



Sickle Cell Disease Research

The Bloodline Newsletter: March 2023

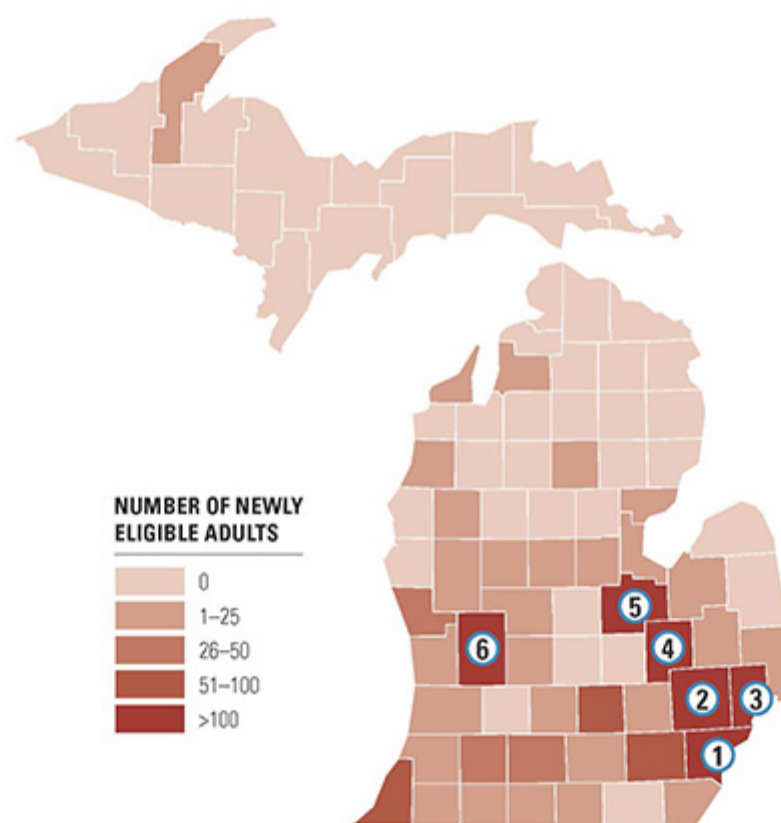


Mission: To improve quality of life, life expectancy, and health among people living with sickle cell disease (SCD).

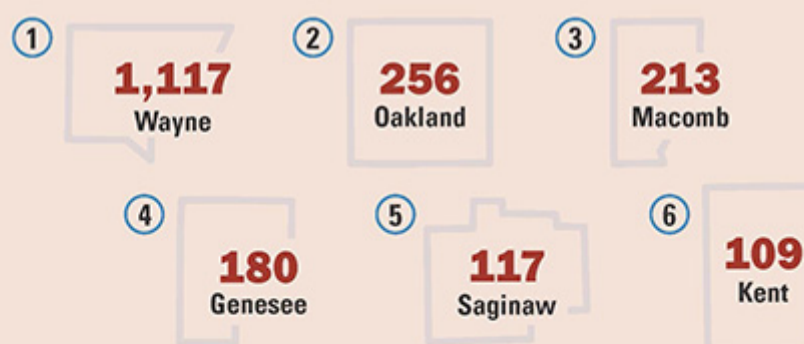
Communications Corner

- SCDC Michigan developed a policy brief, “[State-university partnership to enhance outreach to adults living with sickle cell disease in Michigan](#)” in collaboration with the University of Michigan Institute for Healthcare Policy and Innovation.
- SCDC Michigan updated the infographic, “[Sickle cell disease in Michigan](#),” to include new branding.
- SCDC Michigan’s website is now live: miscdc.org
- In October, SCDC Michigan released its latest Multidisciplinary Team [newsletter](#), which includes recent articles, presentations, and community events by their team and partners.

Half of all Michigan counties are home to adults with sickle cell disease who are newly eligible to enroll in the CSHCS expansion, with the majority living in southeast Michigan.



Counties in Michigan with >100 newly eligible adults living with sickle cell disease



What is the Michigan Sickle Cell Data Collection (MiSCDC) program?

MiSCDC merges numerous sources to gather population-level data to identify people living with sickle cell disease in Michigan and understand their health and healthcare over time.⁶ The data is used to assess gaps in programs and policies related to sickle cell disease. Acquisition and analyses of data to conduct surveillance are made possible through a grant of public health authority authorized by MDHHS.

MiSCDC data sources include: Sickle cell disease clinics in Michigan and state-maintained data such as newborn screening, Michigan Medicaid, Children’s Special Health Care Services, immunization registry, vital records, and comprehensive all-payer databases.

