Overwhelmingly, advances in serious illness research have resulted from NIH-funded universities and academic medical centers.

As you may know, NIH indirect costs cover essential research-related expenses, including biomedical laboratories, data processing and storage, grant financial management, electricity and computing infrastructure, and administrative support. We ask you to ensure that NIH grants include adequate and evidence-based indirect cost support.

Role of the NIH

Beyond the immediate impact on patients and families, reductions in the NIH workforce and funding threaten the United States' leadership in biomedical research. Academic medical centers, hospitals, independent research institutes, and universities drive the research innovations that have transformed healthcare. NIH-funded scientists have led ground-breaking discoveries in pain management, cancer, advanced organ diseases, stroke, and childhood illnesses, dramatically improving both quality and longevity of life. The NIH funding awarded to researchers also produces important economic returns, including supporting more than 400,000 jobs and roughly \$93 billion in economic activity in the U.S.¹

The ability of millions of Americans to live well, remain productive, and continue working into their seventies and eighties is a direct result of NIH-funded science. Reducing NIH resources without an immediate, sustainable funding alternative would cripple our world-leading biomedical research program.

On behalf of the patients, families, and healthcare providers and institutions we represent, we strongly urge you to:

- Prioritize robust funding for NIH in the FY 2025 appropriations bill and

¹ United for Medical Research. NIH's role in sustaining the US economy. 2024. Accessed November 1, 2024. <https://www.unitedformedicalresearch.org/wp-content/uploads/2024/03/UMR-NIHs-Role-in-Sustaining-the-US-Economy-2024-Update.pdf>.

- Ensure NIH facilities and administrative cost reimbursements are sufficient to cover the true costs of conducting research.

The future of serious illness research, patient well-being, and the global leadership of U.S. biomedical science depends on it.

We greatly appreciate your leadership and previous support of advancing palliative care research.

Our organizations welcome the opportunity to discuss this with you. If you have any questions, please contact Daniel E. Smith, acting chair of PQLC at 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
Center to Advance Palliative Care
Children's National Hospital
Coalition for Compassionate Care of California
GO2 for Lung Cancer
Hospice and Palliative Nurses Association
Leukemia & Lymphoma Society
National Alliance for Caregiving
National Brain Tumor Society
National Palliative Care Research Center
Oncology Nursing Society
Pediatric Palliative Care Coalition
Physician Associates in Hospice and Palliative Medicine