

Cystinosis Research Network Board of Directors member, Marybeth Krummenacker, has been named as Chair of the Advocacy Committee of the National Organization for Rare Disorders. Marybeth was elected to NORD's Board of Directors in 2009.

NORD was the driving force behind the Orphan Drug Act of 1983 and has become the world's leading and highly respected advocacy group for the rare disease community both in Washington D.C. and within the pharmaceutical industry. The Advocacy Committee is responsible for developing and recommending regulatory and legislative priorities and policies. One of the first and critically important issues recently announced will be the formation of the "Rare and Neglected Diseases Caucus". The primary role of this caucus will be to bring Congressional attention to the more than 6,000 rare diseases that have no approved therapies; ensuring sufficient funding for research and orphan product development; and to provide opportunity for Members of Congress, families and advocacy groups to exchange ideas and policy concerns.

It is a critically important time for the rare disease community and we at CRN are fortunate to have Marybeth representing not only cystinosis but the entire rare disease community as well.