Michigan Sickle Cell Data Collection (MiSCDC) Program Newsletter

December 2025

MiSCDC Received Year 3 Funding from the CDC

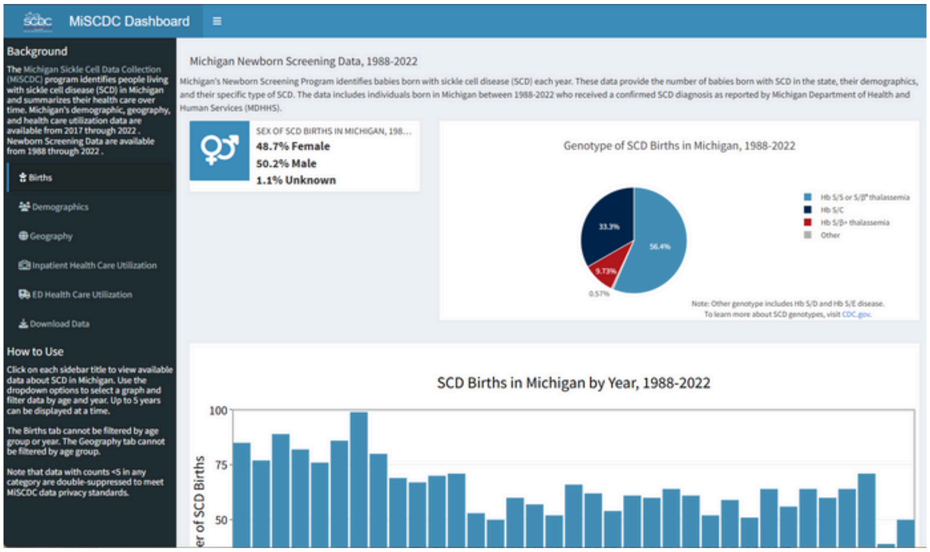
MiSCDC faced uncertainties about the future of the program following the CDC's Division of Blood Disorders and Public Health Genomics team being placed on administrative leave in April. Despite the organizational restructuring, the MiSCDC team received their Year 3 notice of funding in September, giving the program security in continuing its activities.

Data Dashboard Now Live on MiSCDC.org

MiSCDC reports yearly data to the CDC to allow the assessment of trends in diagnosis, treatment, and health care access for people with sickle cell disease (SCD) across the United States.

You can view Michigan's publicly available SCDC data on the interactive MiSCDC Data Dashboard (viewed best on a desktop or laptop). The dashboard includes information about demographics, births, geography, and health care utilization for people living in Michigan with SCD.

Read the updated page about the MiSCDC data methods on our website.



Background

The Michigan Sickle Cell Data Collection (MiSCDC) program identifies people living with sickle cell disease (SCD) in Michigan and summarizes their health care over time. Michigan's demographic, geography, and health care utilization data are available from 2017 through 2022 . Newborn Screening Data are available from 1988 through 2022 .

How to Use

Click on each sidebar title to view available data about SCD in Michigan. Use the dropdown options to select a graph and filter data by age and year. Up to 5 years can be displayed at a time.

The Births tab cannot be filtered by age group or year. The Geography tab cannot be filtered by age group.

Note that data with counts <5 in any category are double-suppressed to meet MiSCDC data privacy standards.

Michigan Newborn Screening Data, 1988-2022

Michigan's Newborn Screening Program identifies babies born with sickle cell disease (SCD) each year. These data provide the number of babies born with SCD in the state, their demographics, and their specific type of SCD. The data includes individuals born in Michigan between 1988-2022 who received a confirmed SCD diagnosis as reported by Michigan Department of Health and Human Services (MDHHS).

SEX OF SCD BIRTHS IN MICHIGAN, 198...
48.7% Female
50.2% Male
1.1% Unknown

Note: Other genotype includes Hb S/D and Hb S/E disease. To learn more about SCD genotypes, visit CDC.gov.

In the News

August 4, 2025

Washtenaw United: Improving access to quality health care for those with sickle cell disease

September 3, 2025

Kids with sickle cell disease face higher risk of dental issues, yet many don't receive needed care

September 5, 2025

Children with sickle cell disease face low dental care utilization despite elevated risks

November 12, 2025

Washtenaw County sickle cell disease researchers and activists see promise in gene therapy, threats in federal funding cuts

Publications

Kranz A, Peng HK, King AA, Clark SJ, Plegue MA, Reeves SL. **Sickle Cell Disease and Dental Care Access Among Medicaid-Enrolled Youths.** *JAMA Netw Open.* 2025 Sep;8;(9):e2529849.

