



SCDC Global Issues Working Group Meeting Agenda
Monday, June 12, 2023, 10:00 A.M. – 11:00 A.M. ET

Register in advance for the meeting (required):

<https://hematology.zoom.us/meeting/register/tjEpf-ysqzkuEtJsU7VI2gs4UDKXZMOxo2eW>

After registering, you will receive a confirmation email with information to join the meeting.

AGENDA

Time	Topic	Lead
10:00 A.M.	Welcome, Zoom Best Practices, and Goals of Call <i>The meeting will start with a welcome, reminder of Zoom best practices, and a review of the meeting agenda and objectives for each item.</i>	<i>Bukola Bolarinwa, LLM, Sickle Cell Awareness Foundation (SCAF) & Haima Health Initiative – Co-Chair;</i> <i>Laurence Noisette, MD, American Society of Pediatric Hematology/ Oncology (ASPHO) – Co-Chair</i>
10:05 A.M.	Discussion: Celebrating Bukola Bolarinwa’s Service as SCDC Global Issues Working Group Co-Chair! <i>Bukola Bolarinwa is stepping down from her role as Co-Chair of the SCDC Global Issues Working Group to welcome new leaders. In reflection of Bukola’s many contributions as Co-Chair, attendees will dedicate a few minutes to share their gratitude and praise for Bukola’s leadership, both within and beyond this role.</i>	<i>Laurence Noisette, MD, ASPHO</i> <i>Group discussion encouraged</i>
10:15 A.M.	Update & Discussion: Finalizing Design for SCD Stakeholders Database Template & Refining Next Steps for Project <i>The Global Issues Working Group is developing a series of Local SCD Stakeholders Databases to identify, document, and connect stakeholders with organizations leading sickle cell work in their local region. During this meeting, the working group will review the project scope and timeline for this effort before discussing edits to the database template and soliciting further feedback. Please come prepared to discuss and share feedback.</i>	<i>Laurence Noisette, MD, ASPHO;</i> <i>Group discussion encouraged</i>
10:35 A.M.	Group Discussion: World Sickle Cell Awareness Day Plans <i>World Sickle Cell Awareness Day 2023 is Monday, June 19th. Each year, the sickle cell community uses this day to raise awareness on sickle cell and advocate for warriors in their local community and worldwide. Attendees are encouraged to share what their organizations are doing to celebrate World Sickle Cell Awareness Day and how the SCDC may be of assistance.</i>	<i>Facilitator: Bukola Bolarinwa, SCAF & Haima Health Initiative – Co-Chair</i> <i>Report Outs: Working Group members</i>

10:45 A.M.	Member Updates <i>SCDC members are encouraged to share information about their organization's SCD-related news, projects, and meetings.</i>	<i>Working Group Members</i>
11:00 A.M.	Adjourn	

SCDC Global Issues Working Group Membership Roster

Member Organization
American Psychological Association (APA)
American Society of Gene & Cell Therapy (ASGCT)
American Society of Hematology (ASH)
American Society for Transplantation and Cellular Therapy (ASTCT)
Association of Public Health Laboratories (APHL)
Australian Sickle Cell Advocacy, Inc.
Axis Advocacy
Caribbean Institute for Health Research (CAIHR)
Caring Cross
Cayenne Wellness Center
Cerus
Clinton Health Access Initiative (CHAI)
Crispr Therapeutics
CSL Behring
Emmaus Medical Life Sciences
European Sickle Cell Federation (ESCF)
U.S. Food and Drug Administration (FDA)
FMDT SOS GLOBI
Foundation for Sickle Cell Disease Research (FSCDR)
Global Alliance of Sickle Cell Disease Organizations (GASCDO)
Global Sickle Cell Disease Network

GlycoMimetics
Hematology and Oncology Society of Africa
Hemex Health
Imara
International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA)
Mellamia Global Foundation
Muhimbili University of Health and Allied Sciences (MUHAS)
National Black Nurses Association (NBNA)
Novo Nordisk
Options for Children in Zambia
Our Sickle Cell Educare Warriors Initiative (OSCEWI)
Pan African Sickle Cell Federation International (PASCFI)
Pathways to Trust
Reach A Child in Africa (RACIZ)
Relife Health Foundation
Sarafinah Sickle Cell Society (SASCELLS)*
Sickle Cell 101
Sickle Cell Adult Provider Network
Sickle Cell Aid Foundation
Sickle Cell Advocacy and Management Initiative (SAMI)
Sickle Cell Awareness Group of Ontario (SCAGO)
Sickle Cell Disease Association of America (SCDAA)
Sickle Cell Disease Association of Canada
Sickle Cell Foundation of Ghana
Sickle Cell Outcome Research program (“SCORE”), the Netherlands
Sickle Cell Research Center
Sickle Cell Research Centre – Uganda
Sickle Cell Society UK
Sickle Cell and Thalassemia Ireland

Sickle Cell Transplant Advocacy and Research Alliance (STAR)
Sickle Cell Uhuru Trust (SCUT)
Sickle Cell Warriors
Smile Sickle Cell Foundation
Tanzania Sickle Cell Warriors Organization
The Shikuri Project Charitable Trust
The Sickle Cell Disease Association of Canada/L'Association D'Anemie Falciforme Du Canada (SCDAC/AAFC)
Terumo BCT
Thalassemia International Federation
Your Non-Profit Guru
Zambian Network for Sickle Cell-Amplified Voices & Advocacy (ZNSAVA)*

**New Global Issues Working Group Member*