Sickle Cell Disease Research

The Bloodline Newsletter: Fall 2018

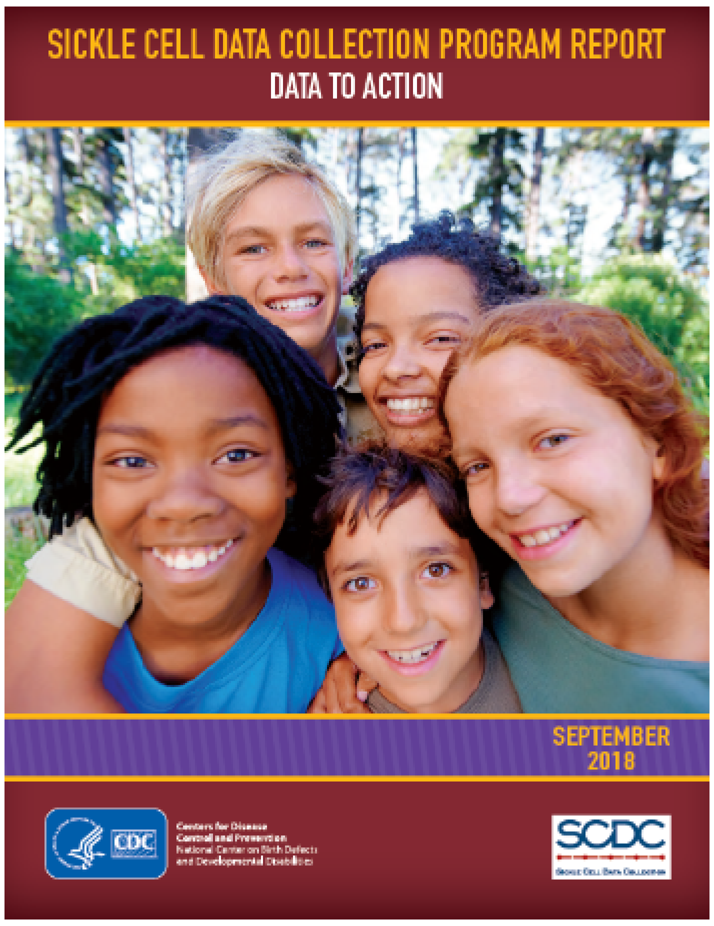
THE BLOODLINE
Sickle Cell Data Collection (SCDC) Program
Quarterly Newsletter

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

- The September 2018 SCDC Program Report: Data to Action details the purpose and impact of the SCDC program



SICKLE CELL DATA COLLECTION PROGRAM REPORT
DATA TO ACTION

SEPTEMBER
2018

CDC
Centers for Disease
Control and Prevention
National Center on Birth Defects
and Developmental Disabilities

SCDC

- September Sickle Cell Awareness Month: CDC shared educational materials on SCD, transition, and minority blood donation; Spanish versions of many of these materials were shared
- California SCDC webinars“Michigan’s plan for sickle cell disease across the lifespan: Lessons learned for California ” webinar (May): Led by Dr. Wanda Whitten-Shurney and Ms. Dominic Smith, this webinar focused on Michigan’s state plan for SCD across the lifespan. The information was very helpful to other states interested in bringing together stakeholders to form an action plan for SCD.“Opioid prescriptions: Disparities and realities ” webinar (August): Led by Dr. Wally Smith, who discussed the health disparities and realities of opioid prescribing in SCD. Dr. Smith shared information about a recent policy change in Virginia that allows physicians who treat SCD patients to prescribe high-dose opioids. He emphasized that advocacy work has “strength in numbers,” and encouraged collaboration among community based organizations.

In the Community

- The Georgia SCDC team met with child health leadership, program staff, and epidemiologists from the Georgia Department of Public Health (GDPH) to strengthen collaborations and update newer staff on SCDC work.

    - GDPH staff continue to use RuSH/PHRESH maps to inform telehealth and SCD outreach clinic decisions. They look forward to using updated maps based on SCDC data.
    - The Georgia SCDC team introduced GDPH staff to South Carolina colleagues who have an HRSA Center of Excellence award for telehealth and are looking for implementation partners.
    - GDPH staff is working to improve newborn screening follow-up, an area that SCDC data could support by providing age-specific prevalence estimates by county of residence, as well as incidence estimates for those newborns seen for follow up at comprehensive SCD centers, public health-sponsored pediatric SCD outreach clinics, and other healthcare provider locations.
- The SCDC team is always open to collaborate with healthcare providers around Georgia. GHPC received an introduction from GDPH to the nurse manager of a pediatric SCD program in Georgia not previously engaged with SCDC. Discussion has focused on opportunities for collaboration, including sharing clinical data on their 260 pediatric patients with SCD.

