March 20, 2020
Updated with additional signatories: March 25, 2020

The Honorable Nancy Pelosi, Speaker
United States House of Representatives
1236 Longworth House Office Building
Washington, D.C. 20515

The Honorable Mitch McConnell, Leader
United States Senate
317 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Kevin McCarthy, Leader
United States House of Representatives
2468 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Charles Schumer, Leader
United States Senate
322 Hart Senate Office Building
Washington, D.C. 20510

Re: Medications Access Must be Included in Third COVID-19 package

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

We, the 212 undersigned organizations, appreciate the work Congress has done so far to respond to the COVID-19 pandemic. We write to strongly encourage you to include provisions regarding access to medications and supplies for people of all ages in the next legislative package.

People with chronic conditions need access to essential and lifesaving medications and supplies on a regular basis. The Centers for Disease Control and Prevention (CDC) has encouraged people who take medications to stock up on extra supplies of their medications to comply with social distancing guidelines and prepare for emergencies. However, many forms of insurance place limits on refills. Further, there are even stricter limits on medications that are controlled substances, indicated for and used to treat epilepsy, mental illnesses, cancer and other serious medical conditions.

We urge Congress to take action to assist people with chronic health conditions to protect themselves in this crisis and maintain access to their medications. Removing burdensome barriers to obtaining medications, including limits on refills or other efforts to ensure supply of these medications, will keep the people we represent out of hospitals and doctors' offices, freeing up space for those with COVID-19. It is a particular concern to maintain a consistent supply for people who take an approved medication that is being studied for use in COVID-19, such as hydroxychloroquine, which is used to treat lupus and rheumatoid arthritis

So far, CMS has encouraged flexibility in Medicare[1] and states have flexibilities through 1135 waivers to relax refill limits.[2] However, implementation is uneven, and plans and states cannot relax controlled substance guidelines on their own. Congress must take immediate, national action to ensure access to medications.

We urge Congress and the Administration to take action to address the following issues:

- Require all payers to allow for provision of an emergency supply of medications and supplies by relaxing restrictions on timing of refills and amounts, to at least the CDC-recommended extra 30-day supply and up to a 90-day supply to reduce returns to the pharmacy[3]

[1] https://www.cms.gov/files/document/hpms-memo-covid-information-plans.pdf
[2] https://www.medicaid.gov/state-resource-center/disaster-response-toolkit/federal-disaster-resources/index.html
[3] https://www.cdc.gov/cpr/prepareyourhealth/00_docs/18_295610-A_PIB_Prescriptions.pdf

- Ensure that these protections extend to medications that are controlled substances indicated for and used to treat epilepsy, mental illnesses, cancer and other serious medical conditions, as well as injectables
- Require all payers to waive prior authorization and utilization management requirements
- Require flexibility regarding use of mail order pharmacies, including out of state mail order pharmacies and other home delivery methods
- Require payers to relax requirements for in-person visits for refills, including allowing visits through telehealth
- Require all payers to establish policies to assist patients with cost-sharing related to their emergency supply or allow for delayed payment of out-of-pocket costs for emergency supplies
- Increase FDA monitoring and reporting of shortages to ensure consistent supply, especially existing medications approved to treat chronic conditions that may be under study or used to treat COVID-19

We appreciate your actions to date and your attention during this time. If you have any questions, contact Rachel Patterson, Epilepsy Foundation, at rpatterson@efa.org.

CC:
Senate Finance Committee Chairman Charles E. Grassley
Senate Finance Committee Ranking Member Ron Wyden
Senate HELP Committee Chairman Lamar Alexander
Senate HELP Committee Ranking Member Patty Murray
House Majority Leader Steny H. Hoyer
House Energy and Commerce Committee Chairman Frank Pallone, Jr.
House Energy and Commerce Committee Ranking Member Greg Walden
House Ways and Means Committee Chairman Richard E. Neal
House Ways and Means Committee Ranking Member Kevin Brady
House Education & Labor Chairman Bobby Scott
House Education & Labor Ranking Member Virginia Foxx
Vice President Mike Pence
Secretary of Health and Human Services Alex Azar
Deborah Birx, White House Coronavirus Response Coordinator
Centers for Medicare and Medicaid Services Administrator Seema Verma
Surgeon General Jerome Adams
National Institute of Allergy and Infectious Diseases Director Anthony Fauci
Centers for Disease Control and Prevention Director Robert Redfield

Sincerely,

ACCSES - The Voice of Disability Service Providers
ADAP Advocacy Association
AIDS Action Baltimore
AIDS Alliance for Women, Infants, Children, Youth & Families
AIDS Foundation of Chicago
Alaska Youth and Family Network
Allegheny Family Network
Allergy & Asthma Network
Alliance for Patient Access
Allies for Independence
ALLvanza
ALS Association
American Academy of Neurology
American Academy of Physical Medicine & Rehabilitation (AAPM&R)
American Association of People with Disabilities
American Association on Health and Disability

