July 25, 2013

The Honorable Dave Camp, Chairman
The Honorable Max Baucus, Chairman
The Honorable Sander Levin, Ranking Minority Member
The Honorable Orrin Hatch, Ranking Member
House Ways and Means Committee
Senate Committee on Finance
1102 Longworth HOB
219 Dirksen Senate Office Building
Washington, DC 20515
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