

July 25, 2103

The Honorable Dave Camp, Chairman  
The Honorable Sander Levin, Ranking Minority Member  
House Ways and Means Committee  
1102 Longworth HOB  
Washington, DC 20515

The Honorable Max Baucus, Chairman  
The Honorable Orrin Hatch, Ranking Member  
Senate Committee on Finance  
219 Dirksen Senate Office Building  
Washington, DC 20510-6200

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

The undersigned organizations represent millions of patients suffering from rare diseases. We are writing to express our strong support for the Orphan Drug Tax Credit (ODTC). We know that Congress is developing tax reform proposals and we strongly urge you to keep this critical tax credit in place.

Under the ODTC, drug manufacturers can claim a tax credit of 50% of the qualified costs of clinical research and drug testing of orphan drugs (drugs for diseases affecting 200,000 Americans or less). The ODTC is part of a package of provisions enacted in 1983 in the Orphan Drug Act that provide incentives for drug companies to develop products for rare diseases. This legislation has been extremely successful. In the decade before the Orphan Drug Act, only ten medicines were developed for rare diseases. Since passage, however, more than 2,700 potential treatments have entered the research pipeline as orphan products and more than 300 have been approved by the FDA. Importantly, these products are often lifesaving; many orphan diseases are seriously debilitating and eventually fatal.

Despite this progress, there are approximately 7,000 rare diseases affecting about 30 million people in the US, many of them children. Nearly 95% of these diseases have no cures or treatments. The ODTC provides necessary incentives for companies to embark on research and development projects to develop treatments to help patients suffering from these diseases. In so doing, the Orphan Tax Credit literally saves lives.

Many of our members have already benefited from the research and product development that has been spurred by the ODTC, but more work needs to be done. Millions of patients are relying on the development of new treatments and cures. The ODTC has been – and will remain – essential to these efforts.

Thank you for your attention to this important matter.

Sincerely,

APBD Research Foundation  
Alliance for Patient Access  
Alpha-1 Association  
ALS Association  
American Association for Dental Research  
American Autoimmune Related Disorders Association  
Aplastic Anemia & MDS International Foundation  
Batten Disease Support and Research Association  
Cancer Support Community

Celiac Disease Center at Columbia University  
Colon Cancer Alliance  
Cooley's Anemia Foundation  
Crohn's & Colitis Foundation  
Cures Within Reach  
Cystic Fibrosis Foundation  
Digestive Diseases National Coalition  
Digestive Health Alliance  
Drew's Hope Research Foundation  
Duke University School of Medicine  
EveryLife Foundation for Rare Diseases  
Fabry Support and Information Group  
Families of Spinal Muscular Atrophy  
Foundation Fighting Blindness  
GBS/CIDP Foundation International  
Global Healthy Living Foundation  
Global Genes| RARE Project  
Hope4Bridget Foundation  
Hypoparathyroidism Association, Inc.  
International Myeloma Foundation  
Jeffrey Modell Foundation  
Jonahs Just Begun  
Little Miss Hannah Foundation  
Mastocytosis Society  
MLD Foundation  
Muscular Dystrophy Association  
National Alopecia Areata Foundation  
National Marfan Foundation  
National MPS Society  
National Tay-Sachs & Allied Diseases Association, Inc.  
NBIA Disorders Association  
Noah's Hope  
Parent Project Muscular Dystrophy  
Parkinson's Action Network  
Patient Services, Inc.  
Polycystic Kidney Disease Foundation  
Pulmonary Hypertension Association  
Rare Disease United Foundation  
Research!America  
RetireSafe  
Rett Syndrome Research Trust  
Sanfilippo Foundation for Children  
Sarcoma Foundation of America  
Scleroderma Foundation  
Short Bowel Syndrome Foundation, Inc  
Society for Women's Health Research

The AIDS Institute  
The International Myeloma Foundation  
The Stop ALD Foundation  
Tuberous Sclerosis Alliance  
US Hereditary Angioedema Association  
Veterans Health Council  
Vietnam Veterans of America