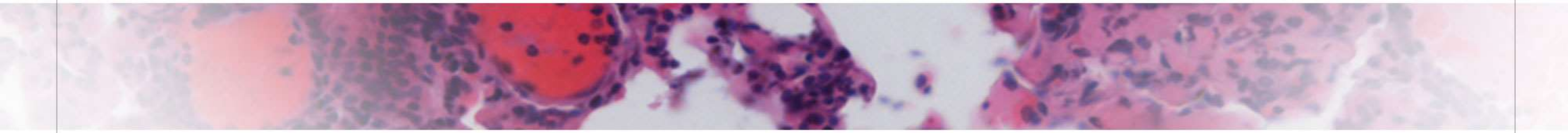
American Society *of* Hematology
Helping hematologists conquer blood diseases worldwide



Welcome to the
Sickle Cell Disease Centers Resource Fair

Visit the tables for more information

HRSA
Health Resources & Services Administration

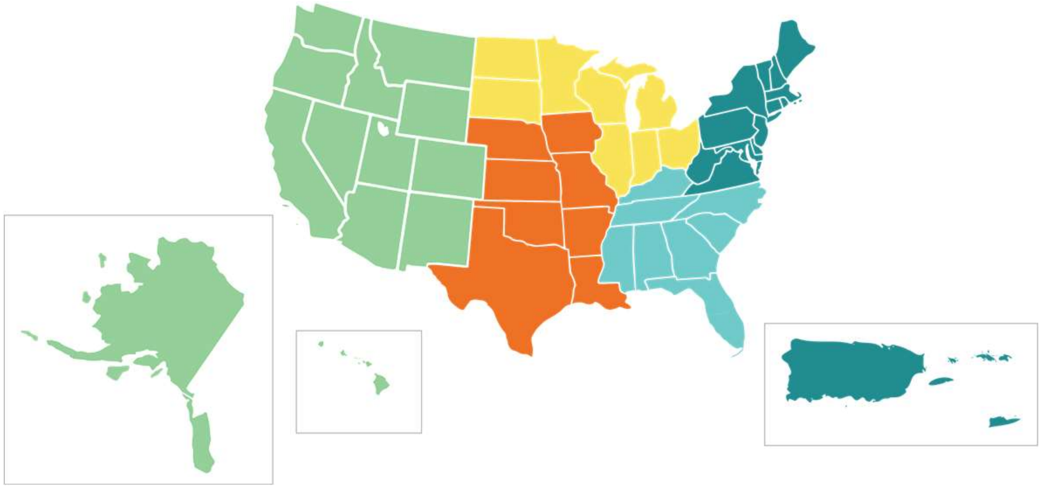
Treatment Demonstration Programs (TDP)

The purpose of TDP is to increase access to quality, coordinated, and comprehensive care for individuals with sickle cell disease (SCD) by:

- Increasing the number of clinicians or health professionals knowledgeable about the care of SCD
- Improving the quality of care provided to individuals with SCD
- Improving care coordination with other providers

Regional Leads

Northeast: Sophie Lanzkron, Ros Stewart
Southeast: JJ Strouse, Julie Kanter
Midwest: Lisa Shook
Heartland and Prairie: Allison King
Pacific: Marsha Treadwell, Diane Nugent, Elliot Vichinsky



