Michigan Sickle Cell Data Collection (MiSCDC) Program Newsletter
July 2026

New policy brief: Newborn Screening Follow-Up in Georgia

A new policy brief was published that discusses long-term newborn screening follow-up as a priority area for policy improvement. The brief discusses lessons learned from Sickle Cell Data Collection states and best practices for follow-up of individuals with sickle cell disease (SCD). Lessons learned in Michigan:

- **Community-Based Organization Follow-Up:** Since 1987, Michigan's Department of Health and Human Services (MDHHS) has partnered exclusively with the Sickle Cell Disease Association of America Michigan Chapter (SCDAA-MI) to conduct follow-up via patient advocates who provide education, ensuring newborns are connected to care and receive follow-up services and timely preventive care, such as antibiotic prophylaxis. This has reduced the number of infants lost to follow-up.

- **Comprehensive Data Integration:** MDHHS manages the Michigan Care Improvement Registry, which performs long-term follow-up and tracks immunizations and treatment compliance for nine conditions, including SCD. MDHHS collaborated with SCDAA-MI to add patient-reported health status assessments to Michigan's Sickle Cell Data Collection Program.

MiSCDC Participation in Research That Heals: Partnering with Patients to Transform SCD Care

The MiSCDC team was honored to participate in Research That Heals: Partnering with Patients to Transform SCD Care, a 1.5-day national forum co-hosted by the National Heart, Lung, and Blood Institute (NHLBI) and the Sickle Cell Disease Association of America (SCDAA). The meeting brought together individuals living with SCD, caregivers, clinicians, researchers, community organizations, and federal partners to discuss how meaningful partnerships can improve SCD research, care, and quality of life.

As part of the meeting, Tiffany Glover and Sarah Reeves presented "Show Me the Data and Tell Me the Stories." The session demonstrated how epidemiologists and community members can interpret the same evidence together, highlighting the value of shared perspectives. By pairing data with lived-experience, the discussion demonstrated how community expertise can deepen our understanding of research findings, identify more effective solutions, shape the questions researchers ask, and ultimately increase the impact of research.

We are grateful to NHLBI and SCDAA for convening this important forum and to Tiffany for sharing her expertise and lived experience throughout our session.

In the News

March 28, 2026

New plan aims to reduce barriers for adults living with sickle cell disease

March 24, 2026

Detroit Evening Report: Michigan's plan to help sickle cell disease patients

MDHHS rolls out new plan to improve care, services for sickle cell patients

March 23, 2026

Michigan unveils new plan to improve sickle cell care

How Michigan is addressing lack of accessible, consistent care for sickle cell disease

Publications

Parks P, Miller JI, Cromartie Jones S, et al. **Acute Care Use Among People With Sickle Cell Disease, Sickle Cell Data Collection Program, 8 US States, 2018.** *Public Health Rep.* 2026 Mar-Apr; 141(2):252-259. doi:10.1177/00333549251387081

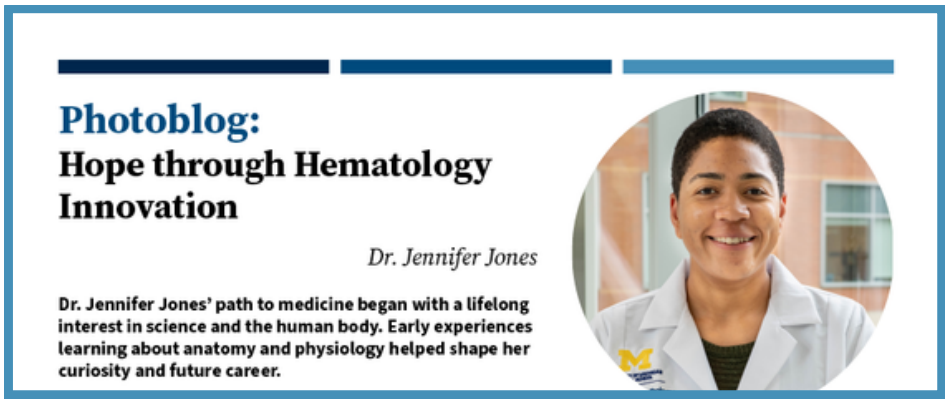
New MiSCDC webpage: Resources for individuals with sickle cell disease and their families

The MiSCDC website now has a page dedicated to share resources that may be helpful for people with SCD and their family members, including a guide to medical transportation options, preparing for Medicaid changes in Michigan, and more. Visit miscdc.org/resources/ to view these resources.