MiSCDC is a collaboration led by the Susan B. Meister Child Health Evaluation and Research Center at the University of Michigan and MDHHS and is funded by the Centers for Disease Control and Prevention (CDC). There are 10 other states with CDC-funded sickle cell data collection programs like MiSCDC.⁷

Trainings & Webinars

SCDC California hosted the webinar “[Depression screening in sickle cell disease: What little we know and why to do it anyway](#)” in February 2023. Depressive symptoms are associated with worse pain (particularly more chronic pain) and reduced quality

of life in SCD. Pat Carroll, MD, director of Psychiatric Services Sickle Cell Center for Adults, Johns Hopkins School of Medicine, shared the literature on depression and depressive symptoms in SCD and offered an approach to screening and management.

Recent Publications

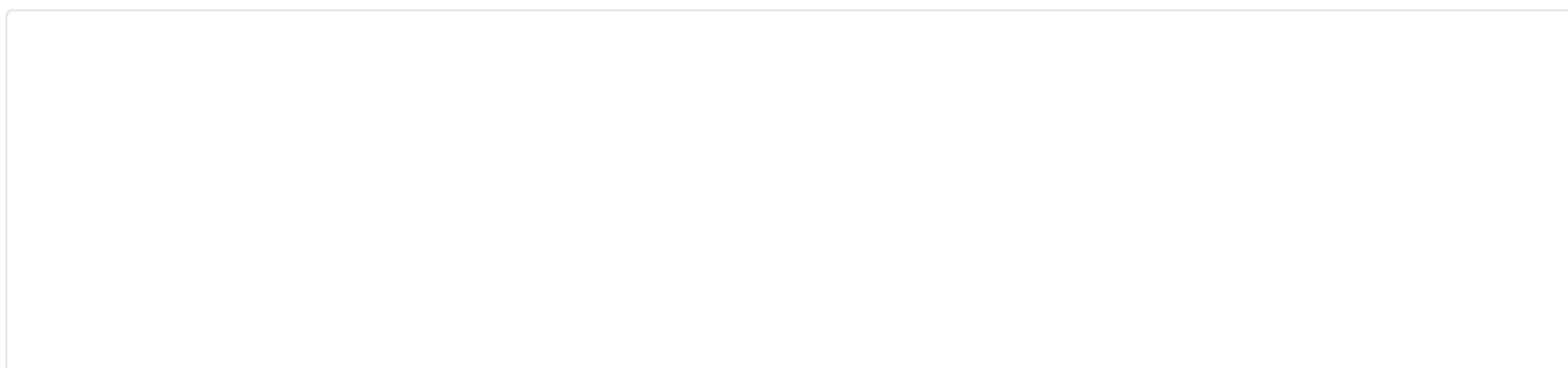
Stephenson, J. [Too Few Children, Teens with Sickle Cell Anemia Receive Screening, Medication to Prevent Serious Complications](#). JAMA Health Forum. 2022 Nov 4;3(11):e224780.

Up-to-Data

- SCDC Georgia data updates
 - A CDC public health researcher requested demographic information from SCDC Georgia and California for 2010–2018. SCDC Georgia responded by re-running annual report data for the requested demographic information in 19 counties. These data would help the researcher to determine the number of children in the age range 0–4 years and 5–17 years to support the discussion section of a manuscript on rates of invasive pneumococcal disease in children with SCD.
 - SCDC Virginia requested a list of variables that they can request from their state Medicaid program for SCD surveillance. SCDC Georgia provided a variable list that includes demographic, clinical, and provider information.
- SCDC Michigan is collaborating with clinicians at Michigan Medicine to support a project funded by the Michigan Department of Health and Human Services (MDHHS) that seeks to examine and improve adherence to recommended clinic appointments; transcranial Doppler ultrasound, magnetic resonance imaging (MRI), and cognitive screening; prescription of prophylactic antibiotics; and use of chelator medications. SCDC Michigan data will be used to inform and validate the patient registry of those treated at Michigan Medicine within the last 3 years.

Presentations & Meetings

- SCDC North Carolina held its biannual advisory council meeting on October 17, 2022, during which findings from the team were presented. Council membership includes representation from clinicians and researchers from SCD centers across North Carolina; people living with SCD; and SCD educators, counselors, and case managers.
- SCDC North Carolina presented SCD surveillance findings at the Governor’s Appointed NC Council on Sickle Cell Disease and Other Blood Disorders on October 28, 2022. Council membership includes people living with SCD, public health officials, community-based organizations, SCD clinicians, and researchers.
- SCDC Michigan’s Krista Latta presented most recent annual report findings at the Michigan Hemoglobinopathy Quality Improvement Committee (HemQIC) Virtual Fall Meeting on November 4, 2022.
- SCDC Michigan’s Dr. Sarah Reeves, SCDC Wisconsin’s Dawn Retherford, SCDC Minnesota’s Dr. Jay Desai, and SCDC Indiana’s Amanda Okolo presented at the Sickle Treatment and Outcomes Research in the Midwest (STORM) Learning Session on November 8, 2022.
- Dr. Sarah Reeves presented “State-university partnership to implement sickle cell disease surveillance in Michigan” to the Lifecourse Epidemiology and Genomics Division of MDHHS on December 5, 2022.
- The following states hosted CDC for in-person site visits:
 - SCDC Georgia’s site visit was held on January 18, 2023. The meeting was attended by SCDC Georgia partners including SCD clinicians, community-based organizations, health services researchers, and the Georgia Department of Public Health. The team discussed SCDC partnerships, engagement with community partners on disseminating SCDC data, and use of SCDC data for studying pain in SCD.





