











Society





















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Foundation



Chronic Disease Coalition



Muscular Dystrophy **Association**







































January 24, 2025

The Honorable John Thune Majority Leader 511 Dirksen Senate Office Building Washington, DC 20510

The Honorable Mike Johnson Speaker 568 Cannon House Office Building Washington, DC 20515

The Honorable Chuck Schumer Minority Leader 322 Hart Senate Office Building Washington, DC 20510

The Honorable Hakeem Jeffries Minority Leader 2267 Rayburn House Office Building Washington, DC 20515

Partnership to Protect Coverage: Healthcare Priorities for the 119th Congress

Dear Senator Thune, Senator Schumer, Congressman Johnson, and Congressman Jeffries,

The undersigned X organizations represent millions of patients and consumers who face serious, acute, and chronic health conditions. Together our 40 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.

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) health care should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care; (2) health care should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) health care 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, or Medicaid. Further, patients and consumers should be able to keep their existing high-quality coverage, and any policy should not undermine quality or affordability.

As Congress contemplates a legislative agenda for the 119th Congress, our organizations would like to elevate several key patient community priorities:

- Improving and Expanding Access to High-Quality, Affordable Insurance Coverage
- Ensuring Medicaid Remains Accessible, Affordable, and Adequate Coverage
- Protecting Patients from Substandard Insurance Products

Improving & Expanding Access to High-Quality, Affordable Insurance Coverage

The ACA's affordability and patient protections were transformational for our patients. To ensure consumers could afford their coverage, Congress established advance premium tax credits (APTC) to help lower the cost of health insurance purchased in the Marketplaces. Under the ACA, individuals earning between 100% and 400% of the federal poverty level (FPL) are eligible for these tax credits on a sliding scale – the lower the income level, the higher the amount of tax credits.

In 2021, Congress made two temporary, but critically important changes to the tax credits: it increased the amount of the tax credits for those between 133% - 400% FPL; and capped premium costs at 8.5% of annual income for individuals and families earning more than 400% FPL.¹ These enhanced tax credits were in effect in 2021 and 2022. Then in response to their success, in 2022, Congress extended these enhanced tax credits again, this time through the end of 2025.

Since the enhanced APTCs were first enacted in 2021, they have helped 9.4 million Americans gain access to high-quality and affordable health coverage – reducing the number of uninsured to just 7.7 percent.² Today, enrollment in the ACA marketplaces is at an all-time high, with more than 21 million people now insured through the marketplaces.³

¹ Center for Budget and Policy Priorities, *Health Insurance Costs Will Rise Deeply If Premium Tax Credit Improvements Expire*. https://www.cbpp.org/research/health/health-insurance-costs-will-rise-steeply-if-premium-tax-credit-improvements-expire ² Assistant Secretary for Planning and Evaluation, *National Uninsured Rate Reaches an All-Time Low in early 2023 after the Close of the ACA Open Enrollment Period* (August 3, 2023),

https://aspe.hhs.gov/sites/default/files/documents/e06a66dfc6f62afc8bb809038dfaebe4/Uninsured-Record-Low-Q12023.pdf
³ Centers for Medicare and Medicaid Services, *Health Insurance Marketplaces 2024 Open Enrollment Report* (March 22, 2024), www.cms.gov/files/document/health-insurance-exchanges-2024-open-enrollmentreport-final.pdf

Enrollment in marketplace plans generated by enhanced APTCs has provided millions of Americans with affordable, comprehensive health coverage by allowing more people to purchase high-quality health insurance coverage that meets their healthcare needs. However, the enhanced APTCs are scheduled to expire by the end of 2025. If Congress fails to act by August of 2025, premiums for Marketplace enrollees will skyrocket, forcing some patients and consumers to abandon the high-quality coverage upon which they have come to rely. Action is urgent because the process for setting rates and developing plans is lengthy and complex.

The drastic change in premium cost could be devastating for the patients and consumers we represent. For example, a family of four making \$60,000 (200% of FPL) would see their monthly marketplace premium increase from \$100 to \$326—an annual increase of about \$2,700. A 60-year-old couple making \$45,000 (228% of FPL) would see monthly marketplace premiums increase from \$117 to \$283 — an annual increase of almost \$2,000.4

Our organizations are also concerned about other actions, Congressional or administrative, that would undermine the operation and integrity of the ACA and its health insurance marketplaces. Using our principles, as we have done in the past, we will continue to evaluate policies, regulations, and legislation that would impact our patient populations.

Ensuring Medicaid Remains Accessible, Affordable, and Adequate Coverage

The purpose of Medicaid is to provide healthcare for low-income individuals and families. In the past, our organizations have strongly opposed changes to the Medicaid program that would restrict access, create unnecessary red tape for patients, arbitrarily restrict funding to states, or starve the program of necessary resources. Today, we again note our strong opposition to these kinds of policies.

