

# About STORM



The purpose of Sickle Treatment and Outcomes Research in the Midwest (STORM) is to bring together the hematology and primary care communities to collaborate with patients and families on quality improvement initiatives to improve access and delivery of care and outcomes for patients with sickle cell disease (SCD) in the Midwest.

## OUR APPROACH

STORM is a collaborative effort that implements quality improvement projects with pediatric and adult hematology practices to build a sustainable network to improve the outcomes and care for patients with sickle cell disease (SCD) in the Midwest. STORM participation is at the institution level or practice level, whereas each participating institution identifies a lead physician and additional clinical faculty and staff who work as members of local site-specific and topic-specific improvement team(s).

## LEADERSHIP

STORM capitalizes on state-level partnerships, bringing together expertise from Indiana, Illinois, Michigan, Minnesota, Ohio and Wisconsin, and utilizes the nationally-recognized capability in quality improvement (QI) science within the James M. Anderson Center for Health Systems Excellence and Internationally-recognized excellence in Hematology within the Cincinnati Comprehensive Sickle Cell Center (CCSCC) at Cincinnati Children's Hospital Medical Center (CCHMC).



## ENGAGEMENT

In order to improve care, STORM engages a variety of stakeholders including patients and family members, as well as pediatric and adult hematology providers, primary care providers, state newborn screening programs, state health departments, community-based organizations, and advocacy groups.

## TRANSPARENCY

The Learning Networks collaboration among centers in pediatrics is essential because no single site has enough patients or data from which to learn about improving care and outcomes. This need has led to the creation of multi-site, practice based, clinical networks called Learning Networks. Both the American Board of Pediatrics and the Patient-Centered Outcomes Research Institute have acknowledged and highlighted the importance of networks in engaging patients and clinicians to improve health outcomes.

## OUR MISSION

To improve the quality of life and health outcomes for all Midwesterners with sickle cell disease.

## OUR GOALS

Our overall program goals are to 1) Increase the number of providers that are treating sickle cell patients, 2) Increase the number of providers prescribing disease-modifying therapies, such as hydroxyurea, and 3) Increase the number of sickle cell patients that are receiving care from providers with greater knowledge of how to treat sickle cell disease.

## OUR STATE LEVEL PARTNERS

- Indiana Hemophilia and Thrombosis Center (IHTC)
- Children's Hospital of Illinois
- Sickle Cell Disease Association of America Michigan (SCDAA-MI)
- Children's Hospital and Clinics of Minnesota
- Cincinnati Comprehensive Sickle Cell Center (CCSCC)
- Medical College of Wisconsin/Children's Hospital of Wisconsin (MCW/CHW)

e: [storm@cchmc.org](mailto:storm@cchmc.org)