



March 10, 2014

The Honorable Ron Wyden, Chairman  
U.S. Senate Committee on Finance  
Washington, D.C. 20510

The Honorable Orrin G. Hatch, Ranking Member  
U.S. Senate Committee on Finance  
Washington, D.C. 20510

The Honorable Dave Camp, Chairman  
U.S. House Committee on Ways & Means  
Washington, D.C. 20515

The Honorable Sander Levin, Ranking Member  
U.S. House Committee on Ways & Means  
Washington, D.C. 20515

Dear Chairmen Wyden and Camp and Ranking Members Hatch and Levin:

A proposal made public by Chairman Dave Camp (R-Michigan) to amend the Internal Revenue Code of 1986 would repeal the *Orphan Drug Tax Credit*, one of the most successful tax credits ever passed by Congress, and one that has literally saved thousands of lives. The National Organization for Rare Disorders (NORD) and the over 130 undersigned patient organizations and professionals within the rare disease community oppose this proposed repeal.

Repeal of this tax credit would be an anti-patient, anti-public health policy, and would squelch medical research and innovation. Repeal would remove one of the major incentives to finding cures and treatments for some of the most challenging diseases.

The credit allows drug manufacturers to claim a tax credit of 50% of certain research costs for orphan drugs (drugs for diseases affecting 200,000 Americans or fewer). Due to this *Orphan Drug Tax Credit*, as well as other incentives, more research is taking place for orphan drugs than ever before. A third of the new drugs being approved by FDA each year are orphan drugs that benefit from the tax credit. Many if not most of these new drugs may never have been developed if this tax incentive did not exist.

The vast majority of people with a rare disease pray every day for medical progress. About 7,000 rare diseases affect 30 million Americans. Only a few hundred rare diseases have an approved drug.

People in this country with rare diseases deserve to be treated with respect and to retain the hope that, someday, a cure or better treatment will be developed for them. Repealing this tax credit is a signal from the Congress that new treatments for people with rare diseases are unimportant. NORD and the undersigned appeals to Congress to block this proposed repeal and to keep the light of hope on for so many who desperately need life-saving interventions.

Orphan drugs don't serve just patients with rare diseases. Patients with more common diseases have benefited from the advancements made in orphan drug development. Access to these treatments has saved medical costs by keeping people healthy and out of the hospital and emergency rooms. New treatments promise to save even more.

NORD and the entire rare disease community urge Congress to reconsider the implications of repealing the *Orphan Drug Tax Credit* as proposed by Chairman Camp, and to keep patients and public health first.

Sincerely,

## **Rare Disease Patient Organizations:**

The AIDS Institute  
Alpha-1 Association  
Alpha-1 Foundation  
Alport Syndrome Foundation  
The ALS Association  
ALS Hope Foundation  
ALS Therapy Development Institute  
Alveolar Capillary Dysplasia Association  
American Autoimmune Related Diseases Association  
American Brain Tumor Association  
American Childhood Cancer Organization  
American Partnership for Eosinophilic Disorders  
Angioma Alliance  
ARPKD/CHF Alliance  
Asbestos Disease Awareness Organization  
The Association for Frontotemporal Degeneration  
Association for Glycogen Storage Disease  
Association of Clinical Research Organizations  
Ataxia-Telangiectasia Society  
Batten Disease Support and Research Association  
The Bili Project Foundation  
CADASIL Association  
Canavan Research Illinois  
Caring for Carcinoid Foundation  
Celiac Sprue Association  
The Cholangiocarcinoma Foundation  
Circadian Sleep Disorders Network  
The CJD Foundation  
Coalition for Pulmonary Fibrosis  
Community Access National Network  
Community Health Charities of America  
Cooley's Anemia Foundation  
Council for Bile Acid Deficiency Diseases  
CSA Foundation  
Cure JM Foundation  
Cystinosis Foundation  
The Desmoid Tumor Research Foundation, Inc.  
Dup15q Alliance  
Dystrophic Epidermolysis Bullosa Research Association of America  
Epilepsy Foundation  
The Everylife Foundation for Rare Diseases  
Fabry Support & Information Group  
Fibromuscular Dysplasia Society of America  
FMD Chat  
FOD Family Support Group  
FORCE: Facing Our Risk of Cancer Empowered  
Foundation Fighting Blindness  
Friedreich's Ataxia Research Alliance

Global Genes  
Global Healthy Living Foundation  
Greater Missouri Tourette Syndrome Association  
The Guthy-Jackson Charitable Foundation  
Hemophilia Federation of America  
Histiocytosis Association  
HypoPARAthyroidism Association  
Immune Deficiency Foundation  
International Cancer Advocacy Network  
International FOP Association  
International Foundation for CDKL5 Research  
International Myeloma Foundation  
International Pemphigus & Pemphigoid Foundation  
Jeffrey Modell Foundation  
Joseph G. Fortier Foundation for MSA  
Kennedy's Disease Association  
Kids V Cancer  
LAL Solace  
Les Turner ALS Foundation  
The Life Raft Group  
Little Miss Hannah Foundation  
Lupus Foundation of Mid and Northern New York, Inc.  
Lymphedema Advocacy Group  
M-CM Network  
March of Dimes  
Marfan Foundation  
Mastocytosis Society  
Mebo Research  
Minnesota PKU Foundation  
MLD Foundation  
Moebius Syndrome Foundation  
Mucopolysaccharidosis Type IV (ML4) Foundation  
Muscular Dystrophy Association  
Myotonic Dystrophy Foundation  
National Adrenal Diseases Foundation  
National Brain Tumor Society  
National Eosinophilia Myalgia Syndrome Network  
National MPS Society  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
National PKU Alliance  
National Tay-Sachs & Allied Diseases Association, Inc.  
NBIA Disorders Association  
Neurofibromatosis Network  
NF Michigan  
Noah's Hope  
The NOMID Alliance  
The Oley Foundation  
Oxalosis & Hyperoxaluria Foundation  
Pachyonychia Congenita Project

Parent Project Muscular Dystrophy  
Parkinson's Action Network  
PCD Foundation  
PFIC Progressive Familial Intrahepatic Cholestasis-Resource for Pediatric Liver Disease  
Phelan-McDermid Syndrome Foundation  
Prevent Cancer Foundation  
Pulmonary Fibrosis Advocates  
Pulmonary Fibrosis Foundation  
Raynaud's Association  
Research!America  
Rothmund-Thomson Syndrome Foundation  
Sarcoid Registry  
Scleroderma Research Foundation  
Shwachman Diamond Syndrome Foundation  
SMA Foundation  
TargetCancer  
Tuberous Sclerosis Alliance  
United Mitochondrial Disease Foundation  
VHL Alliance  
Wilson Disease Association

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CC: Members of the U.S. Senate Committee on Finance  
Members of the U.S. House of Representatives Committee on Ways & Means