November 16, 2016

The Honorable Mitch McConnell
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Harry Reid
Minority Leader
United States Senate
Washington, DC 20510

The Honorable Paul Ryan
Speaker
US House of Representatives
Washington, DC 20515

The Honorable Nancy Pelosi
Minority Leader
US House of Representatives
Washington, DC 20515

Dear Leader McConnell, Leader Reid, Speaker Ryan, and Leader Pelosi:

We, the undersigned 217 organizations, represent a widely diverse community of patients and family caregivers with distinct perspectives; yet we stand united in support of the 21st Century Cures Act and urge you to support and move this legislation forward by the end of 2016. This legislation, which passed the House in July 2015 with broad bipartisan support, will help deliver treatments and cures to people who desperately need them.

It is based on thoughtful recommendations of the entire health community, and we thank the Energy and Commerce and Health, Education, Labor, and Pensions Committees for their tireless work to incorporate our feedback into the legislation.

This is a patient-focused bill that will advance the discovery and development of treatments, strengthen the patient voice in the research and regulatory environment, increase funding for the National Institutes of Health and Food and Drug Administration, and greatly improve our innovation ecosystem.

Millions of Americans are desperately waiting for effective treatments and cures for their chronic disease or disability. The organizations that represent these people with chronic conditions urge Congress to pass the 21st Century Cures Act in 2016 in order to speed the development of treatments and cures. Patients simply can't afford to wait -- time is running out.

Sincerely,

National Organizations:

A Kids’ Brain Tumor Cure (PLGA Foundation)
Abby Grace Foundation
Abigail Alliance for Better Access to Developmental Drugs
Adrenal Insufficiency United
Adult Polyglucosan Body Disease Research Foundation
Aidan Jack Seeger Foundation
AliveAndKickn
Allergy and Asthma Network

