



OSF HealthCare Children's Hospital Joins Forces With West Coast Institute to Diagnose Critically Ill Infants

September 4 2019 11:15 AM



PEORIA – OSF HealthCare Children’s Hospital of Illinois is now collaborating with Rady Children’s Institute for Genomic Medicine(RCIGM)on a research protocol to more effectively diagnose and treat critically ill infants with unexplained illnesses.This commitment to clinical innovation and research collaboration will enhance patient care and further the scientific understanding of rare genetic diseases in children. The goal of genomic medicine is to personalize precise care for a child based on the root cause of their specific disorder.

“As the only full service children’s hospital in Illinois outside Chicago, it is right for us provide this kind of care for families,” says Mike Wells, President, OSF HealthCare Children’s Hospital of Illinois. “We have a history of being pioneers in children’s medicine, and we are pleased to be the first to bring this testing to Illinois and to collaborate with such a world-renowned institution. We believe children, and families, should have this care.”

The team at Rady's Children's Institute in San Diego has pioneered use of rapid whole genome sequencing (rWGS) to diagnose infants in intensive care and provide doctors with the most complete information available about the child's condition. RWGS is the most comprehensive and advanced genetic test available. Just a few drops of blood are needed to scan a baby's entire genetic code for disease-causing errors.

RCIGM swiftly communicates the results to attending doctors, typically in less than three days. Traditional diagnostics test just a few genes at a time and results can take weeks or months to come back. For babies with a rare disease, the wait for answers can lead to a lifelong disability or even death.

"In the past, we just looked at the big chromosome picture, but, now, with this growing technology we can detect even the slightest deviation in the genetic makeup of a baby that causes a problem," said Susan Ramiro, MD, neonatologist and principal investigator, OSF HealthCare Children's Hospital of Illinois and Assistant Professor of Clinical Pediatrics, University of Illinois College of Medicine at Peoria.

"We always want to look for an answer why a baby is sick, and the biggest advantage for this technology is for those babies who are very sick and we don't know why." "The best way to think about it is when you are standing outside of a forest and you see a bunch of trees in front of you, the chromosomes are essentially each individual tree and you're able to identify each tree and see if there is one that's different than another. What we're able to do now with the technology is not only look at the trees, but we're able to go deep into the forest and look at a single branch and what part of the branch –if it's closer to the leaf, is it closer to the trunk –and where those defects lie within the forest themselves," explained M. Jawad Javed, MD, Medical Director, Neonatal Intensive Care Unit, OSF Children's Hospital of Illinois and Associate Professor of Clinical Pediatrics, University of Illinois College of Medicine at Peoria.

OSF Children's Hospital's participation in this initiative with RCIGM will not only help individual patients, but also help advance the science of precision medicine. With each new baby diagnosed, the pool of knowledge about rare genetic diseases and how to treat them will grow and be shared with participating institutions around the world.

"The only way we could make this available to our local children and families is because of the generosity of our donors. The impact on families cared for at OSF HealthCare Children's Hospital of Illinois who will benefit from this is immeasurable," said Tom Hammerton, President, OSF HealthCare Foundation.

The first year of the program is funded, in part, by an anonymous gift of \$200,000 to OSF Children's Hospital of Illinois. It is expected that more than a dozen babies will be tested during the first year of a two-year clinical trial in Peoria.

“It’s our privilege to teamup with our colleagues in Illinois to make genomic medicine available to the children and families in Peoria and all of Illinois,” said Stephen Kingsmore, MD, DSc, President and CEO of Rady Children’s Institute for Genomic Medicine. -30-OSF HealthCare Children's Hospital of Illinois in Peoria is the third largest pediatric hospital in Illinois and the only full service tertiary hospital for kids downstate. With 136 beds and more than 141 pediatric subspecialists, OSF Children's Hospital cares for more children in Illinois than any hospital outside of Chicago. Formally established as a pediatric hospital within the walls of OSF HealthCare Saint Francis Medical Center in 1990, OSF Children's Hospital has over 7,000 admissions; 2,500 newborn deliveries, and 18,000 emergency department visits each year. More at www.osfhealthcare.org/childrens/.

About Rady Children’s Institute for Genomic Medicine: The Institute is leading the way in advancing precision healthcare for infants and children through genomic and systems medicine research.

Discoveries at the Institute are enabling rapid diagnosis and targeted treatment of critically ill newborns and pediatric patients at Rady Children’s Hospital-San Diego and partner hospitals. The vision is to expand delivery of this life-saving technology to enable the practice of precision pediatric medicine at children’s hospitals across California, the nation and the world. RCIGM is a subsidiary of Rady Children’s Hospital and Health Center. Learn more at www.RadyGenomics.org. Follow us on Twitter and LinkedIn.