



Sickle Cell Disease Research

The Bloodline Newsletter: Summer 2020


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

- During Sickle Cell Awareness Month in September, CDC is sharing resources on surveillance, diversity among the SCD community, common complications of SCD, and more. Follow [@CDC_NCBDDD](#) on Twitter to stay updated.
- SCDC Georgia released the brief, *Hospital encounters among adults living with sickle cell disease in Georgia, 2012–2016*.
- CDC released the “Steps to Better Health for People with Sickle Cell Disease” toolkit, which includes common complications of SCD and steps to take for better health. Fact sheets related to this content will be coming soon!
- SCDC California released their new [SCD website](#), which includes information about SCD in California, webinars, data requests, and more.
- Dr. Mary Hulihan (CDC) and Dr. Titilope Fasipe (Baylor College of Medicine) appeared as guests on the September 12th episode of [Saturday Mornings with Joy Keys](#).
- CDC recently produced an American Sign Language [video](#) that shares the reasons why it's helpful for African Americans to give blood to help people with SCD stay healthy. This video is intended for African Americans who are deaf and hearing impaired.



**SICKLE CELL DATA COLLECTION
PROGRAM BRIEF: HOSPITAL ENCOUNTERS
AMONG ADULTS LIVING WITH SICKLE
CELL DISEASE IN GEORGIA 2012–2016**

August 2020

The Georgia Sickle Cell Data Collection Program (SCDC) identified 5,405 adults¹ living with sickle cell disease in Georgia from 2012 through 2016. Adults with sickle cell disease live in almost every county throughout Georgia.

Nearly nine in 10 (88%) of the identified adults with SCD had at least one hospital or emergency department encounter during the five-year period.

AFFILIATED VERSUS UNAFFILIATED

Individuals with SCD and at least one hospital or emergency department visit were further categorized as affiliated or unaffiliated with one of Georgia's two adult comprehensive sickle cell treatment centers — Georgia Comprehensive Sickle Cell Center at Grady Memorial Hospital (Atlanta) and the Sickle Cell Center at Augusta University Medical Center.

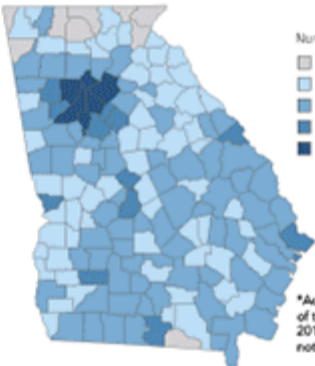
Affiliated adults were defined as being seen by a comprehensive sickle care treatment center and having a confirmed SCD genotype, while unaffiliated adults met previously established criteria as having a likely SCD diagnosis based on having three or more health care encounters within five years that included an SCD diagnosis, but did not have a visit to a comprehensive sickle cell treatment center. Roughly 46% of adults in this study were affiliated with one of these comprehensive centers.

Age

Georgia SCDC data confirms that SCD is no longer a “childhood disease” as it once was considered to be, but data show that SCD still impacts life expectancy. For both the affiliated and unaffiliated groups, the majority of adults are aged 19 to 39 versus 40 years and older. However, more older adults tend to be unaffiliated, possibly indicating a more stable disease course and less need for specialty care.

¹Age is defined as 19 years or older on Jan. 1, 2012.


Figure 1: SCD Prevalence in Georgia by County, 2012–2016




*Addressees are missing for 492 of the individuals with SCD from 2012 through 2016, so they are not reflected on the map.


Figure 2: Demographics of Adults with SCD by Affiliation

| | Affiliated | Total | Unaffiliated |
|----------------|------------|--------|--------------|
| 19 to 39 years | ~1,800 | ~2,200 | ~400 |
| 40+ years | ~1,200 | ~1,800 | ~600 |
| Female | ~1,500 | ~2,000 | ~500 |
| Male | ~1,300 | ~1,800 | ~500 |



404.413.0314
ghpc.gsu.edu
ghpc@gsu.edu





Trainings & Webinars

[“End of life healthcare utilization for those with SCD and the potential need for a palliative care model”](#) (July 2020): Emily E. Johnston, MD, MS and Oyebimpe O. Adesina, MD discussed 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.”

Recent Publications

- Aluc A, Zhou M, Paulukonis ST, Snyder AB, Wong D, Hulihan MM. [Using surveillance to determine the number of individuals with sickle cell disease in California and Georgia, 2005-2016](#). *Ped Hem Onc*. 2020 Aug 12. [Epub ahead of print]
- Majumdar S, Bean CJ, Staercke CD, Bost J, Nickel R, Coates T, et al. [Parvovirus B19 infection in Sickle Cell Disease: An Analysis from the CDC Hemoglobinopathy Blood Surveillance Project](#). *Transfus Med*. 2020 Jun;30(3):226-230.
- Panepinto JA, Brandow A, Mucalo L, Yusuf F, Singh A, Taylor B, et al. [Coronavirus disease among persons with sickle cell disease, United States, March 20–May 21, 2020](#). *Emerg Infect Dis*. 2020 Jul 8;26(10).

Up-to-Data

SCDC

- Responded to questions from the Florida Department of Health and University of the Virgin Islands regarding the technical, administrative, and oversight aspects of establishing an SCD surveillance program in their communities.

SCDC Georgia

- Responded to questions from the Mississippi Department of Health regarding technical, administrative, and oversight aspects of establishing a SCD surveillance program in their communities.
- Consulted with a Children’s Healthcare of Atlanta physician on data to support a research proposal related to COVID-19 and SCD care.
- Updated data on the prevalence, healthcare utilization, mortality, and geography of SCD in Georgia for long-time collaborator Dr. Peter Lane’s presentation to the regional Education and Mentoring to BRing Access to CarE for SCD (EMBRACE) stakeholder advisory board held in August.

Presentations & Meetings

- Susan Paulukonis (SCDC California) and Niani Coker (SCDC California) will present “Impact of economic factors on emergency department (ED) utilization in California’s sickle cell population: Examination of ED utilization rate by household income” at the American Public Health Association Annual Meeting (virtual) on October 27, 2020.
- Susan Paulukonis, Mary Hulihan, Angela Snyder (SCDC Georgia), and Mei Zhou (SCDC Georgia) will present “Hematologist encounters for sickle cell disease patients in Medicaid” at the Foundation for Sickle Cell Disease Research Symposium (virtual) on September 25, 2020.

In The News

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

- [When actions speak louder than words—racism and sickle cell disease](#)
- [Millions of Americans carry the sickle cell trait, many without knowing it. Could they be at risk for severe Covid-19?](#)
- [Red Cross: Black blood matters for some with sickle cell anemia](#)
- [So, what is sickle cell disease again?](#)

- [Could gene therapy cure sickle cell anemia?](#)
- [Teen with sickle cell disease beats back COVID-19](#)
- [Emergency care often not ideal for sickle cell patients in US, survey finds](#)
- [Study: Umbilical cord blood successfully treats rare genetic disorders](#)
- [Sickle cell disease brings higher risk of coronavirus death, but inconsistent treatment](#)
- [This startup might finally cure sickle cell disease—after a century of racist neglect](#)

Announcements

Webinar: “California Institute for Regenerative Medicine (CIRM)”

- **Date/Time:** September 28, 2020, 10:00am–11:30am PST
- **Presenter:** CEO and President of CIRM, Maria Millian, will present on what’s new at the California agency, which funds stem cell research, and on programmatic updates related to SCD.

Contact

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

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