Sickle Cell Disease Research

The Bloodline Newsletter: Winter 2021

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

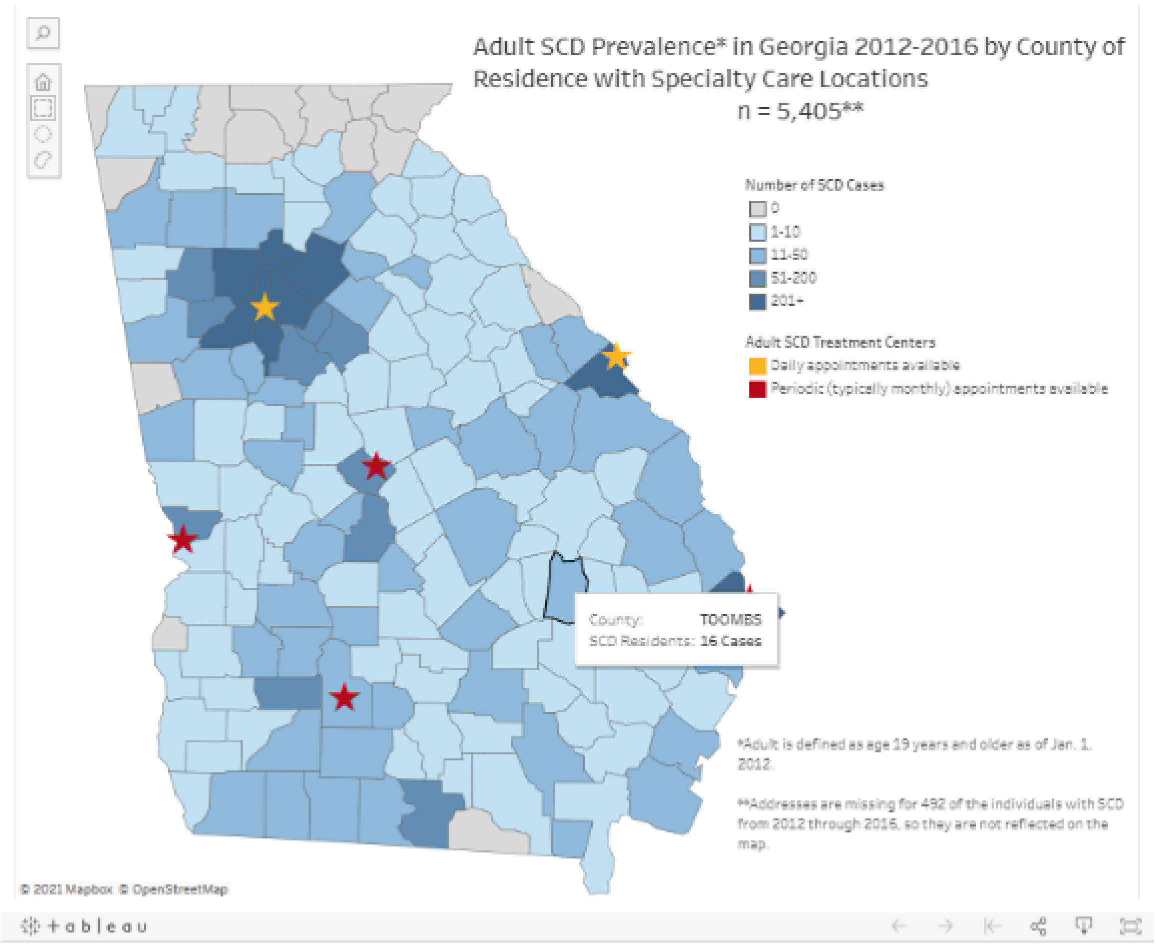
SCDC
Sickle Cell Data Collection

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

Communications Corner

SCDC Georgia developed the following interactive maps:

- SCD births in Georgia by county of residence.
- Adult SCD prevalence with specialty care locations.
- SCD prevalence in Georgia by county.



Adult SCD Prevalence* in Georgia 2012-2016 by County of Residence with Specialty Care Locations
n = 5,405**

*Adult is defined as age 19 years and older as of Jan. 1, 2012.

