

# SICKLE CELL COMMUNITY CONSORTIUM

SCCC

*Unity. Commitment. Progress.*

WWW.SICKLECELLCONSORTIUM.ORG

## 2018

## LEADERSHIP SUMMIT & GENERAL ASSEMBLY



**Evergreen Marriott Conference Resort  
& Stone Mountain Inn  
4021 Lakeview Dr. Stone Mountain, GA 30083**

**March 23-27, 2018**

# SICKLE CELL COMMUNITY CONSORTIUM

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Greetings and happy new year!

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 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, and to ensure that the patient and caregiver sits at the center of community-based solutions. We work to guarantee that the community is directly involved in all aspects of sickle cell education, awareness, advocacy, research, legislation and policy. 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.

The Leadership Summit and General Assembly is the main meeting of the Consortium, during which patient and caregiver-identified priorities are identified and 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: 1. Effective advocacy in the rare disease space, and 2. Maintaining strong sickle cell CBOs. Participants also participate in the business meeting of the Consortium and the annual General Assembly of Advocates and CBOs.

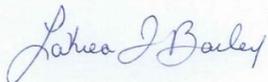
This year marks our third year of organized, strategic activity. By working collectively, we have:

- Launched our Patient-Centered Outcomes Initiative and Clinical Trials Initiative.
- Launched #Show-Up and Speak-up for Sickle Cell, which has ensured that patients and caregivers have the support to attend sickle cell conferences and symposiums. We’ve granted over \$50K in scholarships as part of this initiative.
- Host the annual Sickle Cell Patient & Family Education Symposium (the Warrior Convention)
- Published “*Define Yourself, Define Your Life: A Guide to Living with Sickle Cell Disease*” as part of an ongoing Patient-Powered Educational Literature series.
- Launched a Mental Health Initiative to address the burgeoning need for mental health education and support in the sickle cell community
- Launched Warrior University, an online webinar series to provide continuous advocacy training, CBO best practices guidance and patient-facing disease education.
- And much, much more.

This year we are excited to announce our participation in two PCORI-funded, one HRSA-funded and one CDC/Georgia Policy-funded initiative. We will specifically focus on COMPASS: Community Participation to Advance the Sickle Cell Story, a PCORI: Pipeline to Proposal initiative created by the Consortium 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.

Thank you for your continued support in this endeavor,

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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## SUMMIT SPONSORSHIP 2017

**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.

We currently have **commitment to attend** from over 100 Partners, representing patients, caregivers and 26 CBOs from AL, AR, CA, CO, CT, DE, FL, GA, IN, LA, MD, MI, MN, NC, NJ, NY, OK, PA, SC, TN, and TX. This list is growing. With your help, we can unify and collectively amplify the voice of the sickle cell patient in a productive and beneficial manner. Please consider sponsoring at the various levels below: 1 Platinum (\$50K), 2 Gold (\$40K), 3 Silver (\$25K), 5 Bronze (\$10K), and Advocate (\$5K). In addition to these levels, there are also multiple other ways to support our patient-powered priorities. Your support will ensure that we can provide support and engage a maximum number of patient community leaders.

### LAST YEAR: 2017 LEADERSHIP SUMMIT & GENERAL ASSEMBLY OF ADVOCATES AND CBOs

#### BY THE NUMBERS

- 80 Representatives
- 23 CBOs
- 21 States + Canada
- 4 Days
- 34 Hours of workshops, training, education, strategic solution development and collaborative implementation of those solutions



#### THANK YOU!

2017 LEADERSHIP SUMMIT & GENERAL ASSEMBLY



GOLD



SILVER



BRONZE



ADVOCATE

ATLANTA MARRIOTT PERIMETER CENTER  
MARCH 16 – 19, 2017

#### 2017 Community Partners



LEADERSHIP SUMMIT & GENERAL ASSEMBLY  
ATLANTA, GEORGIA  
March 16 – 19, 2017

**For more information or to sponsor, contact:**

**Dr. Lakiea Bailey** at [Director@sicklecellconsortium.org](mailto:Director@sicklecellconsortium.org); or  
**Kim Davis** at [KDavis@sicklecellconsortium.org](mailto:KDavis@sicklecellconsortium.org)  
**Office: (706) 204 - 9269**

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## OVERVIEW OF 2018 SUPPORTER BENEFITS

The Sickle Cell Community Consortium holds two meetings annually for which support is requested from SCD Community Stakeholders. These meetings are particularly suited to Industry partners who are researching new therapies and represent opportunities to reach a diverse population of patients and caregivers eager to hear updates on drug development, research and new information on active and future clinical trial opportunities.

The Annual Leadership Summit & General Assembly in Spring is the meeting of all Consortium partners and affiliated participants working in collaboration with the Consortium. This Summit provides an opportunity to interact with key opinion leaders and the executive leadership of sickle cell CBOs throughout the country. During the Summer, SCCC will jointly host the Sickle Cell Patient and Caregiver Educational Symposium, in collaboration with several partnered CBOs.

