

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  
Fibromuscular Dysplasia Society of  
America  
Fibrous Dysplasia Foundation  
Fight Colorectal Cancer  
FMD Chat  
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 Eczema 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

Tremor Action Network  
Trisomy 18 Foundation, Inc.  
United Leukodystrophy Foundation  
United Spinal Association  
US Pain Foundation  
Usher 1F Collaborative  
Usher 2020 Foundation  
Usher Syndrome Coalition  
Wake Up Narcolepsy  
Wellness Warrior Foundation

***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