Statement by 91 Patient Organizations in Opposition to the House of Representatives' Repeal of the Orphan Drug Tax Credit

Washington, D.C., November 20, 2017 – "Last week, the House of Representatives voted to repeal the Orphan Drug Tax Credit (ODTC) as part of the *Tax Reform and Jobs Act* (H.R.1). Our organizations, which collectively represent millions of individuals with rare diseases, are disappointed and dismayed by this harmful repeal.

The Orphan Drug Tax Credit has proven to be one of the most important incentives for developing innovative therapies for rare diseases or conditions. Without the Orphan Drug Tax Credit, 33 percent fewer therapies could be developed for our patients going forward.

Now that the House has voted to repeal the ODTC, it is more important than ever for the Senate to protect the 30 million Americans with a rare disease.

Unlike the House bill, the Senate Finance Committee proposal does not repeal the Orphan Drug Tax Credit entirely. However, we remain concerned that it cuts the credit's value nearly in half by lowering its value from 50 percent of qualified clinical testing expenses to 27.5 percent.

Our organizations support the Orphan Drug Tax Credit because it saves lives. We will not stand idly by as Congress deliberates on diminishing the hope of the 95 percent of individuals with a rare disease still waiting for their very first treatment. Any proposal that stands in their way to finally obtaining a safe and effective therapy is unacceptable.

We implore Congress to join the thousands of patients, families, doctors, caregivers, and patient organizations across the country who are fighting for this credit. We cannot afford to move backwards."

Signers:

A Kids' Brain Tumor Cure Foundation
Adenoid Cystic Carcinoma Research Foundation
Alpha-1 Foundation
Alport Syndrome Foundation
ALS Association
American Cancer Society Cancer Action Network
American Lung Association
American Partnership for Eosinophilic Disorders
American Porphyria Foundation
Amyloidosis Research Consortium
Angelman Biomarkers and Outcome Measures Alliance
Aplastic Anemia and MDS International Foundation
Association for Creatine Deficiencies
Benign Essential Blepharospasm Research Foundation
Bridge the Gap - SYNGAP Education and Research Foundation
CCHS Network
Chloe's Fight Rare Disease Foundation
CJD Aware!
Consortium of Multiple Sclerosis Centers

Congenital Adrenal hyperplasia Research, Education & Support Foundation, Inc.
CureSMA
Cyclic Vomiting Syndrome Association
Cystinosis Research Network
Dystonia Advocacy Network
Dystonia Medical Research Foundation
Epilepsy Foundation
Everylife Foundation for Rare Diseases
Fabry Support & Information Group
Family Caregiver Alliance
Fibrous Dysplasia Foundation
FOD Family Support Group
Foundation Fighting Blindness
Foundation for Angelman Syndrome Therapeutics
Foundation for Prader-Willi Research
Foundation for Sarcoidosis Research
Friedreich's Ataxia Research Alliance
GBS|CIDP Foundation International
Hemophilia Federation of America
Hermansky-Pudlak Syndrome Network Inc.
Huntington's Disease Society of America
Hydrocephalus Association
Immune Deficiency Foundation (IDF)
Indian Organization for Rare Diseases
International Myeloma Foundation
International Pemphigus & Pemphigoid Foundation
International Waldenstrom's Macroglobulinemia Foundation
Jack McGovern Coats' Disease Foundation
Klippel-Trenaunay (K-T) Support Group
Li-Fraumeni Syndrome Association (LFS Association / LFSA)
The Life Raft Group
Little Miss Hannah Foundation
Lung Cancer Alliance
The Marfan Foundation
The Michael J. Fox Foundation
Mila's Miracle Foundation
Moebius Syndrome Foundation
The Myositis Association
National Alopecia Areata Foundation
National Brain Tumor Society
National Health Council
National Hemophilia Foundation
National MPS Society
National Organization for Albinism and Hypopigmentation
National Organization for Rare Disorders (NORD)
National PKU News
NBIA Disorders Association
NephCure Kidney International
NGLY1.org

Parent Project Muscular Dystrophy (PPMD)
PCD Foundation
Prader-Willi Syndrome Association (USA)
Prevent Blindness
PRISMS, Inc (Parents and Researchers Interested in Smith-Magenis Syndrome)
PSC Partners Seeking a Cure
Pulmonary Fibrosis Foundation
Pulmonary Hypertension Association
Quincy's Quest Foundation
RASopathies Network
RYR-1 Foundation
Sarcoma Foundation of America
Scleroderma Foundation
Sick Cells
The Sitosterolemia Foundation
The Snyder-Robinson Foundation
SSADH Association
Tuberous Sclerosis Alliance
United Mitochondrial Disease Foundation
US Hereditary Angioedema Association
Vasculitis Foundation
VHL Alliance
The XLH Network, Inc.