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

Trainings & Webinars

- "California Institute for Regenerative Medicine (CIRM)" (September 2020): CEO and President of CIRM, Maria Millian, presented on what's new at the California agency, which funds stem cell research, and on programmatic updates related to SCD.
- A toolkit of materials for building capacity to implement SCDC is now available. The toolkit is a collection of resources to help programs build the foundation for a SCD surveillance system in their state.

Recent Publications

Wilson-Frederick S, Hulihan M, Mangum A, Khan T, Geibel R, Malsberger S, et. al. Medicaid and CHIP sickle cell disease report, T-MSIS analytic files (TAF) 2017. Baltimore, MD: Center for Medicaid and CHIP Services, Division of Quality and Health Outcomes, Center for Medicare & Medicaid Services. 2021.

In the Community

- SCDC Georgia provided resources to SCD community members, medical providers, and state legislators attending the Be the Match Sickle Cell Policy Forum. These resources helped to support discussions about policy solutions to healthcare access barriers faced by the SCD community.

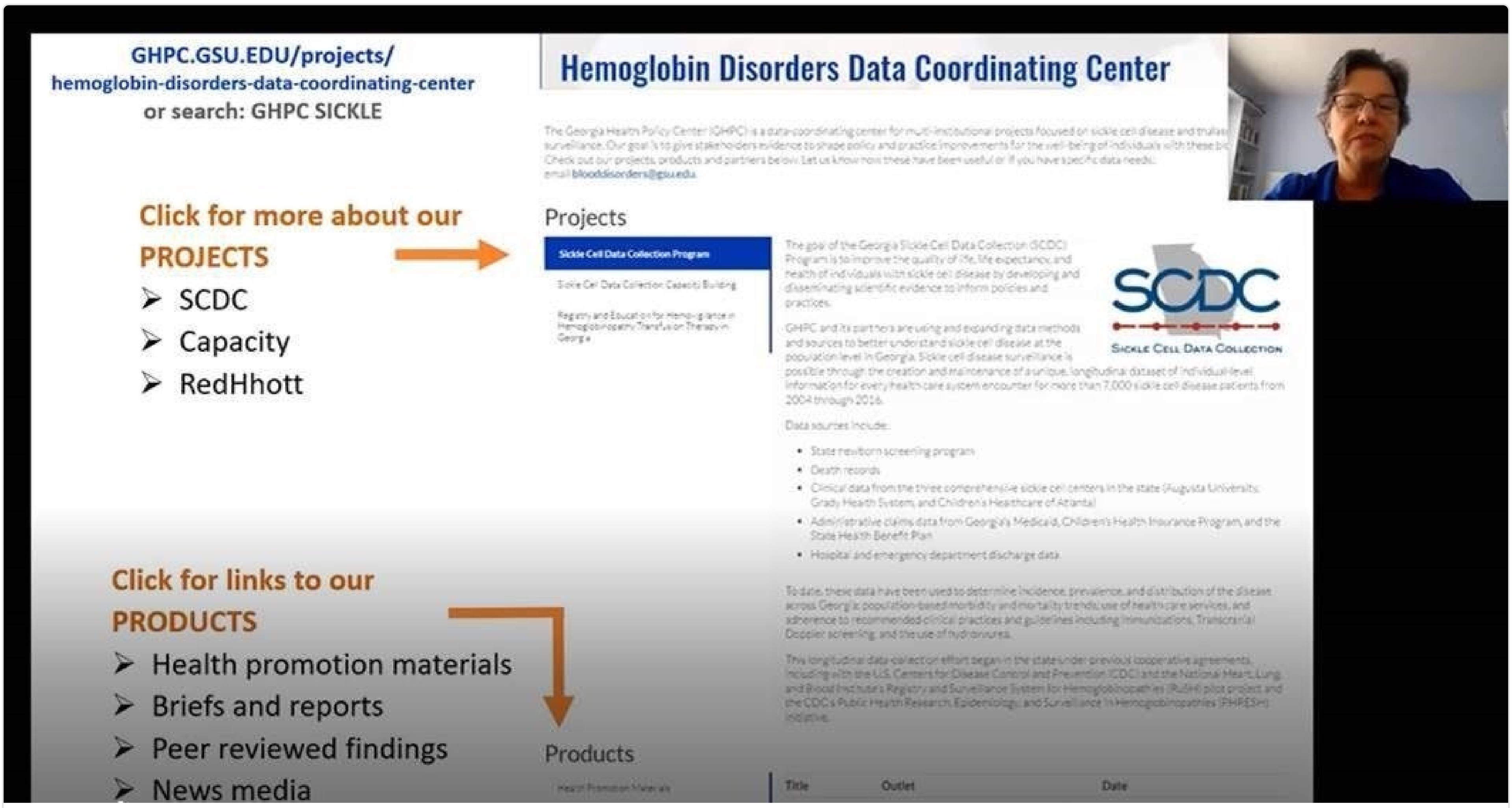
- SCDC California is collaborating with Cayenne Wellness Foundation and Sickle Cell Anemia Awareness San Francisco. These organizations will help SCDC California to survey the information needs of stakeholders, create and disseminate educational materials, and develop targeted outreach efforts for the SCD community.

