

March 20, 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: Potential Aid for Patient and Community-Based Organizations Impacted by Coronavirus**

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

The 215 undersigned organizations write regarding prospective federal intervention to support the airline, travel, and other targeted industries impacted by the coronavirus (COVID-19) epidemic. **We urge you to also include nonprofit patient advocacy community-based organizations within any federal aid packages or supplemental appropriations measures**, as many have been and will be significantly harmed by reduced charitable giving, travel restrictions, fund-raising event cancellations, and reduced meeting attendance as a result of COVID-19. Because of their tax-exempt status, this may necessitate targeted assistance or reshaping tax code-related assistance.

As non-partisan, nonprofit organizations our mission is to serve the patients and communities we represent at no-cost. We are the groups helping the people most impacted by the virus, those with underlying chronic conditions that often result in more severe cases of illness. We expect demand for their invaluable services will only increase during this public health emergency, while at the same time seeing significant reductions in revenue. In addition, the nonprofit sector is the third largest workforce in the U.S., behind retail and manufacturing<sup>1</sup>. In order to continue their valuable work, it is critical that patient advocacy and community-based organizations and other nonprofits be included in any legislation aimed at stemming the growing economic burden of the COVID-19 pandemic.

The spring season is the time of year when many patient advocacy and community-based organizations hold important charitable events that drive a significant portion of their revenue. This includes runs/walks, bike rides, and galas. As you no doubt aware, the fast-spreading COVID-19 epidemic has prompted the cancellation of thousands of these types of events, as well as other mission-critical scientific and membership conferences.

The loss of these meetings and conferences is especially difficult as they play a significant role in advancing science and educating patients and providers. These

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<sup>1</sup> <https://www.urban.org/research/publication/nonprofit-sector-brief-2015-public-charities-giving-and-volunteering>

meetings are largely dependent on in-person attendance at convention centers, hotels, and other event facilities. Thus, the impact of cancellations is, in fact, exponential. The groups not only lose important revenue that helps them support people with chronic conditions, they also forfeit substantial, non-refundable expenses obligated to hotels, event spaces, and vendors. We believe it would be unfair to propose financial relief for businesses such as hotels or other venues, that will collect large sums in cancellations fees, without considering the plight of the nonprofits paying those cancellation fees.

Many associations operate similarly to small businesses and are greatly impacted if employees are forced to take sick leave or are quarantined as a result of COVID-19 exposure. We are aware the Administration and Congress are considering measures for small businesses that may require cash flow assistance amid the outbreak, and **urge that tax-exempt entities be included in any temporary aid designed to stem the economic fallout resulting from COVID-19.**

Additionally, we also are concerned by potential impacts on individual and corporate giving in a time when health-related organizations are most needed. Congress should ensure communities are able to support their local nonprofits during this crisis by enacting a **targeted, temporary giving incentive** that enables all residents, regardless of whether they claim itemized deductions, to receive a tax incentive for giving to the work of charitable nonprofits responding to, or suffering from, the coronavirus.

Specifically, we ask that you assure that any additional economic relief or stimulus legislation:

- Incentivize all Americans to support the vital work of America's charities, by enacting an "above-the-line" or universal charitable deduction for contributions through the end of 2021. Further, to help those who step forward to help America's charitable organizations to immediately assist the most vulnerable, Congress should permit taxpayers to donate today – at the height of the pandemic – and claim the benefit from these deductions on 2019 tax returns.
- Make tax credits and deductions applicable not just to income taxes, but to the taxes nonprofits pay, such as payroll taxes. Further, Congress should also ensure that relief and stimulus legislation designed to assist for-profit businesses in the areas of unemployment insurance, employee retention, and risk insurance must also address the unique challenges and realities that nonprofits face.
- Include \$60 billion in emergency stimulus funding aimed at helping adversely affected national and local organizations. These funds can be distributed quickly through multiple funding streams, including, but not limited to, expansion of the Economic Injury Disaster Loan program for nonprofit employers, emergency grants to nonprofits operating under grants from federal, state, local, or other pass-through entities, and other mechanisms to ensure the continued flow of charitable donations.