Alliance for Aging Research
Alliance for Cryoglobulinemia
Alport Syndrome Foundation
Alström Syndrome International
Alzheimer's Association
American Association for Respiratory Care
American Autoimmune Related Diseases Association
American Behcet's Disease Association
American Cancer Society Cancer Action Network
American Foundation for Suicide Prevention
American Heart Association
American Kidney Fund
Amyloidosis Research Consortium
Angioma Alliance
Arthritis Foundation
Association for Creatine Deficiencies
Association for Research in Vision and Ophthalmology
Asthma and Allergy Foundation of America
Ataxia Telangiectasia Children's Project
Autism Speaks
Autoinflammatory Alliance
Barth Syndrome Foundation
Bcureful
Bear Necessities Pediatric Cancer Foundation
Bert's Big Adventure
Beyond Celiac
Bridge the Gap- SYNGAP Education and Research Foundation
Cardio-Facio-Cutaneous International Caregiver Action Network
Caregiver Voices United
Central Pain Syndrome Foundation
Charles E. Holman Morgellons Disease Foundation
Chase After a Cure
Chasing Life Project
CheckOrphan
Children's Cardiomyopathy Foundation
Children's Craniofacial Association
Children's PKU Network
CLOVES Syndrome Community
Coalition Duchenne
Coalition for Clinical Trials Awareness
Colon Cancer Alliance
Congenital Adrenal Hyperplasia Research, Education and Support Foundation (CARES Foundation)
Congenital Hyperinsulinism International Consortium of Multiple Sclerosis Centers
Conquer Myasthenia Gravis
COPD Foundation
Cure CMD
Cure HHT
Cure JM Foundation
Cure Sanfilippo Foundation
CureCADASIL
CureDuchenne
Cutaneous Lymphoma Foundation
DADA2 Foundation
Debra of America
Dementia Alliance International
Dravet Syndrome Foundation
Drew's Hope Scientific Research Foundation
Dysautonomia International
Dyskeratosis Congenita Outreach, Inc.
Epilepsy Foundation
Erik Metzler Foundation, Inc.
EURORDIS- Rare Diseases Europe
EveryLife Foundation for Rare Diseases
Fabry Support & Information Group
Fanconi Anemia Research Fund
FasterCures
Fibrous Dysplasia Foundation
Fibromuscular Dysplasia Society of America
Fibrous Dysplasia Foundation
Fight Colorectal Cancer
FORCE: Facing Our Risk of Cancer Empowered
Foundation for Prader-Willi Research
Friends of Cancer Research
Garrett The Grand
Gene Giraffe Project
Genetic Alliance
Global Colon Cancer Association
Global Genes
Global Healthy Living Foundation
G-PACT
Guardian Hands Foundation
Hannah's Hope Fund for GAN
Hereditary Neuropathy Foundation Inc.
Hermansky-Pudlak Syndrome Network Inc.
Hope4Bridget
HSAN1E Society
Hunter Syndrome Foundation
Huntington's Disease Society of America
Hydrocephalus Association
International Cancer Advocacy Network (ICAN)
International Essential Tremor Foundation
International FOP Association
International Foundation for Autoimmune Arthritis
International Organization of Multiple Sclerosis Nurses
International Pemphigus & Pemphigoid Foundation
International WAGR Syndrome Association
International Waldenstrom's Macroglobulinemia Foundation (IWMF)
JDRF
Jonah's Just Begun-Foundation to Cure Sanfilippo
Kalel's MPS Superhero Foundation
Klippel-Feil Syndrome Freedom
K-T Support Group
Leiomyosarcoma Direct Research Foundation (LMSdr)
Little Miss Hannah Foundation
LMSarcoma Direct Research Foundation
LuMind Research Down Syndrome Foundation
Lung Transplant Foundation
LUNGevity
Lupus and Allied Diseases Association
Lupus Foundation of America
Lupus Friends and Family Foundation
Lupus Research Alliance
Lymphangiomatosis & Gorham's Disease Alliance
M-CM Network
Mended Hearts
Miracle for Madison & Friends
MLD Foundation
Moebius Syndrome Foundation
Narcolepsy Network
National Alliance on Mental Illness
National Alopecia Areata Foundation
National Eczea Association
National Fragile X Foundation
National Health Council
National Kidney Foundation
National Lymphedema Network
National MPS Society
National Multiple Sclerosis Society
National Organization for Rare Disorders (NORD)
National Patient Advocate Foundation
National Psoriasis Foundation
National Tay-Sachs & Allied Diseases Association, Inc. (NTSAD)
Neurofibromatosis Network
NGLY1.org
Noah’s Hope
Norton & Elaine Sarnoff Center for Jewish Genetics
NUBPL Foundation
Organic Acidemia Association
Osteogenesis Imperfecta Foundation
Oxalosis & Hyperoxaluria Foundation
Parent Project Muscular Dystrophy
PBCers Organization
PCa Blue Inc.
PFO Research Foundation
PKD Foundation
PMG Awareness Organization
Prevent Cancer Foundation
PTEN Hamartoma Tumor Syndrome Foundation
Pulmonary Fibrosis Advocates
PXE International
Rally Foundation for Childhood Cancer Research
Rare and Undiagnosed Network (RUN)
Rare Disease United Foundation
RASopathies Network
Regenerative Medicine Foundation
Research!America
RetireSafe
Rush to Live Organization
RYR-1 Foundation
Sarcoma Foundation of America
Shwachman-Diamond Syndrome Foundation
Sjögren's Syndrome Foundation
Smashing Walnuts Foundation
Solve ME/CFS Initiative
Spina Bifida Association
SSADH Association
St. Baldrick's Foundation
Taylor's Tale
The AIDS Institute
The ALS Association
The Association for Frontotemporal Degeneration (AFTD)
The Atypical HUS Foundation
The Choroideremia Research Foundation, Inc.
The Global Foundation for Peroxisomal Disorders
The Kortney Rose Foundation
The LAM Foundation
The Mastocytosis Society
The Michael J. Fox Foundation
The Nicholas Conor Institute
Tourette Association of America

State and Local Organizations:

Center for Independence of the Disabled, NY
Crestwood School District
Central Florida Behavioral Health Network
Florida Society of Clinical Oncology (FLASCO)
H.E.A.L.S of the South (Hepatitis Education, Awareness and Liver Support)
Lupus Alliance of Long Island/Queens
Lupus Alliance of Upstate New York
Lupus Foundation of Florida

Lupus Foundation New England
Lupus Foundation of Northern California
Lupus LA
Lupus Foundation of Pennsylvania
North Carolina Rare Disease Coalition
New England Regional Genetics Group, Inc. (NERGG)
Rare NY
Rhode Island Ehlers Danlos Syndrome Awareness and Support
Sarcoidosis of Long Island

Cc: The Honorable Barack Obama, President, United States
The Honorable Lamar Alexander, Chairman, Senate Committee on Health, Education, Labor, & Pensions
The Honorable Patty Murray, Ranking Member, Senate Committee on Health, Education, Labor, & Pensions
The Honorable Fred Upton, Chairman, House Committee on Energy and Commerce
The Honorable Frank Pallone, Ranking Member, House Committee on Energy and Commerce