



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

Professionals in the Rare Disease Community:

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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