











Multiple Sclerosis























































February 1, 2021

The Honorable Charles Schumer U.S. Senate 322 Hart Senate Office Building Washington, DC 20510

The Honorable Mitch McConnell U.S. Senate 317 Russell Senate Office Building Washington, DC 20510

The Honorable Nancy Pelosi U.S. House of Representatives 1236 Longworth House Office Building Washington, DC 20515

The Honorable Kevin McCarthy U.S. House of Representatives 2468 Rayburn House Office Building Washington, DC 20515

RE: Patient Community Healthcare Priorities for Reconciliation

Dear Leader Schumer, Leader McConnell, Speaker Pelosi, and Minority Leader McCarthy:

Our 29 organizations represent millions of patients and consumers who face serious, acute, and chronic health conditions. We have a unique perspective on what individuals and families need to prevent disease, cure illness, and manage chronic health conditions. The diversity of our organizations and the

populations we serve enable us to draw upon a wealth of knowledge and expertise that is an invaluable resource in this discussion.

In early 2017, our organizations agreed upon three principles that we use to help guide our work on health care to continue to develop, improve upon, or defend the programs and services our communities need to live longer, healthier lives. These principles state that: (1) healthcare must be adequate, meaning that healthcare coverage should cover treatments patients need; (2) healthcare should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) healthcare should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care.

Congress has an urgent opportunity to expand access to high-quality, affordable healthcare coverage through the budget reconciliation process. Coverage is more important now than ever, as patients and their families weather the dual crises of the COVID-19 pandemic and the economic downturn. We therefore urge Congress to take immediate steps to pass the following policies that help patients and people with pre-existing conditions:

- Increase the availability and generosity of advance premium tax credits (APTCs). Congress should also consider increasing affordability by changing the APTC benchmark from the current silver plan to a higher-level plan, such as gold.
- Immediately fix the family glitch to ensure that families with unaffordable employer-based coverage can access the Affordable Care Act (ACA)'s advance premium tax credits and costsharing assistance.
- Secure and strengthen the Medicaid program both now and in the future by:
 - Increasing the Medicaid federal medical assistance percentage (FMAP) to at least 14 percent, while preserving the Maintenance of Effort (MOE) provision to ensure patients do not lose coverage or experience reductions in the quality of their coverage
 - Incentivizing states to expand Medicaid by providing 100 percent FMAP for the first three years that states expand their Medicaid programs.
 - Implement automatic policies that will stabilize the Medicaid program during the current and future economic downturns.

Expand the Availability and Generosity of APTCs for Marketplace Coverage

Increased premiums, deductibles, and co-pays have left many low- and middle-income families struggling to afford health care. By increasing the eligibility for and expanding the generosity of APTC, more consumers would be able to afford health insurance on the individual marketplace.

Currently, APTCs are only available for consumers making between 100 and 400% of the federal poverty level and are based on the cost of a silver plan. Additionally, many families with lower incomes find coverage to be unaffordable even with the current subsidies. Making APTCs more generous will ensure consumers can afford to buy coverage. Increasing the availability and amount of subsidy support will potentially improve the overall makeup of the risk pool, helping to stabilize the individual markets. Affordability remains a barrier for many Americans to purchase adequate insurance via the ACA's insurance marketplace.

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¹ Insert link to health care reform principles

Our organizations strongly support increasing financial support for individuals and families and urge policymakers in the Administration and Congress to increase the number of people eligible for and the generosity of APTCs. Congress should also consider increasing affordability by changing the APTC benchmark from the current silver plan to a higher-level plan, such as gold.

Fix the Family Glitch

The "family glitch" refers to the unintentional effect of the ACA's mechanism for defining whether an employer-based insurance plan is affordable for a given employee. This glitch effectively bars many low-and middle- income families from receiving the ACA's premium and cost-sharing subsidies. Under current law, the IRS deems employer-based insurance as affordable when the premium for self-only coverage is less than 9.69% of an individual's annual income. When an individual in a family is offered employer-based insurance that technically meets this definition, the entire family becomes ineligible for tax subsidies on the Marketplace—even if the premium for family coverage under the same plan is significantly higher and unaffordable based on the family's total income. Eliminating the family glitch through legislation would allow families to afford high-quality coverage while also reducing the number of uninsured Americans, improving the risk pool and potentially decreasing premiums.

We urge Congress to immediately fix the family glitch to ensure that families with unaffordable employer-based coverage can access the ACA's advance premium tax credits.