For example, per capita caps and block grants are designed to reduce federal funding for Medicaid, forcing states to either make up the difference with their own funds or make cuts to their programs that would reduce access to care for the patients we represent. Altering Medicaid financing threatens the financial stability of the program and access to care for patients and families. Arbitrarily placing a cap on the amount of federal contribution also leaves states in an untenable position of managing the healthcare costs of a new treatment, a national disaster, or a pandemic without any federal assistance. Additional barriers put in place for ground-breaking but expensive treatments could restrict patients' access to lifesaving care.

Similarly, work reporting requirements create unnecessary red tape for patients. Increasing administrative barriers will decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. For example, when Arkansas implemented a similar policy, the state terminated coverage for over 18,000 individuals who were otherwise eligible for Medicaid before a federal court halted the state's efforts. These coverage losses would be much more severe on a national scale, and failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with serious, acute and chronic diseases.

Research consistently finds that Medicaid enrollees who are able to work are already doing so, and that enrollees who are not employed are typically unable to work as a result of their own health or because they are providing caretaking services for others; in fact, some researchers have argued that Medicaid may already

⁴ Center for Budget and Policy Priorities, *Health Insurance Costs Will Rise Deeply If Premium Tax Credit Improvements Expire*. https://www.cbpp.org/research/health/health-insurance-costs-will-rise-steeply-if-premium-tax-credit-improvements-expire

⁵ Robin Rudowitz, MaryBeth Musumeci, and Cornelia Hall, "A Look at February State Data for Medicaid Work Requirements in Arkansas," Kaiser Family Foundation, December 18, 2018. Available at: https://www.kff.org/medicaid/issue-brief/a-look-at-november-state-data-for-medicaid-work-requirements-inarkansas/; Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018. Available at: http://d31hzlhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf.

improve the likelihood of enrollee employment by providing steady and consistent access to healthcare, noting linkages between healthcare access, health status, and employment.^{6,7}

Protecting Patients from Substandard Insurance Products

Prior to the enactment of the ACA, it was difficult—and often impossible—for people with or at risk of serious illnesses to get or keep affordable, high-quality health insurance. Today, issuers are required to provide comprehensive coverage and are prohibited from using unfair coverage restrictions that discriminate against people with serious and chronic illnesses on the basis of their pre-existing conditions.

In the past, Congress and the Administration have advanced policies that would reverse these critically important protections – allowing issuers to discriminate based on gender, pre-existing conditions, and other factors. Short-term limited-duration insurance (STLDI), healthcare sharing ministries, Farm Bureau plans, grandfathered plans, association health plans, multiple employer welfare arrangements (MEWAs) and other arrangements subject only to ERSIA are just some of the products that have the potential to undermine the health and financial wellbeing of patients and consumers. These "non-compliant" products are not a solution to any of the issues facing our health insurance system and actively endanger the health and financial security of those who enroll in them.

Conclusion

Patients with serious and chronic conditions cannot afford to go without insurance that meets their healthcare needs. As such, we urge Congress to take immediate action to permanently extend the enhanced APTCs and protect patient populations who rely on coverage through Medicaid and the ACA marketplaces. Please contact Katie Berge (Katie.Berge@lls.org), Jelani Murrain (Jelani.Murrain@cancer.org), and Ashleigh Tharp (atharp@cff.org) if you have questions or would like to meet with members of the Partnership. We thank you for your attention to this issue and welcome the opportunity to discuss it further.

Sincerely,

AiArthritis

ALS Association

American Cancer Society Cancer Action Network

American Diabetes Association American Heart Association American Kidney Fund American Liver Foundation American Lung Association

Arthritis Foundation

Asthma and Allergy Foundation of America

Cancer Support Community

Cancer Care

Child Neurology Foundation Chronic Disease Coalition Crohn's & Colitis Foundation Cystic Fibrosis Foundation
Epilepsy Foundation of America

Family Voices - National

Foundation for Sarcoidosis Research Hemophilia Federation of America Immune Deficiency Foundation Lupus Foundation of America Lutheran Services in America

March of Dimes

Muscular Dystrophy Association National Alliance on Mental Illness National Bleeding Disorders Foundation National Coalition for Cancer Survivorship

National Eczema Association
National Health Council

⁶ Madeline Guth, Patrick Drake, Robin Rudowitz, and Maiss Mohamed, Understanding the Intersection of Medicaid & Work: A Look at What the Data Say, KFF, April 23, 2023. Available at: https://www.kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-work-a-look-at-what-the-data-say/.

⁷ Sherry A. Glied and Dong Ding, Medicaid Work Requirements Wouldn't Increase Employment and Could Imperil Future Labor Market Participation, The Commonwealth Fund, May 24, 2024. Available at: https://www.commonwealthfund.org/blog/2023/medicaid-work-requirements-wouldnt-increase-employment-and-could-imperil-future-labor.

National Kidney Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Patient Advocate Foundation
National Psoriasis Foundation
Pulmonary Hypertension Association
Susan G. Komen
The AIDS Institute
The Leukemia & Lymphoma Society
WomenHeart: The National Coalition for Women with Heart Disease