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NATIONAL













**BLEEDING DISORDERS** 













Monday, May 5<sup>th</sup>, 2025

The Honorable Mike Johnson Speaker of the House of Representatives U.S. House of Representatives Washington, D.C. 20515

The Honorable John Thune Majority Leader U.S. Senate Washington, D.C. 20510

The Honorable Brett Guthrie Chairman, Energy & Commerce Committee U.S. House of Representatives Washington, D.C. 20510

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

The Honorable Charles Schumer Minority Leader U.S. Senate Washington, D.C. 20510

The Honorable Frank Pallone Ranking Member, Energy & Commerce Committee U.S. House of Representatives Washington, D.C. 20510

Dear Speaker Johnson, Minority Leader Jeffries, Majority Leader Thune, Minority Leader Schumer, Chairman Guthrie, and Ranking Member Pallone:

The undersigned 37 organizations represent millions of patients and consumers who face serious, acute, and chronic health conditions. Together, our organizations offer unique and important perspectives on what individuals and families need to prevent disease, cure illness, and manage their health. The diversity of our organizations and the populations we serve enables us to draw upon extensive knowledge and expertise that can be an invaluable resource as Congress considers any legislation that would reform our healthcare system.

Today, on behalf of millions of patients we represent across the United States, we write with one voice to express our deep alarm and strong opposition to the devastating Medicaid cuts being considered for inclusion in the FY25 budget reconciliation package.

In March of 2017, our organizations came together to form the Partnership to Protect Coverage (PPC). Together, we agreed upon three overarching principles to guide any work to reform and improve the nation's healthcare system. These principles state that: (1) healthcare should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care; (2) healthcare should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) healthcare must be adequate, meaning healthcare coverage should cover treatments patients need.

Access to high-quality, affordable health insurance is essential to maintaining and improving the health of everyone living in the United States. Our organizations stress that any changes to existing law must not jeopardize the healthcare coverage that Americans currently have through employers, the private market, Medicare, Medicaid, or the Children's Health Insurance Program (CHIP). Further, patients and consumers should be able to keep their existing high-quality coverage, and any policy should not undermine quality or affordability.

The policies under consideration by the Energy & Commerce Committee for inclusion in the budget reconciliation package fail this test. They would make healthcare less accessible, less affordable, and less generous—clearly violating the promise of Speaker Johnson that the House would be "very careful not to cut a benefit for anyone who is eligible to receive it and relies upon it." In fact, the hundreds of billions in proposed cuts to Medicaid would do exactly that: this legislative package includes changes that will force states to cut or altogether eliminate Medicaid benefits for workers with low incomes, children, seniors, and disabled Americans.

This <u>deeply popular</u>, lifesaving program covers over 70 million low-income individuals, people with disabilities, seniors, families, and adults with very low incomes. It is not simply a line item in a budget—it is a lifeline for millions of working Americans.

## **Healthcare Cuts Threaten Patients' Lives**

The concurrent budget resolution requires that the House Energy & Commerce Committee approve a package of policies that will cut federal spending by at least \$880 billion. As the nonpartisan Congressional Budget Office has confirmed, this savings target is impossible to meet without large cuts to federal healthcare programs like Medicare and Medicaid. With all Medicare policies reportedly off the table, the only way the Committee can meet its target is by making bone-deep cuts to Medicaid.

Yet, the policies being considered for inclusion in the reconciliation package would force patients and families out of the program. Under these cuts, Medicaid enrollees will face layers of red tape, neverending eligibility tests, and service delays that will jeopardize lives. These budget-driven barriers will mean fewer doctors, fewer hospitals, fewer treatments, and fewer opportunities to manage serious illnesses. While vague promises about exceptions and exemptions are rumored, we know from real-life experience that carve-outs and special arrangements have never worked. They simply add further bloat to the contracts handed out to private corporations paid to stand up yet another big government program, while reducing the funds that could and should be spent on patient care.

