



February 25, 2025

The Honorable John Thune
Majority Leader
United States Senate
Washington, D.C. 20510

The Honorable Chuck Schumer
Democratic Leader
United States Senate
Washington, D.C. 20510

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
Washington, DC 20515

Dear Majority Leader Thune, Democratic Leader Schumer, Speaker Johnson, and Leader Jeffries:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, which consists of patient advocacy groups, healthcare professionals, and scientific organizations representing Americans who care deeply about childhood cancer. We write to express concern about potential changes to Medicaid that would impede access and threaten needed health coverage for children with cancer and other diseases.

Cancer remains the most common cause of death by disease among children in the United States. Unfortunately, 1 in 5 children diagnosed with cancer in the U.S. will not survive, and for the ones who do, the battle is never over. By the age of 50, more than 99% of survivors have a chronic health problem, and 96% have experienced a severe or life-threatening condition caused by the toxicity of the treatment that initially saved their life, including: brain damage, loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more. By the time a child in treatment for cancer today reaches the age of 50, we want these statistics to be far less grim.

Medicaid and the Children's Health Insurance Program (CHIP) provide quality, affordable healthcare coverage for nearly 80 million people, including over 37 million children, or roughly half of all children in the US.¹ For children with cancer, Medicaid plays an especially critical role as a safety net. In many states, a child is eligible for Medicaid and CHIP coverage upon receiving a childhood cancer diagnosis, emphasizing the need for timely access to quality, uninterrupted care.

Many children with complex medical needs like childhood cancer are only able to receive the specialty care and supportive services they need due to the Medicaid program, even children with private insurance as their primary payer. Research has shown that pediatric patients who experience disruptions in their Medicaid coverage are more likely to have advanced-stage

¹ KFF. "Monthly Child Enrollment in Medicaid and CHIP." Accessed February 12, 2025.
<https://www.kff.org/medicaid/state-indicator/total-medicare-and-chip-child-enrollment/>.

disease and worse survival rates than patients without disruptions.² Compared to adolescent and young adult patients continuously enrolled in Medicaid, those with newly gained Medicaid or other Medicaid enrollment patterns were 54% and 18%, respectively, more likely to present with stage IV lymphoma.³ This research shows that Medicaid coverage plays a key role in catching and treating cancers in children early.⁴

We are deeply concerned by policy proposals and comments in the media about plans to make severe cuts to the Medicaid program. Any changes to Medicaid’s financing structure – including but not limited to block grants and per capita caps – or other policies that shift costs to states, like cuts to the federal medical assistance percentage (FMAP) – would not only impact children enrolled in Medicaid but would also threaten the financial viability of the pediatric healthcare system overall. Children’s hospitals, which provide the vast majority of childhood cancer care, rely on Medicaid financing as a large proportion of their budgets.⁵

Further, cuts to eligibility and benefits and the addition of any barriers to coverage, such as work reporting requirements, would add needless red tape to enrollment and would severely harm children with cancer and their families. For example, when Arkansas implemented work requirements for its Medicaid program in 2018, more than 18,000 beneficiaries lost coverage in just 10 months – nearly a quarter of those subject to the requirement⁶. Research is clear that children are more likely to be enrolled in health coverage if their parents are as well,⁷ meaning that any coverage losses for parents will have a disproportionate impact on children.

Work requirements may also impact caregivers of children with cancer who are unable to work due to the demands of cancer treatment or young adults with cancer who may not yet be eligible for insurance via their employer or may not be able to work due to their diagnosis. Many young adults rely on Medicaid, especially the Medicaid expansion, for coverage, and research shows a clear increase in survival for young adults with cancer in Medicaid expansion states.⁸

² Xin Hu et al., Association Between Medicaid Coverage Continuity and Survival in Patients With Newly Diagnosed Pediatric and Adolescent Cancers. *JCO Oncol Pract* 0, OP.24.00268
DOI:10.1200/OP.24.00268

³ Zhang, Xinyue Elyse, Sharon M. Castellino, K. Robin Yabroff, Wendy Stock, Patricia Cornwell, Shasha Bai, Ann C. Mertens, Joseph Lipscomb, and Xu Ji. “Medicaid Coverage Continuity Is Associated with Lymphoma Stage among Children and Adolescents/Young Adults.” *Blood Advances* 9, no. 2 (January 16, 2025): 280–90.
<https://doi.org/10.1182/bloodadvances.2024013532>.

⁴ Barnes JM, Neff C, Han X, Kruchko C, Barnholtz-Sloan JS, Ostrom QT, Johnson KJ. The association of Medicaid expansion and pediatric cancer overall survival. *J Natl Cancer Inst.* 2023 Jun 8;115(6):749-752. doi: 10.1093/jnci/djad024. PMID: 36782354; PMCID: PMC10248835.

⁵ Heller, Richard E., Aparna Joshi, Robin Sircar, and Shireen Hayatghaibi. “Medicaid and the Children’s Health Insurance Program: An Overview for the Pediatric Radiologist.” *Pediatric Radiology* 53, no. 6 (2023): 1179–87.
<https://doi.org/10.1007/s00247-023-05640-7>.

⁶ Sommers BD, Chen L, Blendon RJ, Orav EJ, Epstein AM. Medicaid Work Requirements In Arkansas: Two-Year Impacts On Coverage, Employment, And Affordability Of Care. *Health Aff (Millwood)*. 2020 Sep;39(9):1522-1530. doi: 10.1377/hlthaff.2020.00538. PMID: 32897784; PMCID: PMC7497731.

⁷ Jennifer E. DeVoe, et al. “The Association Between Medicaid Coverage for Children and Parents Persists: 2002-2010.” *Maternal and Child Health Journal* 19, no. 8 (2015): 1766-74. <https://pubmed.ncbi.nlm.nih.gov/25874876/>.

⁸ Xu Ji, et al. “Survival in Young Adults With Cancer Is Associated With Medicaid Expansion Through the Affordable Care Act.” *Journal of Clinical Oncology* 41, no. 10 (2023): 1909-1920. <https://pubmed.ncbi.nlm.nih.gov/36525612/>.

Our organizations strongly oppose changes to the Medicaid program that would restrict access, cut needed funding to states, create burdensome red tape, or reduce the quality or availability of services for children or their families.

Thank you for your leadership on behalf of children with cancer. We look forward to working with you to improve the lives of childhood cancer patients, survivors, and families. Should you have any questions or need additional information, please contact Rosalie Abbott, Co-Chair of the Alliance for Childhood Cancer, at Rosalie.abbott@stbaldricks.org, or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at mink@stanford.edu.

Sincerely,

The Alliance for Childhood Cancer

American Academy of Pediatrics
American Cancer Society Cancer Action Network
American Childhood Cancer Organization
American Society of Pediatric Hematology/Oncology
The Andrew McDonough B+ Foundation
Association for Clinical Oncology
Association of Pediatric Oncology Social Workers
Children's Brain Tumor Foundation
Children's Cancer Cause
Dana-Farber Cancer Institute
The Leukemia & Lymphoma Society
MIB Agents Osteosarcoma
National Brain Tumor Society
Pediatric Brain Tumor Foundation
Rally Foundation for Childhood Cancer Research
St. Baldrick's Foundation
St. Jude Children's Research Hospital