



## 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