

March 20, 2017

The Honorable Mitch McConnell
Senate Majority Leader
U.S. Capitol Building, S-230
Washington DC 20510

The Honorable Paul Ryan
Speaker of the House
U.S. Capitol Building, H-232
Washington, DC 20515

Dear Leader McConnell and Speaker Ryan:

The undersigned organizations write to express grave concern about proposals put forth in the American Health Care Act (AHCA) to alter the fundamental structure and purpose of Medicaid, a vital source of health care for patients with ongoing health needs.

We feel compelled to speak out against proposals to phase out Medicaid expansion and implement per capita caps, which threaten the ability of Medicaid to provide critical health care services to many of our most vulnerable citizens. These proposals aim to achieve cost savings of approximately \$880 billion, according to the Congressional Budget Office, at the expense of tens of millions of patients who rely on Medicaid for life-sustaining care.¹ While we appreciate the opportunities we have had to work with your staff, we cannot support the Medicaid provisions in this bill and cannot accept policies that prioritize cutting costs by limiting patients' access to care.

Medicaid is Critical for Patients

Medicaid is a crucial source of coverage for patients with serious and chronic health care needs. Pregnant women depend on Medicaid, which covers roughly 50 percent of all births including many high-risk pregnancies.² Medicaid covers cancer patients: nearly one-third of pediatric cancer patients were enrolled in Medicaid in 2013 and approximately 1.52 million adults with a history of cancer were covered by Medicaid in 2015.³ Over fifty percent of children and one-third of adults living with cystic fibrosis rely on Medicaid to get the treatments and therapies they need to preserve their health.⁴ Nearly half of children with asthma are covered by Medicaid or CHIP and adults with diabetes are

¹ Congressional Budget Office. *Cost Estimate: American Health Care Act*. (Online). March 2017. Available: <https://www.cbo.gov/publication/52486>

² March of Dimes. *Maternity and Newborn Care in Medicaid*. (Online). Feb 2017. Available: http://www.marchofdimes.org/materials/March-of-Dimes-Maternity-and-Newborn-Care-in-Medicaid_Feb2017.pdf

³ American Cancer Society. *Estimate of Adults with a History of Cancer Covered by Medicaid in 2015*. January 2017., National Center for Health Statistics. *National Health Interview Survey*. 2015., NPCR: U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2013 Incidence and Mortality Web-based Report*. 2016.

⁴ Cystic Fibrosis Foundation Patient Registry. *2015 Annual Data Report*. (Online). 2016. Available: <https://www.cff.org/Our-Research/CF-Patient-Registry/2015-Patient-Registry-Annual-Data-Report.pdf>

disproportionally covered by Medicaid as well.^{5,6} The patients we represent are eligible for Medicaid through various pathways, including through income-related and disability criteria.

Reject Per Capita Caps

The proposal to convert federal financing of Medicaid to a per capita cap system is deeply troubling. This policy is designed to reduce federal funding for Medicaid, forcing states to either make up the difference with their own funds or cut their programs by reducing the number of people they serve and the health benefits they provide.

For patients with ongoing health care needs, this means that Medicaid may no longer cover the care and treatments they need, including breakthrough therapies and technology. In order to save money, the per capita caps are set to grow more slowly than expected Medicaid costs under current law.⁷ As the gap between the capped allotment and actual costs increases over time, states will be forced to constrain eligibility, reduce benefits, lower provider payments, or increase cost-sharing. Moreover, by capping the federal government's contribution to Medicaid in this manner, states will be less able to cover the cost of new treatments. This could be devastating for people with serious diseases, for whom groundbreaking treatments represent a new lease on life. For people with cystic fibrosis, cancer, and other diseases, new therapies can be game changers that improve quality of life and increase life expectancy. In fact, we have already seen Medicaid programs respond to current budget constraints by using clinically inappropriate criteria to restrict access to therapies old and new. A per capita cap will only exacerbate the downward pressure on Medicaid budgets and will further reduce access to these therapies for patients.

Pairing financing reforms with increased flexibility, as has often been proposed, would further undermine Medicaid's role as a safety net for patients. Without current guardrails provided by federal requirements—coupled with reduced federal funding—states will have the authority to reduce benefits and eligibility as they see fit and to impose other restrictions, such as waiting periods and enrollment caps. These policies have serious implications for patients—for a person with cancer, enrollment freezes and waiting lists could mean a later-stage diagnosis when treatment costs are higher and survival is less likely. For a person with diabetes, this would risk the ability to adequately manage the disease. Many of our patients rely on costly services that will be quickly targeted for cuts if states are given such flexibility, so it is imperative that current federal safeguards remain in place.

Maintain Medicaid Expansion

While the AHCA has been described as preserving Medicaid expansion for those already enrolled in coverage, we are concerned that estimates show that eliminating the enhanced match for any enrollee

⁵ Centers for Disease Control and Prevention. *Asthma: Health Care Coverage Among Children*. (Online). November 2016. Available: https://www.cdc.gov/asthma/asthma_stats/

⁶ Kaiser Commission on Medicaid and the Uninsured. *The Role of Medicaid for People with Diabetes*. (Online). November 2012. Available: http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8383_d.pdf

⁷ Congressional Budget Office. *Cost Estimate: American Health Care Act*. (Online). March 2017. Available: <https://www.cbo.gov/publication/52486>

with even a small gap in coverage would actually result in millions of people losing coverage.^{8,9} By eliminating the enhanced federal match for any enrollee with a gap in coverage, eventually states will be on the hook for billions of dollars to continue covering this population—an insurmountable financial hurdle. Additionally, seven states have laws that would effectively end Medicaid expansion immediately or soon thereafter when the expansion match rate is eliminated. Nearly half of adults covered by the Medicaid expansion are permanently disabled, have serious physical or mental conditions—such as cancer, stroke, heart disease, arthritis, pregnancy, or diabetes—or are in fair or poor health.¹¹ Repealing Medicaid expansion will leave these patients without coverage they depend upon to maintain their health.