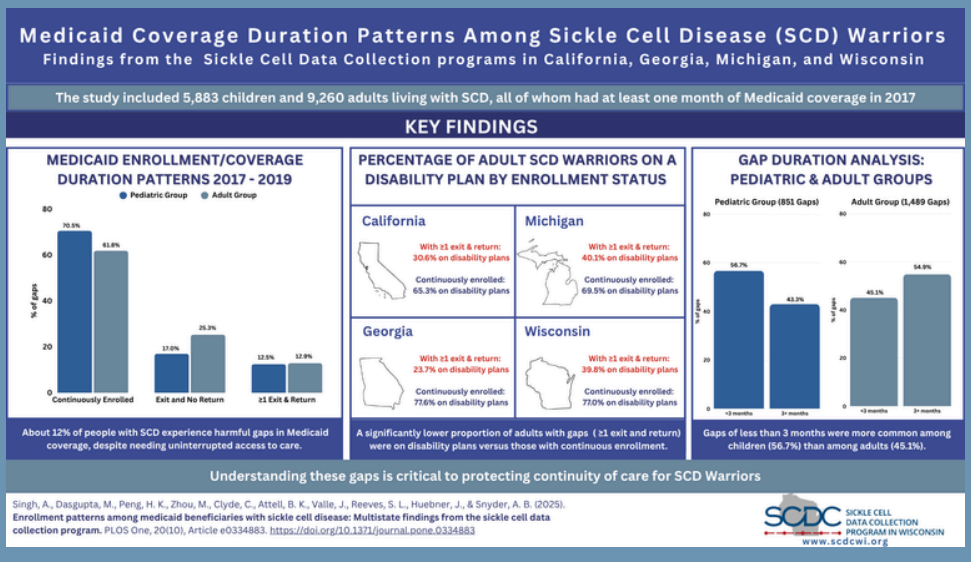
New Photoblog: Dr. Jennifer Jones

The MiSCDC highlights *Hope through Hematology Innovation,* featuring Dr. Jennifer Jones and her work advancing care for individuals with blood disorders. From personalized transfusion strategies to her commitment to patients with SCD and thalassemia. Dr. Jones' story reflects both innovation and compassion in hematology.

Read the full photoblog here.



Data Corner

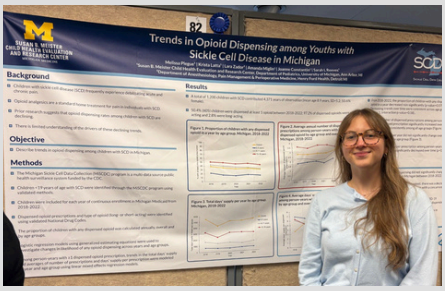


Presentations

May 7, 2026
Michigan Medicine Pediatric Research Symposium, Ann Arbor

Oral presentation: Krista Latta, MiSCDC lead statistician, **"Incidence of Venous Thromboembolism among Youth with Sickle Cell Disease"** presented by Dr. Sharon Singh (below). *Health Services Research awardee.*

Poster presentation: Missy Plegue, Statistician Expert, **"Trends in Opioid Dispensing among Youths with Sickle Cell Disease in Michigan"** presented by Amanda Miglin (below).



Sickle Cell News from MDHHS

MDHHS Releases Updated Sickle Cell Disease Strategic Plan

MDHHS has released Michigan's updated SCD Strategic Plan, outlining priorities and guiding efforts to improve sickle cell care and outcomes across the state.

Building on decades of progress, Michigan's updated plan focuses on strengthening systems of care and support for people living with SCD, their caregivers, health care providers and communities statewide. Grounded in the lived experiences of people living with SCD and informed by current science and standards of care, the plan is intended to help inform policy, strengthen partnerships and guide public health and clinical efforts - with a goal of using data to drive decision-making, measure impact, and improve healthcare utilization and outcomes.

We invite you to review the updated plan and consider how the recommendations may inform policy, data, and clinical priorities.

To read the full plan and explore more about the efforts, visit the *Centering Voices: Michigan's Plan to Address Sickle Cell Disease Across the Lifespan* webpage.