American Autoimmune Related Diseases Association
American Behcet's Disease Association
American Council of the Blind
American Diabetes Association
American Urological Association
Angelman Syndrome Foundation
Arthritis Foundation
Asian Pacific Health Foundation
Association of Asian Pacific Community Health Organizations
Association of Nurses in AIDS Care
Association of University Centers on Disabilities
Asthma and Allergy Foundation of America
Autism Science Foundation
Autism Society of America
Autistic Self Advocacy Network
Batten Disease Support and Research Association
Bazelon Center for Mental Health Law
BPAN Warriors
Brain Injury Association of America
Bridge the Gap - Syngap Education and Research Foundation
CA Chronic Care Coalition
Cancer Support Community
CancerCare
Caregiver Action Network
Center for Adoption Support Education
Center for Health Law and Policy Innovation
Center for Medicare Advocacy
Center for Public Representation
Child Neurology Foundation
Children and Adults with Attention-Deficit/Hyperactivity Disorder
Christopher & Dana Reeve Foundation
Chronic Care Policy Alliance
Chronic Disease Coalition
Citizens United for Research in Epilepsy (CURE)
Coalition on Positive Health Empowerment
CommunicationFIRST
Community Access National Network (CANN)
Community Catalyst
COPD Foundation
Costello Syndrome Family Network
Crohn's & Colitis Foundation
CureSHANK
Cutaneous Lymphoma Foundation
Cystic Fibrosis Foundation
Desert AIDS Project
Developmental and Epileptic Encephalopathies Project (DEE-P Connections)
Disability Rights Education & Defense Fund
Doose Syndrome Epilepsy Alliance
Dravet Syndrome Foundation
Dup15q Alliance
Each One Teach One Together, Inc Georgia Easterseals
Epilepsy Alliance North Carolina
Epilepsy Foundation
Epilepsy Foundation Arizona
Epilepsy Foundation Iowa
Epilepsy Foundation of Colorado
Epilepsy Information Service of Wake Forest School of Medicine
Epilepsy Leadership Council
Equality California
Families On The Move Of NYC, Inc.
Families Together Inc./Family to Family Health Center
FamilieSCN2A Foundation
Family Based Services Association of NJ
Family Connection of South Carolina
Family Involvement Center
Family Network on Disabilities
Family Reach
Family Support Organization of Essex County
Family Voices
Family Voices Indiana
Family Voices NJ
Family Voices of Wisconsin
Fight Colorectal Cancer
Friedreich’s Ataxia Research Alliance (FARA)
Genetic Alliance
Georgia AIDS Coalition
GLMA: Health Professionals Advancing LGBTQ Equality
Global Colon Cancer Association
Global DARE Foundation
Global Healthy Living Foundation
GO2 Foundation for Lung Cancer

GRIN2B Foundation
Hawai'i Families As Allies
HealthHIV
Hep B United
Hepatitis B Foundation
Hepatitis Education Project
HIV Dental Alliance
HIV Medicine Association
Hope for HIE
Hope For Hypothalamic Hamartomas
Human Rights Campaign
Idaho Federation of Families for Children's Mental Health
Idaho Parents Unlimited
International Myeloma Foundation
International Pemphigus Pemphigoid Foundation
Johns Hopkins University School of Medicine
Justice in Aging
Keck School of Medicine of USC
Kidsz Paradise Inc.
KIF1A.ORG
Lakeshore Foundation
Lennox-Gastaut Syndrome (LGS) Foundation
Leukemia and Lymphoma Society
LUNGevity Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
Lupus Research Alliance
Lutheran Services in America-Disability Network
MANA, A National Latina Organization
Medicare Rights Center
Mended Hearts & Mended Little Hearts
Men's Health Network
Mickie's Miracles
Miles for Migraine
MLD Foundation
Mountain State Parents CAN
Muscular Dystrophy Association
My Girls, Inc.
NAMI San Diego
NASTAD
National Alliance for Hispanic Health
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Association of Hispanic Nurses
National Association of State Head Injury Administrators
National Black Nurses Association
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Coalition for Cancer Survivorship
National Coalition for LGBT Health
National Council for Behavioral Health
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Health Law Program
National Hispanic Council on Aging
National Hispanic Medical Association
National Kidney Foundation
National Organization for Rare Disorders
National Patient Advocate Foundation
National Viral Hepatitis Roundtable
NBIA Disorders Association
Nebraska Family Support Network
New Jersey Association of Mental Health and Addiction Agencies, Inc.
Noah's Hope - Hope4Bridget
NORSE Institute
North Carolina Families United
Ovarian Cancer Research Alliance
Parent Educational Advocacy Training Center (PEATC)
Parent Support Network of Rhode Island
Parent/Professional Advocacy League
Parents Helping Parent (San Jose, CA)
Partnership for Innovation and Empowerment
Partnership to Fight Chronic Disease
PATH Parent to Parent/Family Voices of CT
Phelan-McDermid Syndrome Foundation
Prevent Blindness
PSC Partners Seeking a Cure
PVNH Support & Awareness
PXE International
RASopathies Network
Ring Chromosome 20 Alliance
Robert G Gish Consultants LLC
Silver State Equality-Nevada
Sophie's Neighborhood

SPAN Parent Advocacy Network (SPAN)
Sudden Arrhythmia Death Syndromes (SADS) Foundation
Susan G. Komen
SynGAP Research Fund
Tash
Texas Parent to Parent
The AIDS Institute
The Arc of the United States
The Brain Recovery Project: Childhood Epilepsy Surgery Foundation
The Family Cafe, Inc.
The Hemispherectomy Foundation
The International Foundation for CDKL5 Research
The Parents' Place of MD
The Reflex Sympathetic Dystrophy Syndrome Association
The Simon Foundation for Continence
The Younger Years & Beyond: Local Chapter of The Federation of Families for Children's Mental Health
TN Voices
Total Family Care Coalition
Tuberous Sclerosis Alliance
United Ostomy Associations of America
United Spinal Association
University of Cincinnati UCEDD/Ohio F2F
Utah Family Voices
Vasculitis Foundation
Vietnamese American Cancer Foundation (VACF)
Wilson Disease Association
Wishes for Elliott: Advancing SCN8A Research
WomenHeart: The National Coalition for Women with Heart Disease
Wyoming Family Voices