The Bloodline Newsletter: July 2023

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

SCDC
Sickle Cell Data Collection

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

Communications Corner

- CDC shared resources on the SCDC program in observance of World Sickle Cell Day.
- SCDC California released the infographic “Living without essential healthcare.”
- SCDC California developed the infographic “How can we better support people with sickle cell disease?” in collaboration with Sickle Cell Anemia Awareness San Francisco and Cayenne Wellness Center.
- SCDC Michigan developed the brief “Michigan Sickle Cell Data Collection program CDC site visit.”
- SCDC North Carolina launched its program website: https://sites.duke.edu/ncscdc/. The website includes an overview of the NC SCDC program, surveillance findings, a data request form, and resources for the SCD community.
- SCDC Tennessee released its inaugural newsletter on May 31. It will be published quarterly with data updates and partner activities. Email Amanda Young at ajyoung@memphis.edu to receive a copy and to be added to the subscriber list.
- SCDC Wisconsin has released the infographic “Newborn screening for sickle cell disease in Wisconsin.”

North Carolina Sickle Cell Data Collection Program

Using Surveillance to Improve the lives of North Carolinians with Sickle Cell Disease. Check our surveillance data to learn more!

North Carolina Sickle Cell Data Collection Program

About Us

The North Carolina Sickle Cell Data Collection (NC SCDC) program implements state-wide sickle cell disease surveillance in NC and disseminates aggregate-level surveillance findings regarding the epidemiology and healthcare utilization patterns of sickle cell disease in the state.

Program Goals

- To provide a better understanding of healthcare needs
- To improve care for people living with sickle cell disease in North Carolina

NC SCDC is funded by the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection program. Learn more about our funding.

Trainings & Webinars

SCDC California hosted the webinar “Aging with sickle cell disease: Strategies for assessing and managing functional impairment” in May 2023. Charity Oyedeji, assistant professor in the Duke University Division of Hematology, presented on strategies for comprehensively evaluating age-associated changes in health and physical function as adults with SCD advance in age. Potential strategies to maintain and improve function in older adults with SCD were also discussed.

Recent Publications

- Okolo AI, Jacob SA, Dixon BE, Valvi NR, Janson IA, Hardesty BR. Increasing visibility of sickle cell disease in Indiana: Establishing baseline prevalence using integrated data from multiple sources. Public Health Rep. 2023 May 26;333549231170229. doi: 10.1177/00333549231170229.
- Paulukonis ST, Snyder A, Smeltzer MP, Sutaria AN, Hurden I, Latta K, Chennuri S, Vichinsky E, Reeves SL. COVID-19 infection and outcomes in newborn screening cohorts of sickle cell trait and sickle cell disease in Michigan and Georgia. J Pediatr Hematol Oncol. 2023 May 1;45(4):174-180. doi: 10.1097/MPH.0000000000002671. Epub 2023 Mar 20.
- Reeves SL, Horiuchi S, Zhou M, Paulukonis S, Snyder A, Wilson-Frederick S, Hulihan M. Case ascertainment of sickle cell disease using surveillance or single administrative database case definitions. Public Health Rep. 2023 May 19;333549231166465. doi: 10.1177/00333549231166465.
- Singh A, Sontag MK, Zhou M, Dasgupta M, Crume T, McLemore M, Galadanci N, Randall E, Steiner N, Brandow AM, Koch K, Field JJ, Hassell K, Snyder AB, Kanter J. Evaluating the discriminatory ability of the Sickle Cell Data Collection program’s administrative claims case definition in identifying adults with sickle cell disease: Validation study. JMIR Public Health Surveill. 2023 Jun 28;9:e42816. doi: 10.2196/42816.
- Smeltzer MP, Reeves SL, Cooper WO, Attell BK, Strouse JJ, Takemoto CM, Kanter J, Latta K, Plaxco AP, Davis RL, Hatch D, Reyes C, Dombkowski K, Snyder A, Paulukonis S, Singh A, Kayle M. Common data model for sickle cell disease surveillance: Considerations and implications. JAMIA Open. 2023 May 27;6(2):ooad036. doi: 10.1093/jamiaopen/ooad036.

