Statement by 36 Patient Organizations in Opposition to the Senate’s Proposed Weakening of the Orphan Drug Tax Credit

Washington, D.C., November 14, 2017 – “Today, the Senate Finance Committee continues its consideration of the Tax Cuts and Jobs Act. Our organizations, which collectively represent millions of individuals with rare diseases, stand united in opposition to the Senate Finance Committee’s proposal to substantially weaken the Orphan Drug Tax Credit (ODTC).

The Orphan Drug Tax Credit is one of the most important incentives for developing innovative therapies for rare and neglected populations. Without the Orphan Drug Tax Credit, 33 percent fewer therapies could be developed for our patients going forward.

The Senate proposal would change the formula for calculating the credit, cutting the incentive in half for many rare disease populations. In addition, the proposal would limit which orphan therapies qualify for the credit, thus disincentivizing development for many individuals with rare diseases.

We cannot afford to move backward. Ninety-five percent of individuals with rare diseases are still waiting for their first treatment, and any proposal that stands in their way to finally obtaining a safe and effective therapy is unacceptable.

Thousands of Americans with rare diseases and their families have contacted Congress to voice their concern, and over 200 patient organizations support this credit.

We urge all Senators to stand with the 30 million Americans with a rare disease and fight for the Orphan Drug Tax Credit.”
Signers:

Alpha-1 Foundation
ALS Association
American Cancer Society Cancer Action Network
American Lung Association
Autism Speaks
Crohn’s & Colitis Foundation
Dystonia Medical Research Foundation
Dystonia Advocacy Network
Epilepsy Foundation
EveryLife Foundation for Rare Diseases
Fibrous Dysplasia Foundation
Friedreich’s Ataxia Research Alliance
GBS|CIDP Foundation International
Huntington’s Disease Society of America
Immune Deficiency Foundation
International Foundation for Functional Gastrointestinal Disorders
International Pemphigus & Pemphigoid Foundation
Lung Cancer Alliance
The Marfan Foundation
The Michael J. Fox Foundation
Muscular Dystrophy Association
National Alopecia Areata Foundation
National Brain Tumor Society
National Hemophilia Foundation
National Organization for Rare Disorders (NORD)
National PKU Alliance
National Spasmodic Dysphonia Association
NephCure Kidney International
Parent Project Muscular Dystrophy (PPMD)
Parkinson Voice Project
Pulmonary Fibrosis Foundation
Pulmonary Hypertension Association
Scleroderma Foundation
United Mitochondrial Disease Foundation
US Hereditary Angioedema Association
Wilkins Parkinson’s Foundation