Secure and Strengthen the Medicaid Program

Medicaid plays a crucial role in the health of individuals and families with disabilities and lower income across the United States by providing access to preventive services, treatment, disease management, and care coordination. It is clear that the Medicaid program is a critical access point for patients, particularly those with serious and chronic diseases. We recommend that Congress take the following steps to secure the strength and longevity of this critical program.

Increase the Medicaid FMAP

State Medicaid programs provide a vital safety net, including during times of national crisis, covering traditionally underserved populations. Our organizations strongly supported the 6.2 percent increase in the FMAP for states in the Families First Coronavirus Response Act and urge Congress to raise the FMAP increase from 6.2 to at least 14 percent in future legislation, with additional targeted funding for home and community-based services. Between February and September of 2020, Medicaid enrollment grew by 6.1 million, with enrollment expected to have continued to grow when additional data is available. Additional support for states is essential to ensuring that state Medicaid programs can meet this increased demand for coverage and continue to provide quality and affordable health care to the patients we represent both now and into the future.

Recognizing the importance of continuous Medicaid coverage, the Families First Coronavirus Response Act included maintenance of effort requirements for the enhanced FMAP that prevent states from imposing more restrictive eligibility standards or increased cost-sharing during the public health emergency, as well as significantly limit the circumstances in which states can disenroll current or newly enrolled members. These protections are critical to ensuring that patients with serious and chronic conditions continue to receive affordable and accessible coverage during a period in which there will be

 $^{^2\} https://www.kff.org/coronavirus-covid-19/issue-brief/analysis-of-recent-national-trends-in-medicaid-and-chip-enrollment/$

enormous pressure on states to reduce costs. Our organizations strongly urge Congress to preserve these protections in any future legislation.

<u>Incentivize Remaining States to Expand Medicaid</u>

The COVID-19 crisis has, as previously discussed, highlighted the pressing need to reduce our nation's uninsured rate. Those without health insurance may fear seeking help because of the cost of treatment, contributing to poorer health outcomes for themselves as well as continued community spread of this disease. Expanding Medicaid coverage to all individuals with incomes below 138 percent of the federal poverty level (\$2,525/ month for a family of three) could extend coverage to 4.8 million uninsured adults living in states that have not taken up this expansion to date.³ The benefits of expansion are clear, including improved access to coverage and positive health outcomes for patients, as well as economic benefits to states and hospitals.⁴

Our organizations therefore urge Congress to significantly enhance FMAP funding for states that expand their Medicaid programs to 100% for three years – a financial incentive that was available to states that expanded their programs in 2013.

Implement Policies that Stabilize Medicaid Funding during Economic Downturns

During times of economic crisis, patients and families rely on Medicaid and other safety net programs. Yet, the same economic downturns that lead to job losses and reduced incomes also put significant pressure on state budgets—threatening access to Medicaid for eligible enrollees. In addition to supplementing the generosity of federal matching funds for Medicaid, Congress should pass legislation that would establish automatic, counter-cyclical FMAP increases to secure state Medicaid programs when state revenues decline as a result of recessionary pressures.⁵

Conclusion

Our organizations enter the 117th Congress ready to work on efforts that improve coverage and care for the millions of patients and people with pre-existing conditions. If you have any questions, or would like to discuss any of the priorities listed above further, please direct your staff to contact Katie Berge of the Leukemia & Lymphoma Society at katie.berge@lls.org. Thank you for your consideration.

Sincerely,

Alpha-1 Foundation
ALS Association
American Cancer Society Cancer Action Network
American Diabetes Association
American Heart Association
American Kidney Fund
American Lung Association
Arthritis Foundation
Asthma and Allergy Foundation of America

³ https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/

⁴ https://www.kff.org/medicaid/report/the-effects-of-medicaid-expansion-under-the-aca-updated-findings-from-a-literature-review/

⁵ https://www.macpac.gov/publication/automatic-countercyclical-financing-adjustment-review-of-draft-chapter-and-recommendation-decision/

Cancer Support Community

Cancer Care

Cystic Fibrosis Foundation

Epilepsy Foundation

Family Voices

Hemophilia Federation of America

Immune Deficiency Foundation

Mended Hearts & Mended Little Hearts

Muscular Dystrophy Association

National Alliance on Mental Illness

National Hemophilia Foundation

National Multiple Sclerosis Society

National Organization for Rare Disorders

National Patient Advocate Foundation

Pulmonary Hypertension Association

Susan G. Komen

The AIDS Institute

The American Liver Foundation

The Leukemia & lymphoma Society

United Way Worldwide

WomenHeart: The National Coalition for Women with Heart Disease