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 Medicare¹ 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 pharmacy³

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³ [https://www.cdc.gov/cpr/prepareyourhealth/00_docs/18_295610-A_PIB_Prescriptions.pdf](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 rpaterson@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 Kidney Fund
American Urological Association
Angelman Syndrome Foundation
Arthritis Foundation
Asian Pacific Health 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