June 18, 2015

The Honorable Fred Upton 2183 Rayburn House Office Building Washington, DC 20515

The Honorable Joe Pitts 420 Cannon House Office Building Washington, DC 20515

The Honorable Diana DeGette 2368 Rayburn House Office Building Washington, DC 20515 The Honorable Frank Pallone 237 Cannon House Office Building Washington, DC 20515

The Honorable Gene Green 2470 Rayburn House Office Building Washington, DC 20515

Dear Chairman Upton, Ranking Member Pallone, Chairman Pitts, Ranking Member Green, and Representative DeGette:

We, the undersigned 251 organizations, represent a widely diverse community of patients and family caregivers with distinct perspectives; yet we stand united in support of H.R. 6, the 21st Century Cures Act.

This bill is based on the hard work and thoughtful recommendations of the entire health community, and we thank you for your 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 regulatory environment, increase funding for the National Institutes of Health and Food and Drug Administration, and greatly improve our innovation ecosystem.

Just as Democrats and Republicans have come together to craft a bipartisan bill that cleared the Energy and Commerce Committee with a unanimous vote, so, too, do we affirm our support of this game-changing legislation.

Sincerely,

## National Organizations:

A Kids' Brain Tumor Cure (aka The Pediatric Low Grade Astrocytoma Foundation) Abigail Alliance for Better Access to Developmental Drugs Addario Lung Cancer Foundation Adrenal Insufficiency United AIDS Alliance for Women, Infants, Children, Youth & Families The AIDS Institute Ali's Angels Foundation Allergy & Asthma Network Alliance for Aging Research Alliance for Lupus Research Alliance for Patient Access

Alliance for the Adoption of Innovations in

Medicine (Aimed Alliance)

Alpha-1 Foundation The ALS Association

Alstrom Syndrome International

Alzheimer's Association

Alzheimer's Drug Discovery Foundation

American Aging Association

American Association for Geriatric Psychiatry

American Association for Long Term Care

Nursing

American Association for Respiratory Care American Association of Diabetes Educators

American Association of Kidney Patients

American Autoimmune Related Diseases

Association

American Behcet's Disease Association

American Brain Tumor Association

American Epilepsy Society

American Federation for Aging Research American Foundation for Suicide Prevention

American Foundation for the Blind

American Kidney Fund

American Neurological Association

American Nurses Association

American Partnership for Eosinophilic Disorders

American Society of Nephrology

**Amputee Coalition** 

Ara Parseghian Medical Research Foundation

**Arthritis Foundation** 

Assisted Living Federation of America

The Association for Frontotemporal

Degeneration

Association for Glycogen Storage Disease

Association for Research in Vision and

Ophthalmology

Association of University Centers on Disabilities

Asthma and Allergy Foundation of America

**Autism Speaks** 

Batten Disease Support and Research

Association

Bcureful

**BRBN** Alliance

Bridge the Gap-SYNGAP Education and

Research Foundation

CancerCare

Cardio-Facio-Cutaneous International

Caregiver Action Network Celiac Disease Foundation

Childhood Brain Tumor Foundation

The Children's Medical Research Foundation,

Inc.

Children's PKU Network

Choroideremia Research Foundation, Inc.

Chris4Life Colon Cancer Foundation

Coalition for Clinical Trials Awareness

Coalition for Pulmonary Fibrosis

Colon Cancer Alliance

Congenital Adrenal Hyperplasia Research,

Education & Support Foundation (CARES

Foundation, Inc.)

Continuing Medical Education Coalition

**COPD** Foundation

Cure Alzheimer's Fund

Cure Cancer, P.C.

Cure HHT

CureDuchenne

Dementia Alliance International

Depression and Bipolar Support Alliance

Dysautonomia International

**Easter Seals** 

The Eden Alternative

Emphysema Foundation for Our Right To

Survive

**Epilepsy Foundation** 

Erdheim-Chester Disease Global Alliance

EveryLife Foundation for Rare Diseases

FasterCures – A Center of the Milken Institute

Fibro Gal Agency LLC

Fight Colorectal Cancer

The Foundation for Ichthyosis & Related Skin

Types, Inc.

Foundation for Sarcoidosis Research

Friedreich's Ataxia Research Alliance

Friends of Cancer Research

Garrett the Grand – Batten Fighter

**GBS-CIDP** Foundation International

Gene Giraffe Project

Genetic Alliance

The Gerontological Society of America GIST Cancer Awareness Foundation Global Colon Cancer Association

Global Genes

Global Liver Institute

GNE Myopathy International Guardian Hands Foundation

Hannah's Hope Fund

HealthHIV

Hepatitis Foundation International

Hispanic CREO

Huntington's Disease Society of America

Hydrocephalus Association Immune Deficiency Foundation

Intacranial Hypertension Research Foundation

International Cancer Advocacy Network
International Essential Tremor Foundation
International Foundation for Autoimmune
Arthritis

International Myeloma Foundation International Pemphigus & Pemphigoid

Foundation

International Waldenstrom's Macroglobulinemia

Foundation

**JDRF** 

Jonah's Just Begun – Foundation to Cure

Sanfilippo Judson's Legacy

Klippel-Feil Syndrome Freedom The Kortney Rose Foundation

The LAM Foundation LatinosAgainstAlzheimer's

The Leukemia & Lymphoma Society

Little Miss Hannah Foundation

LuMind Research Down Syndrome Foundation

Lung Cancer Alliance Lung Transplant Foundation LUNGevity Foundation

Lupus and Allied Diseases Association, Inc.

