

April 22, 2025

The Honorable Brett Guthrie Chairman House Energy and Commerce Committee 2125 Rayburn House Office Building Washington, D.C. 20515

The Honorable Frank Pallone Ranking Member House Energy and Commerce Committee 2322A Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael D. Crapo Chairman Senate Finance Committee 219 Dirksen Senate Office Building Washington, D.C. 20510

The Honorable Ron Wyden Ranking Member Senate Finance Committee 219 Dirksen Senate Office Building Washington, D.C. 20510

Dear Chairman Guthrie, Chairman Crapo, Ranking Member Pallone, and Ranking Member Wyden:

On behalf of the National Coalition for Hospice and Palliative Care, we urge you to protect Medicaid funding and oppose any budget reconciliation proposals that threaten access to palliative and supportive care for children with serious illnesses. We are concerned that the House-passed budget resolution (H.Con.Res.14) requires the House Energy and Commerce Committee to produce at least \$880 billion in savings. As your committees consider policies to achieve required savings, we urge you to protect Medicaid funding. Cuts to Medicaid would jeopardize essential care for babies and children living with serious illness, leaving families without access to life-sustaining medical support.

As palliative care clinicians and patient advocates, we witness firsthand how Medicaid provides a lifeline to children with conditions such as pediatric cancers, genetic disorders, and complex chronic illnesses. Medicaid covers nearly half of all children and youth with special health care needs, including those who rely on home- and community-based services (HCBS), medical equipment, and hospital-based palliative care. i,ii,iii Without Medicaid, these children would face delayed or denied care, increased hospitalizations, and the risk of institutionalization—at much higher costs to the healthcare system.

Pediatric palliative care programs help reduce hospitalizations and improve care coordination, allowing families to care for their children at home rather than in hospitals or long-term care facilities. iv By keeping families intact and reducing preventable emergency department visits, Medicaid-funded palliative care actually lowers overall healthcare expenditures while ensuring the best possible quality of life for medically complex children.

We strongly urge you to protect Medicaid funding and oppose any budget proposals that threaten access to palliative and supportive care for children with serious illnesses. These cuts would be **devastating for the most vulnerable children and their families.** We appreciate your leadership and ask for your continued commitment to safeguarding Medicaid and ensuring that all children have access to the care they need to survive and thrive.

Sincerely,

American Academy of Hospice and Palliative Medicine

Ann and Robert H. Lurie Children's Hospital of Chicago

A Rosie Place for Children

AE Body Alchemy, LLC

Bridges HealthCare, Inc

Capital Caring Health

Center to Advance Palliative Care

Chapters Health System

Children's Coping Connection

Children's Hospice and Palliative Care Coalition of California

Coalition for Compassionate Care of California

Connecticut Association for Healthcare at Home

Courageous Parents Network

Crescent Cove

C-TAC

Ecumen Hospice

George Mark Children's House

Georgia Hospice and Palliative Care Organization

Healing Rhythms Music Therapy, LLC

HealthCare Chaplaincy Network

Healwell

Heartlinks

Hero's Path Palliative Care

Hosparus Health

Hospice & Palliative Care Federation of Massachusetts

Hospice & Palliative Care Network of Maryland

Hospice and Palliative Care Association of Iowa

Hospice and Palliative Care Association of New York State

Hospice and Palliative Nurses Association

Hospice Council of West Virginia

Hospice of Northwest Ohio

Houston Hospice

Illinois Hospice & Palliative Care Organization

Kansas City Hospice & Palliative Care

Kōkua Mau

Kyle's Mountain House

Life House Atlanta Children's Respite, Inc.

LifeSprings Consulting Group, LLC

Louisiana Mississippi Hospice & Palliative Care Organization

Loving Home Hospice for Children

Mason's Light House

Michigan Homecare and Hospice Association

Minnesota Palliative Care Advisory Council

Missouri Hospice & Palliative Care Association

Mountain Valley-Love's PEAK (Providing Empathy and Assurance for Kids)

National Center for Pediatric Palliative Care Homes

National Partnership for Healthcare and Hospice Innovation

Ohio Pediatric Palliative Care and End-of-Life Network

Oregon Hospice & Palliative Care Association

Our Lady of Peace Hospice and Home Care

Pediatric Palliative Care Coalition

Pediatric Palliative Care Coalition of Minnesota

Physician Associates in Hospice and Palliative Medicine

Rainbow Hospice Care, Inc.

Rays for Rare

Social Work Hospice and Palliative Network

Society for Social Work Leadership in Health Care

Society of Pain and Palliative Care Pharmacists

Sound Connections Counseling

Stillwater Hospice

Texas ~ New Mexico Hospice & Palliative Care Organization

The Alliance for the Advancement of End-of-Life Care

VNA Health

Washington State Hospice & Palliative Care Organization

i National Hospice and Palliative Care Organization. *NHPCO Pediatric Facts and Figures 2023 Edition*; 2023. Accessed March 11, 2025. https://www.nhpco.org/wp-content/uploads/NHPCO_Pediatric_Facts_Figures_2023.pdf ii Lindley LC, Lyon ME. A Profile of Children with Complex Chronic Conditions at End of Life among Medicaid Beneficiaries: Implications for Health Care Reform. *Journal of Palliative Medicine*. 2013;16(11):1388-1393. doi: 10.1089/jpm.2013.0099

iii Williams E, Musumeci M. Children with Special Health Care Needs: Coverage, Affordability, and HCBS Access. KFF. Published October 4, 2021. https://www.kff.org/medicaid/issue-brief/children-with-special-health-care-needs-coverage-affordability-and-hcbs-access/

iv Gans D, Hadler MW, Chen X, et al. Cost Analysis and Policy Implications of a Pediatric Palliative Care Program. *Journal of Pain and Symptom Management*. 2016;52(3):329-335. doi: https://doi.org/10.1016/j.jpainsymman.2016.02.020