In the Community

- Piedmont Health Services and Sickle Cell Agency hosted the SCDC North Carolina community town hall meeting on March 9 at the International Civil Rights Center and Museum, in Greensboro, North Carolina. This event served as an opportunity to bring the SCD community together, share findings from SCDC North Carolina, and engage in conversations about issues important to the SCD community. Approximately 80 people attended in person and on Facebook Live.
- MTS Sickle Cell Foundation in Georgia partnered with the Georgia Public Library Service to raise awareness about SCD and sickle cell trait among 409 public library facilities across the state, with the potential of reaching 10.8 million library cardholders. SCDC Georgia supported this effort by providing data on individuals diagnosed with SCD and printing educational brochures, posters, and flyers for dissemination.

Up-to-Data

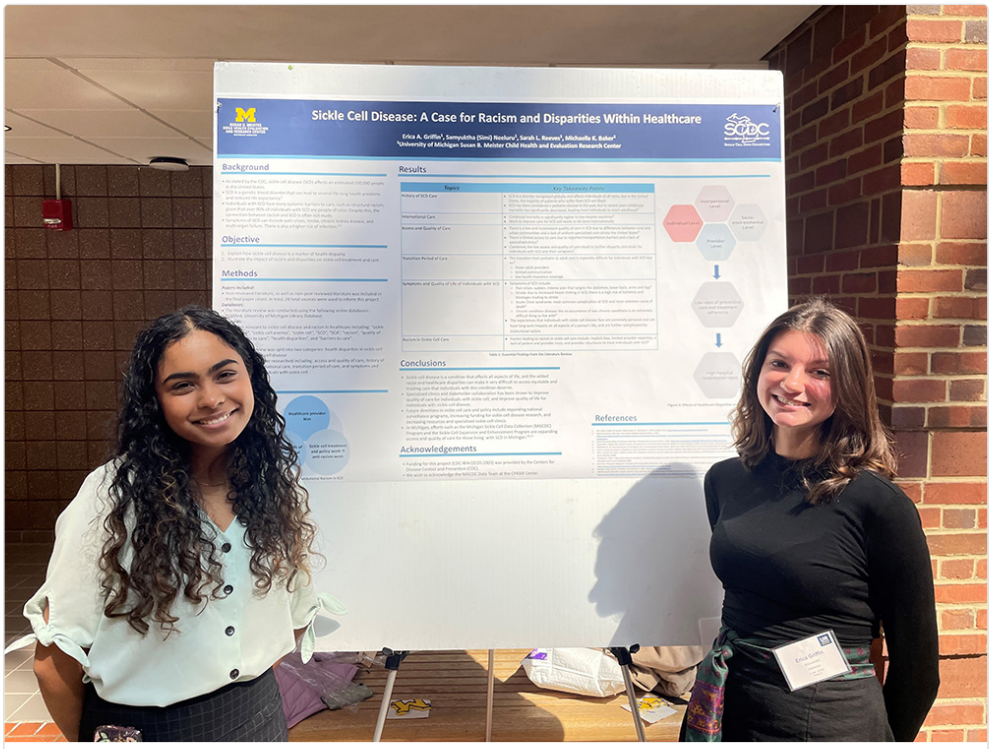
Each SCDC state has its own unique process for groups to access collected data. Recently available forms of data access are included in this newsletter.