Lupus Foundation of America Lupus Research Institute

LymeDisease.org

Lymphangiomatosis & Gorham's Disease

Alliance

The Mastocytosis Society

M-CM Network

MdDS Balance Disorder Foundation

Men Against Breast Cancer Men's Health Network Mental Health America

The Michael J. Fox Foundation for Parkinson's

Research

Miracle for Madison & Friends

MLD Foundation

Moebius Syndrome Foundation

The Mucolipidosis Type IV (ML4) Foundation

Muscular Dystrophy Association

Myasthenia Gravis Foundation of America

The Myositis Association

National Alliance for Caregiving

National Alliance for Eye and Vision Research

National Alliance on Mental Illness National Alopecia Areata Foundation

National Association for Uniformed Services National Association of Hispanic Nurses National Coalition for LGBT Health National Council for Behavioral Health National Down Syndrome Society

National Eczema Association

National Foundation for Celiac Awareness National Foundation for Ectodermal Dysplasias

National Fragile X Foundation National Health Council

National Hispanic Medical Association

National Kidney Foundation National MPS Society

National Multiple Sclerosis Society

The National Organisation for People Living

with Hepatitis B

National Organization of Vascular Anomalies

National Osteoporosis Foundation National Pancreas Foundation

National Patient Advocate Foundation

National Prostate Cancer Awareness Foundation

**National Psoriasis Foundation** 

National Task Group on Intellectual Disabilities

and Dementia Practices

National Tay-Sachs & Allied Diseases

Association

**NBIA** Disorders Association

Noah's Hope

NTM Info & Research

**Oncology Nursing Society** 

Oncology Resource Networks, LLC Osteogenesis Imperfecta Foundation OWL – The Voice of Women 40+ Parent Project Muscular Dystrophy

Parkinson's Action Network Parkinson's Disease Foundation

Patient Services, Inc. PCD Foundation

Pediatric Hydrocephalus Foundation

**PKD** Foundation

Platelet Disorder Support Association

Powerful Patient Inc.

Prader-Willi Syndrome Association (USA)

Preeclampsia Foundation Prevent Cancer Foundation Pulmonary Fibrosis Advocates

**PXE** International

Rally Foundation for Childhood Cancer

Research

Rare and Undiagnosed Network
Rare Cancer Research Foundation
Rare Disease United Foundation

RARE Science, Inc.

RASopathies Network USA

Relapsing Polychondritis Awareness and

Support Foundation, Inc.

Research!America

ResearchersAgainstAlzheimers

RetireSafe Rush To Live

S.L.E. Lupus Foundation

SaludUSA

Sanfilippo Foundation for Children Sarcoma Foundation of America Save Your Liver Foundation Self-Management Alliance

The Simon Foundation for Continence

Sjögren's Syndrome Foundation Solidarity Project Advocacy Network

Sophia's Fund

Spina Bifida Association

Taylor's Tale

Tourette Association of America

Transplant Buddies Tremor Action Network

The United Leukodystrophy Foundation

**US** Pain Foundation

Us TOO International, Prostate Cancer Education and Support Network

USAgainstAlzheimer's

USAgainstAlzheimer's Activists Network USAgainstAlzheimer's Clergy Network

Veterans Health Council Vietnam Veterans of America Vitiligo Support International Volunteers of America

WomenAgainstAlzheimer's

## State and Local Organizations:

Alzheimer's and Dementia Alliance of

Wisconsin

Alzheimer's Tennessee Banner Alzheimer's Institute Benjamin Rose Institute on Aging

**Boley Centers** 

Center for BrainHealth at The University of

Texas at Dallas

Central Florida Behavioral Health Network

Elder Care Advocacy of Florida

Florida Society of Clinical Oncology

H.E.A.L.S of the South

Institute of Human Virology at the University of

Maryland School of Medicine

Louisiana Women's Network

Lupus Alliance of Long Island/Queens

Lupus Foundation of Florida, Inc.

Lupus Foundation of Northern California

Lupus Foundation of Pennsylvania

Lupus Foundation of Southern California

Lupus LA

Lupus Society of Illinois

Myasthenia Gravis Foundation of Illinois New England Regional Genetics Group

New Orleans Council on Aging

Pennsylvania Prostate Cancer Coalition USF Health Byrd Alzheimer's Institute Yerkes National Primate Research Center