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Children’s Wisconsin: Named Center of Excellence by National Organization for Rare Disorders® (NORD)

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MILWAUKEE, Wis., Nov 12, 2021 — The Children’s Wisconsin Undiagnosed and Rare Disease Program was recognized as a Center of Excellence by the National Organization for Rare Disorders (NORD).

“It is a great honor to be recognized for the work we do as it relates to patients with undiagnosed and rare diseases,” said Donald Basel, MD, medical director of the Genetics and Genomics Program at Children’s Wisconsin. “We are in good company with the other highly acclaimed centers around the country, and this recognition offers additional ability to leverage our combined resources to better serve the community.”

Children’s Wisconsin joins a highly select group of 31 medical centers nationwide as part of an innovative network seeking to expand access and advance care and research for rare disease patients in the United States. The Center of Excellence program aims to promote outstanding treatment for rare disease patients, establish a network of medical centers and clinics, elevate collaboration, improve standards of care, advance research and increase awareness about rare diseases in the broader medical and patient communities.

“Right now, far too many rare diseases are without an established standard of care. The Centers of Excellence program will help set that standard — for patients, clinicians and medical centers alike," said Ed Neilan, MD, PhD, chief scientific and medical officer of NORD. "We are proud to announce Children's Wisconsin as a NORD Rare Disease Center of Excellence and look forward to their many further contributions as we collectively seek to improve health equity, care, and research to support all individuals with rare diseases."

The Children's Wisconsin Undiagnosed and Rare Disease Program was formed more than a decade ago and, today, includes a team of 30 highly trained and experienced pediatric subspecialists, many of whom lead their field nationally. Utilizing a strong clinical program that incorporates the latest in diagnostic testing through research, nearly 40 percent of the children in the program receive a proper diagnosis — one of the highest diagnosis rates in the country.

"The Nelson Service for Undiagnosed and Rare Diseases at Children's Wisconsin provides comprehensive multidisciplinary evaluations for patients and families facing diagnostic dilemmas," said Dr. Basel, who is also section chief and professor of pediatric genetics and associate director of Undiagnosed & Rare Diseases at the Medical College of Wisconsin. "The combination of the team's clinical expertise and the first fully integrated clinical Genomic Medicine Program in the United States, which is also accredited by the College of American Pathologists, gives hope to parents and children from all over the country who are suffering from undiagnosed conditions."

The Children's Wisconsin team includes pediatric experts in cardiology, dermatology, developmental biology, endocrinology, gastroenterology, genetics, infectious diseases, neonatology, nephrology, neurology, radiology, rheumatology/immunology, pathology, library sciences and informatics.

According to the National Institute of Health, any disease that affects fewer than 200,000 people in the United States is considered rare. There are more than 7,000 rare diseases and 30 million Americans estimated to be currently living with rare diseases. More than 90 percent of rare diseases lack an FDA-approved treatment.

People living with rare diseases frequently face many challenges in finding a diagnosis and quality clinical care. The average rare disease diagnosis can take six years and require up to 12 specialists and multiple medical tests. By designating and establishing a network of specialized centers and experts, NORD is bringing together leaders in the field from across the country to reduce the time to diagnosis and improve the availability and coordination of multi-specialty clinical care. These Centers of Excellence will strive to push the rare disease field forward by collaborating to develop new care guidelines, improve medical and family education, create safe and effective referral pathways, and innovate around new treatments, therapies, and research.

Each center was selected by NORD in a competitive application process requiring evidence of staffing with experts across multiple specialties to meet the needs of rare disease patients and significant contributions to rare disease patient education, physician training and research. The NORD Rare Disease Centers of Excellence program is formulated to achieve better outcomes for all members of the rare disease community. This collaborative partnership strives to push the rare disease field forward by establishing and implementing new standards of care and innovating around new treatments, therapies, and research.

For more information on the NORD Rare Disease Centers of Excellence program and the full list of centers, visit the program website.