- New SCDC newborn screening data is available here.
- SCDC North Carolina developed a data analysis request process that enables members of the SCD community to request aggregate-level data. The purpose of the data request process is to support SCD-specific quality improvement initiatives, clinical care, grant applications, and health policy in North Carolina. Requesters are highly encouraged to reach out to nc_sickledata@duke.edu to discuss their requests before submitting them.
  - Three submitted data requests have been completed (data analyses were done and results were provided to the requestors) and are being used to support the following:
    - A statewide initiative to improve emergency department pain management for SCD
    - A grant application
    - A conversation with a legislative assistant to a North Carolina senator
- SCDC Georgia provided
  - Demographic, incidence, and prevalence data on the state’s SCD population to an SCD community-based organization (CBO). This data will support the development of a toolkit to educate faith-based leaders about SCD.

  - Prescription usage data for two SCD medications (hydroxyurea and Endari) to an SCD CBO that wanted to understand prescription trends and usage. The data will help the CBO raise awareness about the use of these medications among provider-patient groups as well as support education efforts in the wider SCD community.
  - Acute care utilization data (emergency department and inpatient) along with insurance status for individuals diagnosed with SCD between the ages of 19 and 25 years to a hematologist/oncologist and SCD specialist. The data will be used to help better understand healthcare transition challenges in relation to loss of insurance coverage.

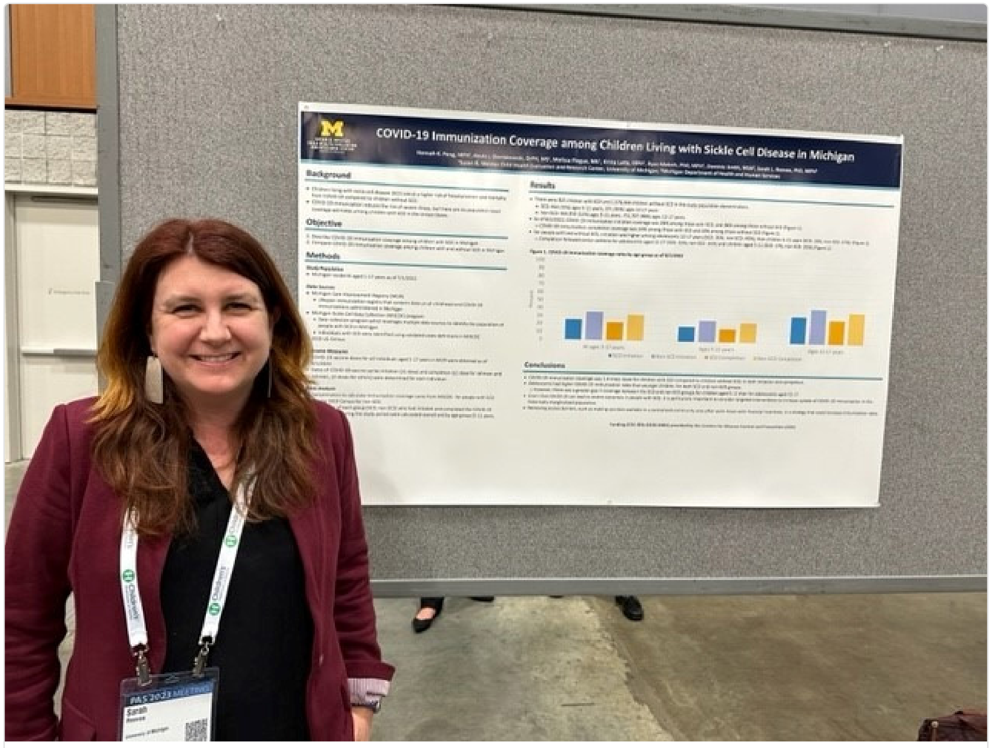
Presentations & Meetings

- “Sickle cell disease: A case for racism and disparities within healthcare” at the University of Michigan Undergraduate Research Symposium and the NextGenEducated Health Conference on Health Equity and Social Justice (Simi Neeluru and Erica Griffin, SCDC Michigan)