View visual abstract

Singh A, Dasgupta M, Peng HK, et al. **Enrollment patterns among Medicaid beneficiaries with sickle cell disease: Multistate findings from the Sickle Cell Data Collection Program.** *PLoS One.* 2025 Oct; 20(10):e0334883.

Quantitative Report

In September, MiSCDC published a quantitative report of data about the health information of people living with SCD in Michigan. The findings of this report allow for the identification and description of gaps in services, quality of care, and opportunities for improvement.

This report, which was used to inform the development of the updated MDHHS Strategic Plan for SCD, outlines the demographics, births, deaths, health plan enrollment, health care utilization, immunizations, receipt of preventive care, and receipt of disease modifying treatments for Michiganders with SCD.

Select findings from 2018-2022 in the quantitative report include:

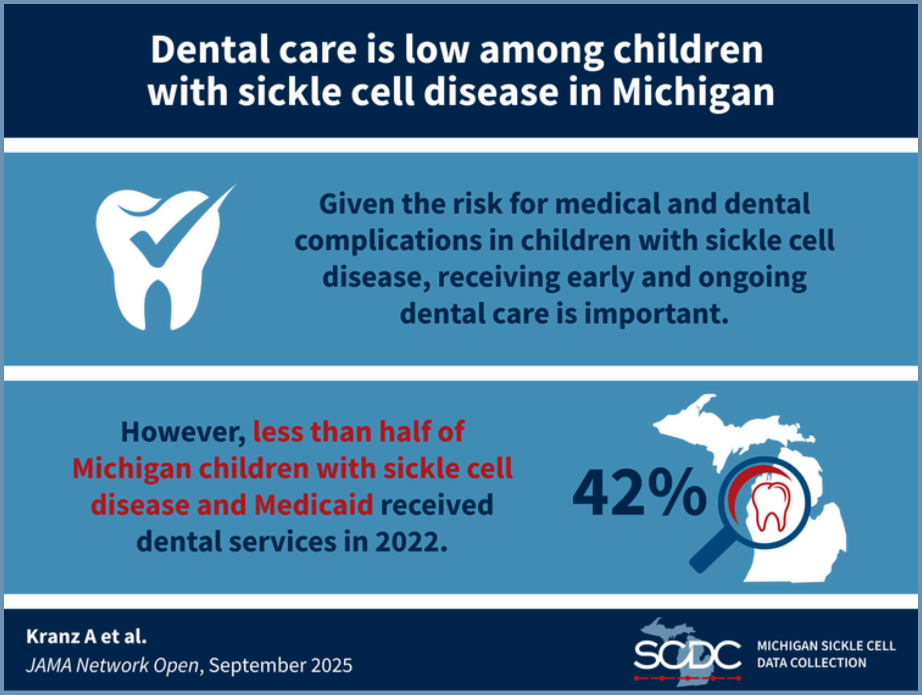
- The proportion of individuals with SCD enrolled in any Medicaid program was approximately 85%, with half enrolled in a full coverage plan for 12 months.
- Approximately three out of five people with SCD did not have a hematologist visit in a year. Individuals with SCD should have at least one visit with a hematologist every year; two or more hematologist visits in a year have been associated with higher uptake of life-saving preventive services.
- Among children with SCD, completion of the primary immunization series was over 80%, higher than the overall population average. However, rates of influenza and COVID-19 immunization among people with SCD are substantially lower compared to the overall population.
- Less than 5% of people with SCD had any new disease modifying therapies (Endari, Oxbryta, Adakveo).

Read the full report here.

Meeting with Michigan Representatives

In July, MiSCDC principal investigator, Dr. Sarah Reeves, met with Michigan Representatives Morgan Foreman and Curtis VanderWall about SCD in Michigan. She shared data from MiSCDC, opportunities for policy engagement, and future directions of the program.

Data Corner



Dental care is low among children with sickle cell disease in Michigan

Given the risk for medical and dental complications in children with sickle cell disease, receiving early and ongoing dental care is important.

