



October 11, 2013

The Honorable Harry Reid, Majority Leader
United States Senate
Washington, D.C. 20510

The Honorable Mitch McConnell, Minority Leader
United States Senate
Washington, D.C. 20510

The Honorable John Boehner, Speaker
United States House of Representatives
Washington, D.C. 20515

The Honorable Nancy Pelosi, Minority Leader
United States House of Representatives
Washington, D.C. 20515

Dear Majority Leader Reid, Speaker Boehner, Minority Leader McConnell, and Minority Leader Pelosi:

The undersigned individuals represent patients with rare diseases who rely on government in so many ways: for research to develop new treatments for our diseases, for regulatory oversight of our medications, for support of the government services that we all need. We are outraged that the Congress has permitted the Federal government to shut down, and we respectfully request that you do everything in your power to enable the government to open again as quickly as possible.

There are 30 million Americans with rare diseases. Many of these diseases are chronic and genetic. Many are diagnosed in childhood. All are different, but all have a few things in common:

- We know that the research sponsored by the National Institutes of Health has led to many new treatments for our diseases;
- We know that the standards set by the Food and Drug Administration, and its review process, are essential for these treatments to be developed and made available to us;
- We know that services such as the Social Security Administration's Compassionate Allowance initiative for expediting disability claims enable many of us to lead productive lives.

When the government shuts down, we all lose confidence in its capacity to do its job. The people who invest in the development of new therapies must have confidence that the government is fully and efficiently functioning. The researchers who are developing new therapies for our diseases need confidence that the guidance provided by the government regulators will be knowledgeable and consistent.

We recognize that there are ideological differences that underlie the debate in Washington over the shutdown. We know there are additional financial issues that will soon come before the Congress. What we ask, however, is that the entire government not be held hostage as the debates proceed. The shutdown harms people like us, and we have every right to expect more from our government.

Sincerely,

Rare Disease Patient Advocacy Organizations:

4p-Support Group
AKU Society of North America
Alliance for Cryoglobulinemia
Alström Syndrome International
Alternating Hemiplegia of Childhood Foundation
American Behcet's Disease Association
American Latex Allergy Association
Aplastic Anemia & MDS International Foundation
Association for Frontotemporal Degeneration
Association of Gastrointestinal Motility Disorders, Inc.
Batten Disease Support & Research Association
Breath of Hope, Inc.
CADASIL Association
CADASIL Together We Have Hope
CARES Foundation
Caring for Carcinoid Foundation
CFC International
Children's PKU Network
CJD Aware!
Circadian Sleep Disorders Network
Congenital Hyperinsulinism International
Council for Bile Acid Deficiency Diseases
CurePSP
Cushing's Support & Research Foundation
Cystinosis Foundation
Cystinosis Research Network
Desmoid Tumor Research Foundation
Dravet Foundation
Dupuytren Foundation
Esophageal Cancer Action Network
EDSers United
Fabry Support and Information Group
FACES: The National Craniofacial Association
FOD Family Support Group
Foundation for PSP/CBD & Related Brain Diseases
Foundation for Sarcoidosis Research
Friedreich's Ataxia Research Alliance
GBS/CIDP Foundation International
Genetic Alliance
Hepatitis Foundation International
HHT Foundation International
Histiocytosis Association
Hypoparathyroidism Association, Inc.
Immune Deficiency Foundation
Incontinentia Pigmenti International Foundation
International Foundation of CDKL5 Research

International Rett Syndrome Foundation
International WAGR Syndrome Association
Jack McGovern Coats Disease Foundation
Kennedy's Disease Association
Little Miss Hannah Foundation
Marfan Foundation
Mastocytosis Society
M-CM Network
Mesothelioma Applied Research Foundation
MHE Research Foundation
MPN Research Foundation
Moebius Syndrome Foundation
Mucopolysaccharidosis Type IV Foundation
Myotonic Dystrophy Foundation
National Gaucher Foundation, Inc.
National Eosinophilia-Myalgia Syndrome Network
National MPS Society
National Niemann-Pick Disease Foundation
National Organization for Rare Disorders
National PKU Alliance
National Tay-Sachs and Allied Diseases Association
Neurofibromatosis Northeast
Noonan Syndrome Foundation
OrthostaticTremor.org
PANDAS Network.org
Pediatric Neurotransmitter Disease Association
Pulmonary Hypertension Association
PSC Partners Seeking a Cure
Pulmonary Fibrosis Foundation
PXE International
RA Spondyloarthropathies Foundation
Reflex Sympathetic Dystrophy Syndrome Association
Sarcoma Foundation of America
Scleroderma Foundation
Stevens Johnson Syndrome Foundation
Tarlov Cyst Disease Foundation
Trisomy 18 Foundation
Von Hippel-Lindau Alliance

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