Sickle Cell Disease Research

The Bloodline Newsletter: January 2022

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 Michigan's Sickle Cell Disease Partners Call to Action Brief is available online.
- SCDC Georgia launched an educational video describing their program and how SCD stakeholders can access the program data to bring about policy, practice, and community-level changes for people living with SCD in Georgia.

Trainings & Webinars

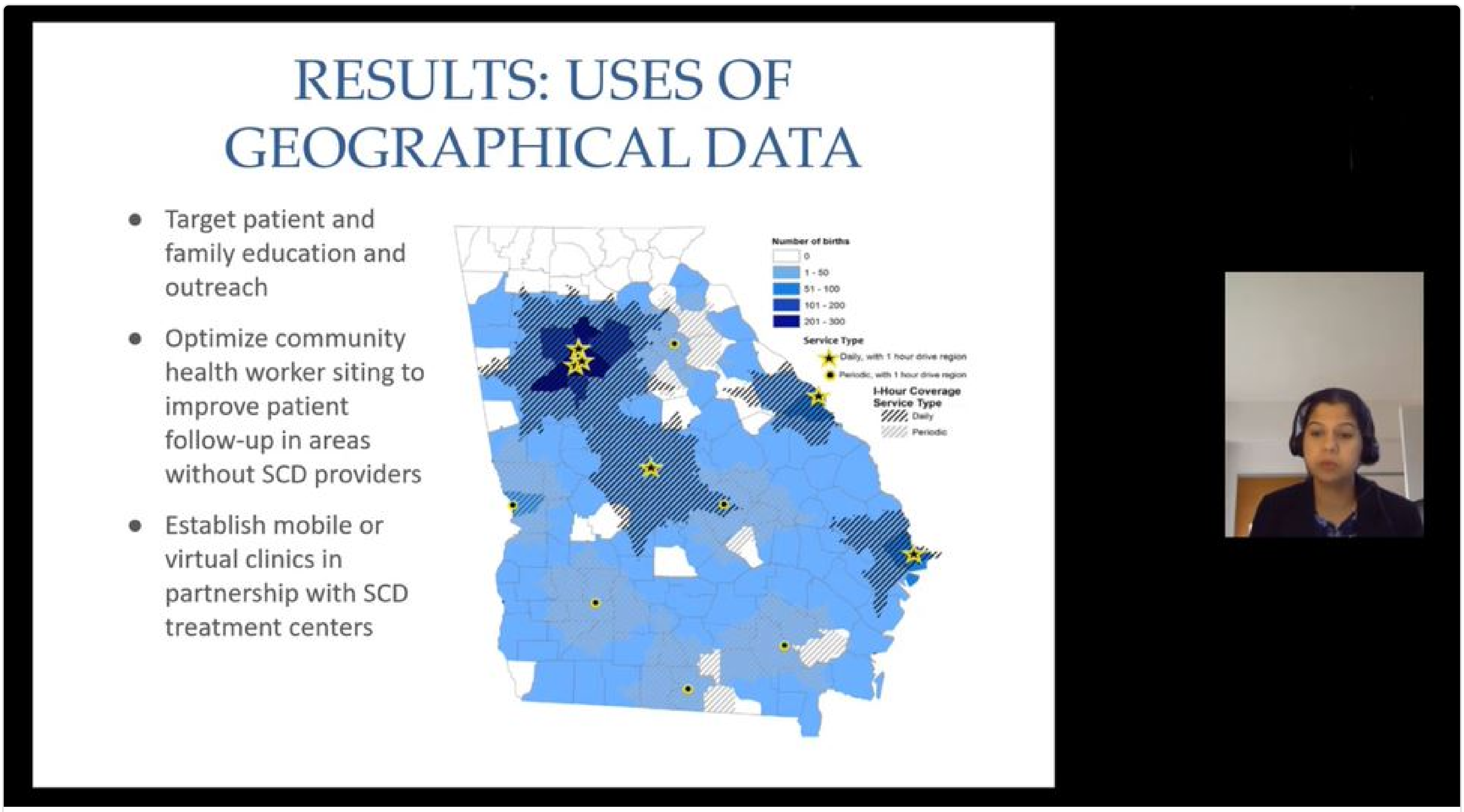
"Physical activity and exercise in people living with sickle cell disease" (November 2021): Dr. Ogunsile gave a broad overview of the perceived hesitations, current data, and future direction of physical activity in SCD.

