



## Sickle Cell Disease Research

### *The Bloodline* Newsletter: July 2022

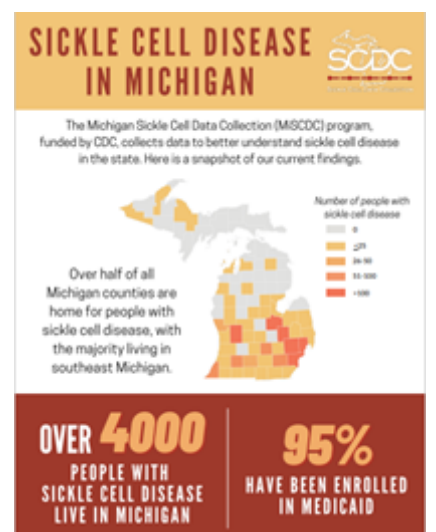
**THE BLOODLINE**  
Sickle Cell Data Collection (SCDC) Program  
Quarterly Newsletter



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

## Communications Corner

- CDC shared resources on emergency department care for SCD ahead of World Sickle Cell Day, which is observed on June 19.
- The [CDC SCDC FAQs](#) webpage was recently updated.
- SCDC Indiana created a [fact sheet](#) that explains what the SCDC program in the state is and the data collected thus far. The fact sheet will be shared with stakeholders and on social media.
- SCDC Michigan released an infographic, "[Sickle cell disease in Michigan](#)."
- SCDC Michigan's Sarah Reeves was featured in the story, "[How can health disparities for kids with sickle cell disease be decreased?](#)" from the report, "[Michigan answers for kids: Research highlights from C.S. Mott Children's Hospital](#)."



## Trainings & Webinars

- SCDC California hosted the webinar "[COVID-19 outcomes among individuals with sickle cell disease](#)" in May 2022. Ashima Singh from the Medical College of Wisconsin presented on COVID-19 outcomes among people living with SCD compared with those who do not have SCD and risk factors for severe COVID-19 illness for the SCD population.
- SCDC California will host a webinar "Medical-Legal Partnership: An Interdisciplinary Approach to Pediatric Patients with Sickle Cell Disease" on August 4, 2022, 1:00–2:30 p.m. ET. The presentation will be given by Pam Kraidler and Christina Scott from Atlanta's [Health Law Partnership](#) (HeLP), a program that works with the families of pediatric patients at Children's Healthcare of Atlanta, including families of children with SCD. [Register here](#).

## In the Community

- SCDC Georgia was recently awarded internal seed funding from Georgia State University for their project, "Building Research Expertise Across Teams for Health Equity (BREATHE) in Sickle Cell Disease." The funding is part of a new university-wide initiative "[Research Innovation and Scholarly Excellence](#) [\[link\]](#)," and will support collaboration among disciplines of economics, psychology, nursing and among members of the SCD community to develop a research agenda for SCD pain studies.
- SCDC Michigan is one of four awardees of the University of Michigan Institute for Healthcare Policy and Innovation's [2022 Policy Sprints initiative](#) for their project "Leveraging population-based surveillance to identify individuals with sickle cell disease eligible for expanded benefits through Children's Special Health Care Services." Awardees receive funding for timely, policy-relevant projects that inform system-level solutions to advance health equity.

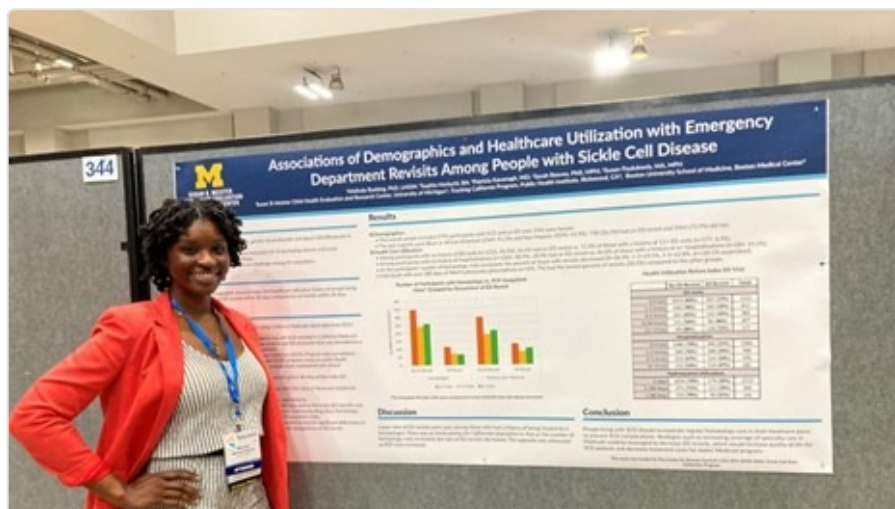
# Up-to-Data

SCDC Georgia provided SCDC surveillance data to the following:

- A SCD clinic in metro Atlanta received data showing low rates of hydroxyurea prescriptions for people with SCD on Medicaid between 2006–2018 despite some improvement (25% in 2006 to 37% in 2018). These data could help researchers learn if hydroxyurea prescription rates have dropped more recently due to FDA approvals on new drugs or therapies.
- The office of Representative Buddy Carter (Georgia’s District 1) received SCD data for the 17 counties surrounding Savannah, Georgia. During a meeting facilitated by the Government Relations team of the American Society of Hematology (ASH), SCDC Georgia presented demographic information, healthcare utilization, and payor information for the 834 patients in that area. The purpose of the meeting was to provide information related to bill [H.R.6216](#) that would establish a demonstration project for state Medicaid programs to improve care for people with SCD. Additional insights regarding SCD clinical care were provided by Memorial Health Savannah, one of the clinical sites contributing to SCDC Georgia data.

