



June 24, 2015

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

The Honorable Kevin McCarthy, Majority Leader
United States House of Representatives
Washington, D.C. 20515

The Honorable Steny Hoyer, Minority Whip
United States House of Representatives
Washington, D.C. 20515

The Honorable Steve Scalise, Majority Whip
United States House of Representatives
Washington, D.C. 20515

Dear Speaker Boehner, Majority Leader McCarthy, Minority Leader Pelosi, Majority Whip Scalise, and Minority Whip Hoyer:

On behalf of the 30 million men, women, and children affected by one of the nearly 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) and its member organizations thank the House Committee on Energy and Commerce for its leadership on the 21st Century Cures Act (H.R.6). NORD supports passage of this legislation which holds great promise for the rare disease patient community.

We believe there are several provisions in this bill that could greatly improve the discovery, development, and delivery of treatments and cures to the underserved and neglected rare disease patient community, including \$10 billion in additional mandatory funding for the National Institutes of Health (NIH) and \$550 million in additional mandatory funding for the Food and Drug Administration (FDA).

We hope that you prioritize the health and well-being of our nation's most vulnerable citizens by supporting this legislation.

Sincerely,

The National Organization for Rare Disorders and its members:

Acid Maltase Deficiency Association (AMDA)
Acromegaly Community
Alagille Syndrome Alliance
Alpha-1 Foundation
Alport Syndrome Foundation
Alternating Hemiplegia of Childhood Foundation
American Autoimmune & Related Diseases
American Behcet's Disease Association
American Brain Tumor Association
American Multiple Endocrine Neoplasia Support
American Partnership for Eosinophilic Disorders (APFED)
American Porphyria Foundation
American Self Help Group Clearinghouse
American Syringomyelia & Chiari Alliance Project
Amyloidosis Support Groups
APBD Research Foundation
Aplastic Anemia & MDS International Foundation
Association for Creatine Deficiencies
Association for Frontotemporal Degeneration (AFTD)
Association for Glycogen Storage Disease
Association of Gastrointestinal Motility Disorders
Ataxia Telangiectasia Children's Project
Autoinflammatory Alliance
Basal Cell Carcinoma Nevus Syndrome Life Support Network
Batten Disease Support & Research Association
Benign Essential Blepharospasm Research Foundation
Breath of Hope
Cardio Facio Cutaneous International
Caring for Carcinoid Foundation
Charcot-Marie Tooth Association
Children's Cardiomyopathy Foundation
Children's Craniofacial Association
Children's PKU Network
Children's Tumor Foundation
Cholangiocarcinoma Foundation
Chromosome 18 Registry & Research Society
Chromosome Disorder Outreach
Chronic Granulomatous Disease Association
Cicatrical Alopecia Research Foundation (CARF)
CLOVES Syndrome Community
Cluster Headache Support Group
Coalition for Pulmonary Fibrosis
Congenital Hyperinsulinism International
Consortium of Multiple Sclerosis Centers

Cornelia de Lange Syndrome Foundation
Council for Bile Acid Deficiency Diseases
Cure CADASIL/CADASIL Association
Cure HHT
Cure SMA
CurePSP Foundation for PSP/CBD & Related Brain Diseases
Cushing Support & Research Foundation
Cutaneous Lymphoma Foundation
Cystinosis Foundation
Cystinosis Research Network
Daybreak Children's Rare Disease Fund
debra of America
Desmoid Tumor Research Foundation
Dravet Syndrome Foundation
Dup15q Alliance
Dysautonomia Foundation
Dystonia Medical Research Foundation
Ehlers Danlos National Foundation
Erdheim-Chester Disease Global Alliance
The Erythromelalgia Association
Family Caregiver Alliance
Family Support Network of North Carolina
Fat Disorders Research Society
Fibromuscular Dysplasia Society of America
Fibrous Dysplasia Foundation
Foundation Fighting Blindness
Foundation for Ichthyosis & Related Skin Types
Foundation for Prader-Willi Research
Friedreich's Ataxia Research Alliance (FARA)
GBS/CIDP Foundation International
Genetic Alliance
Global Foundation for Peroxisomal Disorders
Gut Check Clostridium Septicum Foundation
The Guthy - Jackson Charitable Foundation
Hemophilia Federation of America
Hereditary Disease Foundation
Hereditary Leiomyomatosis & Renal Cell Cancer Family Alliance
Hereditary Neuropathy Foundation
Hermansky-Pudlak Syndrome Network
Histiocytosis Association
Hope for Hypothalamic Hamartomas
Hydrocephalus Association
HypoPARathyroidism Association
ICE Epilepsy Alliance (Intractable Childhood Epilepsy Alliance)
Immune Deficiency Foundation
In Need of Diagnosis

