May 13, 2014

Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attention: CMS-9943-IFC
P.O. Box 8016
Baltimore, MD 21244-8016


Dear Sir or Madam,

On behalf of the over 30 million Americans with a rare disease, many of which rely on third party non-profit, charitable organizations for assistance in accessing critical life-altering and often life-saving therapies, the National Organization for Rare Disorders (NORD) gratefully submits the following comments on the interim rule regarding “Third Party Payment of Qualified Health Plan Premiums under the Patient Protection and Affordable Care Act”, published in the March 19, 2014, Federal Register.

The CMS Interim Rule CMS-9943-IFC regarding the third party payment of premiums to qualified health plans, if made permanent, would allow health insurance companies in the federal marketplace to deny premium assistance from independent charities like NORD. We are strongly opposed to the interim rule. This rule could result in drastically limited access to these crucial therapies within the Exchanges.

This interim rule is also confounding, as it does not apply the standard used by Medicare to the new insurance policies in the exchanges. NORD suggests consistency across these programs and asks that the same standard for third party non-profit, charitable organizations used in Medicare also apply to the Exchanges. It has been our observation that the interpretation of this interim rule has allowed Exchange plans to prohibit acceptance of third party premium payments from charities such as NORD.

Since the passage of the Orphan Drug Act in 1983, the National Organization for Rare Disorders (NORD) has partnered with the Department of Health and Human Services (DHHS) and its agencies to ensure that patients who are suffering from a rare disorder have access to all available and appropriate healthcare services. NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the
organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

In 1987, NORD established the first-ever patient assistance program for medications. Over the past 25 years, NORD has administered more than 380 patient assistance programs on behalf of over 1.3 million patients with the principle goal of ensuring fair and reasonable access to appropriate medical care and life-saving orphan therapies. No one understands the suffering and healthcare needs of our patients better than NORD, the organization specifically established to serve them. Without our programs, many of our patients would not have access to care.

Thank you for the opportunity to communicate with you regarding this issue of critical concern to the rare disease community. For questions regarding NORD or the above comments, please contact Diane Dorman, Vice President of Public Policy, at ddorman@rarediseases.org or (202) 588-5700 ext. 102.

Respectfully,

Peter L. Saltonstall
NORD President and CEO