



SICKLE CELL DATA COLLECTION PROGRAM HIGHLIGHTS

SEPTEMBER 18, 2019

DATA FROM NEW PARTNERS!

SCDC California has new clinical case report data from

- Children's Hospital of Orange County,
- University of California San Diego/Rady Children's Hospital-San Diego,
- Zuckerberg SF General Hospital,
- Center for Inherited Blood Disorders
- Stanford University/Lucille Packard Children's Hospital!



We expect additional new data files this spring from other clinical partners.

SHARING DATA

SCDC California responded to requests for SCDC data from a variety of sources, including:

- A team of researchers working on a grant proposal to better understand the links between SCD and cancer.
- Community-based organizations that are developing policy messages on Hispanic /Latinx people living with SCD and access-to-care challenges for adults in Southern California.



PUBLICATION

Journal Article

SCDC California contributed to article by Emily Johnston in Journal of Palliative Medicine, Aug 7, 2019. Looks at healthcare utilization in the last year of life of those in CA with SCD who have died.



PRESENTATIONS

- SCDA: Two abstracts accepted for presentation on the older adult population with SCD in CA, Baltimore, MD, October, 2019
- Foundation for Sickle Cell Disease Research 2019 Sickle Cell Disease Research and Educational Symposium: SCDC data were used to develop an abstract, “Newborn Screening Data for Sickle Cell Disease in California and Georgia, 2004—2016: Implications for Health Interventions,” June, 2020

STRATEGIC PLANNING

National Academies of Sciences, Engineering, and Medicine

- California SCDC's Susan Paulukonis is on an ad hoc committee to develop a strategic plan and blueprint for addressing sickle cell disease in the United States.
- This project was commissioned by the Department of Health and Human Services' Office of Minority Health
- A report will be available in 2020



FUNDING



- California Legislature: Appropriated funds for the development of a three-year sickle cell disease (SCD) center pilot program.
- Included funding to support and expand sickle cell disease surveillance

CALIFORNIA SCDC



- Social media



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