









CANCER*care*\*



















**Asthma and Allergy** 

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## The Partnership to Protect Coverage Urges Congress to Not Cut Our Health Care - May 20, 2025 -

On behalf of millions of patients and consumers we represent across the United States who face serious and chronic health conditions, our organizations urge Congress to oppose cuts that will terminate healthcare for millions and compromise the integrity and affordability of Medicaid and the Marketplace. As drafted, the reconciliation package would terminate coverage for millions of people enrolled in Medicaid and marketplace coverage at a time when they are already struggling to afford soaring healthcare costs.

There is an effort to reassure lawmakers that these deep cuts can be safely advanced under the banner of curbing 'waste, fraud, and abuse.' When the patients we represent lose their health coverage because of these cuts, they will be acutely aware of the reality behind lawmakers' claims.

## Medicaid and the ACA are not line items in a budget—they are literally lifelines for the patients we serve:

- Brian, a young father in Texas, died of leukemia in 2022 because he couldn't afford insurance or the outof-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.

Patients with chronic diseases have no uniform experience; but each one is deserving of care. Efforts to parse who is deserving of care and who is not will wreak havoc on the lives of the patients we represent.

If these cuts become law, millions stand to lose coverage entirely, hitting low and moderate-income patients and families hardest. At a time when costs for American households are already stretched to the breaking point, we cannot afford to rip away any pathway to high-quality, affordable coverage.

We urge congressional leaders to reject these cruel and reckless policies that would cut or terminate healthcare for millions of American families. Now is the time to protect the health and economic security of the American people – not take away the care they need to survive.

For more about the Partnership to Protect Coverage, click here.

To view our letters and statements, <u>click here</u>.