

Sickle Cell Disease Research



Sickle Cell Disease Research

## The Bloodline Newsletter: Spring 2020

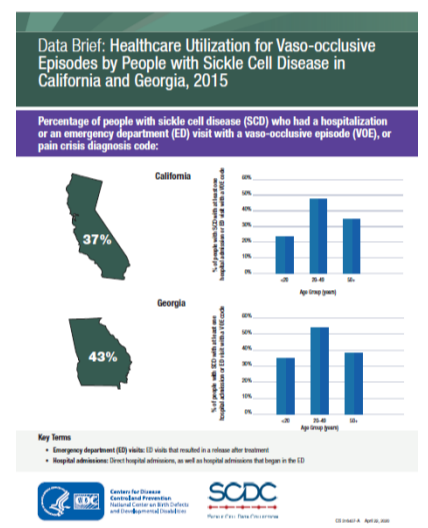
**THE BLOODLINE**  
Sickle Cell Data Collection (SCDC) Program  
Quarterly Newsletter



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

### Communications Corner

- CDC will be sharing personal stories about SCD, blood donation resources, and videos about the many faces of SCD on June 19. Stay updated by following us on Twitter at [@CDC\\_NCBDDD](https://twitter.com/CDC_NCBDDD).
- CDC redesigned its [SCDC program](#) website with a cleaner, more streamlined layout and improved navigation.
- “[Surveillance resources](#)” have been added to CDC’s SCDC Capacity Building website.
- CDC’s “[Healthcare utilization for vaso-occlusive episodes by people with sickle cell disease in California and Georgia, 2015](#)” data brief shows that pain crises, which can be excruciating, are the most common reason patients with SCD go to the emergency department (ED) or hospital.
- SCDC Georgia released the brief, “[Sickle cell disease prevalence in Georgia](#)” and published an [interactive map](#) of SCD prevalence by county of residence for 2012–2016, along with other maps on the project’s webpage.
- SCDC Georgia launched a [new webpage](#) that provides original video content for providers, patients, and the public. Offerings include recordings of the “[Building Sickle Cell Disease Data Collection capacity](#)” series conducted since October 2019.



### Trainings and Webinars

- “[Diversifying the blood donor pool: The need for African American donors to support sickle cell patients](#)” (March 2020): Dr. Yvette Marie Miller, Executive Medical Officer of the American Red Cross Biomedical Services at the Donor and Client Support Center in Charlotte, NC, spoke on the importance of diversifying the donor pool, identifying challenges, and highlighting successful donor recruitment.
- “[SCDC program findings and activities & future directions](#)” (May 2020): Ten years since beginning public health surveillance for SCD, the California and Georgia SCDC programs shared the programs’ histories and future directions, current information about the population of those with SCD in these states, and key findings from recent analyses.

### Up-to-Data

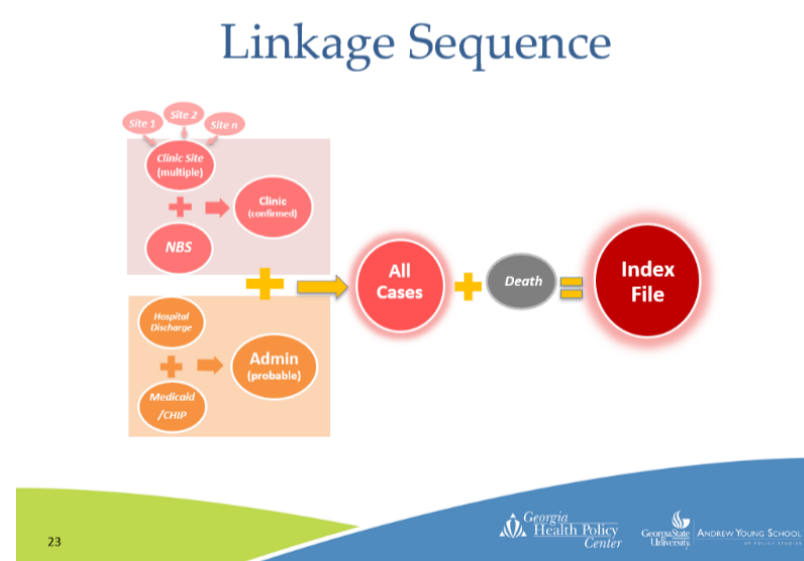
SCDC Georgia responded to data requests from

- Boston University School of Medicine regarding the link between timing of outpatient visits and hospital readmissions following an ED visit for SCD.
- University of California, Davis regarding the use of hydroxyurea and young adult mortality with SCD.

