



**FOR IMMEDIATE RELEASE**

**Children's Health<sup>SM</sup> opens new clinic specifically focused on treating and researching rare Pitt Hopkins Syndrome (PTHS)**

DALLAS (May 12, 2015) – [Children's Health<sup>SM</sup>](#) announced today the opening of the second Pitt Hopkins Syndrome (PTHS) clinic in the nation. PTHS is a rare genetic condition affecting a specific gene in chromosome 18, called TCF4. PTHS is characterized by intellectual disability and developmental delay, breathing problems, recurrent seizures (epilepsy), and distinctive facial features.

The number of identified PTHS patients worldwide is approximately 500, however there are many who are believed to remain undiagnosed. The new clinic will be part of the Center for Autism and Developmental Disabilities (CADD) at Children's Health.

"We are honored and privileged to launch the second clinic, solely devoted to PTHS in the nation at Children's Health. The real aim of opening this clinic is to make life better for children living with this condition and to provide much-needed resources to their families as we continue to research the root of the condition and its impact," explained Dr. Sailaja Golla, pediatrics, neurology and neurotherapeutics specialist at Children's Health and assistant professor at UT Southwestern Medical Center.

Under the direction of Dr. Golla and the CADD and supported by the Pitt Hopkins Research Foundation, the clinic will focus on providing knowledge-based medical care and serving the comprehensive medical needs of children with PTHS. With the creation of the clinic, patients and their families will have access to multiple specialists and medical resources.

The Pitt Hopkins Research Foundation will provide its administrative structure, such as meeting planning and referrals, to the new Dallas clinic. Additionally, Children's Health will be part of a group of medical institutions and clinicians devoted to learning more about Pitt Hopkins through the foundation's development of the Pitt Hopkins Clinic & Research Consortium.

"Our goal is that all families will have access to quality evaluation, treatment recommendations and care within a reasonable geographic distance from their homes. The Dallas clinic's central location in the U.S. will hopefully allow families greater access to care from around the globe," said Audrey Davidow, president of the Pitt Hopkins Research Foundation.

The first clinic was set up at Massachusetts General Hospital in Boston under the direction of Dr. Ronald Thibert and Dr. David Sweetser, and generously supported by Nancy LeGendre and Walter Herlihy, parents of two young women living with Pitt Hopkins Syndrome.

The new Children's Health CADD clinic will provide coordinated care with access to a clinical geneticist, neurologist, psychologist, gastroenterologist and pulmonologist. Children's Health is seeking to improve the health and quality of life for children with PTHS and to begin collecting a natural history of patients to further research the condition with the opening of the clinic.

Individuals living with PTHS may suffer from developmental delays, limited speech, low muscle tone, extreme breathing problems, seizures, gastrointestinal issues, and autistic or hyperactive behaviors including great excitability. Affected individuals have distinctive facial features, and many have limited mobility.

Genetic testing became available after discovery of mutations in the TCF4 gene as the cause of Pitt Hopkins Syndrome in 2007, but clinical suspicion for testing was limited to the most profoundly affected patients.

The clinic will be located in the Medical District of Dallas at 6363 Forest Park Road, Bass Building – 5th floor, Dallas TX 75235. For more information please call (214) 648-0102 or visit [childrens.com/pitt-hopkins-syndrome](http://childrens.com/pitt-hopkins-syndrome) or [www.pitthopkins.org](http://www.pitthopkins.org).

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### **About Children's Health System of Texas**

Children's Health System of Texas (Children's Health<sup>SM</sup>) is one of the nation's leading pediatric health care systems, providing a full spectrum of healthcare services for children in Dallas, North Texas and surrounding regions. Children's Health includes a clinically integrated network featuring the flagship hospital Children's Health Children's Medical Center Dallas, as well as Children's Health Children's Medical Center Plano and Children's Specialty Center Southlake, 18 Children's Health Pediatric Group primary care centers, home health, physician practices and professional services and a pediatric research institute. For more information, please visit [www.childrens.com](http://www.childrens.com).

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