Up-to-Data

- SCDC Georgia received a data request from CRISPR Therapeutics for prevalence (by gender and payer), cost, and comorbidities/comorbid complications to support discussions with state legislators and government officials about patient quality of life and cost impacts of SCD.
- SCDC California's data linkage is now complete. Updated tables will be presented during the upcoming SCDC California webinar on February 10, 2021 (see Announcements).

Presentations & Meetings

- SCDC Georgia hosted the SCDC Stakeholder Advisory Meeting on January 20, 2021, with participation from clinicians, community-based organizations, Department of Public Health, and public health experts. The group discussed data, research, and policy priorities for SCDC Georgia.



GHPC.GSU.EDU/projects/
hemoglobin-disorders-data-coordinating-center
or search: GHPC SICKLE

Click for more about our PROJECTS
- SCDC
- Capacity
- RedHhott

Click for links to our PRODUCTS
- Health promotion materials
- Briefs and reports
- Peer reviewed findings
- News media

Hemoglobin Disorders Data Coordinating Center

Projects

Products

Jane Branscomb presenting during the virtual SCDC Stakeholder Advisory Meeting.

- The following presentations were given at the Annual Sickle Cell Disease Research and Education Symposium in September 2020:
    - *Insurance Patterns of Medicaid Beneficiaries with Sickle Cell Disease in California and Georgia, 2014 to 2016*
      Main finding: Almost 75% of people with SCD in California and 61% in Georgia were covered by Medicaid across all 3 years. While people aged 20–29 years had the lowest percentage of continuous Medicaid coverage and shortest duration of continuous coverage, those aged 50–59 years had the longest coverage gaps. Long-term insurance coverage for people with SCD may be an important consideration for Medicaid policymakers in both states.
    - *Hematologist Encounters Among Medicaid Patients who have Sickle Cell Disease*
      Main finding: Among adults with SCD who have Medicaid health insurance, approximately half in California and a third in Georgia were not seen by a hematologist during 2016–2018. Among the pediatric population, about a third in California and a quarter in Georgia were not seen by a hematologist during the 3-year period.
    - *Geographic Mobility Among Medicaid Beneficiaries with Sickle Cell Disease in California and Georgia, 2014 to 2016*
      Main finding: The majority of Medicaid beneficiaries with SCD did not relocate beyond county boundaries over 3 years of follow-up, suggesting that frequent mobility may not be a primary concern for SCD service planning.

