

SICKLE CELL COMMUNITY CONSORTIUM

SCCC

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2017

LEADERSHIP SUMMIT & GENERAL ASSEMBLY



**Atlanta Marriott Perimeter Center
246 Perimeter Center Pkwy NE
Atlanta, GA 30346**

March 16 – 19, 2017

For sponsorship information contact Dr. Lakiea Bailey,
Director@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, which is itself set against a teal background.

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Greetings,

The Sickle Cell Community Consortium is pleased to announce the 2017 Leadership Summit & General Assembly of Advocates and Community-based organizations (CBOs). The Consortium is a 501(c)(3) not-for-profit collective of Sickle Cell Community-Based Organizations (CBOs), Community Partners, Sponsored Patient Organizations, Patient/Caregiver Advocates and Healthcare/Research Advisors - 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 2017 Leadership Summit and General Assembly, March 16-19, 2017 in Atlanta, 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.

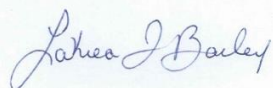
This year we are excited to launch our CLINICAL TRIALS INITIATIVE as a continuation of the Patient-Centered Outcomes Initiative of 2016. The focus of our Patient-Centered Outcomes Initiative is two-fold:

- Direct involvement of Patients and Caregivers in topic generation and prioritization for Patient-Centered Outcomes Research
- Patient-focused development of Alternative Endpoints and Surrogate Markers in Clinical Trial Design

As we move into the next phase of this initiative, we will apply the collective power of the Patient, Caregiver and CBO General Assembly to define patient-identified barriers to minority participation in clinical trials. Our strength is in our unity. Drawing upon existing research, and in partnership with the Consortium network of community partners and healthcare/research advisers, we will tackle the social constructs and deeply rooted misconceptions that inform patient/caregiver opinion and impede increased participation in clinical trials.

For more information, to register to attend, or sponsorship information, please contact Dr. Lakiea Bailey at Director@sicklecellconsortium.org. We look forward to working with you.

Sincerely,

A handwritten signature in blue ink that reads "Lakiea J Bailey".

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

director@sicklecellconsortium.org

o | 706.619.6029

m | 706.452.3193

f | 706.619.6029

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2016 LEADERSHIP SUMMIT & GENERAL ASSEMBLY OF ADVOCATES AND CBOS: SUPPORT AND OUTCOMES

BY THE NUMBERS

- 70 Representatives
- 21 CBOs
- 17 States
- 4 Days
- 31 Hours of workshops, training, education, strategic solution development and collaborative implementation of those solutions



2016 LEADERSHIP SUMMIT SPONSORS



Last year marked our first Leadership Summit & General Assembly, which brought together over 70 individuals, representing 21 community-based organizations (CBOs) from 17 states. This diverse group of stakeholders defined community priorities, formed strategic partnerships and launched several national initiatives. With support:

- Patients and caregivers participated in over a dozen conferences and symposiums at part of *#Show-Up and #Speak-Up for Sickle Cell*
- Launched our Patient-Centered Outcomes 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 3rd Annual Sickle Cell Patient & Family Education Symposium (co-hosted by Sickle Cell Warriors, Inc., Sickle Cell 101, and IASCNAPA)
- Organized a Mental Health Workgroup (Priority #1)
- Developed a Transition Workgroup
- Formed the Sickle Cell Men's Action Network in collaboration with Sickle Cell Champions Association (Priority #2)
- Developed (but not yet launched) a social media webinar series (Priority #3)

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2017 LEADERSHIP SUMMIT & GENERAL ASSEMBLY

The Leadership Summit & General Assembly is 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.

This year we are expecting over 100 participants, representing 26 CBOs from Alabama, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Indiana, Louisiana, Maryland, Michigan, Minnesota, North Carolina, New Jersey, New York, Oklahoma, Pennsylvania, South Carolina, Tennessee and Texas.

To attend the summit or obtain sponsorship packages please contact Dr. Lakiea Bailey, Director@sicklecellconsortium.org.



