Who We Are. As a full-service, mission-driven nonprofit, we are patients, family members, advocates, educators, clinicians, and researchers united by a single purpose—to solve the greatest challenges and unmet needs in rare disease patient care, treatment, and research. Together, with the more than 25 million Americans impacted by rare diseases, we are on this journey, navigating a complex path and forging a way toward answers, cures, and lives transformed.

NORD is the only organization working at the intersection of care, research, policy, and community for all rare diseases.

CARE
For many, we are a first step toward hope, action, and progress. Whether it is help searching for a diagnosis, a specialist, or clinical trials, we provide ease of access to world-class care and expertise.

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.

POLICY AND ACTION
We are rooted in the advocacy that spurred a movement resulting in the passage of the world’s first law incentivizing drug development for rare diseases—the Orphan Drug Act of 1983. We continue to fight for life-changing laws, policies, and programs today.

COMMUNITY
We support and strengthen a diverse network of more than 340 Patient Advocacy Organizations that together serve more than a half million rare disease patients.

40 YEARS OF FIRSTS
For 40 years, NORD has been a national steward, an unwavering partner, and a steadfast presence helping those battling and caring for rare diseases feel seen, heard, supported, and connected.

• 1983: Orphan Drug Act
• 1987: Rare Disease Patient Assistance
• 2014: IAMRARE® Collaborative Research Platform
• 2021: NORD’s Rare Disease Centers of Excellence Network

Join us in our quest to reimagine what’s possible and transform lives. Visit rarediseases.org

Alone we are RARE.
Together we are STRONG.®