



## Horizon Pharma Gift Establishes First Clinical Team Endowment at Children's National Rare Disease Institute

February 26, 2018

**The endowment will support a clinical care team dedicated to providing rare disease patients with earlier intervention and more consistent treatment over the course of their lifetimes**

WASHINGTON, Feb. 26, 2018 (GLOBE NEWSWIRE) -- Children's National Health System and Horizon Pharma plc are pleased to announce the creation of the *Horizon Pharma Clinical Care Endowment*, the first clinical team endowment at the Children's National Rare Disease Institute (CNRDI). The endowment is made possible by a generous \$3 million commitment over six years from Horizon Pharma USA, Inc., a wholly owned subsidiary of Horizon Pharma plc. – a biopharmaceutical company dedicated to improving the lives of people living with rare diseases.

Currently, it is estimated that one in 10 Americans has a rare disease – approximately 80 percent of which are genetically based. Additionally, the National Institutes of Health (NIH) reports that more than 80 percent are childhood diseases, and more than 25 percent of children admitted to pediatric hospitals have a rare disease.

 [RDlstack\\_09\\_27\\_17.jpg](#)

The *Horizon Pharma Clinical Care Endowment* will provide stable support for an expert care team at the CNRDI. Each team will consist of a clinical geneticist and support team members – such as genetic counselors, nutritionists and social workers – all specializing in the care of children with rare disease.

"Patients and families with rare conditions deserve a medical home – a trusted place with the medical knowledge to provide quick, clear answers and the expert care they need," said Marshall Summar, MD, director of the CNRDI. "We are grateful for Horizon and their support of our mission to make the Children's National Rare Disease Institute that home. This endowment will support a dedicated team that can provide optimal, comprehensive care to more patients and ensure that families will have a trusted source for all aspects of their health care."

This long-term support provided by the *Horizon Pharma Clinical Care Endowment* will give the CNRDI a firm foundation for treating patients earlier, more consistently, and over the course of their lifetime. Horizon's commitment marks the first donor-funded endowment at the CNRDI.

"The Children's National Rare Disease Institute is an important step in better defining the journey from diagnosis to treatment for people living with rare disease and their families," said Timothy P. Walbert, chairman, president and chief executive officer, Horizon Pharma plc. "We consistently hear stories from people who spent many years in search of a diagnosis, followed by more years searching for the right team of specialists – suffering through a painful journey with devastating consequences. Our hope is that the *Horizon Pharma Clinical Care Endowment* and the Institute will disrupt this all-too-familiar rare disease trajectory by joining exceptional rare disease specialists together in one place."

The CNRDI is a first-of-its-kind center focused exclusively on advancing the care and treatment of children and adults with rare genetic diseases. It is the first Center of Excellence (COE) for the National Organization for Rare Disorders (NORD) and aims to provide a medical home for patients and families seeking the most advanced care and expertise for rare genetic conditions that remain largely unknown to the general medical community.

According to the National Institutes of Health (NIH), any disease, illness or disorder that affects fewer than 200,000 people in the United States is considered to be rare. Yet, of the more than 7,000 rare diseases known to exist, fewer than 500 (roughly five percent) have a known treatment approved by the U.S. Food and Drug Administration (FDA).

### About Children's National Health System

Children's National Health System, based in Washington, D.C., has been serving the nation's children since 1870. Children's National is [#1 for babies](#) and ranked in every specialty evaluated by *U.S. News & World Report* including placement in the top 10 for: [Cancer](#) (#7), [Neurology](#) and [Neurosurgery](#) (#9), [Orthopaedics](#) (#9) and [Nephrology](#) (#10). Children's National has been designated two times as a Magnet<sup>®</sup> hospital, a designation given to hospitals that demonstrate the highest standards of nursing and patient care delivery. This pediatric academic health system offers expert care through a convenient, community-based primary care network and specialty outpatient centers. Home to the Children's Research Institute and the Sheikh Zayed Institute for Pediatric Surgical Innovation, Children's National is one of the nation's top NIH-funded pediatric institutions. Children's National is recognized for its expertise and innovation in pediatric care and as a strong voice for children through advocacy at the local, regional and national levels. For more information, visit [ChildrensNational.org](http://ChildrensNational.org), or follow us on [Facebook](#) and [Twitter](#).

### About Horizon

Horizon Pharma plc is focused on researching, developing and commercializing innovative medicines that address unmet treatment needs for rare and rheumatic diseases. By fostering a growing pipeline of medicines in development and exploring all potential uses for currently marketed medicines, we strive to make a powerful difference for patients, their caregivers and physicians. For us, it's personal: by living up to our own potential, we are helping others live up to theirs. For more information, please visit [www.horizonpharma.com](http://www.horizonpharma.com), follow us [@HZNPplc](#) on Twitter or like us on [Facebook](#).

**Contact:**

Simone Hunter

Matt Flesch

[shunter@childrensnational.org](mailto:shunter@childrensnational.org) [media@horizonpharma.com](mailto:media@horizonpharma.com)

301-821-1392

224-383-3211

 [Primary Logo](#)

Source: Horizon Pharma plc