We are delighted to welcome Be The Match as a new community partner, along with StoryCorps, Xcentric Media, Online Media Interactive and FGM Story, LLC. In response to a need identified by our partners, we are excited to include a Creative Content video production workshop and laboratory. It doesn't take expensive equipment to make quality videos. Partners that sign-up for this workshop will learn the tips and tricks to capture an audience and produce quality video content. Participants will have access to the Creative Content lab to obtain hands-on practice with basic level hardware and software, as they learn to produce content that promotes sickle cell awareness, education and their CBO brands.



Xcentric Media will be onsite to provide professional headshots and StoryCorps will join us to collect and share our stories. StoryCorps is a national project whose mission is to preserve and share humanity's stories, to build connections between people and create a more just and compassionate world. We are grateful to StoryCorps for helping us kick off #OurStoriesMatter. This invaluable archive will be stored for future generations at the Library of Congress. We will continue #OurStoriesMatter throughout the year to collect stories from Warriors throughout the Country.

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AGENDA OVERVIEW

MARCH 16, 2017 – MARCH 19, 2017

*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.

Thursday, March 16:

- **Registration (10 AM – 1 PM)**
The Registration Table will be located in the Lobby of Atlanta Marriott Perimeter Center hotel. Partners are requested to register by noon. All others should register by 1 PM. Registration will open again at 8 AM on Fri. March 17th.
- **Welcome Reception (2 PM – 3 PM)**
- **Opening of the 2nd Session of the General Assembly (3 PM – 5 P)**
Official opening of the Second Session of the General Assembly of CBOs, Patients and Caregivers.
 - Consortium Charter, By-laws and Rules of Procedure: Approval, Amendments and Addendums
 - 2016 Outcomes & General Assembly Session I Priorities Progress Reports
- **Creative Content Workshop (5pm -8pm)**

Friday, March 17:

- **Best Practices I (9am – 12:45pm)**
These morning 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.
- **Lunch (1 PM – 1:55 PM)**
- **General Assembly I (2pm – 5pm)**
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.
- **IN-PERSON AUCTION**
Join the CBOs, patients and caregivers of the Sickle Cell Community Consortium as we host our second annual auction with Silent Auction Pro.

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Saturday, March 18:

- **General Assembly II (9am -12pm)**
This session will focus on collectively developing solutions to address community needs and concerns, and 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.
- **BE THE MATCH (12pm -12:15pm)**
We are excited to welcome Be The Match as they share new initiatives to increase donor availability for sickle cell warriors.
- **Lunch (12:30 PM – 1:30 PM) – Clinical Trials Initiative**
Launch of the 2017 Clinical Trials Initiative
- **Research/Industry Roundtable (1:35 PM – 2:25 PM)**
Roundtable discussion with leaders from research/pharmaceutical industry. Q&A with direct engagement and interaction with CBO directors and patient community leaders.
- **Business Meeting (2:30 PM – 4 PM)**
- **Working Group Meetings (4 PM – 5 PM)**
- **Dinner (5 PM)**

Sunday, March 19:

- **Breakfast Buffet (9 AM – 10 AM)**
The Business of Advocacy: Proposals, Budgets, Requests For Funds
- **Best Practices II (10 AM – 12 PM)**
Continuation of best practices for developing and growing strong non-profit organizations.
- **Creative Content Workshop II (10 AM – 12 PM)**
- **Close of the 2nd Session of the General Assembly**

[RESERVE YOUR ROOM AT THE ATLANTA MARRIOTT PERIMETER CENTER](#)

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MARCH 16 – 19, 2017

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SICKLE CELL COMMUNITY ONLINE & LIVE AUCTION

Help a great cause and pick up something you like...
The Sickle Cell Community Consortium Presents its first **LIVE** Auction.

March 13th – 17th 2017

Join us online as we auction off great items, packages, and fun things to do.