Michigan Governor Gretchen Whitmer Continues Support for Sickle Cell Awareness Day in 2026

Michigan Governor Gretchen Whitmer maintains the state's commitment to SCD by proclaiming June 19, 2026, as Sickle Cell Awareness Day in Michigan. The proclamation aligns with World Sickle Cell Awareness Day, an international day observed to increase public knowledge and understanding of SCD, the challenges of patients and their families, and to improve the lives of those living with SCD throughout the world.

Read the governor's full proclamation here.

MDHHS Awards $400,000 to Expand and Improve Sickle Cell Care

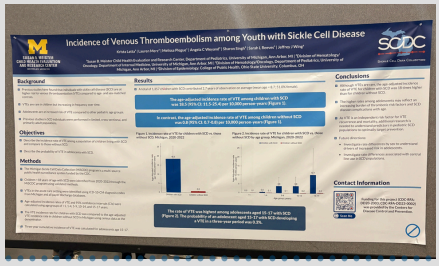
The MDHHS has awarded nearly $400,000 for five projects to help increase care to individuals with SCD through a competitive grant process. This grant program offers resources to providers that help increase patient access to quality, integrated health care and use disease-modifying therapies, as well as improve acute care services delivered to patients living with SCD. The organizations awarded are: Henry Ford Health, University of Michigan Adult and Pediatric SCD clinics, Bronson Health Foundation, and Children's Hospital of Michigan.

Read more about the funded projects here.

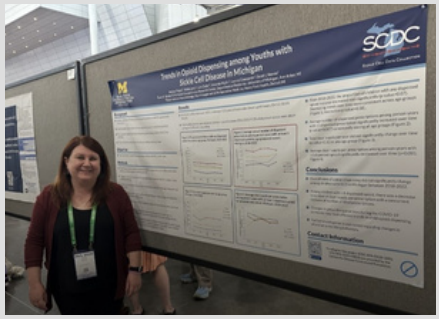
Presentations Continued

April 24-27, 2026
Pediatric Academic Societies Annual Conference, Boston

Poster presentation, Krista Latta, MiSCDC lead statistician, **"Incidence of Venous Thromboembolism among Youth with Sickle Cell Disease"** presented by Dr. Sarah Reeves.



Poster presentation, Missy Plegue, Statistician Expert, **"Trends in Opioid Dispensing among Youths with Sickle Cell Disease in Michigan"** presented by Dr. Sarah Reeves (below).



Sickle Cell News from MDHHS

New! Michigan Sickle Cell Educational Network Exchange

Michigan Sickle Cell Educational Network Exchange (MiSCENE) is a new collaborative effort led by MDHHS's Blood Disorders Unit and the MiSCDC program.

Launching in early 2027, MiSCENE will bring together clinicians, healthcare professionals, community partners, and individuals with lived experience to learn, connect, and share ideas for improving sickle cell care across Michigan. Through quarterly sessions, participants will explore practical resources, standards of care, and insights from those directly impacted by SCD.

MiSCENE
Michigan Sickle Cell Educational Network Exchange Network
Setting the scene for sickle cell education

Longstanding SCD partners will receive updates and invitations in the coming months. With questions about MiSCENE or about participating, please contact Shanee Kilpatrick at KilpatrickS@michigan.gov.

Community Announcements

Save the Dates: 2026 Sickle Cell Disease Awareness Walks in Michigan

- **Sickle Cell Matters Awareness Walk Detroit**
  Saturday, September 12th, 9am-1pm
  Charles H. Wright Museum
  Sponsorships are available. Learn more at scdaami.org.

- **Annual Sickle Walk Flint**
  Saturday, September 19th, 9am
  Max Brandon Park

- **Strides for Sickle Cell Walk Ann Arbor**
  Sunday, September 20th, 9am
  Gallup Park

- **Step Up for Sickle Cell Grand Rapids**
  Saturday, September 26th, time TBD
  U of M Health-West

SCDAA National Convention

The 54th Annual National Convention will be held October 15-17 2026, in Concord, North Carolina. To learn more about the convention, visit sicklecelldisease.org/annual-national-convention/

We welcome you to share our newsletter with friends and colleagues. To receive future MiSCDC newsletters, please register here.

Your participation and support are valued.