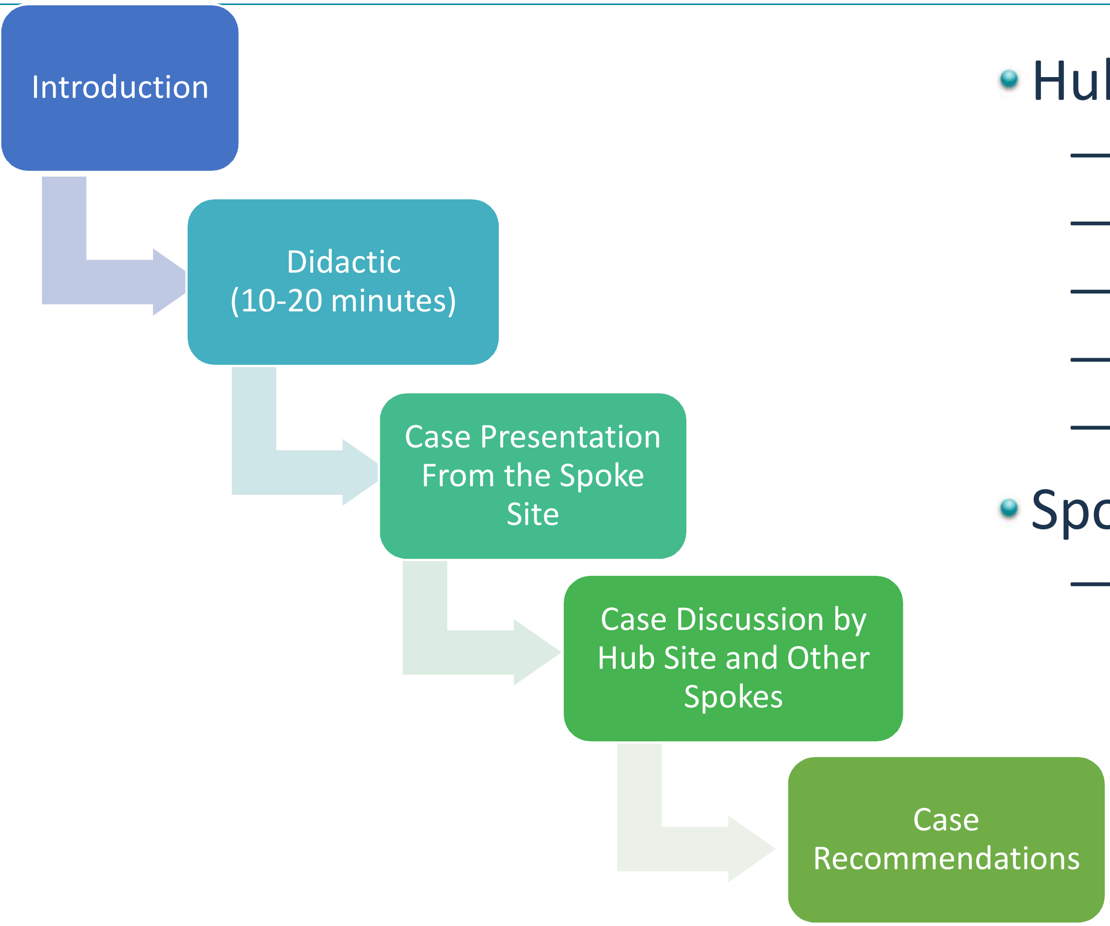
TDP, Treatment Demonstration Programs

Overcoming the Lack of Hematology Expertise: ECHO Telementoring

- Project ECHO is Telementoring and not Telemedicine
- Mentorship relationships between less experienced providers and those with more experience
  - —Like a clinic/case conference with individuals separated by distance
  - —Multiple providers simultaneously

https://www.youtube.com/watch?v=VAMaHP-tEwk

Sickle Cell TeleEcho



Introduction

Didactic (10-20 minutes)

Case Presentation From the Spoke Site

Case Discussion by Hub Site and Other Spokes

Case Recommendations

- Hub
  - —Adult and pediatric hematology
  - —Primary care
  - —Pain management expertise/psychiatry
  - —Social work
  - —Community health workers
- Spokes
  - —Providers taking care of people with SCD

Sickle Cell ECHO Telementoring Directory

Advanced Practice Providers

Johns Hopkins University, monthly, 3rd Thursday 12-1 pm EST, email sinerge@jhmi.edu
University of Alabama at Birmingham, 1st Wednesdays 4-5 pm, EST, email sonjasmith@UABMC.edu

Pediatric Providers

Rhode Island Hospital, 2nd and 4th Thursdays 10-11 am EST, email DMedeiros1@Lifespan.org

All Providers

Johns Hopkins University, weekly, Wednesdays 1-2 pm EST, email sinerge@jhmi.edu
Virginia Commonwealth University, 1st Wednesdays 12:30-2 pm EST, email sjohnson42@vcu.edu
Washington University, St. Louis, 3rd Friday 11-12 pm CST, email easowt@wustl.edu
Cincinnati Children's Hospital, 3rd Thursday 12-1 pm EST, email Christina.Bennett@cchmc.org
Duke University, psychosocial sessions, 2nd Tuesdays 11-12 pm CT, email rem88@duke.edu
Duke/Atrium, 1st and 3rd Thursdays 11:30 am CT, email rem88@duke.edu
University of Alabama at Birmingham, 2nd and 4th Tuesday, monthly at 4-5 pm CST, email sonjasmith@UABMC.edu
Emory, HEAL curative therapies ECHO, 2nd and 4th Mondays 4:00-5:15 pm, email shannon.l.smith@emory.edu
Center for Inherited Blood Disorders/UCSF Benioff Children's, monthly, dates vary, email svora@c3dibd.org

