

Children's Hospital of Philadelphia and Northwell Health Approved for \$8.5 Million PCORI Research Funding Award

Funding Award Will Support Project to Improve Quality of Life for Youth with Sickle Cell Disease Transitioning to Adult Care

Philadelphia, Pa. – September 19, 2017 – Researchers at Children's Hospital of Philadelphia (CHOP) and Northwell Health's Cohen Children's Medical Center have been approved for a \$8.5 million funding award by the Patient-Centered Outcomes Research Institute (PCORI) to study how to improve quality of life for youth with sickle cell disease as they transition to adult care.

The study will assess the effectiveness of two support interventions in providing self-management tools to enhance the transition from pediatric to adult health care providers for youth 17 years and older with sickle cell disease. The research team will compare the interventions – a six-month community health worker program and a mobile health application – to usual care to see if these tools improve the patients' ability to care for themselves, stay connected with their doctors, avoid visits to the emergency room, and, ultimately, experience better quality of life.

"While transitioning to the adult health care system is difficult to navigate for many youth and their families, those with chronic conditions and complex medical needs face particularly challenging barriers," said Dr. David Rubin, director of PolicyLab and medical director of population health at CHOP. "We've heard from youth with sickle cell disease and their families that the transition of their care is their greatest concern, beyond their health. With this study, we're seeking to understand what tools we can provide outside of the doctor's office so these patients feel actively involved in the transfer of their health care."

Sickle cell disease is a group of genetic red blood cell disorders that causes severe pain and anemia, increases risk for infections, and damages organs throughout the body. The disease usually presents in childhood; approximately 100,000 Americans are living with the disease today. Young adults with sickle cell disease experience a seven-fold increase in mortality rates during the years that they transition to adult care.

"Although young people with sickle cell disease are more likely than ever to live into adulthood, we know that their transition to adult health care is often accompanied by loss of insurance coverage, a decrease in the quality of life, and other challenges that endanger their health," said Dr. Kim Smith-Whitley, director of the Comprehensive Sickle Cell Center at CHOP. "As a pediatrician who specializes in sickle cell disease, I want to know what are the best tools that I can provide my patients so that when they progress out of the children's hospital, they are supported and empowered to manage their care."

"We've done a lot of research on what are the types of interventions – namely around youth community health workers and mobile health interventions – that could assist young adults with sickle cell disease in their transition to adult care. Now, we're excited to continue partnering with these young adults to learn which of these tools work best for them," said Dr. Sophia Jan, chief of general pediatrics at Cohen Children's Medical Center and medical director of Northwell Health's Health Homes Serving Children. "What we learn will not only help patients make informed decisions and feel more prepared for the transition from pediatric to adult care, but provide everyone involved in patients' well-being – their families, pediatric and adult health care providers,

health systems and policymakers – with better tools and more knowledge to build a successful model for transition of care for all youth with complex medical needs.”

This study was selected for funding through a PCORI funding announcement specifically focused on comparing different ways to manage the transition of people with sickle cell disease from pediatric to adult care.

“This project was selected for PCORI funding for its potential to fill an important gap in our understanding of how to improve care for older adolescents and young adults with sickle cell disease. It will provide useful information to help patients weigh the effectiveness of their care options,” said PCORI Executive Director Joe Selby, MD, MPH. “We look forward to following the study’s progress and working with Children’s Hospital of Philadelphia and Northwell Health’s Cohen Children’s Medical Center to share the results.”

Drs. Rubin, Smith-Whitley and Jan’s award has been approved pending completion of a business and programmatic review by PCORI staff and issuance of a formal award contract.

PCORI is an independent, nonprofit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions. For more information about PCORI’s funding, visit www.pcori.org . <http://www.pcori.org/funding/opportunities>.

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About PolicyLab at Children’s Hospital of Philadelphia: PolicyLab at Children’s Hospital of Philadelphia (CHOP) is dedicated to achieving optimal child health and well-being by informing program and policy changes through interdisciplinary research. Founded in 2008, PolicyLab is a Center of Emphasis within the CHOP Research Institute, one of the largest pediatric research institutes in the country. With more than 25 highly-regarded faculty and 35 passionate staff who bring expertise from myriad of fields covering health, research and health policy, our work focuses on improving public systems, improving health care delivery and improving child health outcomes. For more information, visit <http://www.policylab.chop.edu>.

About Children’s Hospital of Philadelphia: Children’s Hospital of Philadelphia was founded in 1855 as the nation’s first pediatric hospital. Through its long-standing commitment to providing exceptional patient care, training new generations of pediatric healthcare professionals and pioneering major research initiatives, Children’s Hospital has fostered many discoveries that have benefited children worldwide. Its pediatric research program is among the largest in the country. In addition, its unique family-centered care and public service programs have brought the 546-bed hospital recognition as a leading advocate for children and adolescents. For more information, visit <http://www.chop.edu>.

About the Steven and Alexandra Cohen Children’s Medical Center of New York

Founded in 1983, Cohen Children’s Medical Center -- part of Northwell Health -- is a 202-bed hospital dedicated exclusively to the care of children. The specialists in the hospital’s national and international programs cover an entire range of specialties. State-of-the-art care for children’s medical, surgical, and dental needs are provided in both inpatient and outpatient settings. The facility is the largest provider of pediatric health services in New York State, serving 1.8 million children in Brooklyn, Queens, and Nassau and Suffolk Counties. For the 11th consecutive year in 2017, Cohen’s was ranked among the nation’s best children’s hospitals in U.S. News & World Report’s 2017-18 “America’s Best Children’s Hospitals” survey, achieving top-50 rankings in nine of 10 pediatric specialties.