

July 24, 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,