November 13, 2015

The Honorable Jerry Moran, Chairman
Subcommittee on Agriculture, Rural Development,
Food and Drug Administration, and Related Agencies
Committee on Appropriations
United States Senate
Washington DC 20510

The Honorable Robert Aderholt, Chairman
Subcommittee on Agriculture, Rural Development,
Food and Drug Administration, and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

The Honorable Jeff Merkley, Ranking Member
Subcommittee on Agriculture, Rural Development,
Food and Drug Administration, and Related Agencies
Committee on Appropriations
United States Senate
Washington DC 20510

The Honorable Sam Farr, Ranking Member
Subcommittee on Agriculture, Rural Development,
Food and Drug Administration, and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

Dear Chairmen Moran and Aderholt, and Ranking Members Merkley and Farr:

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.

As you work to finalize the FY 2016 Agriculture Appropriations budget, we respectfully urge you to make increased appropriated funding for the United States Food & Drug Administration a national priority. Specifically, we are requesting $2.8 billion for the FDA's FY 16 budget authority appropriation. This amount is $200 million above FY 15 funding, about $160 million above currently proposed House/Senate FY 16 funding, and $52 million above the President's FY 16 request.

With only approximately 450 FDA-approved orphan therapies to treat over 7,000 rare diseases, the FDA is incredibly important to finding treatments and cures for the 95% of rare diseases that currently have no treatment. An appropriately funded FDA will ensure safe, effective, and innovative therapies for rare diseases are able to quickly move through the regulatory process to reach the patients that so sorely need them.

Congress has already shown its commitment to facilitating expedient review of novel therapies. In July, the House of Representatives passed the 21st Century Cures Act, legislation which is intended to speed and improve the process for approving therapies. The Senate is working on parallel legislation. Not only does this legislation show the importance of a well-funded FDA, but the responsibilities included within the bill only increase the importance of funding the FDA.

Thank you again for your commitment to our nation's most vulnerable citizens, and we thank you for your time and attention to this important matter. For questions regarding NORD or the above comments, please contact Paul Melmeyer, Associate Director of Public Policy, at pmelmeyer@rarediseases.org or (202) 588-5700, ext. 104.

Sincerely,

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