



# 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 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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