

THE SICKLE CELL COMMUNITY CONSORTIUM

3RD ANNUAL LEADERSHIP SUMMIT &
GENERAL ASSEMBLY OF CBO'S



Friday March 23-Tuesday March 27, 2018

Atlanta Evergreen Marriott Conference Resort

4021 Lakeview Dr, Stone Mountain, GA
30083

www.sicklecellconsortium.org

SICKLE CELL COMMUNITY CONSORTIUM

The logo for the Sickle Cell Community Consortium (SCCC) features the letters "SCCC" in a bold, teal, sans-serif font. The letters are contained within a white square that has a teal border.

Unity. Commitment. Progress.

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Greetings,

The Sickle Cell Community Consortium is pleased to announce the 2018 Leadership Summit & General Assembly of Patients, Caregivers and Community-based organizations (CBOs). The Consortium is a 501(c)(3) not-for-profit collective of Patients, Caregivers, CBOs, Community Partners, and Sponsored Patient Organizations - each dedicated to sickle cell advocacy, education, research, community awareness and patient support throughout the country. The Consortium was created to provide an organizing arm to enable our communities to identify and address local and national needs. Patterned after the United Nations, and following a model of Collective Impact, we provide a platform to “amplify the power of the patient voice”. As part of this collaborative effort, we are excited to host the 2018 Leadership Summit and General Assembly, March 23-27, 2018 in Stone Mountain, Georgia. This meeting is open to the public. You are invited to join us as we continue to effect patient-powered change in our community.

The Leadership Summit and General Assembly is the main meeting of the Consortium, during which patient and caregiver-identified priorities are defined. All Consortium partners from throughout the country gather annually to participate in this meeting. We use this time to provide training and best practices session on:

- Effective advocacy in the rare disease space
- Maintaining strong sickle cell CBOs.

Participants also participate in the business meeting of the Consortium and the annual General Assembly of Advocates and CBOs.

The General Assembly is the primary organ and decision-making body of the Consortium. Comprised of partnered CBOs, sponsored patient organizations, and patient and caregiver advocates, this group is tasked with defining and prioritizing the top needs and gaps within the sickle cell community; developing community-based solutions; and identifying the CBO, community and corporate partnerships best equipped to execute those solutions. Working in partnership with healthcare/research advisers and community partners, patients, caregivers and CBOs lead the teams dedicated to tackling each priority.

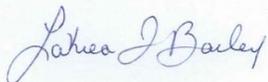
This year we are excited to present “COMPASS: Community Participation to Advance the Sickle Cell Story”. The focus of this PCORI-funded project is to capture the patient voice in determining patient priorities to bridge the gap between research, practice and true outcomes (change) for the sickle cell community. COMPASS represents a continuation of our Patient-Centered Outcomes Initiative designed to:

- Educate and engage sickle cell patient and caregivers on patient-reported outcomes (PRO) and comparative effectiveness research (CER)
- Directly involve patients and caregivers in identification and prioritization of CER research topics
- Provide a platform for patient-focused development of Alternative Endpoints and Surrogate Markers in Clinical Trial Design

Birtherd out of community desire to have a seat at the table (and not just a voice in the crowd), this initiative will was designed to engage patients, caregivers and CBOs to generate a list of patient-identified research priorities and CER questions through engagement, education and empowerment. The findings will be used to inform researchers, physicians, policy makers, funding agencies, community-based organizations, and other entities about the research needs of sickle cell patients, using the patients’ VOICE and prepare sickle cell CBOs for participation in CER projects.

Collectively, the Summit is our opportunity, as patients, caregivers, advocates and allies, to create positive, sustainable change in the sickle cell community. You are invited to join us as we undertake this task.

Sincerely,

A handwritten signature in blue ink that reads "Lakiea J Bailey". The signature is written in a cursive, flowing style.

Lakiea J Bailey, Ph.D.
Executive Director
Sickle Cell Community Consortium

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2018 LEADERSHIP SUMMIT & GENERAL ASSEMBLY

The Leadership Summit & General Assembly represents the annual gathering of all Consortium partners and affiliated participants. This Summit provides an opportunity to interact with key opinion leaders and the executive leadership of sickle cell CBOs throughout the country. We are expecting over 100 participants, representing 26 CBOs from AL, AR, CA, CO, CT, DE, FL, GA, IN, LA, MD, MI, MN, NC, NJ, NY, OK, PA, SC, TN, TX....and growing.

2018 LEADERSHIP SUMMIT AGENDA OVERVIEW

FRIDAY, MARCH 23, 2018	
2:00 PM	Opening of the General Assembly
	2:00 Welcome & Opening
	2:15 2017 Review: Mental Health Update
	2:30 2017 Review: Transition Toolkit & Workgroup
	2:45 2017 Review: SCD Anthology
	3:00 2017 Review: Patient Toolkit
	3:15 2017 Review: Engaging the Warrior Man
	3:30 Warrior University
	3:45 Parent-to-Parent
4:00 PM	BEST PRACTICES
SATURDAY, MARCH 24, 2018	
10:00 AM	FOCUS ON RESEARCH
	10:00 COMPASS: Community Participation to Advance the Sickle Cell Story
	HRSA EMBRACE project update
	CDC/GA Policy Community Project update
1:00 PM	LUNCH
2:00 PM	GENERAL ASSEMBLY I: THE DOCKET
SUNDAY, MARCH 25, 2018	
10:00 AM	GENERAL ASSEMBLY II: THE SOLUTION
1:00 PM	LUNCH
2:00 PM	GENERAL ASSEMBLY II (cont): EXECUTION – 1 st Committee Meetings
3:00 PM	BUSINESS MEETING
MONDAY, MARCH 26, 2018	
10:00 AM	BEST PRACTICES
1:00 PM	LUNCH
2:00 PM	BEST PRACTICES
TUESDAY, MARCH 27, 2018	
9:00 AM	BREAKFAST
10:00 AM	BEST PRACTICES
11:00 AM	CLOSE OF THE 2018 GENERAL ASSEMBLY