Quality Improvement

Jacobi Medical Center, 1st and 3rd Wednesdays 11-12 am EST, email lakewr@nychhc.org

Community-based Organizations

Children's Sickle Cell Foundation, 3rd Wednesdays 3-4 pm EST, email mmatthews@cscfkids.org
Candice's Sickle Cell Fund (Stigma in the ED), monthly schedule varies, email crystalrivas973@outlook.com

THE NATIONAL ALLIANCE OF SICKLE CELL CENTERS

Mission: Support sickle cell disease (SCD) centers in delivering high-quality comprehensive care by:

- Setting standards of care and promoting their adoption
- Identifying opportunities and resources to strengthen SCD centers
- Advocating for access to comprehensive care to improve health outcomes, quality of life, and survival

Goals:

1. Create an infrastructure for adult and pediatric SCD centers to define, enhance, and promote the adoption of standards of care that comprise a comprehensive care center for individuals with SCD
2. Develop tools and share information with SCD centers to use in implementing and operating a comprehensive care model within their organization
3. Utilize a national clinical registry, Globin Research Network for Data and Discovery (GRNDaD), to optimize quality improvement and assurance
4. Work with other organizations (ASH, SCDAA, CDC, etc) on opportunities and resources (federal, state, and private) that SCD centers can utilize to sustain funding and ensure equitable access to comprehensive care

National Alliance
of Sickle Cell Centers

Overview of ASH's SCD Initiative

Access to Care

- New SCD Guidelines
- Expanded Education and Training
  - SCD Adult Centers Workshop
- *Bringing Sickle Cell Disease to Life* Podcast Series

Research

- ASH Research Collaborative
  - SCD Data Collection Platform and Learning Community
  - SCD Clinical Trials Network

Global

- Consortium on Newborn Screening in Africa (CONSA)

SCD Policy Strategy

- Raise SCD Awareness
- Enhance Federal SCD Activities
- Improve Reimbursement for SCD Care and Treatment

SCD Coalition

SICKLE CELL DISEASE COALITION

- 100+ Members
- *www.scdcoalition.org*

ASH
RESEARCH
COLLABORATIVE™
Accelerating Progress
in Hematology

Research Acceleration

Clinical Care Enhancement

Collaboration

ASH
RESEARCH
COLLABORATIVE™
Accelerating Progress
in Hematology

Clinical Trials Network

Research Ready Sites

Contact us ✉ **info@ashrc.org**

Data Hub

Real World Data

Learning Community

Quality Improvement

Sickle Cell Adult Provider Network (SCAPN)

SCAPN
Sickle Cell Adult
Provider Network

How Do I Join?

www.SCAPN.org
Facebook Group

Mission:

- The Sickle Cell Adult Provider Network (SCAPN) was officially established in 2002 with a mission to establish a network for healthcare providers who serve adults with sickle cell disease

Network:

- This was the first and only national organization that:
  - Offers a home for healthcare professionals from multiple disciplines who focus on **adult-oriented** research and clinical care
  - Provides education/training, mentorship, and advocacy

Opportunities:

- Ask complex medical questions
- Meet other like-minded colleagues
- Job opportunities
- Publication opportunities
- Research

SICKLE CELL DISEASE IMPLEMENTATION CONSORTIUM (SCDIC)

GOALS

- Develop a SCD Registry of **2,400 individuals** from 8 treatment centers, ages 15-45, that can be **followed over time through surveys** and medical record abstraction
- Conduct a **needs-based community assessment** of the barriers to care for individuals with SCD
- Design **implementation research studies** that address identified barriers to care

NEEDS ASSESSMENT STUDIES

TOPICS

- Hydroxyurea
- Pain
- Quality of Care
- ED Care

METHODS

- Surveys
- Key Informant Interviews
- Focus Groups

OUTCOMES

3 Implementation Workgroups

Care Redesign
Improve ED Care
Reduce Unaffiliated Patients

RATIONALE

- The lives of many adults with SCD are marked by high mortality, severe pain, and progressive decline in functional status
- Many patients do not have access to continuous high quality health care
- Lack of studies that examine the barriers to treatment

SCDIC
Sickle Cell Disease Implementation Consortium

ALIGN STUDY–SPECIFIC AIMS

- Assess overall effectiveness of EHR-embedded individual pain plans (IPP) on improving patient and provider outcomes associated with pain treatment in the ED setting
- Assess the adoption, implementation, and maintenance of the IPP at each participating site
- Assess barriers and facilitators to the use of EHR-embedded IPPs