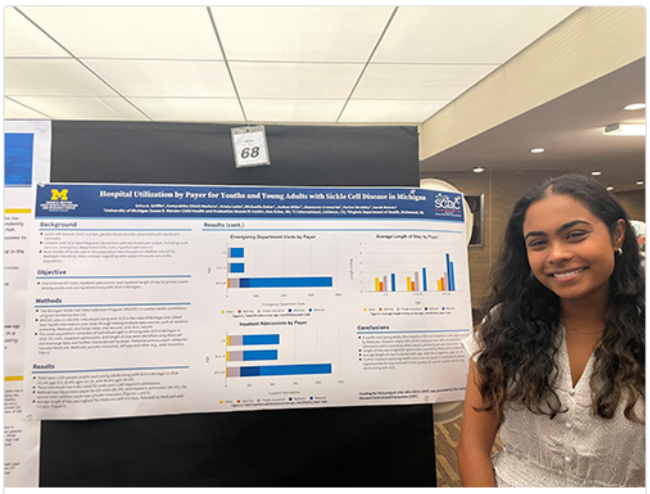
Left to right: Simi Neeluru and Erica Griffin

- “COVID-19 immunization coverage among people living with sickle cell disease in Michigan” at the 18th Annual Michigan Epidemiology Conference, the Pediatric Academic Societies 2023 Poster Presentation, and the University of Michigan Department of Pediatrics Annual Pediatric Research Symposium (Hannah Peng and Sarah Reeves, SCDC Michigan)

