May 6, 2020

The Honorable Mitch McConnell Majority Leader United States Senate S-230, The Capitol Washington, D.C. 20510

The Honorable John Thune Majority Whip United States Senate S-208, The Capitol Washington, D.C. 20510 The Honorable Charles Schumer Minority Leader United States Senate S-221, The Capitol Washington, D.C. 20510

The Honorable Dick Durbin Minority Whip United States Senate S-321, the Capitol Washington, D.C. 20510

Dear Leaders McConnell and Schumer and Senators Thune and Durbin:

We, the undersigned organizations, appreciate the Congressional response to the COVID-19 pandemic and its economic impact. We write to encourage you to provide at least \$2 billion in bridge funding in future Congressional COVID-19 relief packages to assure the stalled research supported by non-profit organizations, voluntary health associations, science societies, and foundations, can resume once researchers return to their labs.

We are deeply concerned about the economic consequences that the COVID-19 pandemic will have on America's research pipeline. The non-profit and voluntary health organization research community is a critical part of America's drug research and development pipeline. It is the fourth largest contributor for U.S. medical and health research and development expenditures, and funds thousands of early and mid-career scientists and researchers each yearⁱ. Collectively this sector of the research community invests at least \$6-7 billion each year to advance biomedical research and disease knowledge, translate biomedical research into novel therapies, and support early and mid-level scientists to ensure a robust scientific workforceⁱⁱ.

The decreases in revenue that these organizations are experiencing as a direct result of the COVID-19 pandemic will significantly impact their ability to fund basic or clinical research and will hinder completion of ongoing research and clinical trials, effectively bringing innovation to a stand-still. Costs associated with bringing research back online are unbudgeted expenses and many organizations do not have the ability to cover these costs due to the economic consequences of the COVID-19 pandemic. Researchers supported by these organizations often use this funding to build towards larger federal grants from the National Institutes of Health or other federal research agencies. We are concerned that a decrease in research funding from this community will force many researchers to abandon important research projects, including disease specific research, and will result in a gap of needed researchers for years to come.

In this time of extreme uncertainty, we believe Congress can provide vital support for the research occurring at America's non-profit, foundations, associations and voluntary health research community. We urge Congress to act swiftly to provide at least \$2 billion in emergency funding to support the research occurring through these organizations, who play such a critical role in advancing disease knowledge, expediting the development of novel therapies, and supporting America's broader research and scientific workforce.

Sincerely,

Accelerated Cure Project
Alliance for Aging Research
Alpha-1 Foundation
ALS Association

Alzheimer's Association

American Academy of Neurology

American Academy of Physical Medicine and Rehabilitation

(AAPM&R)

American Association of Neuromuscular & Electrodiagnostic

Medicine

American Autoimmune Related Diseases Association

American Behcet's Disease Association. (ABDA)

American Brain Coalition

American Cancer Society Cancer Action Network

American College of Clinical Pharmacy

American Diabetes Association

American Foundation for Suicide Prevention

American Heart Association

American Institute for Cancer Research (AICR)

American Liver Foundation

American Lung Association

American Parkinson Disease Association

American Psychiatric Association

American Society for Pharmacology and Experimental

Therapeutics

American Society for Radiation Oncology

American Thoracic Society

Anxiety and Depression Association of America

Arthritis Foundation

Association for Clinical and Translational Science

Association of Black Cardiologists

Association of University Professors of Neurology

Beyond Celiac

Cancer Support Community

Caregiver Action Network

Celiac Disease Foundation

Children's Cancer Cause

Children's Cardiomyopathy Foundation

Clinical Research Forum

Coalition for Clinical and Translational Science

Conquering CHD

Consortium of Multiple Sclerosis Centers

Cooley's Anemia Foundation

Crohn's & Colitis Foundation

CureSHANK

Debbie's Dream Foundation: Curing Stomach Cancer

Digestive Disease National Coalition

Dystonia Advocacy Network

Dystonia Medical Research Foundation

Ear Community, Inc.

Endocrine Society

Epidermolysis Bullosa Research Partnership

Epilepsy Foundation

Fibrous Dysplasia Foundation

Fight Colorectal Cancer

FORCE: Facing Our Risk of Cancer Empowered

Foundation for Sickle Cell Disease Research

Friedreich's Ataxia Research Alliance (FARA)

GBS | CIDP Foundation International

GO2 Foundation for Lung Cancer

Greater Tampa Bay Oral Health Coalition

Hydrocephalus Association

International Organization of MS Nurses

International Pemphigus and Pemphigoid Foundation

International Pemphigus Pemphigoid Foundation

Interstitial Cystitis Association

JDRF

Jeffrey Modell Foundation

KidneyCAN

LUNGevity Foundation

Lupus and Allied Diseases Association, Inc.

Lupus Foundation of America

Lupus Research Alliance

Lymphangiomatosis & Gorham's Disease Alliance

Lymphatic Education & Research Network

Mental Health America

Mesothelioma Applied Research Foundation

METAvivor

MLD Foundation

Movement Disorders Policy Coalition

Muscular Dystrophy Association

National Alliance on Mental Illness

National Alopecia Areata Foundation

National Ataxia Foundation

National Cancer Registrars Association

National Eczema Association

National Health Council

National Multiple Sclerosis Society

National Organization for Tardive Dyskinesia

National Organization of Rare Disorders

National Pancreas Foundation

National Psoriasis Foundation

NephCure Kidney International

Oncology Nursing Society

Pancreatic Cancer Action Network

Parkinson's Foundation

Parkinson's Unity Walk

Patient Services, Inc.

Patrick Risha CTE Awareness Foundation

Phelan-McDermid Syndrome Foundation

Prevent Blindness

Project Sleep

Pulmonary Fibrosis Foundation

Pulmonary Hypertension Association

Research!America

Restless Legs Syndrome Foundation

RetireSafe

Scleroderma Foundation

Sjögren's Foundation

Sleep Research Society

Society for Immunotherapy of Cancer

Solve ME/CFS Initiative

St. Baldrick's Foundation

The Brain Donor Project

The Brain Recovery Project: Childhood Epilepsy Surgery

Foundation

The Marfan Foundation

The Michael J. Fox Foundation for Parkinson's Research

The Oral Cancer Foundation

The Parkinson Alliance

The TMJ Association

Triage Cancer

U. S. COPD Coalition

United Ostomy Associations of America

US Hereditary Angioedema Association

ⁱ Research America. U.S. Investments in Medical and Health Research and Development 2013 – 2018. https://www.researchamerica.org/sites/default/files/Publications/InvestmentReport2019 <a href="https://www.researchamerica.org/sites/default/files/Publications/InvestmentRep

ii Health Research Alliance. HRA Analyzer.