



Who We Are

Alone we are rare. Together we are strong.®



ABOUT US

The National Organization for Rare Disorders (NORD®) is the only independent U.S. organization working at the intersection of care, research and policy for all rare diseases and the more than 30 million Americans living with a rare disease.

We are rooted in 40 years of rare disease patient advocacy that spurred a movement. That movement, resulted in the passage of the world's first law incentivizing drug development for rare diseases— the Orphan Drug Act of 1983. Today, we continue to fight for life-changing care, treatments, policies and research.

Our Mission

Our mission is to improve the health and well-being of people with rare diseases by driving advances in care, research and policy.

Who We Serve

NORD supports the estimated 1 in 10 Americans living with a rare disease. We do so by collaborating with and educating patients and caregivers, clinicians, world-class medical institutions, researchers and policymakers. Together, we are united by a single purpose — to solve the greatest challenges facing the rare disease community.

Our Focus



CARE

Whether it is help searching for a diagnosis, a specialist or clinical trials, we open pathways to world-class care and expertise.



POLICY

NORD is widely trusted and uniquely positioned to serve as a unified voice with legislators and other decision-makers on policies impacting the rare disease community.



RESEARCH

We accelerate and advance innovation in rare disease care and treatment through research grants, studies, patient registries, partnerships and our Rare Disease Centers of Excellence network.



COMMUNITY

We support and strengthen a diverse network of more than 330 patient advocacy organizations with a collective reach of six million.

OUR IMPACT

40 years ago, NORD's founders won the fight to pass the Orphan Drug Act – and we haven't stopped fighting. Here are some highlights from the past few decades:



880+

orphan drugs have been FDA-approved as a result of the Orphan Drug Act.*

* As of the end of 2022.

Source: Orphanet Journal of Rare Diseases



NORD launched the nation's **first rare disease patient assistance program** in 1987, providing urgently needed financial support to thousands of patients and caregivers.



NORD lobbied and helped launch the **first NIH Office of Rare Diseases Research**, which serves as the federal focal point for rare disease biomedical research.



NORD developed the **first natural history patient registry platform** to serve the rare disease patient community. Today the IAMRARE® patient registry platform serves more than 35 patient registries.



The NORD Rare Disease Centers of Excellence Network is the **first and only world-class network of U.S. hospitals and medical institutions** dedicated to diagnosing, treating and researching all rare diseases.

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Learn more at rarediseases.org