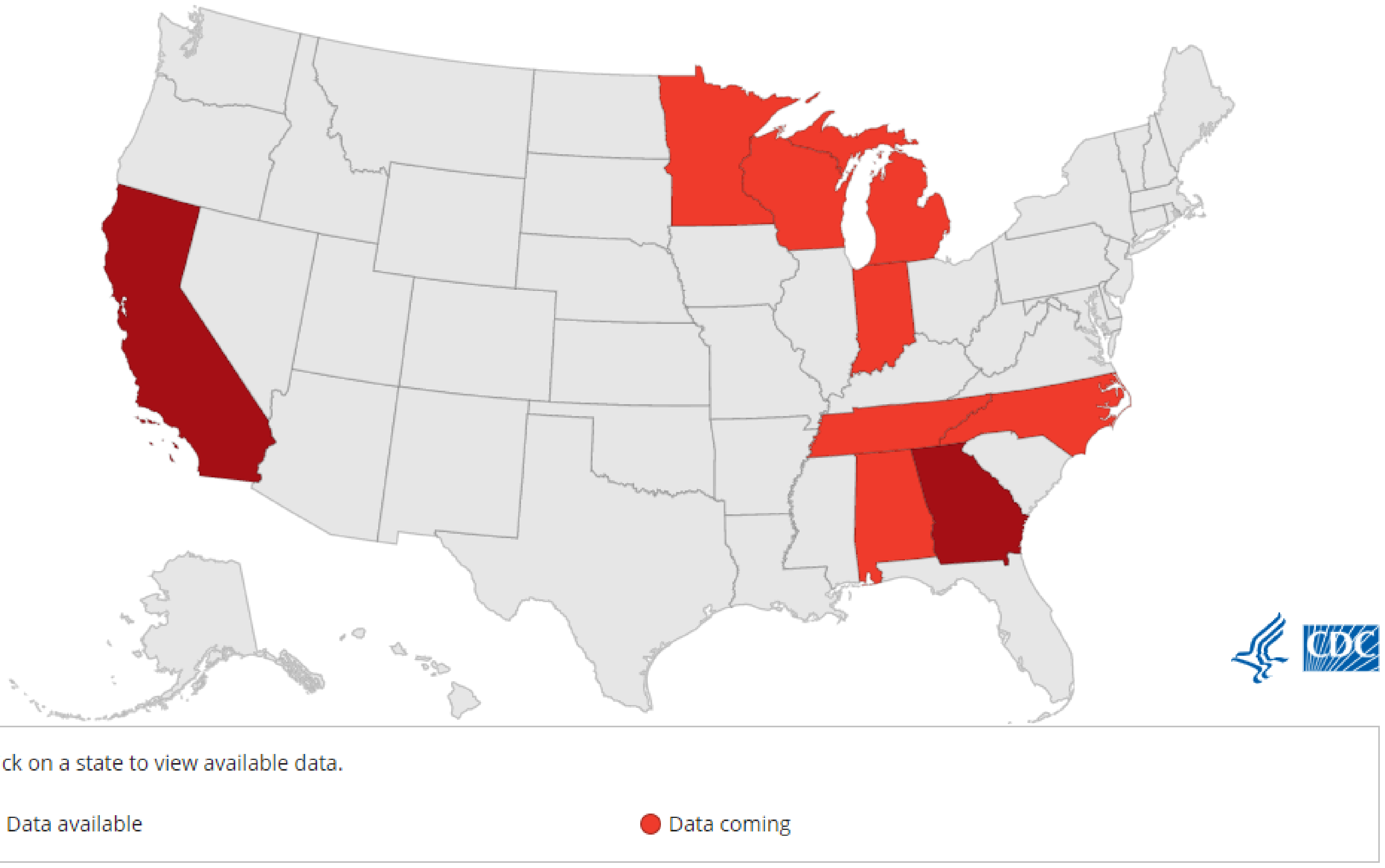
In The News

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, information, and products presented on the site.

- Coronary outcomes were not worse in five large prospective sickle cell trait cohorts
- ADM Brett Giroir, MD interview: The momentum of sickle cell care
- CRISPR-based treatment offers hope in tough-to-treat blood disorders
- New diagnostic technology accurately tests for anemia, sickle cell disease
- Study identifies potential trends in pediatric sickle cell mortality
- How does iron deficiency affect pregnant women with sickle cell disease?
- Commentary: Sickle cell disease studies should diversify recruitment strategies
- New technology diagnoses sickle cell disease in record time
- Emergency physicians have potential to improve sickle cell care
- Throughout pandemic, sickle cell patients suffer quietly at home
- Carrying sickle cell trait may make you vulnerable to COVID-19, UTHealth research shows

Announcements

- In 2020, CDC funded expansion of the SCDC program from two to nine states to collect essential data on SCD. The project aims to provide information that may be used to improve policy and healthcare standards, inform best practices, and illuminate pathways to deliver innovative treatments and cures in ways that can help address health disparities in SCD.



The SCDC program works with teams in the shaded states on the map above to collect and link data from several sources.

- **Webinar**: “New Data from CA SCDC“
  Date/Time: Wed, Feb 10, 2021 10:00am–1:00pm PST

Description: The California SCDC program will discuss new data sources, new data totals, and present on the upgrade to their data linkage system. Register here.

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.

SUBSCRIBE

Last Reviewed: June 30, 2023