Sickle Cell Disease Research

The Bloodline Newsletter: Fall 2019

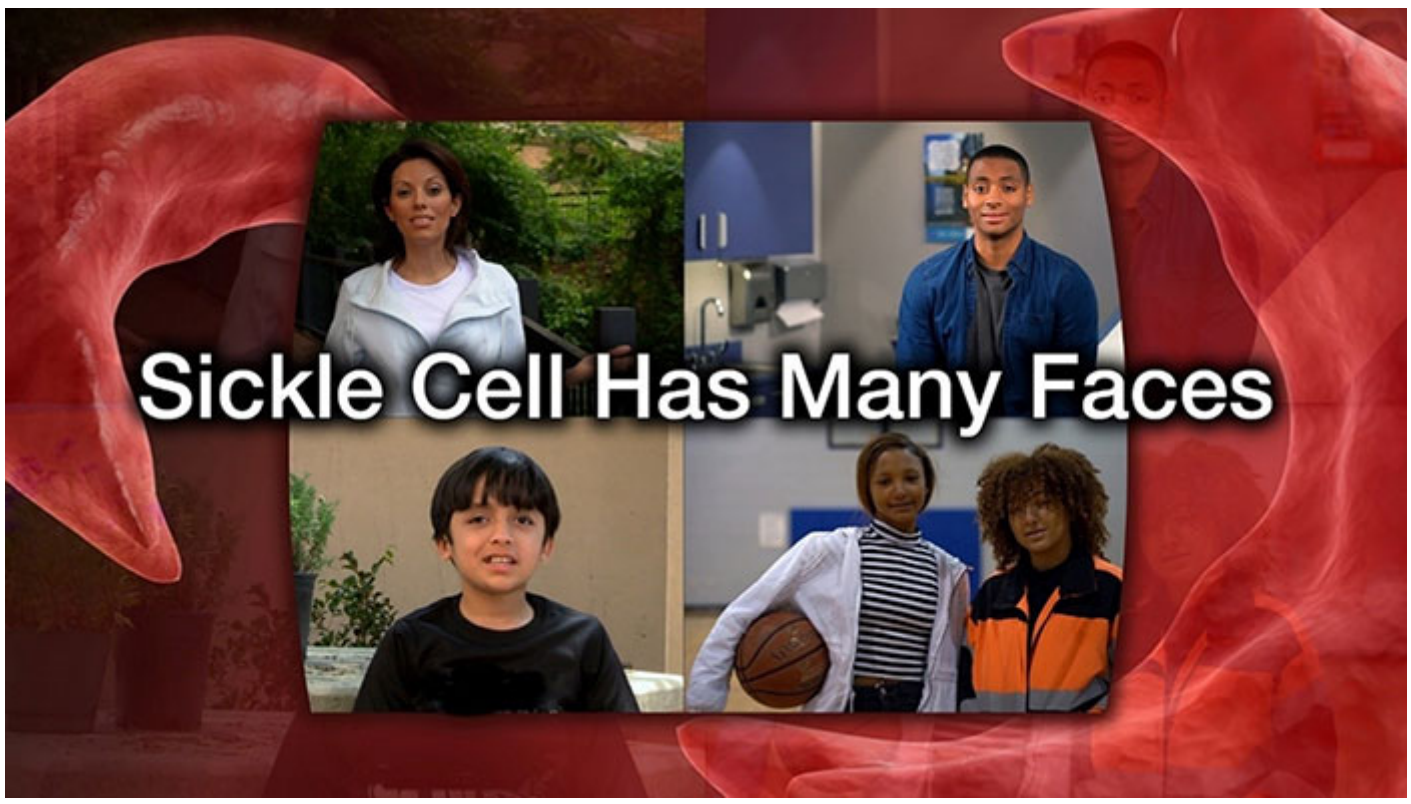
THE BLOODLINE
Sickle Cell Data Collection (SCDC) Program
Quarterly Newsletter

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

- SCDC Georgia's Sickle Cell Data Collection Program Brief: Access to Care for Children examines geographical access to specialized care, based upon a 1-hour driving radius to either daily or periodic specialty care clinics.
- SCDC Georgia's MAPS: The Geography of Sickle Cell Disease in Georgia allows users to hover over an area or marker for data on SCD births in Georgia, 2004–2016.
- CDC's SCDC Data Brief: Hydroxyurea Use Among Medicaid Beneficiaries with Sickle Cell Disease in California and Georgia, 2006–2016 shows that although the use of hydroxyurea (HU) among Medicaid beneficiaries with SCD increased over time, many beneficiaries with severe complications of SCD do not use HU.
- CDC's new videos feature people with SCD of diverse backgrounds who share that SCD can affect anyone, no matter what one looks like or where their family comes from:
  - "Sickle Cell Has Many Faces." (for a general audience)
  - "A Message for Healthcare Providers: Sickle Cell Has Many Faces."
- CDC's "Mimi's Story," highlights how throughout her life, healthcare providers have doubted Mimi when she told them she has SCD, causing delays in getting the treatment she needs.