Sign-up here: <http://tinyurl.com/SCD-Auction-2017-signup>



Scan the QR code above to place your bids

OR

Go to m.silentauctionpro.com on your **mobile device** and enter group number **708**

Place bids from your computer at <http://tinyurl.com/auction-computer-tablet-bids>

If you're in the Atlanta area join us in person for our live event at:

Atlanta Marriott Perimeter Center

March 17th 2017

Our goal is to raise \$30,000 to support patient-powered projects and initiatives, provide support for patients and caregivers to #Show-Up and #Speak-Up for Sickle Cell Disease, and provide best practices training, infrastructure support and resources to Sickle Cell CBOs across the country in support of their mission to promote awareness and provide education and direct patient services throughout their local regions.

Tickets for the LIVE Event: <http://tinyurl.com/SCD-Auction-2017-tickets>

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February 14, 2017

Sickle Cell Community Consortium
525 Tribble Gap Rd. #1195
Cumming, GA 30040

GREETINGS!

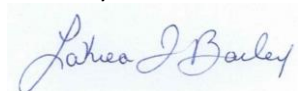
The Sickle Cell Community Consortium (the Consortium) is a national collaborative of sickle cell community-based organizations (CBOs), patients, caregivers, healthcare providers and researchers, working collectively to equip and empower every individual living with sickle cell disease to be full participants, and lead the charge, in sickle cell advocacy, education, research, legislation and policy. Sickle cell disease is a devastating, hereditary blood disorder that can cause those living with this disease excruciating pain, debilitating fatigue and life-threatening tissue/organ damage. Since it was first identified in Western literature, the brave individuals living with this disease were expected to wait quietly for death. We, the patients, caregiver and CBOs of the Consortium reject this entirely and have pledged to fight for our lives and to be the authors of the change we wish to see in our community.

This year the Sickle Cell Community Consortium will host an online auction March 13th – March 17th to raise funds for the work that we do. The online auction will end with a live event at the Atlanta Marriott Perimeter Center on March 17th. Our goal is to raise \$30,000 to support patient-powered projects and initiatives, provide support for patients and caregivers to #Show-Up and #Speak-Up for Sickle Cell Disease, and provide best practices training, infrastructure support and resources to sickle cell CBOs across the country in support of their mission to promote awareness and provide education and direct patient services throughout their local regions.

In celebration of the will and drive of our patients and their caregivers, and in support of the mission of the CBOs throughout Georgia and abroad, please consider contributing an item, service or monetary donation to our auction. Your donation will be acknowledged by announcing the store's support on the auction website, Consortium social media and all participants of auction and annual Leadership Summit (occurring concurrently with the auction). Your logo will be placed on all related material and your business information on all printed and electronic materials. Your support has a meaningful impact on the work that we do and ensures that the Sickle Cell Community Consortium will continue to serve the CBOs, patients and caregivers dedicated to creating a sustainable impact in the sickle cell community. All donations are tax deductible.

Please feel free to contact me directly with all questions, comments or concerns. Thank you for your support.

Sincerely,



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

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PLEDGE FORM

Thank you for donating to the Sickle Cell Community Consortium. The purpose of this form is to register your donation for your tax purposes and to create a catalog of donated items for the online program. Your generous donation will support the patient-powered projects, platforms and initiatives of the Sickle Cell Community Consortium. Please provide as much detail as possible. All donations are tax deductible. Please complete a separate form for each donation. This form can be [completed electronically](https://goo.gl/forms/FxYgCHXEBUecgvZu2) at <https://goo.gl/forms/FxYgCHXEBUecgvZu2>

Donor or Company Name:
Contact Address:

Email Address:
Contact Phone Number:
(Is this phone text-enabled? May we text you with updates and/or reminders about the auction?) [Y / N]:

Donation Name:
Retail Value:
Suggested Starting Bid:

Donation Description (Please enclose a picture if appropriate):

Please Select below:

☐ Donation is enclosed with this form.

☐ Donation will be mailed or dropped off (No later than March 1st):

Atlanta APEX Museum
C/O Mr. Dan Moore
135 Auburn Ave.
Atlanta, Georgia

☐ Donor would like item picked up (please notate any instructions to that regard below)

Additional Comments:

o | 706.619.6029

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