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2018 LEADERSHIP SUMMIT AGENDA SESSIONS

MARCH 23, 2018 – MARCH 27, 2018

*Consistent with Consortium commitment to full transparency, all meetings, sessions and workshops connected to the Leadership Summit and General Assembly of CBOs are open to the public. The floor will not be open to public comment during the Consortium Business Meeting.

*Although all sickle cell stakeholders are invited to observe, the General Assembly of CBOs is designed to be entirely self-driven by Patient Advisors, Families and Partner CBOs. Industry participation is limited.

BEST PRACTICES

These sessions, taught by a diverse range of experts in the non-profit sector, are devoted to providing lessons and workshops on building strong community-based, not-for-profit organizations. These sessions also focus on expert patient advocacy for our patient and caregiver leaders within the sickle cell community.

GENERAL ASSEMBLY I

The General Assembly, comprised of representatives from each CBO, community partners and patient advisors, is the decision-making body of the Consortium. It is the job of this group to collectively identify needs, gaps or problems within the sickle cell community; to develop community-centered, patient-led solutions; and identify partnerships equipped to execute effective solutions in a manner that incentivizes cooperation and collaboration between CBOs. General Assembly I will focus on the current state of sickle cell care, research, treatment options and policy, leading to the discussion "where do we, as a group, go from here?" Consortium staff will prepare a summary of this discussion to present during General Assembly II.

GENERAL ASSEMBLY II

This session will focus on collectively developing solutions to address community needs and concerns, then identify partnerships among our diverse stakeholders best equipped to execute these solutions. Each CBO team is tasked with applying the model of "Collective Impact" to identify, address and execute the mutually agreed upon solution through a joint plan of action. (Our step-by-step process to collect data and measure result through shared accountability is available for review.) The Consortium serves as a backbone organization to manage resources and coordinate CBO teams.

BUSINESS MEETING

This afternoon session is dedicated to engaging CBO leaders in a discussion about the power of the patient voice and patient-centered outcomes research. This is the beginning of a multi-step process, continued at the 10th SCD Research & Educational Symposium in April, two online patient-engagement meetings and culminating at the 3rd Annual Sickle Cell Warriors, Inc. Patient and Family Gathering & Education Symposium.

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Harnessing the power of the patient voice.

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THE LEADERSHIP SUMMIT: SUPPORT AND OUTCOMES

This year marks our third year hosting the Leadership Summit & General Assembly. Last year we brought together over 80 individuals, representing 23 community-based organizations (CBOs) from 21 states and Canada. This diverse group of stakeholders defined community priorities, formed strategic partnerships and launched several national initiatives. In the three years since this meeting began our patient, caregiver and CBO partners have developed, launched and powered many amazing initiatives (including, but not limited to):

- Patients and caregivers have participated in dozens of conferences and symposiums at part of *#Show-Up and #Speak-Up for Sickle Cell*
- Launched our Patient-Centered Outcomes Initiative
- Launched the Clinical Trials Initiative
- Published the first in a series of Patient-Powered Educational Lectures “*Define Yourself, Define Your Life: A Guide to Living with Sickle Cell*”.
- Powered the Annual Sickle Cell Patient & Family Education Symposium (the Warrior Convention), co-hosted annually by partnered sickle cell CBOs in the community.
- Organized a Mental Health Initiative and host bi-monthly community discussions on mental health concerns.
- Developed the Transition Workgroup and prioritized development of a Transition Toolkit.
- Formed the Sickle Cell Men’s Action Network in collaboration with Sickle Cell Champions Association.
- Launched Warrior University, beginning with the Social Media Webinar series.
- Launched COMPASS: Community Participation to Advance the Sickle Cell Story, a PCORI supported project.
- Partnered to develop a physical toolkit to aid the patient and caregiver in self-care.
- Prioritized the development of a Sickle Cell Anthology to showcase the life and talent of the sickle cell patient and caregiver.

With support from:

2016 LEADERSHIP SUMMIT SPONSORS



2017 SPONSORS & SUPPORTERS



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The 2018 Leadership Summit & General Assembly of Patients, Caregivers and CBOs will be held Friday, March 23, 2018 to Tuesday, March 27, 2018. Non-partner registration and sponsorship package information is available upon request. Please contact Dr. Lakiea Bailey for more information.

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COMPASS

COMMUNITY PARTICIPATION TO ADVANCE THE
SICKLE CELL STORY



"Nothing For US, Without US"

-- THE SICKLE CELL COMMUNITY CONSORTIUM