The proposed financing reforms are a fundamental shift away from Medicaid’s role as a safety-net for some of the most vulnerable members of our society. Repealing Medicaid expansion would leave millions without the health care they rely on. Our organizations represent and provide care for millions of Americans living with ongoing health care needs who rely on Medicaid and we cannot support policies that pose such a grave risk to patients.

We hope that we can continue our dialogue as you move forward in this process to arrive at solutions that provide all Americans with high-quality, affordable care regardless of an individual’s income, employment status, health status, or geographic location.

Sincerely,

ADAP Advocacy Association
AIDS Action Baltimore
The AIDS Institute
Alpha-1 Foundation
Alport Syndrome Foundation
ALS Association
American Academy of Pediatrics
American Behcet’s Disease Association
American Congress of Obstetricians and Gynecologists
American Diabetes Association
American Lung Association
American Parkinson Disease Association
American Society of Hematology
American Thoracic Society
Amyloidosis Support Groups Inc.
ARPKD/CHF Alliance

Arthritis Foundation
Batten Disease Support & Research Association
Bladder Cancer Advocacy Network
Bridge the Gap - SYNGAP Education and Research Foundation
Bronx Lebanon Hospital Center Department of Family Medicine
CADASIL Together We Have Hope Non-Profit
Cancer Support Community
Child Neurology Foundation
Children’s Cause for Cancer Advocacy
Children’s Dental Health Project
Chronic Illness and Disability Partnership
Community Access National Network

⁸ S&P Global Market Intelligence. *The U.S. Health Insurance Market is Poised to Move to a Defined-Contribution from a Defined-Benefit System of Federal Financing*. (Online). March 2017. Available: https://www.globalcreditportal.com/ratingsdirect/renderArticle.do?articleId=1811131&SctArtId=418648&from=C&nsI_code=LIME&sourceObjectId=10006958&sourceRevId=3&fee_ind=N&exp_date=20270307-22:26:18

⁹ Congressional Budget Office. *Cost Estimate: American Health Care Act*. (Online). March 2017. Available: <https://www.cbo.gov/publication/52486>

¹¹ Brantley, Erin, et. al. *Myths About the Medicaid Expansion and the ‘Able-Bodied’*. Health Affairs Blog. (Online) March 2017. Available: <http://healthaffairs.org/blog/2017/03/06/myths-about-the-medicaid-expansion-and-the-able-bodied/>

Congenital Adrenal Hyperplasia Research
Education & Support Foundation, Inc.
COPD Foundation
Cure HHT
Cutaneous Lymphoma Foundation
Cystic Fibrosis Foundation
Cystinosis Research Network
debra of America
Endocrine Society
Fibrous Dysplasia Foundation
First Focus Campaign for Children
FORCE: Facing Our Risk of Cancer
Empowered
Foundation for Prader-Willi Research
Friedreich's Ataxia Research Alliance (FARA)
Genetic Alliance
Hannah's Hope Fund
Hide & Seek Foundation for Lysosomal
Disease Research
Hispanic Health Network
Hope for Hypothalamic Hamartomas
Huntington's Disease Society of America
Immune Deficiency Foundation
The International Pemphigus and
Pemphigoid Foundation
Kids v Cancer
Latino Commission on AIDS
LFS Association (Li-Fraumeni Syndrome
Association)
Liver Health Connection
March of Dimes
Medicare Rights Center
MLD Foundation
Moebius Syndrome Foundation
Muscular Dystrophy Association (MDA)

NASTAD (National Alliance of State &
Territorial AIDS Directors)
National Alliance on Mental Illness
National Coalition for Cancer Survivorship
National Health Law Program
National Hemophilia Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Patient Advocate Foundation
National Tay-Sachs & Allied Diseases
Association (NTSAD)
National Urea Cycle Disorders Foundation
National Viral Hepatitis Roundtable
NBIA Disorders Association
Needle Exchange Emergency Distribution
(NEED)
Parent Project Muscular Dystrophy (PPMD)
Parkinson Alliance
The PCD (Primary Ciliary Dyskinesia)
Foundation
Polycystic Kidney Disease Foundation
Pulmonary Fibrosis Foundation
PXE International
Rett Syndrome Research Trust
Scleroderma Foundation
The Sudden Arrhythmia Death Syndromes
Foundation
T1D Exchange
Trisomy 18 Foundation
Tuberous Sclerosis Alliance
United Way Worldwide
VHL Alliance
Wilson Disease Association
Wishes for Elliott: Advancing SCN8A
Research

CC: Senate Minority Leader Charles E. Schumer
Senate Finance Committee Chairman Orrin Hatch
Senate Finance Committee Ranking Member Ron Wyden
House Minority Leader Nancy Pelosi
House Energy and Commerce Committee Chair Greg Walden
House Energy and Commerce Committee Ranking Member Frank Pallone
Secretary of Health and Human Services Thomas Price