The nation's leading patient advocacy and community-based organizations stand ready and able to assist Congress and the administration in combating the COVID-19 outbreak in addition to meeting our mission to serve people with complex health conditions. But, they will need to be sure they can be financially stable through present and future uncertainties.

Thank you for your consideration.

Sincerely,

A Cure In Sight  
Able2 Enhancing potential, inc  
Adrenal Insufficiency United  
Aidan Jack Seeger Foundation  
Alagille Syndrome Alliance  
AliveAndKickn  
All Things Kabuki  
Allergy & Asthma Network  
Alliance for Aging Research  
ALS Association  
Alzheimer's Association  
Alzheimer's Impact Movement  
American Academy of Physical  
Medicine and Rehabilitation (AAPM&R)  
American Association for  
Psychoanalysis in Clinical Social Work  
American Association of Suicidology  
American Association on Health and  
Disability  
American Association on Intellectual  
and Developmental Disabilities  
American Autoimmune Related  
Diseases Association  
American Council of the Blind  
American Counseling Association  
American Diabetes Association  
American Heart Association  
American Kidney Fund  
American Lung Association  
American Mental Health Counselors  
Association (AMHCA)  
American Parkinson Disease  
Association  
American Society for Reproductive  
Medicine  
American Speech-Language-Hearing  
Association  
American Thoracic Society  
Amputee Coalition  
Angioma Alliance  
Anxiety and Depression Association of  
America  
Arthritis Foundation  
Asthma and Allergy Foundation of  
America  
Batten Disease Support & Research  
Association  
Beyond Celiac  
Brain Injury Association of America

Brian Grant Foundation  
Bridge the Gap - Syngap Education and  
Research Foundation  
Cancer Support Community  
Caregiver Action Network  
Celiac Disease Foundation  
Center for Independence of the  
Disabled, NY  
Center of Family Love  
CFC International  
Charcot-Marie-Tooth Association  
Child Health & Resilience Mastery  
(CHARM)  
Children's Cardiomyopathy Foundation  
Children's Craniofacial Association  
Christopher & Dana Reeve Foundation  
Chronic Migraine Awareness inc  
CLOVES Syndrome Community  
CMA, Inc.  
Coalition For Headache And Migraine  
Patients (CHAMP)  
Colorectal Cancer Alliance  
Community Health Charities  
Congenital Hyperinsulinism International  
COPD Foundation  
Crohn's & Colitis Foundation  
Cure SMA  
CureDuchenne  
Danielle Byron Henry Migraine  
Foundation  
Davis Phinney Foundation for  
Parkinson's  
Depression and Bipolar Support Alliance  
Diabetes Patient Advocacy Coalition  
DIRECT Center for Independence  
Dreamsickle Kids Foundation  
Ear Community, Inc.  
Epilepsy Foundation  
Every Mother Counts  
Family Voices Indiana  
Fibrous Dysplasia Organization  
Fight Colorectal Cancer  
FORCE: Facing Our Risk of Cancer  
Empowered  
Friedreich's Ataxia Research Alliance  
GBS|CIDP Foundation International  
Genetic Alliance  
Global Alliance for Behavioral Health  
and Social Justice

Global Lives Institute  
Glut1 Deficiency Foundation  
GO2 Foundation for Lung Cancer  
Gould Syndrome Foundation  
Greater Tampa Bay Oral Health  
Coalition  
GRIN2B Foundation  
Hawai'i Parkinson Association  
HealthHIV  
Hemophilia Federation of America  
Hermansky-Pudlak Syndrome Network  
Inc.  
Histiocytosis Association  
Huntington's Disease Society of  
America  
Hydrocephalus Association  
Independence Care System, Inc.  
International Fibrodysplasia Ossificans  
Progressiva (FOP) Association  
International Myeloma Foundation  
International OCD Foundation  
International Pemphigus Pemphigoid  
Foundation  
JDRF  
Jett Foundation  
KIF1A.ORG  
Klippel-Trenaunay Support Group  
KrabbeConnect  
Lakeshore Foundation  
Leukemia & Lymphoma Society  
Little Hercules Foundation  
Little Miss Hannah Foundation  
LUNGevity Foundation  
Lupus Foundation of America  
Lymphangiomatosis & Gorham's  
Disease Alliance  
Lymphatic Education & Research  
Network  
Lymphoma Research Foundation  
M-CM Network  
March for Moms  
Melanoma Research Foundation  
Mended Hearts  
Mental Health America  
Mesothelioma Applied Research  
Foundation  
Michigan Parkinson Foundation  
Minority Corporate Counsel Association  
MitoAction  
MLD Foundation  
Moebius Syndrome Foundation