- Responded to data requests from Networking California for Sickle Cell Care to support siting new clinics around the state and determining the relationship between types and frequencies of outpatient visits and prescriptions filled.
- Is developing county-specific data to show how many people meeting the SCDC case definition are in key counties throughout the state and where they live. These data will help the newly established network of Community Health Workers with outreach efforts.
- Shared regional data with Sickle Cell Anemia Awareness San Francisco for its April town hall meeting on COVID-19.

## Presentations and Meetings

- On May 19, 2020, SCDC California’s Susan Paulukonis met with the unaffiliated patient team of the Sickle Cell Disease Implementation Consortium, a multistate effort funded by the National Heart, Lung, and Blood Institute to improve access to care and outcomes for adolescents and adults with SCD. The group discussed how surveillance could inform identification of unaffiliated patients and evaluation of interventions to bring them into comprehensive/quality care.
- On April 16, 2020, CDC’s Mary Hulihan provided two SCDC overviews during events convened by Cincinnati Children’s Hospital Medical Center: The morning’s presentation was for their annual Hemoglobinopathy Counselor Training Course and the afternoon’s presentation was for their Sickle Treatment & Outcomes Research in the Midwest TeleECHO (Extension for Community Healthcare Outcomes) series.
- On April 6, 2020, several members of CDC’s Division of Blood Disorders participated in the Women’s SCD Health Workshop, hosted by The Foundation for Women and Girls with Blood Disorders. A significant topic of discussion was how SCDC data could be analyzed to better understand the health and health care of women with SCD.
- On April 1, 2020, SCDC Georgia convened data providers to discuss ongoing surveillance methods, the uses and needs of these methods, and potential new datasets that can be linked to the state’s SCDC data. Participants included pediatric and adult sickle cell providers from the four participating clinical sites; department of public health newborn screening epidemiology and program staff; newborn screening follow-up nurses; and project staff.



SCDC Georgia presented their data linkage sequence during their stakeholder convening on April 1, 2020.

- SCDC Georgia serves on the Minority Blood Donation workgroup for the national chapter of Sickle Cell Disease Coalition, and shares [research findings and products](#) about diversifying the blood supply for people with hemoglobin disorders in need of transfusions on the workgroup’s monthly calls. On the April 1, 2020 call, SCDC Georgia shared clinicians’ feedback on pandemic-related concerns about the blood supply.
- On March 11, 2020, Networking California for Sickle Cell Care brought together a group of people interested in coordinating data collection, sharing, and analysis in California. SCDC California presented new data, including the number of patients in the state and payer information; plans were drafted to conduct analyses on cost of care and transition effectiveness.
- Five (of nine) site visits with recipients of the Capacity Building for Sickle Cell Surveillance (DD19-1906) grant were completed:
  - North Carolina (March 12)
  - Georgia (April 1)
  - Indiana (April 9)
  - Tennessee (May 14)

- Alabama (May 22)

Although each of these site visits were held virtually, both the recipients and CDC benefited from presentations by state partners; in-depth discussions about the recipients' SCD surveillance infrastructure; and brainstorming about future activities, funding, and sustainability of the work. The remaining site visits will take place this summer.

## In the News

- [Blood donation: 'Completely altruistic, so much benefit to so many people'](#)
- [Ongoing concerns related to COVID-19 and sickle cell](#)
- [Sickle Cell Association issues COVID-19 guidelines for US reopening](#)
- [Health alert for people with sickle cell disease and their caregivers](#)
- [Everyday hero: Doctor on the front lines in sickle cell fight](#)
- [A pilot study to screen for poor academic performance in children with sickle cell disease in the outpatient setting](#)
- [Opioids to treat the pain resulting from sickle cell disease](#)
- [The cost of gene therapy in treating sickle cell disease](#)
- [Gene-based therapy should cure HIV and sickle cell for everyone](#)

## Announcements

**Webinar:** "End of life healthcare utilization for those with SCD and the potential need for a palliative care model"

**Date/Time:** Wednesday, July 1, 2020, 10:30– 12:00 p.m. PDT.

**Presenters:** Emily E. Johnston, MD, MS and Oyebimpe O. Adesina, MD will discuss the findings of their recently published article, "Acute care utilization at end of life in sickle cell disease: Highlighting the need for a palliative approach." Register [here](#).

## Contact

For any questions about the SCDC program, contact Mary Hulihan ([ibx5@cdc.gov](mailto:ibx5@cdc.gov)) or Mandip Kaur ([wvx6@cdc.gov](mailto:wvx6@cdc.gov)).

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

[SUBSCRIBE](#)

Last Reviewed: June 30, 2023