

NORD® RARE DISEASE Centers of Excellence

National Organization for Rare Disorders (NORD®)

WORLD-CLASS RARE DISEASE PATIENT CARE & RESEARCH

The National Organization for Rare Disorders (NORD®) Rare Disease Centers of Excellence is the first-of-its-kind network of U.S. medical institutions dedicated to diagnosing, treating and researching ALL rare diseases.

Each of the 40 Centers across the U.S. offers world-class doctors in all major specialties and features skilled medical teams experienced in diagnosing and treating a wide array of rare diseases. Additionally, each Center is engaged in research and works closely with physicians and patients to identify and develop new therapies for rare diseases.

Together, these Centers are focused on bringing expert rare disease care and research closer to where patients live.

Our Goals

The NORD Rare Disease Centers of Excellence are working together to share knowledge and best practices to improve the lives and well-being of those living with a known or suspected (undiagnosed) rare disease. Together, these Centers are collaborating to solve the greatest medical challenges and unmet needs of the rare disease community with a focus on five key areas:



**Shortening the
Time to Diagnosis**



**Increasing Multi-Site
Clinical Trials**



**Improving Access
to Quality Care**



**Training Future Rare
Disease Specialists**



**Accelerating Research
and New Therapy
Development**



Find a NORD Rare Disease Center of Excellence Near You:

For the most up-to-date listing of our Centers, please visit:
rarediseases.org/rare-disease-centers-of-excellence



Alone we are rare. Together we are strong.®



OVERVIEW



A network of

40

NORD® Rare Disease Centers of Excellence serving patients nationwide.



8 of the top 10 U.S.
News & World Report
children's hospitals



6 of the 7 top multi-
state regional hospitals
for treating children



Equipped with
experts to care and
treat the full range
of rare diseases



18 of the top 20 U.S.
News & World Report
research medical
schools



NORD®
National Organization
for Rare Disorders

Current NORD Rare Disease Centers of Excellence



Alabama

- University of Alabama Birmingham Medicine/Children's of Alabama

Arizona

- Mayo Clinic

California

- Children's Hospital of Orange County/University of California Irvine
- CHLA + Keck NORD Center of Excellence for Rare Disorders
- Stanford Medicine Children's Health – NORD Center of Excellence for Rare Disorders
- University of California Los Angeles – NORD Center of Excellence
- University of California San Francisco/Benioff Children's Hospitals

Colorado

- University of Colorado Anschutz Medical Campus/Children's Hospital Colorado/UCHealth

Connecticut

- Yale NORD Center of Excellence for Rare Disorders

Florida

- Cleveland Clinic Center for Rare Diseases
- Mayo Clinic
- University of Miami Miller School of Medicine

Georgia

- Emory Division of Medical Genetics /Children's Healthcare of Atlanta

Illinois

- NORD Rare Disease Center for Excellence at Ann & Robert H. Lurie Children's Hospital of Chicago and Northwestern University

Indiana

- Indiana University Health/Indiana University School of Medicine

Iowa

- University of Iowa Health Care

Maryland

- Johns Hopkins Medicine/Kennedy Krieger Institute

Massachusetts

- Harvard Medical School Affiliated Hospitals – NORD Center of Excellence for Rare Disorders

Michigan

- Michigan Medicine NORD Center of Excellence

Minnesota

- Mayo Clinic
- M Health Fairview-University of Minnesota Masonic Children's Hospital

Missouri

- Washington University/Barnes-Jewish Center Healthcare

Nebraska

- University of Nebraska Medical Center Munroe-Meyer Institute, Omaha Children's Hospital and Nebraska Medicine

New York

- Columbia University Irving Medical Center
- New York Center for Rare Diseases
- Department of Genetics and Genomic Sciences, Icahn School of Medicine at Mount Sinai
- New York-Presbyterian/Weill Cornell Rare Disease Center

North Carolina

- Duke Health Rare Disease Center
- University of North Carolina Chapel Hill Children's - North Carolina Children's Hospital

Ohio

- Cincinnati Children's Hospital Medical Center/University of Cincinnati Medical Center
- Cleveland Clinic Center for Rare Diseases
- Nationwide Children's Hospital/ Ohio State University

Pennsylvania

- Penn Medicine/Children's Hospital of Philadelphia
- University of Pittsburgh Medical Center - Center for Rare Disease Therapy

Tennessee

- Vanderbilt University Medical Center

Texas

- Baylor College of Medicine/Baylor St. Luke's Medical Center/Texas Children's Hospital
- University of Texas Houston McGovern Medical School
- University of Texas Southwestern Medical Center

Utah

- University of Utah Medical Genetics

Washington

- University of Washington School of Medicine and Seattle Children's Hospital NORD Rare Disease Center of Excellence

Washington, DC

- Rare Disease Institute at Children's National Hospital

Wisconsin

- Children's Wisconsin/Medical College of Wisconsin
- University of Wisconsin Center for Rare Disease

ABOUT NORD

Since 1983, NORD has fought to improve the health and well-being of people with rare diseases by driving advances in care, research and policy. We're an independent and bipartisan nonprofit dedicated to reimagining a future where every person with a rare disease and their families live their best lives.



Alone we are rare. Together we are strong.®

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