



April 23, 2021

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

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

RE: Patient Community Healthcare Priorities for to Improve Health Care Access

The 34 undersigned organizations, representing millions of patients and consumers across the country who face serious, acute, and chronic health conditions, urge Congress to enact additional legislation that will help support the health and wellbeing of the American public. Together, we represent more than 120 million people with pre-existing conditions in the U.S., many of whom have increased risk of infection and/or adverse health outcomes as a result of the COVID-19 pandemic.

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.¹ 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 get, keep, and understand and not pose a barrier to care.

Address Affordability of Health Insurance Premiums

Despite gains made by the Affordable Care Act (ACA) and the American Rescue Plan Act, disparities in coverage persist and many people remain unable to afford health insurance due to high premiums.

Congress should take additional steps to improve affordability by:

- Permanently codifying the increased generosity and expanded eligibility for advance premium tax credits (APTCs);
- Aligning the affordability of individual market insurance with employer sponsored insurance (ESI) by re-setting the definition of affordability for ESI at 8.5% and no longer indexing the affordability test to inflation; and
- Fixing the “family glitch” that locks out families from accessing APTCs if a single member has an offer of employer sponsored individual coverage that is considered affordable, even if family coverage would not be considered affordable.

Address Affordability of Health Insurance Out-of-Pocket Costs

In addition to the continued unaffordability of premiums, many people with coverage still cannot access care due to high cost sharing requirements. Congress should take action to ensure that coverage provides meaningful, equitable, and affordable access to care by:

- Shifting the APTC benchmark from silver plans to gold plans to decrease out of pocket exposure for patients;
- Ensuring that actuarial value (AV) of plans accurately reflect the financial risk faced by most consumers enrolled in the plan.² This can be achieved through adjusting the standard population used to calculate AV and disregarding claims from outliers³; and
- Taking other actions to address the rising out of pocket costs faced by enrollees in the individual market and ESI, such as through potentially incorporating deductible and cost-sharing into definitions of affordability.

Support and Expand Medicaid Coverage

The American Rescue Plan Act took important steps to expand Medicaid coverage, particularly for individuals in non-expansion states and for postpartum coverage, and our organizations encourage you

¹ Consensus Healthcare Reform Principles:

<https://www.epilepsy.com/sites/core/files/atoms/files/Patient%20Groups%20Consensus%20Health%20Care%20Reform%20Principles.pdf>

² A study published in Health Affairs found that the share of costs actually borne by consumers was typically much higher than would be suggested by the AV. Polyakova, M., Hua, L. M., & Bundorf, M. K. (2017). Marketplace plans provide risk protection, but actuarial values overstate realized coverage for most enrollees. *Health Affairs*, 36(12), 2078-2084. doi:[10.1377/hlthaff.2017.0660](https://doi.org/10.1377/hlthaff.2017.0660)

³ As described in: Center for Medicaid & Medicare Services. (2020, March 6). Final 2021 Actuarial Value Calculator Methodology. Retrieved from <https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/Final-2021-AV-Calculator-Methodology.pdf>. pg. 11.

to maximize the impact of those investments and continue to build upon them in future legislative packages. Additionally, Congress should take action to improve the continuity of Medicaid coverage for both children and adults by making continuous eligibility mandatory for both of those populations.

Limit Inadequate Short-Term Limited Duration and Other Non-compliant Plans

The need for adequate, affordable, and accessible coverage has become even more important during the COVID-19 pandemic. Unfortunately, sub-par insurance plans continue to proliferate, confusing consumers and leaving them under-covered, as many of our groups detailed in a recent report.⁴ Congress should take action to protect consumers by restricting access to short-term limited duration insurance and other non-compliant plans.

Conclusion

We are 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 Rachel Patterson of the Epilepsy Foundation at rpatterson@efa.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
Cancer Support Community
CancerCare
Chronic Disease Coalition
Cystic Fibrosis Foundation
Family Voices
Epilepsy Foundation
Hemophilia Federation of America
Immune Deficiency Foundation
Lutheran Services in America
Mended Hearts & Mended Little Hearts
Muscular Dystrophy Association
National Alliance on Mental Illness
National Coalition for Cancer Survivorship
National Health Council
National Hemophilia Foundation
National Kidney Foundation
National Multiple Sclerosis Society

⁴ Under-Covered: How “Insurance-Like” Products Are Leaving Patients Exposed. March 2021.
https://www.ils.org/sites/default/files/National/undercovered_report.pdf

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