MESH STUDY–SPECIFIC AIMS

- Compare the days of hydroxy urea (HU) covered by prescriptions at baseline and after 6 months of *InCharge Health*
- Compare the change in provider prescribing of HU at baseline and 9 months
- Evaluate the barriers and facilitators to the adoption of both mHealth Interventions

SCDIC
Sickle Cell Disease Implementation Consortium

UNAFFILIATED PATIENTS WORKING GROUP

Goal is to understand **how and why individuals with sickle cell disease become unaffiliated** from SCD care through the following studies:

Delphi Consensus Process

- Define someone with sickle cell disease who is "unaffiliated" from sickle cell disease care
- Specify what it means to be a sickle cell disease specialist

Quantitative Surveys

- Gather data about barriers to care and potential strategies to connect or re-connect patients to care

SCDIC
Sickle Cell Disease Implementation Consortium

Sickle Cell Disease Association of America, Inc.

Working Together to Save Lives

Mission: To advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure.

Vision: The leader in promoting and advancing initiatives focused on people affected by sickle cell conditions worldwide.

National Services:

National Awareness and Fundraising
Research and Gene Therapy Support
Professional Health Education
Public Health Education
Capacity Building and Technical Assistance
Legislative/Government Advocacy

SCDAA–Who We Are, What We Do

WE SERVE as the **national voice for SCD** as the only organization working to resolve issues surrounding sickle cell disease and sickle cell trait. Since 1972, the organization has been on the forefront of improving the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions.

WE PROMOTE the **search for a cure** for all people in the world with sickle cell disease.

WE JOIN with our **53 community-based member organizations** and affiliates located in 29 states to collectively serve over 500,000 children and adults with sickle cell disease.

WE CONNECT SCD warriors to our **Clinical Trial Finder** — a centralized, simple-to-navigate website to help people with sickle cell disease, their families and caregivers find clinical trials: www.sicklecelldisease.org/clinical-trial-finder.

WE TRAIN hundreds of **Community Health Workers (CHW)** across the nation to assist families, helping to manage their healthcare strategy and access to care.

WE ADVISE on current **medical news affecting you** through SCDAA's Medical and Research Advisory Committee (MARAC). The committee, comprised of world-renowned SCD experts, provides vital disease, trial and therapy updates as they happen.

WE LEAD by building leadership skills, the **Leadership Academy** helps community-based organizations and SCD professionals become even more productive, with capacity building and information.

WE ADVOCATE through the **National Sickle Cell Advocacy Network (NSCAN),** so patients and families know they are not alone. Together with our community-based organizations, we have created a strong network that includes caregivers, clinicians, stakeholders and experts.

WE PARTNER **together with organizations** like the American Red Cross, Emmaus Life Sciences, Novartis' Generation S Campaign and Pfizer, to name a few, to conduct blood drives and raise SCD awareness.

Legislative Advocacy and Priorities-2022

- **Co-sponsor the Sickle Cell Disease Comprehensive Care Act (H.R. 6216/S. 3389)**
  - Would establish a "demonstration" program in up to 10 states through the Centers for Medicaid and Medicare (CMS)
  - This bill improves patient access to care and promotes coordination between multidisciplinary teams
- **$25 Million for the Center for Disease Control's Sickle Cell Disease Data Collection Program**
  - The CDC estimates that an annual investment of $25 million is needed to implement the SCD surveillance provision of the 2018 SCD law
  - The NASEM report on SCD highlights the critical need to establish a national system for SCD data collection
  - Impact: Data collection is necessary to improve national incidence and prevalence data, better identify health disparities, and evaluate strategies to improve quality of life and lower costs associated with treating the population
- **$15 Million for the Sickle Cell Disease Treatment Demonstration Program**
  - The 2018 SCD law reauthorized the Sickle Cell Disease Treatment Demonstration Program (SCDTDP) to help coordinate service delivery for individuals with SCD, train health professionals, and provide access to genetic counseling and testing
  - The reauthorization also calls for SCDTDP to develop best practices for the coordination of services for adolescents transitioning from pediatric to adult healthcare. Due to the lack of adequate protocols and care coordination, people with SCD struggle with the transition to adulthood.
  - Impact: Continued program efforts will accelerate the identification and implementation of best practices and procedures for SCD care