Centers for Disease
Control and Prevention

Sickle Cell Disease Research

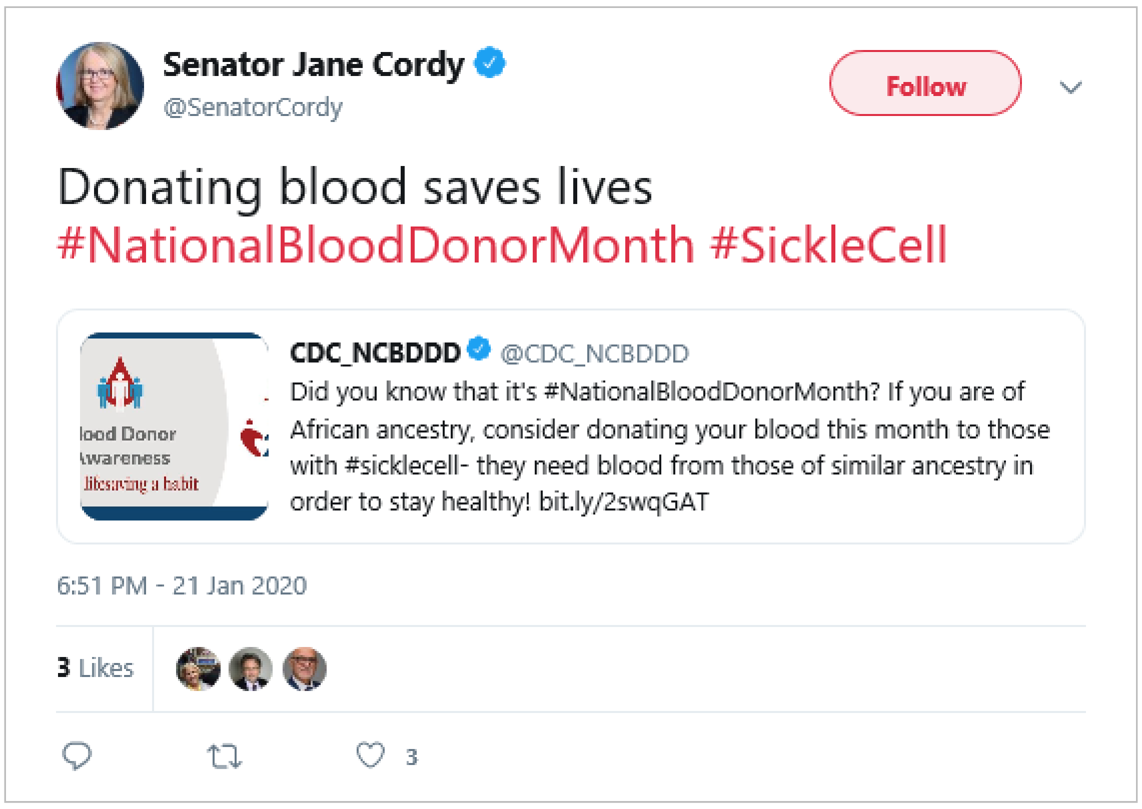
The Bloodline Newsletter: Winter 2020

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



Senator Jane Cordy @SenatorCordy

Donating blood saves lives #NationalBloodDonorMonth #SickleCell

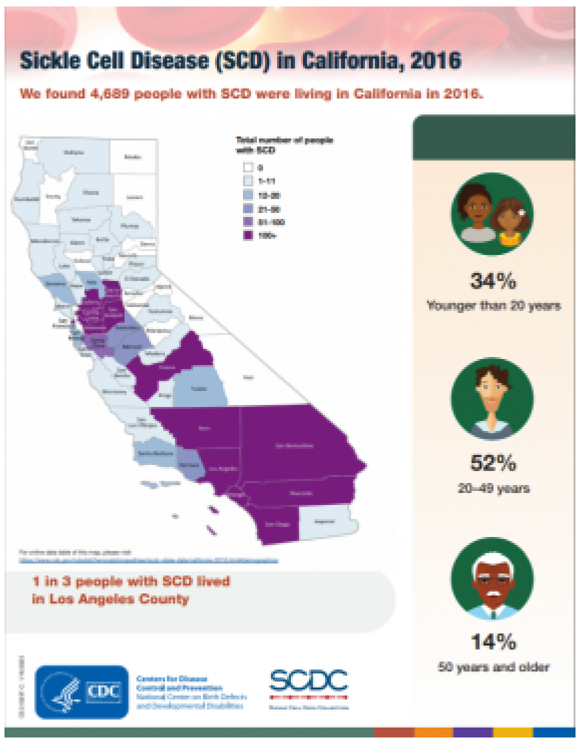
CDC_NCBDDD @CDC_NCBDDD
Did you know that it's #NationalBloodDonorMonth? If you are of African ancestry, consider donating your blood this month to those with #sicklecell- they need blood from those of similar ancestry in order to stay healthy! bit.ly/2swqGAT

