

# New Project Web Page: CASickleCell.org/CADData

The screenshot shows a web browser window displaying the CASickleCell.org/CADData page. The browser's address bar shows the URL "casicklecell.org/caddata". The page content includes a navigation menu with links for HOME, ABOUT US, CENTERS, DATAMAP, GALLERY, RESOURCES, EVENTS, ADVOCACY CORNER, and CONTACT. The main heading is "CALIFORNIA Sickle Cell RESOURCES" with a "FREE webinar SIGN UP" button. The page features logos for the California Rare Disease Surveillance Program, California Environmental Health Tracking Program, and the CDC Foundation. A central text block describes the Sickle Cell Disease Longitudinal Data Collection Project in California, which collects and analyzes data on the health and health care of Californians living with sickle cell disease (SCD). The project is run by the California Rare Disease Surveillance Program, a part of the California Environmental Health Tracking Program and the Public Health Institute. A "Project Overview" section explains that the longitudinal data collection system collects consistent information about the health and health care of a specific group of people (population) over long periods of time in order to study trends. This project will meet the following objectives:

- Help understand how many people are living with SCD in California and their health status;
- Provide information needed to establish cost-effective practices that help improve and potentially extend the lives of people with SCD;
- Determine how well current systems of care are meeting the needs of people with SCD and inform the development of new models of care that may better meet those needs; and
- Provide accurate, up-to-date information and guidance for clinical care providers, patients, families, advocates, policy makers and government agencies.

A photograph of a man and a young girl is shown next to the objectives. The man is wearing a green shirt and sunglasses, and the girl is wearing a pink helmet and a purple shirt. They are both smiling and looking at the camera. The man is holding a small object in his hand, and the girl is holding a small object in her hand. The background is a blurred outdoor setting.

At the bottom of the page, it states: "This project is the first step in building a sustainable data collection system that could include information on everyone diagnosed with SCD in the United States, not just..."

On the right side of the page, there is a sidebar with a "Project Materials:" section listing "Dec. 2015 Report" and "Webinar 1", and a "Partner Program:" section listing "NORTHERN CALIFORNIA NETWORK OF CARE FOR SICKLE CELL DISEASE".

The browser window shows the date "Wednesday, January 20th, 2016" and the time "8:50 AM 1/20/2016".

# Susan Paulukonis, CA Sickle Cell Disease Long Term Data Collection



# Mary Hulihan, CDC

## Division of Blood Disorders

---



Dr. James Eckman, Emory  
University

■ School of Medicine



# CALIFORNIA SICKLE CELL DISEASE LONG TERM DATA COLLECTION

January 2016 Update  
Susan Paulukonis

# California SCD Long Term Data Collection

- RuSH and PHRESH projects in CA 2010-2014
- Building on lessons learned to have statewide population based data on how many people have SCD and their experience
- Funded by the CDC Foundation, with support from Pfizer and Biogen
- Directed by the CDC Division of Blood Disorders
- Planned 2015-2020
- CA Rare Disease Surveillance/Public Health Institute/CA Dept. of Public Health

# Objectives

- Gather data from administrative, clinical and newborn screening sources and link
- Understand and share information about important issues in SCD
- Answer questions that support changes in health care policy, clinical research and clinical care



# Milestones: Nov. 2015 – Jan. 2016



- State IRB approval for data collection
- Plan for data linkage established
  - ▣ Search indexing methodology vs. public health data linkage methodology
  - ▣ Staff changes in IT
- Request for Vital Records; death 2004-2013 submitted
- Request for Medicaid data initiated



# Activities: Nov. 2015 – Jan. 2016



- Report on SCD in California
- Stakeholder meetings with CBOs, clinicians, pharmaceutical researchers
- Engagement with and support of another state conducting SCD surveillance
- Launch of web presence at [www.casicklecell.org](http://www.casicklecell.org)
- Initiation of video education project
- Initiation of outreach plan with community partners in LA County
- Response to state legislator's request for data
- Mortality paper (with CDC and Georgia) accepted
- Development of manuscript about ED Utilization in CA

# Next Webinar: Drug Development for Sickle Cell Disease



- How do the potential therapies work?
- How does the drug development pipeline function?
- How are clinical trials designed, and where do they take place?
- How do pharmaceutical companies work with the FDA?

Summer 2016 (exact date/time TBD)