



Mission Statement

The National Organization for Rare Disorders (NORD), a 501(c)3 organization, 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 service.

What is A Rare Disorder?

A rare or "orphan" disease affects fewer than 200,000 people in the United States. There are more than 6,000 rare disorders that, taken together, affect approximately 25 million Americans. One in every 10 individuals in this country has received a diagnosis of a rare disease. For almost twenty years, NORD has served as the primary non-governmental clearinghouse for information on rare disorders. NORD also provides referrals support groups and other sources of assistance.

Our Sources of Funding

NORD is not a government agency. It is a non-profit, voluntary health agency that exists to serve rare-disease patients and their families. Our primary sources of funding are contributions, membership fees, and revenues from the sale of our products, such as our books and Rare Disease Database reports. Most of the money donated to NORD goes directly to programs and services. Copies of our annual report are available upon request.

Founded in 1983

NORD was established in 1983 by patients and families who worked together to get the *Orphan Drug Act* passed. This legislation provides financial incentives to encourage development of new treatments for rare diseases.

NORD Services and Programs

NORD provides information about diseases, referrals to patient organizations, research grants and fellowships, advocacy for the rare-disease community, and Medication Assistance Programs that help needy patients obtain certain drugs they could not otherwise afford.