Incontinentia Pigmenti International Foundation
Indian Organization for Rare Diseases
International FOP Association
International Foundation for CDKL5 Research
International FPIES Association
International Myeloma Foundation
International Pemphigus & Pemphigoid Foundation (IPPF)
International Rett Syndrome Foundation
International WAGR Syndrome Association
Iron Disorders Institute
Jack McGovern Coats' Disease Foundation
Jareds Juggernaut To Cure Sarcomas
The JMML Foundation
Joshua Frase Foundation
Julia's Wings Foundation
Kennedy's Disease Association
Klippel Trenaunay (KT) Support Group
LAL Solace
The LAM Foundation
Les Turner ALS Foundation
Liam's Land Organization
Life Raft Group
Locks of Love
Lowe Syndrome Association, Inc.
Lymphangiomatosis & Gorham's Disease Alliance
Martin Mueller IV Achalasia Awareness Foundation, Inc.
The Mastocytosis Society
M-CM Network
MEBO Research
Melorheostosis Association
Mesothelioma Applied Research Foundation
MitoAction
Moebius Syndrome Foundation
The Morgan Leary Vaughan Fund
MPN Research Foundation
MSUD Family Support
Mucopolysaccharidosis Type IV Foundation
Myasthenia Gravis Foundation of America
Myocarditis Foundation
Myositis Association
Myotonic Dystrophy Foundation
Narcolepsy Network
National Adrenal Diseases Foundation
National Alopecia Areata Foundation
National Ataxia Foundation
National Brain Tumor Society

National Eosinophilia Myalgia Syndrome Network
National Foundation for Ectodermal Dysplasias
National Fragile X Foundation
National Hemophilia Foundation
National Lymphedema Network
National MPS Society
National Multiple Sclerosis Society
National Niemann-Pick Disease Foundation
National Organization for Albinism & Hypopigmentation (NOAH)
National PKU Alliance
National PKU News
National Spasmodic Dysphonia Association
National Spasmodic Torticollis Association
National Tay-Sachs & Allied Diseases Association
National Urea Cycle Disorders Foundation
NBIA Disorders Association
Neurofibromatosis Network
NTM Info & Research
Ocular Melanoma Foundation
Organic Acidemia Association
Osteogenesis Imperfecta Foundation
Oxalosis & Hyperoxaluria Foundation
Parent Project Muscular Dystrophy
Parkinson's Disease Foundation
PCD/KS Foundation
PKD Foundation
Platelet Disorder Support Association
PMP Research Foundation
Prader-Willi Syndrome Association, USA
PRISMS (Parents & Researchers Interested in Smith-Magenis Syndrome)
PSC Partners Seeking A Cure
Pulmonary Fibrosis Foundation
Rare Cancer Research Foundation
RASopathies Network USA
Recurrent Respiratory Papillomatosis Foundation
Reflex Sympathetic Dystrophy Syndrome Association
Rothmund-Thomson Syndrome Foundation
Sarcoid Networking Association
Sarcoma Foundation of America
Scleroderma Research Foundation
Short Bowel Syndrome Foundation
Shwachman-Diamond Syndrome Foundation
The Snyder-Robinson Foundation
Soft Bones: The US Hypophosphatasia Foundation
Sotos Syndrome Support Association
Spastic Paraplegia Foundation

SSADH Association
Stevens - Johnson Syndrome Foundation
Sturge-Weber Foundation
TargetCancer Foundation
Tarlov Cyst Disease Foundation
TNA - The Facial Pain Association
Tourette Syndrome Association
Tuberous Sclerosis Alliance
Turner Syndrome Society of the United States
United Leukodystrophy Foundation
United Mitochondrial Disease Foundation
US Hereditary Angioedema Association
Vasculitis Foundation
Vestibular Disorders Association
VHL Alliance
Williams Syndrome Association
Wilson Disease Association
Worldwide Syringomyelia & Chiari Task Force
The XLH Network

For additional information, contact Paul Melmeyer, Associate Director of Public Policy, National Organization for Rare Disorders (NORD), pmelmeyer@rarediseases.org, (202) 588-5700 ext. 104.