Recent Publications

- Mathias JG, Nolan VG, Klesges LM, Badawy SM, Cooper WO, Hankins JS, Smeltzer MP. Hydroxyurea use after transitions of care among young adults with sickle cell disease and Tennessee Medicaid insurance. *JAMA Netw Open*. 2021 Oct 1;4(10):e2128971.
- Kanter J, Meier ER, Hankins JS, Paulukonis ST, Snyder AB. Improving outcomes for patients with sickle cell disease in the United States, making the case for more resources, surveillance, and longitudinal data. *JAMA Health Forum*. 2021;2(10):e213467.

Presentations & Meetings

- During the Sickle Cell Disease Association of America (SCDAA) Annual Convention on October 12, 2021,
    - SCDC Wisconsin presented “Surveillance for sickle cell disease in Wisconsin.”
    - SCDC Georgia presented on how they are using their state’s community partnerships to move data to action for the SCD population.



RESULTS: USES OF GEOGRAPHICAL DATA

- Target patient and family education and outreach
- Optimize community health worker siting to improve patient follow-up in areas without SCD providers
- Establish mobile or virtual clinics in partnership with SCD treatment centers

Sangeetha Lakshmanan presenting during the virtual 2021 SCDAA Annual Convention.

- SCDC Georgia hosted its Stakeholder Advisory meeting on October 27, 2021, with participation from clinicians, community-based organizations, staff from the Georgia Department of Public Health, and public health experts. The group discussed data, research, and policy priorities including future analyses on topics such as immunization adherence among children with SCD, maternal morbidity and mortality among pregnant women with SCD, impact of COVID-19 on individuals with SCD and studying mortality in individuals with SCD.
- SCDC North Carolina gathered for its second bi-annual meeting on November 10, 2021 to review the program’s progress to date, brainstorm Lay Communication Work Group strategies for success, and continue discussion regarding prioritization of data analyses. Attendees included SCD researchers and clinicians, sickle cell educator counselors, a representative from the Governor’s NC Appointed Council on Sickle Cell Disease and Other Blood Disorders, and people with lived experience. Preliminary surveillance results from SCDC North Carolina were shared. The Advisory Council identified two priorities for data analyses:
    - geographic distribution of people living with SCD relative to clinical centers
    - transition from pediatric to adult care
- CDC held the SCDC program’s quarterly meeting on December 8, 2021. The meeting covered core evaluation measures; policy, communications, and community-based organization workgroup updates; and publication overviews.

SCDC CBO Workgroup Updates

- Purpose: To create a space for collaboration among the SCDC program CBOs on communication and policy activities that engage stakeholders (such as patients, providers, partners and policy audiences) on the impact of SCDC.
- Monthly meetings
  - September: No meeting (CBOs joined quarterly meeting)
  - October: CBO presentation-"Sickle Cell Disease in California: Information Gap Survey Findings"
  - November: Communications plan walk-thru
- Meeting slides, notes, and resources are emailed and uploaded to WG's SharePoint

Mandip Kaur presenting community-based organization workgroup updates during the SCDC quarterly meeting.

In The News

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

- A sickle cell heads-up is often overlooked
- More potent version of Global Blood sickle-cell drug improves hemoglobin response in small study
- Gene therapy shows promise in curing sickle cell
- Man shares life story on the importance of blood donations
- Opinion: Time for a closer look at sickle cell disease
- CEO to use sickle cell clinical trial finder herself
- Commentary: Does living with sickle cell get any easier?
- Commentary: For people with sickle cell disease, add check-ins to checkups
- Quality of life worsens in older children with sickle cell disease
- Titilope Fasipe, MD, PhD: Treating and living with sickle cell disease
- Here's what we know about the new drug for sickle cell disease
- Sickle cell disease and COVID-19
- Sickle cell anemia patient shares how gene therapy treatment changed his life
- Commentary: How Ohio State's comprehensive approach to sickle cell disease treatment focuses on patients' quality of life
- For patients fighting sickle cell disease, finding compassionate care is part of the battle

Announcements

Webinar: "Addressing school-related inequities for individuals living with sickle cell disease"
Date/Time: Tue, Feb 15, 2022 10:30am–12:00pm PST
Registration: https://attendee.gotowebinar.com/register/9009669178039109136

Contact

For any questions about the SCDC program, contact Mary Hulihan or Mandip Kaur.

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Last Reviewed: June 30, 2023