Up-to-Data

- GHPC finalized an updated data use agreement with Augusta University; new clinical data are forthcoming. Four clinical sites contribute to SCDC Georgia's dataset.
- California's SCDC team has reached agreements with a total of 10 clinical sites and community-based partners to provide individual-level data that will help confirm the genotype and care patterns for people living with SCD. Data have been received from four sites to-date, and the remainder of those with agreements are in process.

Presentations and Meetings

- Craig Hooper, Director, Division of Blood Disorders, provided an overview of CDC's SCD work, including SCDC, at the annual symposium of the Foundation for Sickle Cell Disease Research on June 17th.
- The California and CDC SCDC teams joined Global Blood Therapeutics (GBT) on June 19th to celebrate World Sickle Cell Day. The event included presentations from researchers, patient advocates, and GBT staff.
- In June, Georgia SCDC adviser, Dr. Jim Eckman, trained local health department staff in both Swainsboro, GA and Macon, GA on management of SCD (transfusion, hydroxyurea, and new therapies) as part of staffing new source sites for telemedicine, which will be supported by Dr. Abdullah Kutlar, at Augusta University.
- The California and CDC SCDC teams gave presentations about SCDC to interested researchers at the annual Pacific Sickle Cell Regional Collaborative in Phoenix in June. Two researchers approached California SCDC about collaborating on multiple analyses.
- The Georgia, California, and CDC SCDC teams met on several occasions to discuss the development of analyses focused on the pediatric patient cohort and their utilization of the healthcare system as they transition from pediatric to adult care.
- The CDC SCDC team presented their findings on SCD care in the emergency department during the July Sickle Cell Collaborative Monthly Learning Session hosted by Alliant Quality.
- The CDC SCDC team presented SCD educational materials for patients, families, and community members during the quarterly Georgia Refugee Stakeholders meeting on Sept. 2.
- The California, Georgia, CDC, and CDC Foundation SCDC teams met with Pfizer representatives on August 7th to discuss upcoming activities, and were introduced to Pfizer's new team member, Jennifer Hodge.
- The CDC SCDC team attended the National Heart Lung and Blood Institute annual SCD clinical research meetings, the American College of Emergency Physician's Summit on Improving Emergency Department Care for Sickle Cell Disease, and the American Society of Hematology's Sickle Cell Disease Coalition in-person meeting. The team presented information about SCDC, including how the collected data were being utilized. Multiple researchers expressed interest in collaborating on data analyses.

In the News

- Chronic pain leads to higher opioid doses and lower QoL in sickle cell patients
- Approval of sickle cell disease bill by senate committee welcomed by Emmaus Life Sciences
- My battle with sickle cell disease

- Biotech bets on sickle cell disease drug getting swift approval
- Sickle Cell Disease Association and Emmaus partner to increase education, awareness
- Why are Californians with sickle cell falling ‘into a black hole’?
- First results from Phase 3 trial expected to support FDA’s accelerated approval of voxelotor for sickle cell
- Sickle cell advocate wins fight for high-dose opioids
- Howard County family provides support for sickle cell disease patients
- Music therapy helps relieve pain in adults with sickle cell disease, pilot trial suggests
- Enzyme identified as possible novel drug target for sickle cell disease, Thalassemia
- HRI depletion may be effective in treating sickle cell disease
- Potential for cannabis to treat sickle cell disease
- Blood tests and funding can save African lives, especially children, official says
- L-Glutamine oral therapy reduces sickle cell-related pain better than placebo
- White blood cells regulate levels of fetal hemoglobin in sickle cell patients, study shows
- Endari reduces pain crises, hospitalizations in sickle cell patients, Phase 3 Trial shows
- Mount Sinai receives NIH Grant to study use of inhaled corticosteroids for sickle cell treatment

Announcements

Stay tuned for a webinar series about transition from pediatric to adult care. Clinicians and experts in the field of adolescent health and community engagement will discuss their work related to transition.

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).

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Last Reviewed: June 30, 2023