Trainings & Webinars

SCDC California's webinars:

"Unite SC: Collaboration and Community in Sickle Cell" (September 2019): Dr. Nik Abdul Rashid and Ms. Linetta Barnes presented on how a clinical group and community-based organization in Nevada work together to improve care and quality of life for people living with SCD. Ms. Mary Brown and Ms. Jennifer Fields from the Sickle Cell Disease Foundation of California (SCDF) presented on how SCD data can help a community-based organization follow up with patients.

"Adult Health Care for Sickle Cell Disease: How to Make it Better" (November 2019): A panel discussed the barriers and challenges with adult health care for SCD and how to overcome them. The panel included two clinicians, Natalie Merilus, RN, BS, and Ted Wun, MD; and an adult living with SCD, Kamilah Bailey.

Recent Publications

SCDC California worked with Mariam Kayle of Duke University to analyze data on the impact of the Affordable Care Act on Medicaid enrollment for those with SCD in California. SCDC California submitted this analysis to *Pediatric Blood and Cancer*.

Up-to-Data

SCDC Georgia's 2010–2015 annual reports are now available.

Georgia SCDC Program Data

SCDC
Sickle Cell Data Collection

The SCDC program determines how many people live with sickle cell disease and monitors changes in health over time. Click below to view Georgia data, including number of patients, emergency department visits, and hospitalizations.

2015	2012	2005
2014	2011	
2013	2010	

Data to Action

- SCDC Georgia provided a literature review about the costs of care for SCD to the Sickle Cell Foundation of Georgia, which the Foundation used to support discussions about the state's 1115 Medicaid Waiver application.
- SCDC Georgia responded to data requests from the Health Law Partnership, which is exploring a possible study with Children's Healthcare of Atlanta to assess supplemental security income (SSI) eligibility criteria for children with SCD.
- SCDC Georgia provided insights to Washington University in St. Louis on how to use medical claims data to build a retrospective cohort for researching academic support for youth with SCD.
- SCDC Georgia partners, Dr. Jim Eckman and the Sickle Cell Foundation of Georgia, used local SCDC data as part of a SCD management training for clinic and health center primary care providers in Savannah.

Presentations & Meetings

- SCDC California's Susan Paulukonis presented "Older Adults with SCD" at the Sickle Cell Disease Association of America's (SCDAA) Annual National Convention in Baltimore, MD, in October 2019.
- CDC's Mary Hulihan presented "Hospitalizations Among Older Adults with SCD" at SCDAA's Annual National Convention in Baltimore, MD, in October 2019.
- Bi-weekly sessions for the Capacity Building for SCD Surveillance project (DD19-1906) began on November 7, 2019. Learn more about this project here.

In the News

- Too many children live too far from sickle cell treatment they need
- CRISPR for sickle cell disease shows promise in early test
- FDA approves Novartis' Adakveo, 1st treatment for pain crises in teens and adults with SCD
- NIH launches $100 million effort to cure HIV, sickle cell
- Could Africa's DNA help to cure sickle cell disease?
- Gates Foundation, NIH bet on gene therapy to bring cheap HIV and sickle cell cures to Sub-Saharan Africa
- A patient hopes gene-editing can help with pain of sickle cell disease
- Battle with sickle cell: Los Angeles rapper Shaun Sloan releases powerful video 'Wait for Me'
- Hope, frustration mark new era of sickle cell disease
- Potential sickle cell breakthrough
- Gene therapy may aid in sickle cell disease treatment
- How old is too old to go to the pediatrician?
- One woman's inspiring story about her battle with sickle cell

Announcements

Sickle Cell Disease Training and Mentoring Program : A FREE series, taught by hematologists using a case study-based, tele-mentoring approach, that will cover the basics of SCD care, such as pain management, hydroxyurea, and preventive services. This program is made available by the Health Resources and Services Administration and the U.S. Department of Health and Human Services' Office of Minority Health.

Contact

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

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Last Reviewed: June 30, 2023