A few participants of the SCDC Georgia site visit, from left to right: Dr. Robert W. Gibson (Augusta University), Jiajing (Scarlette) Shi [Georgia State University (GSU)], Eric Napierala (GSU), Dr. Angela B. Snyder (GSU), Brandon K. Attell (GSU), Andre D. Moorer (Discovering Moorer2life), Mapillar Dahn (MTS Sickle Cell foundation), Mei Zhou (GSU), Dr. Mary Hulihan (CDC), Sangeetha Lakshmanan (GSU), Fiona Bock (GSU), Shammara Pope (CDC), Zahan A. Panjwani (GSU).

- SCDC Colorado hosted CDC on January 31, 2023. Those in attendance included representatives from the Colorado Sickle Cell Association, Colorado Sickle Cell Treatment and Research Center, Colorado Newborn Screening, Vital Records, and Health Data Compass. Attendees shared successes and difficulties experienced to date and discussed ideas, hopes, and goals for the future of the project.
- SCDC Indiana completed their CDC site visit on February 6, 2023. There were 13 members of the multidisciplinary team from 7 different agencies present (in person and virtually) to share information and ideas. Discussion surrounded year 1 and 2 data, progress regarding the development of a dashboard to house pertinent information, and brainstorming opportunities that lie ahead for year 3 of the project.
- SCDC Alabama hosted an annual update of the Alabama Lifespan Sickle Cell Tracking Access Towards Equality (ALSTATE) grant on February 10, 2023. More than 40 people were in attendance online and in person and represented community-based organizations, the Alabama Department of Public Health, Alabama Medicaid, the Alabama Senate Oversight Commission, both of Alabama's comprehensive sickle cell centers, and CDC, as well as other clinicians, researchers, and administrators.



A few participants of the SCDC Alabama site visit, from left to right: Dr. Antwan Hogue [University of South Alabama (USA)], Dr. Julie Kanter (University of Alabama at Birmingham), Dr. Ardie Pack-Mabien (USA), Dr. Mary Hulihan (CDC), Aleida Johnson (Sickle Cell Disease Association of America—Mobile Chapter).

- SCDC California and CDC's Mary Hulihan met with project stakeholders between February 28 and March 3, 2023. The purpose was to gain a better understanding of the program's impact to date and to discuss opportunities for improving the utility of SCDC data to address the priority needs of the community. Stakeholders included the Sickle Cell Disease Foundation, Cayenne Wellness, UCSF-BCHO, Department of Health Care Services, and Sickle Cell Anemia Awareness San Francisco.
- Dr. Sarah Reeves presented "Using public health surveillance for sickle cell disease" at the Susan B. Meister Child Health Evaluation and Research (CHEAR) Center's Seminar on January 24, 2023.
- SCDC Indiana went to the statehouse on February 27, 2023 in observance of Sickle Cell Advocacy Day, for which the theme is "The Power of Us: Uniting Forces." SCDC data were referenced to educate attendees on the state of SCD. Several patients, medical providers, and caregivers spoke out for SCD warriors.

**THE
POWER
of US** *Uniting
Forces*

2023 Sickle Cell Advocacy Day
11:00 a.m. - 2:00 p.m.
Monday, February 27, 2023
Indiana State Capitol, North Atrium
200 W. Washington St. • Downtown Indy
Lunch will be provided. Register at:
<https://SCDAdvocacyDay2023.eventbrite.com>
Questions? Contact Lisa at lhoffman@ihtc.org

- SCDC Tennessee's Dr. Matthew Smeltzer and his team will present "Chronic comorbidities and sickle cell disease: Surveillance-based findings from Tennessee" at the [Midsouth Data Conference](#) April 6–7, 2023, at the University of Memphis.

Announcements

An SCDC program grant opportunity forecast was posted to grants.gov, [CDC-RFA-DD-23-0002](#). Through this Notice of Funding Opportunity, CDC plans to fund recipients for a 5-year period of performance to implement the SCDC program. There will be two components, component A (implementation and technical assistance) and component B (capacity building and implementation), with the expectation of a close, working one-on-one collaboration between each component B recipient and a component A recipient. The due date for applications is May 11, 2023.

Contact

For any questions about the SCDC program, contact [Mary Hulihan](#) or [Mandip Kaur](#).

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Last Reviewed: April 13, 2023