December 7, 2017

The Honorable Orrin Hatch, Chairman
U.S. Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, D.C. 20510

The Honorable Kevin Brady, Chairman
U.S. House Committee on Ways & Means
1102 Longworth House Office Building
Washington, D.C. 20515

Dear Chairmen Hatch and Brady, and Members of the *Tax Cuts and Jobs Act* Conference Committee:

As organizations representing millions of American men, women, and children with rare diseases, we are writing to request that you preserve the Orphan Drug Tax Credit (ODTC) within the *Tax Cuts and Jobs Act* Conference Report. The Senate's version proposes to cut the credit's value from 50 percent of qualified clinical testing expenses, to 27.5 percent. The House version repeals the credit entirely.

We view the 27.5 percent credit passed as part of the Senate's legislation as the bare minimum, and implore you to strengthen it further. We strongly oppose any additional weakening or outright repeal of this life-saving credit. We also ask that you ensure the Senate's corporate Alternative Minimum Tax (AMT) proposal does not render the values of the ODTC and the Research and Development (R&D) Tax Credit useless.

Under current law, the ODTC allows drug manufacturers to claim a tax credit of 50 percent of the qualified costs of clinical research and drug testing of orphan drugs (drugs for diseases affecting 200,000 Americans or fewer). The ODTC is part of a package of provisions enacted in 1983 in the *Orphan Drug Act* (ODA) that provides incentives for drug companies to develop products for rare diseases. This legislation has been extremely successful.

In the decade before the *Orphan Drug Act*, only 10 medicines were developed by industry for rare diseases. Since 1983, however, more than 3,500 potential treatments have been designated as an orphan drug, and more than 500 orphan therapies have been approved by the Food and Drug Administration (FDA). This is a direct result of the incentives provided by the ODA, including the tax credit.

In June 2015, the National Organization for Rare Disorders (NORD) and the Biotechnology Innovation Organization (BIO) published an economic analysis of the ODTC that found that without the ODTC, approximately 33 percent fewer orphan therapies will be developed going forward. This is precisely what the House version proposes, which would be a critical blow to individuals with rare diseases.

The Orphan Drug Tax Credit is one of the only tax credits that actually saves lives. We believe the ODTC should not be cut at all, and are disappointed that both proposals have done so. We urge the Conference Committee to stand up for the 95 percent of individuals with a rare disease still waiting for a treatment by strengthening the ODTC provision within the final bill, or at the very least ensuring the Senate's 27.5 percent credit remains intact.

We ask you to stand with the 30 million Americans with rare diseases in supporting this life-saving credit.

Sincerely,

A Twist of Fate-ATS
Acromegaly Community Inc.
Adenoid Cystic Carcinoma Research Foundation
ADNP Kids Research Foundation
Adrenal Insufficiency United
Adult Polyglucosan Body Disease Research Foundation
Advocacy & Awareness for Immune Disorders Association (AAIDA)
Alpha-1 Foundation
Alport Syndrome Foundation
ALS Association
American Autoimmmune Related Diseases Association
American Cancer Society Cancer Action Network
American Lung Association
American Partnership for Eosinophilic Disorders
American Porphyria Foundation
Amyloidosis Foundation
Amyloidosis Research Consortium
Amyloidosis Support Groups
Angelman Biomarkers and Outcome Measures Alliance
Angelman Syndrome Foundation
Angioma Alliance
APS Foundation of America, Inc.
The Association for Frontotemporal Degeneration
The Atypical HUS Foundation
Autism Speaks
Autoinflammatory Alliance
Batten Disease Support and Research Association
Bridge the Gap - SYNGAP Education and Research Foundation
CdLS Foundation
Children's Tumor Foundation
Chloe's Fight Rare Disease Foundation
CJD Aware!
Congenital Adrenal hyperplasia Research, Education & Support Foundation (CARES Foundation)
Congenital Hyperinsulinism International
Consortium of MS Centers
Cooley's Anemia Foundation, Inc.
Crohn's & Colitis Foundation
Cure HHT
Cure Sanfilippo Foundation
Cure SMA
CurePSP
Cutaneous Lymphoma Foundation
Dandy-Walker Alliance, Inc.
Deadliest Cancers Coalition
The Desmoid Tumor Research Foundation
Digestive Disease National Coalition

