



June 24, 2015

The Honorable Orrin G. Hatch, Chairman
U.S. Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, D.C. 20510

The Honorable Ron Wyden, Ranking Member
U.S. Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Chairman Hatch and Ranking Member Wyden:

On behalf of the 30 million men, women, and children affected by one of the 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your continuing support of the rare disease community and your leadership ensuring orphan drug incentives remain strong in the United States.

We are writing today to request that you remain mindful of orphan drug incentives in any additions to the Congressional Record developed by the Finance Committee that accompanies the legislation granting the President Trade Promotion Authority (TPA). We are aware that pharmaceutical incentive negotiations have occurred in the Trans-Pacific Partnership (TPP) negotiations, and we urge the Committee to request that incentives for rare disease therapies be considered as trade negotiations continue.

Thank you again for your unwavering commitment to our nation's most vulnerable citizens, and we thank you for your time and attention on this important matter.

Sincerely,

Peter L. Saltonstall
President and CEO