Multiple Sclerosis Association of  
America  
Muscular Dystrophy Association  
Narcolepsy Network  
National Alliance for Caregiving  
National Alliance for Hispanic Health  
National Alliance on Mental Illness  
National Alopecia Areata Foundation  
National Council on Aging  
National Council on Independent Living  
National Diabetes Volunteer Leadership  
Council  
National Eating Disorders Association  
National Eczema Association  
National Forum for Heart Disease &  
Stroke Prevention  
National Foundation for Ectodermal  
Dysplasias  
National Headache Foundation  
National Hemophilia Foundation  
National Kidney Foundation  
National Minority Quality Forum  
National Multiple Sclerosis Society  
National Osteoporosis Foundation  
National Patient Advocate Foundation  
National PKU News  
NGLY1.org  
NORD  
Northwest Parkinson's Foundation  
Obesity Action Coalition  
Organic Acidemia Association  
Osteogenesis Imperfecta Foundation  
Ovarian Cancer Research Alliance  
Pancreatic Cancer Action Network  
Parent Project Muscular Dystrophy  
Parkinson & Movement Disorder  
Alliance  
Parkinson Alliance/Parkinson's Unity  
Walk  
Parkinson Association of Alabama  
Parkinson Association of the Rockies  
Parkinson's Resources of Oregon  
Parkinson's Foundation  
Personalized Medicine Coalition  
Physician-Parent Caregivers  
Physician-Patient Alliance for Health &  
Safety  
Polycystic Kidney Disease Foundation  
Postpartum Support International  
Prevent Blindness  
Prostate Health Education Network, Inc.

Pten Foundation  
PTEN Hamartoma Tumor Syndrome  
Foundation  
Pulmonary Alveolar Proteinosis  
Foundation  
Pulmonary Fibrosis Foundation  
PXE International  
Rare Army  
Rare Kids Network  
RARE-X  
Research!America  
RESOLVE: The National Infertility  
Association  
RUNX1 Research Program  
Sarcoidosis of Long Island  
Say Yes to Hope  
Schizophrenia and Related Disorders  
Alliance of America  
Siegel Rare Neuroimmune Association  
Sjogren's Foundation  
Social Cohesion Resources  
Soft Bones, Inc., The US  
Hypophosphatasia Foundation  
Special Olympics International  
Spina Bifida Association  
St. Baldrick's Foundation  
Superficial Siderosis Research Alliance  
Inc.  
Supporting Our Sisters International Inc.  
Susan G. Komen  
Team Joseph  
The Asthma and Allergy Foundation of  
America  
The College Diabetes Network  
The Familial Hypercholesterolemia  
Foundation  
The FamilieSCN2A Foundation  
The FH Foundation  
The Global Foundation for Peroxisomal  
Disorders  
The Headache and Migraine Policy  
Forum  
The Jansen's Foundation  
The LAM Foundation  
The Mastocytosis Society, Inc.  
The Michael J. Fox Foundation for  
Parkinson's Research  
The Myositis Association  
The Snyder-Robinson Foundation  
The Sturge-Weber Foundation  
The TMJ Association

The Trevor Project  
The XLH Network, Inc.  
Tourette Association of America  
TransGen, Inc.  
Tuberous Sclerosis Alliance  
United Leukodystrophy Foundation  
VHL Alliance  
WomenHeart: The National Coalition for  
Women with Heart Disease  
World Health Education Foundation  
ZERO - The End of Prostate Cancer