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 20510

RE: Patient Community Priorities for COVID-19 Legislation

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

The 28 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 while also slowing the spread of the COVID-19 virus, particularly among vulnerable populations. 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 2017, our organizations agreed upon three overarching principles¹ that guide our work. These principles state that: (1) health care must be adequate, meaning health care coverage should cover treatments patients need, including the services in the essential health benefit package; (2) health care should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) health care should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care. Enrollment should be easy to understand, and benefits should be clearly defined.

The COVID-19 pandemic has made abundantly clear that all people need access to adequate and affordable health insurance coverage now more than ever. Research has demonstrated that access to comprehensive health insurance means access to timely, medically necessary health care. If someone without health insurance today contracts the COVID-19 virus, they may be forced to make the difficult decision to not be tested and treated due to fears about the cost of care. That puts our entire society – particularly the people we represent – at risk.

As Congress considers additional legislation aimed at protecting the financial, physical and mental health of the American people, we note that the following priorities are critical to ensuring quality health insurance coverage is affordable and accessible:

- Provide additional funding for state Medicaid programs, maintain the maintenance of effort provisions included in the CARES Act, and extend the length of time states can use funds.
- Require COVID-19 testing, treatment, vaccines, and recovery services to be provided at no-cost to consumers, regardless of their method of coverage.
- Incentivize states to expand Medicaid.
- Block the implementation, enforcement, and effect of all final rules that expanded availability of non-compliant plans like short-term, limited-duration and association health plans. Codify limits on non-compliant plans into law.
- Extend eligibility and provide subsidies for individuals who have lost employer sponsored coverage.

Accessibility
Health care must be accessible as the connection between health insurance and health outcomes is clear and well documented.²³ Our organizations’ principles state that, “all people, regardless of employment status or geographic location, should be able to gain high-quality coverage without waiting periods or lock outs through adequate open and special enrollment periods”.²⁴ All people need access to quality and affordable health care to manage serious and chronic diseases and be able to access medical care during the current public health emergency.

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⁴ Id.
Additional Funding for State Medicaid Programs

State Medicaid programs provide a vital safety net during this national crisis, covering traditionally underserved populations and helping to stem the spread of the virus. Our organizations strongly supported the 6.2 percent increase in the federal medical assistance percentage (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, 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.

Our organizations also urge Congress to extend the length of time that states can receive these additional funds. The economic impact of COVID-19 is likely to last much longer than the public health emergency declaration. In fact, CBO estimates that the unemployment rate will be nine percent at the end of 2021, meaning that states will see an increased need for Medicaid coverage for months and even years to come. Our organizations urge Congress to extend the FMAP increase beyond the public health emergency declaration and instead tie it to a measure of the economic impact of this crisis. To prepare for the next pandemic or economic downtown, Congress should create an automatic mechanism that ties the FMAP to an economic indicator like unemployment.

Maintain Maintenance of Effort Provisions

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

Incentivize Remaining States to Expand Medicaid

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. 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. Our organizations therefore urge Congress to provide 100 percent FMAP for the first three years that states expand their Medicaid programs, a financial incentive that was

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available to states that expanded their programs in 2013, to help additional states expand their programs at this critical time.

**Block Barriers to Medicaid Coverage**

While our organizations oppose barriers to Medicaid coverage at any time, they are more problematic now than ever before. Given the economic impact of the COVID-19 pandemic, many of our organizations asked the administration to immediately halt policies that would create barriers to gaining and maintaining Medicaid coverage - such as waivers establishing work requirements, eliminating retroactive eligibility, or increasing cost-sharing. Similarly, we have also asked that the block grant policy guidance issued in January 2020 be immediately rescinded.

**Adequacy**

For patients, it is essential that health care be adequate. This means that services and treatments patients need, including those required by individuals with unique and complex health needs, are covered. During the present pandemic, it is paramount that all people, including individuals with pre-existing conditions, have access to high-quality coverage that meets their health care needs.

**Coverage for Testing, Treatment, Vaccines, and Recovery Services**

Experts agree that access to testing, treatment, vaccines, and recovery services are the most important part of slowing and stopping the spread of COVID-19. We appreciate the work that has been done so far, especially passage of the Families First Coronavirus Response Act (H.R. 6201) to ensure that testing and vaccines are no-cost to individuals. As Congress considers additional COVID-19 legislation, we urge policymakers to also ensure that all individual and group market insurance be required to cover all care related to the testing, treatment, vaccines and recovery services from the COVID-19 virus without cost sharing for consumers.

It is critical that testing, treatment, vaccines, and recovery services are provided at no-cost to consumers, regardless of their method of coverage. Removing all cost-related barriers to treatment will ensure that the greatest number of people take action to care for themselves and those around them as this highly contagious virus spreads. Applying these same coverage standards to protect individuals already enrolled in non-compliant plans, like short-term, limited duration (STLD) and association health plans (AHP), is also important to robustly protect individuals, families, and the public health.