However, less than half of Michigan children with sickle cell disease and Medicaid received dental services in 2022.

42%

Kranz A et al.
JAMA Network Open, September 2025

Presentation

September 18, 2025
IQVIA Institute for Human Data Science Research Forum

MiSCDC Workshop entitled, **“Linking Datasets for Public Health Surveillance”** at the IQVIA Institute Research Forum in Boston, MA.

Sickle Cell News from MDHHS

UPCOMING! MDHHS to Release Updated SCD Strategic Plan

To strengthen care and improve outcomes for individuals living with SCD, the Michigan Department of Health and Human Services will soon release the updated SCD Strategic Plan, guiding efforts over the next five years (FY2026-2030).

Building on decades of progress – from early diagnosis through newborn screening to expanding care across the lifespan – the updated plan addresses the needs of people with SCD at every stage of life, along with their caregivers and health care providers.

Grounded in the lived experiences of those with SCD and informed by current science and standards of care, the updated plan outlines six goals to guide action through 2030 and beyond:

1. Implement system changes that center the needs of the SCD community through a collaborative approach.
2. Ensure access to quality, integrated sickle cell treatment and support services statewide.
3. Utilize standards of care and implement protocols that improve patient outcomes.
4. Improve prescription of and adherence to disease-modifying therapies.
5. Provide continuous education to increase awareness of information, best practices, and resources for SCD across the state and for priority groups (i.e., people with SCD and their caregivers, health professionals, general public, schools, and employers).
6. Establish and track metrics to improve health-related outcomes.

To learn more about the plan and Michigan's ongoing efforts to support individuals and families affected by SCD, visit the Michigan Hemoglobinopathy Quality Improvement Program webpage.

Updates to the HemQIP webpage

As the MDHHS Sickle Cell Strategy Team moves closer to releasing Michigan's updated SCD Strategic Plan, the department is excited to share that several new reports and resources used to inform the plan are now available online. They also want to extend their sincere gratitude to the many community members and partners who contributed their time, experiences and insights throughout this process. Your voices have been instrumental in shaping these materials.

You are encouraged to visit the Hemoglobinopathy Quality Improvement Program (HemQIP) updates webpage to explore these resources. For example, an infographic titled *'Sickle Cell Progress in Michigan, A Decade of Change'* (right) is available to support your outreach and education efforts - it's an easy-to-share tool for raising awareness about SCD efforts happening across Michigan.

Continue to check the HemQIP site regularly, as additional resources and the updated SCD Strategic Plan will be shared there as they become available.

Sickle Cell Progress in Michigan

A Decade of Change (2015-2025)

Where Michigan Started

Sickle cell disease (SCD) is the most common inherited blood disorder in Michigan. It was added to the state's newborn screening panel in 1987. Newborn screening is required by law to help find conditions early to support a baby's health. Since then, more than 2,200 Michigan babies have been diagnosed with SCD through screening. Today, about 4,000 people in Michigan are living with SCD.

More than ten years ago, the Michigan Department of Health and Human Services (MDHHS) set out to better understand the experiences of people living with SCD. The goal of that work was to find gaps in health care and support services. Since then, and with invaluable insight from individuals living with SCD, caregivers, advocates and providers, Michigan has worked to address these gaps through statewide activities aimed at improving the SCD care system.

The Progress Made

Expanded Services

With the help of policymakers, MDHHS secured funding to improve SCD care in Michigan. This support helped more clinics provide specialized care, led to the development of an SCD Center of Excellence, expanded access to important services, and increased coverage through Children's Special Health Care Services. Efforts focused on making the shift from pediatric to adult care easier, increasing access to care teams, expanding transcranial doppler screening options, and providing new therapies or treatments for people with SCD.

Better Data

With support from the U.S. Centers for Disease Control and Prevention, MDHHS partnered with the Susan B. Meister Child Health Evaluation and Research Center at the University of Michigan to create the Michigan Sickle Cell Data Collection Program. This program tracks health data to guide policy changes and improve care for people with SCD.

Renewed Approach

MDHHS is improving its commitment to SCD with an updated strategic plan, set to be shared in 2025.