Dravet Syndrome Foundation
Dyskeratosis Congenita Outreach, Inc.
Dystonia Advocacy Network
Dystonia Medical Research Foundation
Epilepsy Foundation
The Erythromelalgia Association
EveryLife Foundation
Fabry Support & Information Group
Fibromuscular Dysplasia Society of America
Fibrous Dysplasia Foundation
FOD Family Support Group
Foundation Fighting Blindness
Foundation for Prader-Willi Research
FRAXA Research Foundation (Fragile X syndrome)
Friedreich's Ataxia Research Alliance (FARA)
Friends of Cancer Research
GBS|CIDP Foundation International
Glut1 Deficiency Foundation
The Guthy-Jackson Charitable Foundation
Hannah's Hope Fund
HCU Network America
Hemophilia Foundation of America
Hermansky-Pudlak Syndrome Network Inc.
HSAN1E Society
Huntington's Disease Society of America
Hydrocephalus Association
The Hyper IgM Foundation
Immune Deficiency Foundation (IDF)
Indian Organization for Rare Diseases
International FOP Association
International Foundation for CDKL5 Research
International Foundation for Functional Gastrointestinal Disorders
International FOXG1 Foundation
International Myeloma Foundation
International Pemphigus & Pemphigoid Foundation
International Waldenstrom's Macroglobulinemia Foundation (IWMF)
Intracranial Hypertension Research Foundation
Jack McGovern Coats' Disease Foundation
The Jansen's Foundation
KIF1A.ORG, Inc.
LAL D Aware
Li-Fraumeni Syndrome Association
The Life Raft Group
Little Miss Hannah Foundation
Lung Cancer Alliance
Lupus Foundation of America

Lymphangiomatosis & Gorham's Disease Alliance
M-CM Network
The Marfan Foundation
The Michael J. Fox Foundation
Mila's Miracle Foundation
MitoAction
MLD Foundation
Moebius Syndrome Foundation
The Morgan Leary Vaughan Fund, Inc. (Morgan's Fund)
Mucolipidosis Type IV Foundation
Muscular Dystrophy Association
Myasthenia Gravis Foundation of America
The Myelin Project
Myocarditis Foundation
The Myositis Association
Myotonic Dystrophy Foundation
National Alopecia Areata Foundation
National Brain Tumor Society
National Health Council
National Hemophilia Foundation
National MPS Society
National Niemann-Pick Disease Foundation, Inc.
National Organization for Albinism and Hypopigmentation
National Organization for Rare Disorders (NORD)
National PKU Alliance
National PKU News
National Spasmodic Dysphonia Association
National Tay-Sachs & Allied Diseases Association
NBIA Disorders Association
NephCure Kidney International
Neurofibromatosis Network
NGLY1.org
The Oral Cancer Foundation
Organic Acidemia Association
Parent Project Muscular Dystrophy (PPMD)
PCD Foundation
PCDH19 Alliance
Phelan-McDermid Syndrome Foundation
Pheo Para Alliance
Pitt Hopkins Research Foundation
PKD Foundation
Post-Polio Health International, including International Ventilator Users Network
PRISMS, Inc (Parents and Researchers Interested in Smith-Magenis Syndrome)
PSC Partners Seeking a Cure
PTEN Hamartoma Tumor Syndrome Foundation
PTEN World

Pulmonary Fibrosis Foundation
Pulmonary Hypertension Association
Rare and Undiagnosed Network (RUN)
RASopathies Network
Research!America
Reflex Sympathetic Dystrophy Syndrome Association
Rett Syndrome Research Trust
RYR-1 Foundation
Sarcoma Foundation of America
Scleroderma Foundation
The Sitosterolemia Foundation
The Snyder-Robinson Foundation
SSADH Association
TargetCancer Foundation
Tarlov Cyst Disease Foundation
Tuberous Sclerosis Alliance
Turner Syndrome Society of the U.S.
United Leukodystrophy Foundation
The United Mitochondrial Disease Foundation
Vasculitis Foundation
VHL Alliance
Wishes for Elliott: Advancing SCN8A Research
Worldwide Syringomyelia & Chiari Task Force
The XLH Network, Inc.

For additional information, contact Paul Melmeyer, Director of Federal Policy, National Organization for Rare Disorders (NORD), pmelmeyer@rarediseases.org, (202) 545-3828.

CC: The Honorable Paul Ryan, Speaker of the House
The Honorable Mitch McConnell, Senate Majority Leader
The Honorable Chuck Schumer, Senate Minority Leader
The Honorable Nancy Pelosi, House Minority Leader
The Honorable Kevin McCarthy, House Majority Leader
The Honorable Ron Wyden, Ranking Member, Senate Committee on Finance
The Honorable Steny Hoyer, House Minority Whip
The Honorable Richard Neal, Ranking Member, House Committee on Ways & Means