## Presentations & Meetings

- SCDC Georgia attended a discussion hosted by Vertex Pharmaceuticals on April 12, 2022, about SCD and the barriers that exist for people with SCD and their families when accessing care in Georgia. Representative El-Mahdi Holly (Georgia’s District 111) was also in attendance. Need for mental health services, strategies and programs for better pain management, and need for additional healthcare resources for people with SCD living in rural Georgia were discussed.
- During the [virtual poster session](#) at the [University of Michigan Pediatric Research Symposium](#), held May 24, 2022, SCDC Michigan’s
  - Krista Latta presented, “Hospitalization and mortality due to COVID-19 among people born 1987–2019 with sickle cell disease or sickle cell trait in Michigan.”
  - Pooja Patel presented, “Acute healthcare utilization for individuals with sickle cell disease in Michigan.”
  - Melinda Rushing presented, “Hydroxyurea utilization patterns among people living with sickle cell disease.”
- SCDC Michigan’s Melinda Rushing presented, “Associations of demographics and healthcare utilization with emergency department revisits among people with sickle cell disease” at Academy Health’s 2022 Annual Research Meeting, held June 4–7, 2022.
- During the Foundation for Sickle Cell Disease Research’s 16th Annual Sickle Cell Disease Research and Educational Symposium and 45th National Sickle Cell Disease Scientific Meeting, held June 10–12, 2022, SCDC California’s



Melinda Rushing presenting during Academy Health’s 2022 Annual Research Meeting.



Sophia Horiuchi presenting during the Foundation for Sickle Cell Disease Research's 16th Annual Sickle Cell Disease Research and Educational Symposium.

- Sophia Horiuchi presented, "Patterns of hydroxyurea utilization among Californians with SCD."
- Susan Paulukonis presented, "Health outcomes among those with sickle cell trait or sickle cell disease with COVID-19 infections in Michigan and Georgia."
- Trisha Wong, Jhaqueline Valle, and Susan Paulukonis presented, "Implications of using iron chelators and hydroxyurea at the same time among Californians with sickle cell disease."
- SCDC North Carolina presented an overview of its SCDC program during a meeting with several members of the North Carolina (NC) Legislative Black Caucus on June 14, 2022. Members of the NC Governor's Appointed Council on Sickle Cell Disease and Other Blood Disorders, NC Department of Health and Human Services–Division of Public Health, Piedmont Health Services and Sickle Cell Agency staff were also in attendance.

## In The News

This section is shared to provide awareness of articles on SCD currently presented in the media. Linking to a nonfederal site does not constitute an endorsement by CDC or any of its employees of the sponsors, information, and products presented on the site.

- [Kidney failure may drive COVID deaths in people with sickle cell trait](#)
- [California SCD clinic, backed by state grant, aims to support patients](#)
- [Sickle cell disease and blood transfusions: benefits, risks, and procedure](#)
- [Sickle Cell Data Collection program to continue key initiatives with \\$2.5M funding increase](#)
- [Baby dream comes true for sickle cell patient](#)
- [Increased risk of ADHD in children exposed to maternal sickle cell disease](#)
- [Supporters set to observe World Sickle Cell Day on June 19](#)
- ['Help one another': Indy doctor, patient with sickle cell push for Black blood donors](#)
- [Hydroxyurea use during pregnancy raises risk of miscarriage, stillbirths](#)
- [Lifetime medical costs for SCD Total \\$1.7M, partly out of pocket: Study](#)
- [Author chronicles daughter's triumph over sickle cell](#)
- [Corticosteroids linked to pain events in patients with sickle cell disease](#)
- [Steroids raise risk of hospitalization for sickle cell patients](#)
- [Many male AYAs with sickle cell disease unaware of disease-related fertility issues](#)
- [Exercise testing is viable for stable sickle cell patients](#)
- [Opinion: My child is more resilient than I realized](#)
- [Study categorizes barriers to care among patients with sickle cell disease](#)

# Announcements

A new Sickle Cell Data Collection (SCDC) program grant opportunity forecast was posted to [grants.gov](https://www.grants.gov), CDC-RFA-DD23-2302. 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 estimated due date for applications is May 11, 2023.

## Contact

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

If you are not currently a subscriber, click the subscribe button below to get SCDC program updates.



Last Reviewed: June 30, 2023