

April 15, 2020

The Honorable Nancy Pelosi
Speaker of the House
United States Congress
H-232 The Capitol
Washington, DC 20515

The Honorable Kevin McCarthy
Majority Leader
United States Congress
H-204 The Capitol
Washington, DC 20515

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

The Honorable Chuck Schumer
Minority Leader
United States Senate
S-220 The Capitol
Washington, DC 20510

Dear Speaker Pelosi, Minority Leader McCarthy, Majority Leader McConnell, and Minority Leader Schumer:

Thank you for enacting important medical access and stimulus provisions in recent legislative packages to respond to the coronavirus. As you consider additional measures to stabilize the economy, the 48 undersigned organizations write to urge you to provide funding for public health and medical research activities. Specifically, we ask you to support targeted education and awareness activities on the coronavirus for chronic illness communities, and to bolster medical research that will go unfunded by nonprofits and other nongovernmental organizations due to the economic recession.

We encourage Congress to establish a targeted fund at the Centers for Disease Control & Prevention (CDC) to support education and awareness activities that provide disease-specific coronavirus information to chronic illness communities. While protecting public health, stay-at-home orders have essentially halted the ability of nonprofits to fundraise, and nonprofits are making painful, across-the-board budget cuts. Despite these cuts, patient-focused organizations are increasing their spending to provide critical information about the coronavirus in a manner that addresses the unique needs of their communities. These education and awareness activities are helping patients access relevant information from a trusted source, and are supporting patients in navigating the healthcare system during this time of medical office closures, potential exposure to COVID-19, drug shortages, and shifts in care settings. According to a recent Morbidity and Mortality Weekly Report, over 89% of patients that are hospitalized for the coronavirus have one or more underlying conditions.¹ We urge Congress to establish a fund at the CDC to partner with patient-focused organizations to promote the information patients need to stay healthy and out of the hospital during this public health emergency.

¹ See https://www.cdc.gov/mmwr/volumes/69/wr/mm6915e3.htm?s_cid=mm6915e3_w, April 8, 2020

We also encourage Congress to provide additional bridge funding for the National Institutes of Health (NIH) to support the broad medical research community. In an effort to stay afloat during this time of economic recession, many nonprofits are cutting millions of dollars from their research portfolios. Many investigators who are critical to developing treatments and improving the quality of patient care will receive less funds, or go unfunded, until nonprofits can return to their normal level of research support. Further, research projects across the nation have been temporarily suspended, and it is expected the resumption of these projects will require additional and unanticipated funding. To address this gap, Congress should step in to maintain the nation's research and development capacity by providing additional funding to the NIH to make up for lost dollars from the private sector, and the interruption of projects from basic to clinical. This additional NIH funding should support both existing research projects that were negatively impacted by the pandemic, as well as new projects which will go unfunded including vulnerable early- to mid-career awards.

Thank you for your tireless efforts to protect the health and livelihood of the nation. We appreciate your consideration for the above funding requests to ensure patients can access credible and specific information on COVID-19, and to sustain our research communities. For additional information, please contact Sarah Buchanan, Director of Advocacy at the Crohn's & Colitis Foundation, at sbuchanan@crohnscolitisfoundation.org.

Sincerely,

American Association of Neuromuscular & Electrodiagnostic Medicine
American Autoimmune Related Diseases Association
American Heart Association
American Kidney Fund
American Liver Foundation
American Neurogastroenterology and Motility Society
Arthritis Foundation
Association for Clinical and Translational Science
Celiac Disease Foundation
Chronic Disease Coalition
Clinical Research Forum
Coalition for Clinical and Translational Science
Community Liver Alliance
Crohn's & Colitis Foundation
Cystic Fibrosis Foundation
Digestive Disease National Coalition
Dystonia Advocacy Network
Dystonia Medical Research Foundation
GBS|CIDP Foundation International
Global Colon Cancer Association
Global Healthy Living Foundation
Global Liver Institute

Immune Deficiency Foundation
International Foundation for Gastrointestinal Disorders
Interstitial Cystitis Association
Lupus and Allied Diseases Association, Inc.
Lymphatic Education & Research Network
METAvivor
Muscular Dystrophy Association
National Alliance on Mental Illness
National Alopecia Areata Foundation
National Kidney Foundation
National Pancreas Foundation
NephCure Kidney International
Patient Services, Incorporated
Pennsylvania Society of Gastroenterology
Project Sleep
Pulmonary Hypertension Association
Restless Legs Syndrome Foundation
Scleroderma Foundation
Sleep Research Society
The American Society for Parenteral and Enteral Nutrition
The Greg and Cathy Griffith Family Foundation
The Leukemia & Lymphoma Society
The Marfan Foundation
The Oley Foundation
United Ostomy Associations of America
US Hereditary Angioedema Association