The real-world consequences of these cuts would be devastating:

- Brian, a young father in Texas, died of leukemia in 2022 because he couldn't afford insurance or the out-of-pocket costs of treatment - costs he wouldn't have faced if Texas had expanded Medicaid.
- Tori, a Pennsylvania mom of a 3-year-old boy with severe Hemophilia A, is able to pay her family's bills and access her son's high-cost treatment and care because of Medicaid coverage. Without it, she worries he could die from lack of access to the medication and specialty doctors needed to maintain his lifelong disease.
- A child living in Michigan with Cystic Fibrosis required oxygen at home, costing her family \$500 a day, on top of medication costs of \$1200/month. She had multiple hospitalizations, which eventually led to a double lung transplant. Even in a middle-income family, these exorbitant costs were affecting the family's ability to pay for necessities such as home utilities and food. Medicaid alleviated this financial burden. Now, as an adult with CF, she is thriving, working full time for the last 10 years at the hospital where she previously received her care.
- Amber lives in Iowa, and her son has Duchenne Muscular Dystrophy. Without coverage through Medicaid, they would not have access to the medications he needs to manage his condition.
- Heather and Ryan live in Texas. They faced their biggest fears when their 3-year-old son, Hutson, was diagnosed with leukemia. Hutson faced side effects from the disease and its lifesaving treatments that no toddler should have to endure from extensive dental work, developmental issues, and mental health challenges. Medicaid saved Hutson's life. Without it, they wouldn't have been able to care for him on schedule and on plan.
- Lysa was diagnosed with stage IV lung cancer in 2011 and Medicaid paid for her first year of treatment. At the time, she was hoping to live to see her daughter graduate from high school. Almost 14 years later, Lysa is about to be a grandmother.
- Annie from Texas, diagnosed with stage 4 breast cancer at 26 years old. She would not be alive today if it were not for Medicaid. It is very difficult to find a medication that her cancer responds to, but the one that keeps her alive costs \$15,000 a month. There is no generic option available.
   She lives in constant fear of the financial obstacles and the stress of navigating how to stay alive.
   Her life depends on Medicaid.
- DeAnna, a North Carolinian with blood cancer, was denied a lifesaving stem cell transplant until her state expanded Medicaid. She is alive today because Medicaid covered her treatment when she was finally able to access coverage in the state.
- John, a California native with severe Hemophilia A, relies on Medicaid and Medicare coverage
  due to years of joint damage common for people with his condition, and recognizes how critical
  this access to coverage is for maintaining his health as a husband and father of two young
  children. John lost his brother at only 9 years old due to a lack of access to affordable healthcare
  coverage to manage his same diagnosis.

- Adrian survived Shaken Baby Syndrome at just six months old. Now two years old, he lives with a
  tracheostomy and feeding tube. His mom, Christi, serves in the U.S. Air Force, stationed at
  Langley AFB in Hampton, VA. Tricare doesn't cover many of the therapies, home nursing, and
  specialized equipment Adrian needs to thrive. His family depends on Medicaid to help cover
  what Tricare doesn't.
- Debbie from Virginia experienced serious health challenges that made it unsafe to live on her
  own. She moved into a skilled nursing facility to get the care she needed. Without Medicaid, she
  couldn't afford the support that keeps her safe and living with dignity. For older adults like
  Debbie who are dually eligible for Medicare and Medicaid, Medicaid helps cover critical services
  Medicare doesn't.
- Alexa lives in Pennsylvania. When her daughter, Penny, was diagnosed with leukemia at just two
  years old, Medicaid gave their family the ability to access the most effective treatments for her
  child. Alexa says that without Medicaid, they would be buried in medical debt just trying to keep
  Penny alive.
- Marty lives in Ohio and knows the difference access makes. With the support of Medicaid and SNAP, he's able to work part-time, pursue a master's degree, and complete an internship critical to his future career opportunities that wouldn't be possible without these programs.
- Sharon, in Indiana, relies on Medicaid for the home health support she needs to manage her
  Muscular Dystrophy so she can live independently. She is afraid that cuts to Medicaid might
  force her to live in a nursing facility and prevent her from living an active and independent life.
- Milly, from Oklahoma, was diagnosed with breast cancer shortly after having her first child while
  finishing college. Because she had Medicaid, she received the treatment she needed and went
  on to graduate from law school, build a thriving legal career, and raise two children. Her future
  was made possible by Medicaid.
- Kristen, from Alaska, was diagnosed with breast cancer during the pandemic and spent 2020
  undergoing radiation and multiple surgeries. Thanks to Medicaid, she was able to focus on
  healing without the added burden of medical debt. A year later, she got married and now has
  private insurance through her husband Medicaid gave her the foundation to move forward.
- A work injury that wouldn't heal led Thomas, from Louisiana, to the ER, where he was
  unexpectedly diagnosed with non-Hodgkin's lymphoma. While his employer-sponsored
  insurance covered much of his treatment, Medicaid helped cover critical out-of-pocket costs like
  co-pays and medications. Now in remission, Thomas is preparing to return to work Medicaid
  helped make that possible.
- Sky and her daughter, Pressley, who lives with a rare disorder called Dravet Syndrome, live in Oklahoma. Medicaid has been critical to ensuring Pressley receives the specialized care she needs to survive and thrive, including therapies, equipment, and specialists.

