



Sickle Cell Disease Research

The Bloodline Newsletter: Winter 2019

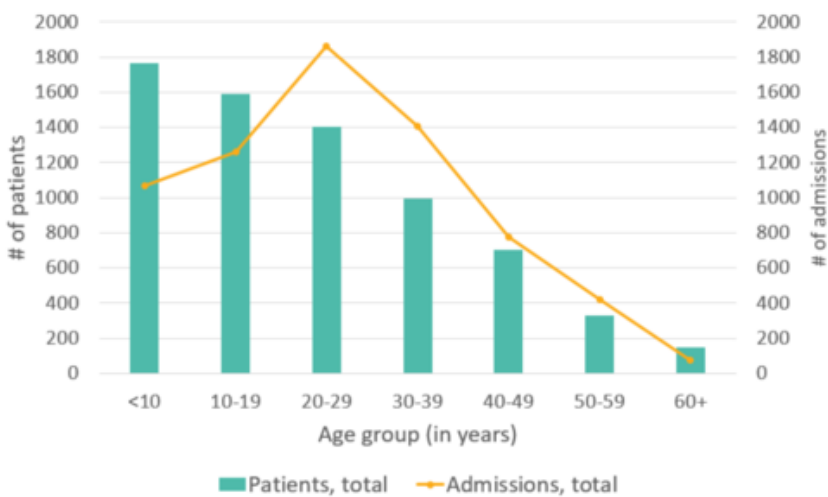


Mission: To improve quality of life, life expectancy, and health among people living with sickle cell disease (SCD).

Communications Corner

Check out these resources:

- [California](#) and [Georgia](#) aggregate 2005 SCDC data
- [Minority blood donation animation](#)
- [Sickle cell trait toolkit](#) now available in French and Spanish
- [Sickle Cell Data Collection Program Brief: Better Access to Outpatient Care May Decrease Emergency Visits and Costs](#) [↗](#)
- Webinars
 - [“Innovations in Healthcare Transition from Pediatric to Adult Care](#) [↗](#)” (November, 2018): Two experts on adolescent health, Peggy McManus, MHS, and Patience White, MD, MA, from the “Got Transition?” program spoke about innovations in healthcare transition from pediatric to adult care.
 - [“Community Health Workers and Mobile Apps for Transition from Pediatric- to Adult-focused Sickle Cell Care](#) [↗](#)” (December, 2018): Kim Smith-Whitley, MD, Clinical Director of the Division of Hematology and Director of the Comprehensive Sickle Cell Center at Children’s Hospital of Philadelphia, spoke about her Patient-Centered Outcomes Research Institute (PCORI)-funded research on how to improve quality of life for youth with SCD as they transition to adult care.



Total number of hospital admissions, GA, 2005

In the Community

CDC's SCDC team met with Sickle Cell Disease Association of America's (SCDAA) Beverley Francis-Gibson and Biree Andimiriam in December 2018, and discussed ways to work together to enhance each other's activities and increase awareness of SCD. As a result of the meeting, the April SCDC webinar will be presented by SCDAA and CDC's SCDC team is working with SCDAA on an analysis of SCDC data, specifically length of stay for SCD hospitalizations.

Up-to-Data

- The Georgia SCDC team responded to requests for SCDC data from a variety of sources, including:
 - Health Resources and Services Administration: request for map of SCD prevalence (all individuals affected by the disease at a particular time) by county and data, depicting differences between children and adults in healthcare utilization and providers involved in their care to inform their State Action Plan.
 - Georgia Department of Public Health: request for prevalence data (children and youth aged 0-18 years and transition-aged youth/young adults aged 13-26 years) for a conference abstract on provision of social services to transition-aged individuals with SCD.
 - Department of Health and Human Services' Office of Minority Health Resource Center: request for prevalence of SCD and sickle cell trait (SCT) in Georgia.
 - University Health Network (in Toronto): physician applied for a Harkness Fellowship in Healthcare Policy and Practice to study the effects of US healthcare policy on access to care and health outcomes for SCD patients.
- The Georgia SCDC team reached out to the Georgia Department of Public Health's Maternal and Child Health Section, Georgia Hospital Association, and WellStar Health System to discuss which data can be provided to inform decision-making.

Presentations and Meetings

- California SCDC's Susan Paulukonis presented at the American Society of Hematology meeting in San Diego on December 1-4, 2018. Susan shared the finding that people living with SCD experience discrete and identifiable states of emergency department (ED) utilization within a given time frame. The California SCDC team will be working to publish and disseminate this information to a wider audience in the near future.
- California SCDC's video submission, "[Stepping Up: A Two-Part CDC Video Series for Teenagers & Young Adults with SCD](#)" was shown at a film festival held at the American Public Health Association Annual Meeting in San Diego in November 2018. The video series focuses on Kevin and Calvinay, two young adults who discuss their transition from pediatric to adult health care, how it has affected them, and how they've overcome challenges.
- The Georgia SCDC team exhibited at the:
 - State of Black Health National Conference (Sept. 11-13, 2018; Atlanta, GA)
 - 46th Annual National Sickle Cell Disease Association of America Convention (Oct. 10-13, 2018; Baltimore, MD)
 - American Public Health Association Annual Meeting and Expo (Nov. 10-14, 2018; San Diego, CA)














Georgia Health Policy Center's Ashley Singleton talking to an attendee at the Sickle Cell Disease Association of America





SCDC Georgia's Sashoy Patterson exhibiting at the State of Black Health National Conference

- Members of the SCDC team met with representatives from Ironwood Pharmaceuticals, CRISPR Therapeutics, and IQVIA in November-December 2018 to explore future joint efforts to expand the reach of the SCDC program.
- Members of the SCDC team presented an overview of SCDC to the National Minority Quality Forum's SCD Workgroup on November 15, 2018 and the Minnesota Department of Health's SCD Forum on December 10, 2018 to provide details about the fundamentals and utilization of the data.

In the News

- [‘I didn’t have the privilege of being average’: Life with sickle cell anemia](#) 
- [HemoType SC is a fast, inexpensive diagnostic tool for sickle cell disease screening, study shows](#) 
- [Opioid use not tied to increase of in-hospital SCD mortality](#) 
- [As opioid backlash grows, sickle cell patients fear they’ll lose critical pain treatment](#) 
- [Marijuana use common in sickle cell patients, highlighting need for more research, study shows](#) 
- [Autologous gene therapy shows promise for sickle cell disease](#) 
- [‘From Nothing to Gangbusters’: A treatment for sickle-cell disease proves effective in Africa](#) 
- [NIH initiative takes ‘multiple-shots’ approach toward cure for sickle cell disease](#) 
- [Sickle cell disease is more complex than previously thought: A psychosomatic component may exist](#) 
- [#NORDSummit – Major issues on table for rare disease patients in US as midterm elections approach](#) 
- [Bipartisan bill aimed at fighting sickle cell disease signed into law by Trump \(NBC News.com\) CDC Mention](#) 

Announcements

- Webinar: “Stepping Up into Adult Care: The Sickle Cell Trevor Thompson Transition (ST3P-UP) Project”
Thursday, February 28, 2019, 12:30 – 2:00 PM PST
Presenters: Ifeyinwa (Ify) Osunkwo, MD, MPH, Carolinas HealthCare System, and Raymona Lawrence, DrPH, MPH, Georgia Southern University
[Join the email list](#)  to receive announcements about upcoming webinars.
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Contact

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Last Reviewed: June 30, 2023