

Sickle Cell Disease Coalition (SCDC) Call/Webinar
Wednesday, March 6, 2019, 10 A.M. EDT
Dial-in number: 1-866-740-1260; Access code: 2920257
Web Login: <https://cc.readytalk.com/r/977jfulnkyxz&eom>

AGENDA

Time	Topic	Lead
10:00 A.M.	Welcome, Introduction of New Members, and Review Goals of Call	<i>Karina Ngaiya, MA</i>
10:10 A.M.	Update on New Data from the Centers for Disease Control and Prevention's Sickle Cell Data Collection Program The program collects health information about people with SCD to study the prevalence, long-term trends in diagnosis, treatment, and healthcare access for people with SCD in the United States. <ul style="list-style-type: none"> • Overview of program • Review data from California and Georgia • Discussion <i>SCDC members are encouraged to provide feedback on what other type of data would be most helpful in future program reports.</i>	<i>Mary Hulihan, DrPH</i> <i>Centers for Disease Control and Prevention</i>
10:30 AM	Overview of Sickle In Africa <ul style="list-style-type: none"> • The Sickle In Africa consortium aims to facilitate research in SCD and then translate this research into healthcare and health outcomes. 	<i>Julie Makani, MD, PhD, FRCP</i> <i>Muhimbili University of Health and Allied Sciences</i>
10:40 AM	Update on SCDC Efforts to Address Blood Supply Challenges in the U.S	<i>Leah Mendelsohn Stone, JD</i> <i>AABB</i>
10:45 A.M.	Updates from Groups <i>SCDC members are encouraged to share information about their organization's sickle cell disease-related news, projects, and meetings.</i>	<i>Group</i>
11:00 A.M.	Adjourn	

Sickle Cell Disease Coalition (SCDC)

Roster

Addmedica
America's Blood Centers
American Academy of Emergency Medicine
American Academy of Pediatrics
American Association of Blood Banks (AABB)
American Public Health Association (APHA)
American Psychiatric Association (APA)
American Red Cross
American Society for Apheresis
American Society for Blood and Marrow Transplantation
American Society for Clinical Pathology
American Society of Hematology
American Society of Nephrology
American Society of Pediatric Hematology/Oncology Nurses (ASPHO)
American Thoracic Society
ApoPharma
American Society of Gene & Cell Therapy (ASGCT)
*ASH Research Collaborative
Association of Pediatric Hematology/Oncology Nurses
Association of Public Health Laboratories
Axis Advocacy
bluebird bio
Center for Medicare and Medicaid Services (CMS)
Centers for Disease Control and Prevention (CDC)
Cerus
College of American Pathologists
Crispr Therapeutics
Doris Duke Foundation
Emergency Department Sickle Cell Care Collaborative
EpiDestiny
FMDT SOS GLOBI
Food and Drug Administration (FDA)
Foundation for Sickle Cell Disease Research
Functional Fluidics
Global Blood Therapeutics
GlycoMimetics
Health Resources and Services Administration (HRSA)
Hematology and Oncology Society of Africa
International Association of Sickle Cell Disease Nurses and Physician Assistants

Ironwood Pharmaceuticals
MAST Therapeutics
Medunik USA
Muhimbili University of Health and Allied Sciences (MUHAS)
National Heart, Lung, and Blood Institute (NHLBI)
National Marrow Donor Program
National Medical Association (NMA)
National Minority Quality Forum (NMQF)
National Institute for Children's Health Quality (NICHQ)
Novartis
Pediatric Hospital Sickle Cell Collaborative
Pfizer
Prolong Pharmaceuticals
*Raremark
Sancilio & Company, Inc.
Sanofi Genzyme
Sickle Cell Adult Provider Network
Sickle Cell Aid Foundation
Sickle Cell Community Consortium
Sickle Cell Disease Association of America
Sickle Cell Disease Association of Canada
Sickle Cell Foundation of Ghana
Sickle Cell Outcome Research program ("SCORE"), the Netherlands
Sickle Cell Society UK
Sickle Cell Warriors
Sickle Transplant Alliance for Research (STAR)
The Global Sickle Cell Disease Network
The Shikuri Project Charitable Trust
Terumo BCT
Thalassemia International Federation
Vanguard Therapeutics, Inc.
Vertex Pharmaceuticals

*Indicates new SCDC member.