The support levels for the 2017 Leadership Summit & General Assembly are designed to enhance meeting attendance and engagement with our supporters. All support levels include allocations for travel grants, from 10% to 50% depending on the support level. Multiple supporters per level are available except for the Platinum level which is exclusive.

Combinations of tiered sponsorship and additional opportunities are offered to encourage more engaged support by way of ancillary events such as a speaker program or reception, as well as additional branding opportunities.

Organization Name:		
Contact Person:		
Email Address:	Phone:	
Mailing Address:		
City:	State:	Zip:

Yes, we would like to be a Supporter of the 2017 National Assembly:

All Support Levels receive \* Supporter Ad package – various print (B&W and Color), Digital and Onsite Signage, Meeting Bag insert, badge lanyards

*PLEASE NOTE: 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 Advocates, Families and Partner CBOs. Industry participation is limited in this portion of the Summit.*

# SUPPORT PACKAGE OPTIONS

## Platinum Support at \$50K or above receives

- Organization's name listed in meeting publicity: press releases, web page and interviews
- Full page color ad in the event program, on site signage (if any) and verbal recognition at the event
- Organization's name and logo featured in social media mentions of the event
- Up to 6 representatives to attend the event
- Dinner Sponsorship (only 1)
- Tuesday Breakfast Sponsorship (only 1)
- In line exhibit space
- 10% of the support will allow Travel Grant for CBO leader and patient/caregiver attendees
- 50% of the support will be allocated for advertising and signage package
- 40% of the support will be allocated for sole sponsorship of a dinner event

## Gold Support (2 available) at \$40K receive

- Organization's name listed in meeting publicity: press releases and web page
- ½ or Full page color ad in the event program, on site signage
- Organization's name and logo featured in social media mentions of the event
- Up to 4 representatives to attend the event
- Lunch event sponsorship (1 of 3)
- In line exhibit space, table
- 10% of the support will allow Travel Grant for CBO leader and patient/caregiver attendees
- 50% of the support will be allocated for advertising and signage package
- 40% of the support will be allocated for sole sponsorship of a dinner event

## Silver Support (3 available) at \$25K receive

- Organization's name listed in meeting publicity: press releases and web page
- ½ color ad in the event program, on site signage
- Organization's name and logo featured in social media mentions of the event
- Up to 3 representatives to attend the event
- In line exhibit space, table
- 15% of the support will allow Travel Grant for CBO leader and patient/caregiver attendees
- 50% of the support will be allocated for advertising and signage package
- 35% of the support will be allocated for sole sponsorship of a breakfast event

## Bronze Support (5 available) at \$10K receive

- Organization's name listed in meeting publicity: web page
- ½ b&w ad in the event program, on site signage (if any)
- Up to 2 to attend the event
- In line exhibit space, table
- 25% of the support will allow Travel Grant for CBO leader and patient/caregiver attendees
- 75% of the support will be allocated for advertising and signage package

## Advocate Support (no limit) at \$5K receive

- Organization's name listed in meeting publicity: web page
- 1/4 b&w ad in the event program
- 1 representative to attend the event
- In line exhibit space, table
- 50% of the support will allow Travel Grant for CBO leader and patient/caregiver attendees
- 50% of the support will be allocated for advertising and signage package

## Creative Content Workshop/Lab Sponsor (no limit) at \$3K receive:

- Organization's name listed in meeting publicity: web page
- 1/4 b&w ad in the event program
- 1 representative to attend the event
- Opportunity to address the Creative Content participants

The Creative Content Workshop and Lab is a new edition to the Summit. Many of our Partnered CBOs and Advocates use video sharing platforms, such as YouTube, to engage with patients and the public. Designed to provide our advocates the training and opportunity to learn effective skills and techniques in content creation, sponsors will enable our partners to embrace a new form of media and content sharing. Sponsors will have the opportunity to address this group and see first-hand the amazing content being created by sickle cell advocates.

**Additional Sponsorship Opportunities:**

For more flexibility, the following additional sponsorship are available to be added to any Support level:

- Ancillary Event, e.g. Advisory panel, Speaker program or Reception \$2K
- Supplemental Travel Grant \$1.5K increments
- Exhibit Space: Table \$500
- Digital Sponsor@: including reciprocal SM posts per subject \$1000 (multiple)
- WiFi/AV Sponsor \$750

**Custom Sponsorship Engagements:**

For Sponsors seeking to tailor their sponsorship please propose combinations of features in the Tiered and Additional categories for consideration. Alternative proposals are welcome and we will attempt to accommodate them if possible. Please forward all Support requests by March 5<sup>th</sup> to:

**Dr. Lakiea Bailey at [Director@sicklecellconsortium.org](mailto:Director@sicklecellconsortium.org); or  
Kim Davis at [KDavis@sicklecellconsortium.org](mailto:KDavis@sicklecellconsortium.org)  
Office: (706) 204 - 9269**

**THANK YOU FOR SUPPORTING THE PATIENTS, CAREGIVERS AND CBOs OF THE SICKLE CELL  
COMMUNITY CONSORTIUM!**