

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<sup>1</sup> and states have flexibilities through 1135 waivers to relax refill limits.<sup>2</sup> 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<sup>3</sup>

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<sup>1</sup> <https://www.cms.gov/files/document/hpms-memo-covid-information-plans.pdf>

<sup>2</sup> <https://www.medicaid.gov/state-resource-center/disaster-response-toolkit/federal-disaster-resources/index.html>

<sup>3</sup> [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 [rpatterson@efa.org](mailto: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 Kidney Fund  
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