These stories are not anomalies. They demonstrate the real-world experience of patients across the country who depend on Medicaid to survive. As Congress considers how deep to cut Medicaid, these lives hang in the balance.

## **Healthcare Cuts Lack Public Support**

These drastic cuts are not what the American people want. A <u>January 2025 poll</u> shows that 84% of Americans believe the federal government is spending too little or the right amount on Medicaid—only 15% believe it spends too much. Medicaid is especially popular among those who know it best: 81% of middle- and lower-income Americans view the program favorably. In fact, majorities of Republicans (67%), Independents (85%), and Democrats <u>agree that Medicaid spending should be preserved</u> or increased.

There's a reason the public supports Medicaid: Medicaid works. The evidence is clear that Medicaid saves lives and improves outcomes. It reduces infant mortality, improves survival rates for cancer patients, lowers the risk of death for people with end-stage renal disease, and reduces opioid overdose deaths. It enables earlier diagnoses and prevents more costly interventions later. Without Medicaid, patients forgo critical care due to cost—placing their health and financial well-being at risk and ultimately raising costs for everyone.

Additionally, the pending expiration of the Affordable Care Act's enhanced premium tax credits threatens to widen already dangerous gaps in coverage. If the premium tax credits are not reauthorized, and deep Medicaid cuts are signed into law, the combined effect would be catastrophic for low- and middle-income patients who are already stretched to the financial brink.

There is an effort to reassure lawmakers that even deep cuts can be safely advanced under the banner of curbing 'waste, fraud, and abuse.' They underestimate the ability of regular people across the country to see through these focus group-tested talking points. The patients and consumers we represent won't be fooled: Any cuts to Medicaid will lead to a loss of benefits. When the patients we represent lose their health coverage because of these cuts, they will be acutely aware of the reality behind lawmakers' claims that these cuts were simply eliminating government waste. Patients and consumers who are forced to navigate the broken healthcare system understand that waste exists, and they want Congress to take it on. But they know the difference between refusing to pay insurers for deceased enrollees and taking Medicaid coverage away from a woman who has to cut back her hours at work to care for an elderly parent with Alzheimer's.

## The Impact of These Cuts Would Be the 119th Congress's Legacy

None of the policies under discussion offer any improvement to an already popular and effective program that serves millions of individuals and families across our country. In fact, they forecast a dangerous path to higher mortality and morbidity, more (not less) government waste, and fewer resources for the sick, elderly, poor, and vulnerable.

Again, with one voice, we urge Congress to reject the harmful and reckless Medicaid cuts being considered for inclusion in the budget reconciliation bill. We call on you to reject these dangerous cuts and reaffirm your commitment to protecting the health and economic stability of millions of Americans.

Sincerely,

AiArthritis
American Cancer Society Cancer Action Network
American Diabetes Association
American Kidney Fund
American Lung Association
Arthritis Foundation
Asthma and Allergy Foundation of America
Autoimmune Association
CancerCare
Crohn's & Colitis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation of America

**EveryLife Foundation for Rare Diseases** 

Family Voices National

Foundations for Sarcoidosis Research (FSR)

Hemophilia Federation of America

Immune Deficiency Foundation

Lupus Foundation of America

Lutheran Services in America

Muscular Dystrophy Association

National Alliance on Mental Illness

**National Bleeding Disorders Foundation** 

National Coalition for Cancer Survivorship

National Health Council

**National Kidney Foundation** 

National Multiple Sclerosis Society

National Patient Advocate Foundation

**National Psoriasis Foundation** 

NMDP (formerly National Marrow Donor Program)

**Pulmonary Hypertension Association** 

Sickle Cell Disease Association of America, Inc.

Susan G. Komen

The AIDS Institute

The Coalition for Hemophilia B

The Leukemia & Lymphoma Society

Volunteers of America

WomenHeart: The National Coalition for Women with Heart Disease