6:51 PM - 21 Jan 2020

3 Likes

3

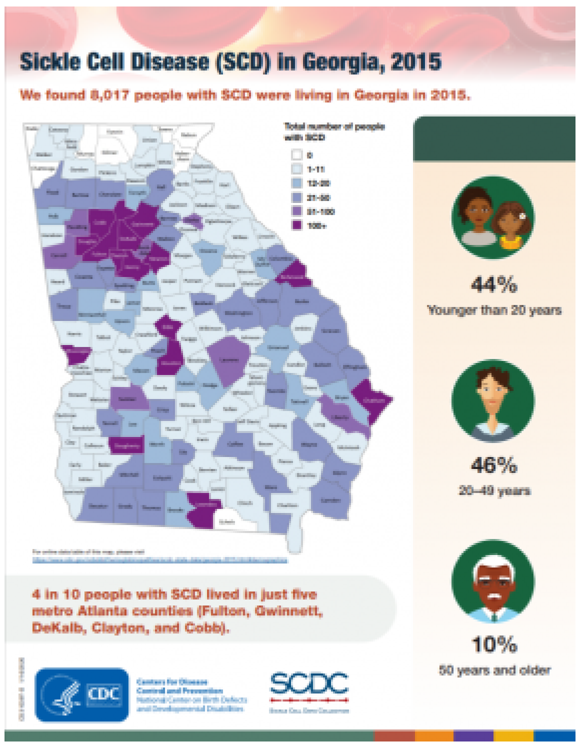
- During January's National Blood Donor Month, CDC shared resources on blood transfusions and minority blood donation.
- SCDC Georgia published three interactive maps on its website highlighting
  - SCD births in Georgia by county of residence, 2004–2016;
  - Pediatric SCD specialty care locations in Georgia and SCD births within one-hour drive by birth location, 2004–2016; and
  - SCD prevalence in Georgia by county of residence, 2012–2016.
- The Georgia Health Policy Center, home to SCDC Georgia, published *GHPC Now*, a commemorative magazine celebrating the Center's 25th anniversary. The magazine includes a feature story on SCDC Georgia, titled "GHPC builds data surveillance to better lives of patients with sickle cell."
- CDC released new fact sheets highlighting the most recent SCDC data for California (2016) and Georgia (2015):
  - "Sickle cell disease (SCD) in…" provides an overview of the demographics and healthcare utilization patterns of people with SCD and is intended for people looking for basic information about those living with SCD.



Sickle Cell Disease (SCD) in California, 2016

We found 4,689 people with SCD were living in California in 2016.

1 in 3 people with SCD lived in Los Angeles County

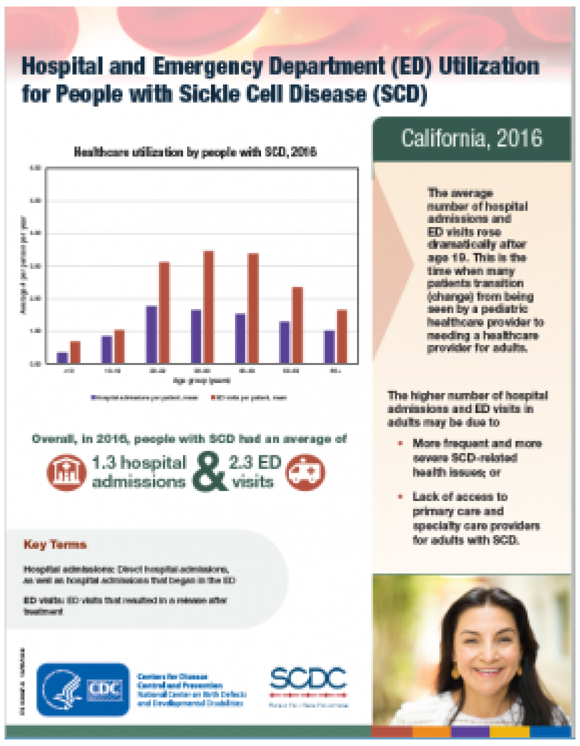


Sickle Cell Disease (SCD) in Georgia, 2015

We found 8,017 people with SCD were living in Georgia in 2015.

4 in 10 people with SCD lived in just five metro Atlanta counties (Fulton, Gwinnett, DeKalb, Clayton, and Cobb).

- “Hospital and emergency department (ED) utilization for people with SCD” provides additional details about healthcare utilization patterns in those with SCD (including readmission and payer information) and is intended for policy officials, public health professionals, and SCDC organizations.