Shaping the Future

As MDHHS continues to amplify the voices of people living with SCD, it is clear that there is still more work to do to support impacted Michiganders. For more information about these programs, email genetics@michigan.gov or visit **Michigan.gov/SickleCell**.

By working together, we aim to:

- Listen to patients and health care providers to understand their needs.
- Support policies and funding to expand SCD care.
- Make resources, education, treatment and support easier to access.

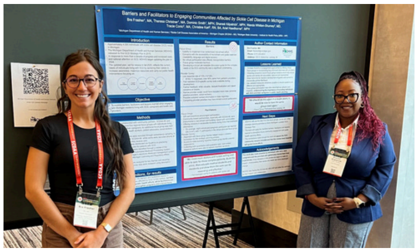
MDHHS
Michigan Department of Health & Human Services

MDHHS-Pub-2180 (09-25)

Sickle Cell News from MDHHS

MDHHS at SCDAA National Convention

Members of the MDHHS Sickle Cell Strategy Team attended the Sickle Cell Disease Association of America's National Convention in October to present their poster, *Barriers and Facilitators to Engaging Communities Affected by Sickle Cell Disease in Michigan.* This work highlights key insights, challenges and lessons learned from engaging Michigan residents living with SCD, their caregivers and health care providers. You can view the presented poster, along with related focus group report and provider survey analysis, on the HemQIP Updates Webpage.



Bre Frasher and Shaneé Kilpatrick

New Funding Opportunity Coming Soon

The MDHHS Hemoglobinopathy Quality Improvement Program continues to build upon the ongoing work of the Sickle Cell Clinic Expansion and Enhancement Program (SCCEE) by releasing a new 3-year grant opportunity. Activities will include the following priority areas:

- Access to quality, integrated health care
- Use of disease modifying therapies
- Delivery of acute care services
- Optimize standards of care and protocols that improve patient outcomes

Please stay tuned, an announcement will be released soon. For information about HemQIP, visit: michigan.gov/sicklecell.

Recognizing Dr. Inoue's Commitment

Congratulations to Dr. Inoue on receiving a special recognition during the annual Sickle Cell Awareness Walk in Flint. The Metropolitan Baptist Tabernacle Sickle Cell Committee honored Dr. Inoue for his endless dedication, strong guidance, and selfless commitment to Michigan's SCD community.

Community Announcements

SCD License Plate Available for Purchase

In June 2024, the Michigan State Legislature approved a fundraising license plate to promote SCD education and treatment awareness. The design was unveiled during the annual 'Sickle Cell Matters Walk' in Detroit this past September, and the plate is now available for purchase.

The Sickle Cell Disease Association of America - Michigan Chapter (SCDAA-MI) is especially proud that Michigan is only the third state in the nation to offer an SCD awareness plate. A portion of the proceeds from the purchase and annual renewal of this new plate will be donated directly to SCDAA-MI to provide ongoing financial support.

For details about the outreach campaign or to schedule an educational presentation, contact Craig Bradley, Outreach and Operations Director, at bradleyc@scdaami.org or 313-719-4127. For more information on how to purchase Michigan's new Sickle Cell fundraising plate, visit Michigan's License Plate Special cause fundraising options webpage.

Community Announcements

Transportation Resource for Michiganders with SCD

MiSCDC has produced a resource website for people with SCD and their families to learn more about options for getting to medical appointments or other care. This resource has been shared with our network of SCD clinics and was distributed at the SCDAA-MI Detroit walk.

To learn more, visit our website.

Transportation shouldn't be a barrier to care.

If you need help getting to your health care appointments, you may be able to find assistance at low or no cost to you!

Some options for transportation assistance include:

- Gas cards
- Bus tokens
- Ride sharing vouchers
- Clinic transport services
- Health insurance transport services
- Paratransit services
- and more...

The Michigan Sickle Cell Data Collection Program has created a guide to help you find and choose the transportation assistance that is best for you.

For help finding free or low-cost assistance, scan the QR code with your smartphone's camera, or visit the web address below.

Scan me

miscdc.org/SCDtransport

SCDAA Awareness Walks

Members of the MiSCDC team from MDHHS and CHEAR attended the SCDAA-MI annual Sickle Cell Maters Walks on September 6th in Flint, September 13th in Detroit, and September 20th in Grand Rapids. The team was able to connect with members of the community and share resources about the MiSCDC program.

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.