**Stop the Issuance of Non-Qualified Health Plans**

Due to the increased availability of subpar insurance products, even Americans with insurance find themselves underinsured during this crisis. Non-compliant plans, like STLD plans and AHPs, are not required to meet federal patient protection standards. Noncompliant plans leave consumers exposed to high out-of-pocket costs for their care and often don’t cover basic health care needs, such as prescription drugs and emergency services.10

These plans are particularly dangerous at this time because they can rescind coverage based on the determination of a pre-existing condition, for which COVID-19 would qualify, and leave patients with no coverage at all in the midst of a crisis. To make matters worse, new evidence suggests that they are being marketed in misleading and even predatory ways to people suffering job or income loss.11
Congress should immediately move to prohibit the Department of Health and Human Services, the Department of Treasury, and the Department of Labor from implementing, enforcing, or in any way giving effect to final rules that expanded availability of short-term, limited-duration and association health plans. Allowing non-compliant plans to enroll more individuals at this time will only increase the number of individuals who do not have coverage of essential COVID-related services, and therefore will require funds from the National Disaster Medical System program for uninsured individuals. Additionally, for those individuals who are already covered by these plans, Congress must ensure that any people who lose this sub-par coverage due to rescission of the rule have a way to purchase comprehensive, affordable coverage that meets their and their families’ needs.

**Coverage for Telemedicine Services**

Telehealth, including telemedicine and telemental health are vital lifelines for those at the greatest risk for the coronavirus. Telemedicine services can ensure access to specialized providers and continuity of care when in-person visits are not a safe option, enabling patients to continue to social distance and avoid hospitals and clinics at the front lines of battling the pandemic. Telemental health enables people to access care to address the fear, stress, and anxiety caused by COVID-19 – a particular concern for individuals with underlying health conditions that the CDC recognizes as being at higher risk for both severe illness and increased stress due to COVID-19. Access and continuity of care are essential to ensuring patients’ health and well-being.

Our organizations commend Congress and the administration for providing greater flexibility and ease of access to telehealth services in recent weeks, including relaxing site of care rules for Medicare beneficiaries; allowing audio-only services for Medicare beneficiaries; allowing Federally Qualified Health Centers and Rural Health Clinics to serve as a distant site for telehealth during the COVID-19 emergency period; and providing $200 million for the Federal Communications Commission (FCC) and $180 million to the Health Resources and Services Administration (HRSA) to support telehealth services.

We understand that the policy changes made in the April 2020 interim final rule are in place for the duration of the public health emergency. However, it will be necessary for people with serious health conditions – those at higher risk of a severe case of COVID-19 – to have access to these services for a longer period of time. High-risk patients and those with compromised immune systems will have to be vigilant about their risk for COVID-19 and other contagious diseases long after the initial crisis period is over, and Congress should extend current flexibilities to ensure these patients can continue to safely access the care they need. Further, Congress should increase funding for patient and provider education around the availability, simplicity, and safety of using telemedicine when appropriate. In addition, we urge HRSA to use this unique moment in time as an opportunity to collect and analyze data on telehealth usage to inform future policies.

**Affordability**

Our organizations recognize that illness impacts individuals of all incomes – now more than ever. We believe that all patients, regardless of their economic situation, should be able to afford the treatment they require. Affordable health care coverage includes reasonable premiums and cost-sharing, including protecting those with pre-existing conditions from being charged more for their coverage.

**Assistance for People Who Have Lost Employer Sponsored Coverage**

As more individuals lose coverage as a result of job loss, it will continue to be critical to retain coverage to adequately combat COVID-19. We therefore encourage Congress to authorize the administration
to allow individuals to extend employer sponsored coverage and provide subsidies to alleviate financial strain after termination. This approach, which was last utilized in 2009 during the financial crisis, allowed workers to receive a 65% premium subsidy for six months to retain coverage. We encourage Congress to consider offering this benefit and increasing the generosity of the subsidy beyond 65% to ensure employers and employees are shielded from financial stress.

Furthermore, keeping an employer plan will allow for continuity of provider networks and medications, which is critical for patients and survivors. Patients, particularly those with high-cost conditions, are among the people most likely to have incurred substantial out-of-pocket spending this early in the calendar year. Facilitating the extension of employer coverage relieves such individuals from having to start a new plan, with new cost-sharing amounts and patient out-of-pocket contributions reset to zero.

In addition, Congress should direct the administration to undertake a robust public education and notification campaign to guarantee there is adequate uptake of this benefit. Congress should also direct the administration to ensure that those who are Medicare-eligible and who time out of COBRA coverage have access to a special enrollment period for Medicare coverage.

Conclusion
As the COVID-19 virus continues to spread across communities in the United States, we urge you and your congressional colleagues to provide the coverage resources individuals and families need to seek and afford timely treatment and care. The above recommendations will help assure that patients will be protected during this crisis and that our health care system will remain viable and available to them after the crisis.

For more information or to discuss further, please direct your staff to contact Katie Berge, Director of Federal Government Affairs 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 Kidney Fund
American Lung Association
Arthritis Foundation
Asthma and Allergy Foundation of America
Cancer Support Community
CancerCare
Cystic Fibrosis Foundation
Epilepsy Foundation
Family Voices
Hemophilia Federation of America
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
National Psoriasis 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
National Psoriasis Foundation
Pulmonary Hypertension Association
Susan G. Komen
The AIDS Institute
The American Liver Foundation
The Leukemia & Lymphoma Society
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WomenHeart: The National Coalition for Women with Heart Disease