

# Sickle Cell Disease and Project ECHO®

## Connecting Providers and Experts to Improve Care, Outcomes and Costs

People with sickle cell disease suffer from episodes of sudden, excruciating pain prompting emergency room visits and frequent hospitalizations. Delayed treatment deprives tissues of oxygen, can exacerbate pain and cause organ damage. Good preventive care and treatment can reduce pain episodes, and unnecessary emergency room visits and hospitalizations, particularly for adults.

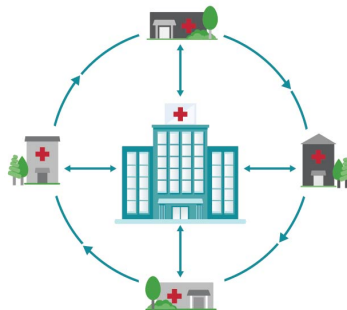
In the United States, nearly 100,000 people have this inherited red blood cell disorder, yet there is a shortage of knowledgeable healthcare providers.

**This is unacceptable. Patients need convenient and consistent access to high quality sickle cell care. There is a way to make that a reality.**

Project ECHO® (Extension for Community Healthcare Outcomes) is an internationally recognized telementoring innovation that builds clinician knowledge in diagnosing and treating complex disorders. Project ECHO connects local clinicians with experts from sickle cell centers to learn skills necessary to deliver high quality sickle cell disease care using this proven telementoring model.

### Moving Knowledge, Not Patients

Through telementoring, ECHO creates access to high-quality specialty care in local communities.



Hub and spoke knowledge-sharing networks create a learning loop:

Community providers learn from specialists.

Community providers learn from each other.

Specialists learn from community providers as best practices emerge.

Through a federal Sickle Cell Disease Treatment Demonstration Program, sickle cell disease expert centers throughout the U.S. have provided Project ECHO telementoring since 2014. This has helped to:

- close the gap in quantity of knowledge providers, especially for adults with sickle cell disease that not only need care for the disease, but whole patient care;
- improve patient health outcomes;
- enhance healthcare delivery;
- and reduce costs.

**There is still a need for more providers to serve the sickle cell disease population. Learn more about joining Project ECHO by contacting your regional sickle cell coordinating center.**

**Northeast Region:** Sickle Cell Disease TeleECHO Clinic Conference Series, hosted by Johns Hopkins University (DC, MD, NJ, NY, VA, PA, DE, WV, Virgin Islands, Puerto Rico) [bailey.house@jhu.edu](mailto:bailey.house@jhu.edu)  
**Midwest Region:** STORM TeleECHO (IL, IN, MI, MN, OH, WI) [storm@cchmc.org](mailto:storm@cchmc.org)  
**Pacific Region:** Western States Telementoring Collaborative for Sickle Cell Disease (AK, AZ, CA, ID, HI, OR, NV, WA) [jennkim@mail.cho.org](mailto:jennkim@mail.cho.org)

**NICHQ**  
National Institute for  
Children's Health Quality