

California Sickle Cell Disease Resource Guide

➤ California Sickle Cell Resources Website

<http://casicklecell.org/>

- California Sickle Cell Care Centers
- Treatment and management standards for providers and patients
- Research programs:
 - PHRESH (Public Health Research Epidemiology & Surveillance for Hemoglobinopathies)
 - Northern California Network of Care for Sickle Cell Disease
- Patient support group and sickle cell disease-related events in California
- Educational videos and Public Service Announcement

➤ California Sickle Cell Disease Fact Sheet for Providers and Patients

<http://www.cdc.gov/ncbddd/sicklecell/freematerials.html>

<http://casicklecell.org/phresh>

- Describes the impact of sickle cell disease in California: birth prevalence, mortality, morbidities, hospitalizations, emergency room visits, etc.

➤ Educational Webinars

<http://scinfo.org/world-wide-resources/cdc-webinars-hemoglobinopathies-and-public-health>

- Public Health Webinar Series on Hemoglobinopathies
- Sample of topics in archived seminars:
 - Baby on Board: What You Need to Know about Pregnancy in the Hemoglobinopathies
 - Improving Quality of Care for Sickle Cell Pediatrics in the Emergency Department
 - Transition of Care for Sickle Cell Disease – Pediatrics to Adult Care
 - Iron overload in Children with Sickle Cell Disease

➤ Complications and Treatments

<http://www.cdc.gov/ncbddd/sicklecell/treatments.html>

<http://casicklecell.org/resources>

<http://www.childrenshospitaloakland.org/main/departments-services/41.aspx>

➤ General Information

<http://scinfo.org/>

- Sickle Cell Information Center

➤ Clinical Trials

<http://clinicaltrials.gov/>

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➤ Sickle Cell Trait

<http://www.cdc.gov/ncbddd/sicklecell/traits.html>

<http://casicklecell.org/resources/general/trait>

➤ NHLBI Guidelines for Care

http://www.nhlbi.nih.gov/health/prof/blood/sickle/sc_mngt.pdf

- The updated Sickle Cell Disease Guidelines are expected to be released in 2014

➤ California Sickle Cell Resources Facebook Page

<https://www.facebook.com/SickleCellResources>

- Ongoing dialogue about sickle cell disease with over 1100 “Likes” as of February 2014

➤ Sickle Cell Disease Self-Management Toolkits

http://www.cdc.gov/ncbddd/sicklecell/documents/livingwell-with-sickle-cell-disease_self-caretoolkit.pdf

<http://casicklecell.org/resources>

➤ Sickle Cell Community Advisory Council of Northern California

<http://www.sccac.net/>

- Provides information and assistance to families of sickle cell disease, educates the public, and assists health institutions and practitioners to deliver better care to patients with sickle cell anemia.

➤ Sickle Cell Disease Foundation of California

<http://www.scdfc.org/>

- Provides education and life-enhancing programs and services to individuals with sickle cell disease, broadens public awareness about sickle cell disease, and promotes medical research and education to ultimately find a cure.

Note: This Sickle Cell Disease Resource Guide is created by the PHRESH (Public Health Research Epidemiology & Surveillance for Hemoglobinopathies) Project, which was funded by the Centers for Disease Control and Prevention.

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