Hospital and Emergency Department (ED) Utilization for People with Sickle Cell Disease (SCD)

California, 2016

Healthcare utilization by people with SCD, 2016

Overall, in 2016, people with SCD had an average of 1.3 hospital admissions & 2.3 ED visits

The average number of hospital admissions and ED visits rose dramatically after age 19. This is the time when many patients transition (change) from being seen by a pediatric healthcare provider to needing a healthcare provider for adults.

The higher number of hospital admissions and ED visits in adults may be due to

- More frequent and more severe SCD-related health issues; or
- Lack of access to primary care and specialty care providers for adults with SCD.

Key Terms

Hospital admissions: Direct hospital admissions, as well as hospital admissions that began in the ED

ED visits: ED visits that resulted in a release after treatment

Hospital and Emergency Department (ED) Utilization for People with Sickle Cell Disease (SCD)

Georgia, 2015

Healthcare utilization by people with SCD, 2015

Overall, in 2015, people with SCD had an average of 1.1 hospital admissions & 2.8 ED visits

The average number of hospital admissions and ED visits rose dramatically after age 19. This is the time when many patients transition (change) from being seen by a pediatric healthcare provider to needing a healthcare provider for adults.

The higher number of hospital admissions and ED visits in adults may be due to

- More frequent and more severe SCD-related health issues; or
- Lack of access to primary care and specialty care providers for adults with SCD.

Key Terms

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In the Community

SCDC California formed the Sickle Cell Surveillance Advisory Group, which serves to gather input and advice from stakeholders (including SCD advocates and family members) to inform SCDC California’s SCD activities, such as programs, products, and collaborations.

Recent Publications

CDC Foundation published “Understanding sickle cell disease: Impact of surveillance and gaps in knowledge” in the journal *Blood Advances* in February.

Up-to-Data

- SCDC Georgia responded to a request for SCDC data from a team of graduate students at Emory University’s Rollins School of Public Health for a project assessing healthcare access to pain management for people with SCD in Georgia.
- SCDC California will be linking recently received 2018 SCD data to existing SCDC data.

Data to Action

SCDC Georgia completed an updated poster and one-page fact sheet “Sickle cell disease in Muscogee County,” that the Association of Sickle Cell Lower Chattahoochee Region will use to educate others about SCD.

Presentations & Meetings

- On January 22 and 23, 2020, CDC hosted a reverse site-visit for CDC-RFA-DD19-1906 recipients to discuss topics and activities related to the cooperative agreement. Topics of discussion included data availability, linkage, and access. This in-person meeting fostered in-depth conversations and brainstorming about next steps to meet project goals. SCDC California and Georgia presented to assist capacity building for the other seven states.
- On February 5, 2020, CDC’s Mary Hulihan presented “Sickle Cell Data Collection: How can surveillance help to improve emergency department care for patients with sickle cell disease?” at the Sickle Cell Learning Collaborative, funded by the Agency for Healthcare Research and Quality and hosted by Duke University.
- On February 25, 2020, Mary Hulihan was a panelist at the 2020 CMS Quality Conference’s session on SCD. The panel provided an overview of multiple projects being led by the U.S. Department of Health and Human Services, including SCDC, for audience members from state Medicaid offices throughout the United States.

CDC-RFA-DD19-1906 recipients discussing SCDC data availability, linkage, and access.

In the News

- Blood transfusion therapy to treat sickle cell disease
- Decoding sickle cell disease
- Nation's largest single-day blood drive successful during National Blood Donor Month
- TLC's T-Boz on living with sickle cell, an incurable crippling disease: 'I went through so much'
- Teen battling rare disorder starts baking company to promote healthy lifestyle
- SCD patients receiving hydroxyurea in the U.S. still face many challenges
- A teenager's breakthrough gene therapy for sickle cell disease
- Effort to control opioids in an ER leaves some sickle cell patients in pain
- Sickle cell disease is complex on its own, but black men with the illness battle its stigmas and stereotypes too
- Sickle cell and myself

Announcements

- A new Notice of Funding Opportunity (NOFO) forecast: Sickle Cell Data Collection program (DD20-2003). This NOFO allows for statewide SCD surveillance. Click "Subscribe" on NOFO page to receive updates about this funding opportunity.
- Webinars
  - The next webinar, "Diversifying the blood donor pool: The need for African American donors to support sickle cell patients" will take place on Tuesday, March 10, 2020, 11 a.m.–12:30 p.m. PST. Dr. Yvette Marie Miller, Executive Medical Officer of the American Red Cross Biomedical Services at the Donor and Client Support Center in Charlotte, NC, will speak on the importance of diversifying the donor pool, identifying challenges, and highlighting successful donor recruitment.
  - Stay tuned for a webinar about the importance of incorporating a palliative approach to SCD care on Wednesday, July 1, 2020.
  - Join the email list to receive announcements about upcoming webinars.

Contact

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

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

Last Reviewed: June 30, 2023