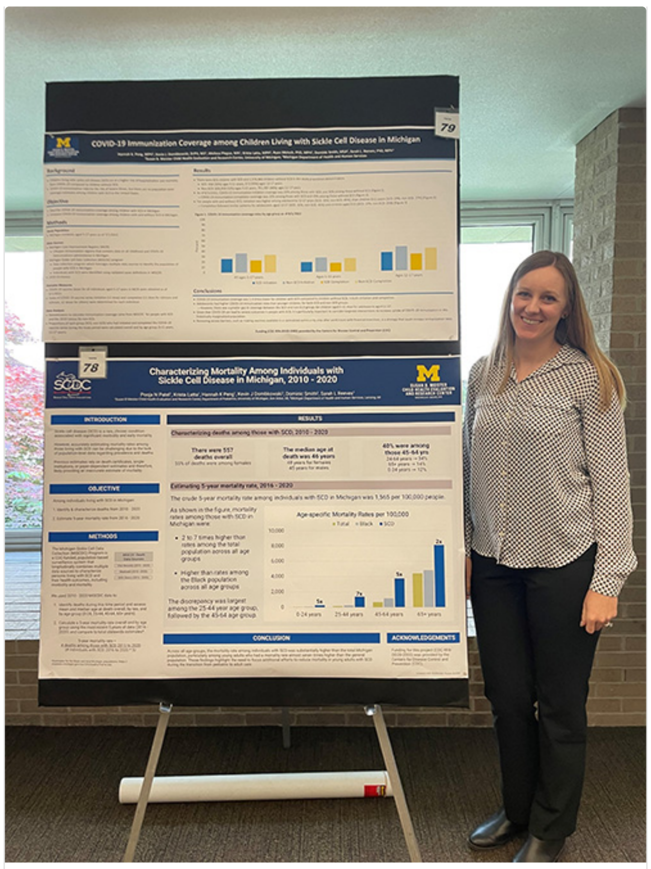


Sarah Reeves

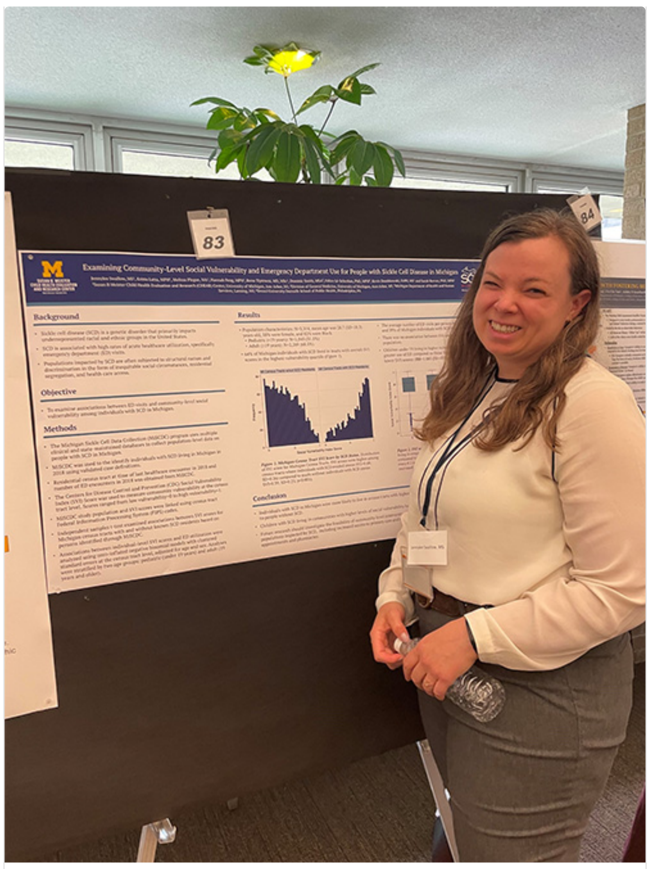
- “Examining community-level social vulnerability and emergency department use for people with sickle cell disease in Michigan” at the 18th Annual Michigan Epidemiology Conference and the University of Michigan Department of Pediatrics Annual Pediatric Research Symposium (Jennylee Swallow, SCDC Michigan)
- “Characterizing mortality among individuals with sickle cell disease in Michigan, 2010 through 2020” at the University of Michigan Department of Pediatrics Annual Pediatric Research Symposium (Pooja Patel and Hannah Peng, SCDC Michigan)
- “Hospital utilization by payer for pediatric patients with sickle cell disease in Michigan” at the University of Michigan Department of Pediatrics Annual Pediatric Research Symposium (Erica Griffin and Simi Neeluru, SCDC Michigan)



Simi Neeluru



Hannah Peng



Jennylee Swallow

- “SCD in California” to the Department of Health Care Services’ Integrated Systems of Care Division (Jackie Valle, SCDC California)
- “Evaluating the Sickle Cell Data Collection program’s administrative case definition for adults with sickle cell disease” at the Foundation for Sickle Cell Disease Research & Educational Symposium (Ashima Singh, SCDC Wisconsin)

Left to right: Janelle Highland, Nicole Steiner, and Ashima Singh

- “Medicaid enrollment patterns in the first 3 years for children with SCD” at the Foundation for Sickle Cell Disease Research & Educational Symposium (Sophie Horiuchi, SCDC California)
- “Sickle cell disease surveillance and research using big data” at the Research Brainstorming Session for the Department of Pediatrics at the Medical College of Wisconsin (Ashima Singh, SCDC Wisconsin)

Upcoming Events

- The 11th Annual Sickle Cell Disease Conference: “More than Sickle Cell Disease,” takes place on September 8–9. The conference, an annual collaboration between Duke University School of Nursing and the University of North Carolina School of Medicine Blood Research Center, will be held virtually. Register here until September 7.
  - Dr. Mariam Kayle, PhD, RN, CCNS, co-PI of SCDC North Carolina will present “Learning about people with SCD in North Carolina,” with a key emphasis on the outcomes and benefits of the SCDC program for the SCD community.
- CDC is hosting the SCDC Summit September 25–28. Save the date and stay tuned for registration details for this virtual event, which is free and open to the public. The summit will showcase SCD surveillance activities taking place in 11 states participating in the SCDC program. Each day of the summit will focus on different topics in the form of presentations and discussion panels that will describe how data is being used to improve the lives of people living with SCD.

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.

SUBSCRIBE

Last Reviewed: July 27, 2023
Source: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention