

# SICKLE CELL COMMUNITY CONSORTIUM Leadership Summit and General Assembly of CBOs

Unity • Commitment • Progress



**THURSDAY, MARCH 16 - SUNDAY, MARCH 19, 2017**

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

[www.sicklecellconsortium.org](http://www.sicklecellconsortium.org)

# Letter from the Director

Welcome to the second annual Sickle Cell Community Consortium Leadership Summit and General Assembly of Patients, Caregivers and Community-Based Organizations (CBOs). We are thrilled to welcome over 100 partners and supporters, representing nearly 30 CBOs from 22 states to beautiful Atlanta, Georgia. The Summit is the main meeting of the Consortium. During your time here we will review our progress from the 2016 General Assembly priorities, provide training on best practices for effective advocacy in the rare disease space and maintaining strong, effective CBOs, and participate in the partner business meeting. We will also convene the 2nd Session of the General Assembly.

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, you will be 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, you will each lead the teams dedicated to tackling each priority.

This year we are excited to launch our CLINICAL TRIALS INITIATIVE as a continuation of the 2016/2017 Patient-Centered Outcomes Initiative (PCOI). As with all Consortium projects, platforms and initiatives, our initial steps were designed by sickle cell Warriors and future directions will be defined and powered by you, the patients, caregivers and CBOs of the Consortium. Collectively, we will tackle the social constructs and deeply rooted misconceptions limiting minority and Warrior participation in clinical trials.

We are also delighted to present the Digital Visual Content Workshop with Creative Space Lab. Partners will have access to experts, hardware and software to improve the creation of visual content. Other partner services include, among others, 30 minute consultations with the Consortium Director of Finance Eric Frempong, professional headshots with Jamie Starr of Xcintric Media, LLC, and CBO spotlight videos with Minimarie Andrews.

The Leadership Summit & General Assembly of patients, caregivers and CBOs is our most important meeting. The Summit is our opportunity to further develop and execute the Consortium's founding mission to provide a platform to harness and amplify the power of the patient voice and to provide infrastructure support and training for sickle cell CBOs. We are grateful to our corporate and community sponsors for your continuous support of this mission. This year's focus on capacity building and fiscal sustainability was made possible, in large part to Global Blood Therapeutics, bluebird bio, Pfizer Pharmaceuticals and Prolong Therapeutics. Thank you to all CBO partners and patient/caregiver Advocates. We are only as effective as your constant drive, will and commitment to our collective cause. THANK YOU!



Lakiea Bailey

Executive Director, Sickle Cell Community Consortium

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# Our Sponsors & Supporters

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# At - A - Glance

## THURSDAY, MARCH 16

- ❑ **Registration**  
Atlanta Marriott Perimeter Center hotel lobby
- ❑ **Press Conference**  
Fair Treatment in the Emergency Department
- ❑ **Welcome Reception**
- ❑ **Opening of the 2nd General Assembly**
  - ❑ 2016 Outcomes & General Assembly Session I: Priorities, Progress Reports
- ❑ **Best Practices I: Digital Video Content & Creative Space Lab**  
Best practices on designed increase the media literacy of all participants by offering a solid foundation of basic knowledge and technique to aid in the creation of visually appealing digital content on par with industry standards.

## FRIDAY, MARCH 17

- ❑ **Breakfast**
- ❑ **Best Practices II**  
These morning sessions, taught by a diverse range of experts in the nonprofit sector, are devoted to providing lessons and workshops on building strong community-based, not-for-profit organizations.
- ❑ **Lunch**
- ❑ **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. General Assembly I focuses on collectively defining and prioritizing needs, gaps or problems within the sickle cell community. Topic were placed on the Docket electronically prior to the start of the meeting.

## SATURDAY, MARCH 18

- ❑ **Breakfast**
- ❑ **General Assembly II**  
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.
- ❑ **Be the Match**  
We are delighted to welcome Be The Match, presenting on “Increasing access to bone marrow transplants for sickle cell disease patients”.
- ❑ **Lunch - Clinical Trials Initiatives**  
Launch of the 2017 Clinical Trials Initiatives
- ❑ **Clinical Trials Roundtable**  
This session features a roundtable discussion with industry representatives for active clinical trials and a clinical trial patient safety expert. The roundtable discussion will be followed by a question and answer session with patient, caregiver and CBO Summit participants.
- ❑ **Business Meeting**  
This session serves as the business meeting for Consortium infrastructure, main committees and the financial report. ALL partners are requested to attend and to join at least one Main Committee, in addition to at least one priority project committee.

## SUNDAY, MARCH 19

- ❑ **Working Breakfast**
- ❑ **Best Practices III & IV**  
Continuation of best practices for developing and growing strong non-profit organizations
- ❑ **Closing of the 2nd General Assembly**

# About the Sickle Cell Community Consortium

## ABOUT THE CONSORTIUM

**The Sickle Cell Community Consortium was founded** in February 2014 by a core group of patients and caregivers while attending the FDA Patient-Focused Drug Development meeting. For several years many in the community expressed a need to create a unified platform to support the many CBOs (both large and small) throughout the country as they work to ensure that the voice of the sickle cell patient and caregiver was central in all areas of research, legislation, advocacy, education and policy. Realizing that several of the key players in this discussion would be in Maryland for the FDA meeting, Dr. Lakiea Bailey convened the first meeting to lay the foundation for what would become the Sickle Cell Community Consortium. Over the course of the year that followed, she, along with Velvet Brown-Watts, Kena Drew, Douglas Deveaux, Laveda Wallace-Page, Nikki Peterson and a host of other patient and caregiver advocates, worked to establish the Consortium as a US-based not-for-profit collective of sickle cell stakeholders and opinion leaders. The Consortium's first official act was to organize and support the attendance of Warriors and Caregivers to 2014 (and 2015) SCDA Advocacy Day on Capitol Hill. The Consortium became an official 501(c)3 designated non-profit in August 2015 and held the first Leadership Summit and General Assembly of CBOs in March 2016.

**Organized in a manner similar to the United Nations**, Consortium partner CBOs retain their autonomy, while uniting to apply a model of Collective Impact to tackle deeply rooted social, media and legislative problems and barriers. The CBOs, along with Community Partners and Patient/Family Advisors, work together to identify and directly address community needs. The General Assembly, comprised of Partner CBOs and advisors, form the decision-making body of the Consortium tasked with forming mutually beneficial partnerships to develop and execute strategies and solutions to address the needs, gaps and concerns identified by the collective sickle cell community.

**Although we are a young organization**, by working collectively, Consortium partners have accomplished a great deal in a very short amount of time. In 2016, we provided over \$50,000 in travel, lodging and registration for patients and caregivers to #SpeakUp and #ShowUp for sickle cell and helped to coordinate patient/caregiver participation in sponsored meetings and focus groups throughout the country. The July Sickle Cell Patient and Family Education Symposium, co-hosted by Sickle Cell 101, IASCNAPA and Sickle Cell Warriors, Inc., was attended by over 100 patients, caregivers, researchers and providers. All workshops, panels and education session topics were chosen by sickle cell patients and caregivers. We launched our Patient-Centered Outcomes Initiative and formed the Mental Health Workgroup, the Sickle Cell Mens Action Network (M.A.N.) and the Transition Workgroup. The first project in the Patient-Powered Educational Literature series was developed, funded and completed. The final product "A Guide to Living with Sickle Cell" was written for sickle cell warriors by sickle cell warriors and is now available.

**Together, the patients, caregivers and supporters** of the Consortium have worked to define and alter the landscape of the sickle cell community for current and future generations. All projects are created and completed directly by our community. We are only able to succeed by working as a collective unit and invite all warriors, caregivers and CBOs to work with us as we equip and empower the sickle cell community to become full participants and lead the charge in sickle cell advocacy, education, research, legislation and policy.



# SCCC Board & Staff



**Lakiea J. Bailey, PhD.**  
**Executive Director of SCCC**

Dr. Lakiea Bailey is a sickle cell disease advocate, educator and research scientist. Diagnosed with sickle cell disease at age three, she has become a passionate advocate for those living with rare diseases and is committed to serving as a voice of encouragement and empowerment within the sickle cell community.

Despite the devastating symptoms of sickle cell, Dr. Bailey was determined to complete her educational goals, earning a Bachelor degree in Biochemistry and Molecular Biology in 2001 and a Doctorate degree in Molecular Hematology and Regenerative Medicine in 2012. During the course of her education, Dr. Bailey was named a Southern Regional Education Board (SREB) Doctoral Scholar, was the recipient of multiple honors and awards, including the Fisher Scientific Award for Overall Excellence in Biomedical Research, the Medical College of Georgia Alumni Association Award, the Georgia Regents University Leadership Award and was inducted in the Alpha Upsilon Phi honor society. She believes that through hard work, diligence, patience and faith, even the seemingly most impossible obstacles can be overcome.

Dr. Bailey recognizes that her success is due to the strength and commitment of many amazing advocates and supporters in her life and is determined to provide the same support and encouragement to others in the sickle cell community. She is therefore committed to serving as a resource for the sickle cell patient population as an advocate, educator, mentor and public speaker. Dr. Bailey is the Executive Director of the Sickle Cell Community Consortium, a coordinated network of sickle cell disease community-based organizations throughout the United States, a contract consultant with bluebird bio, has served as a patient engagement consultant with Pfizer Pharmaceuticals and sits on the Research Advisory Board for the Foundation for Sickle Cell Disease Research. Dr. Bailey enjoys traveling across the nation promoting sickle cell awareness and education and is available for sickle cell and health-related community events, conferences and seminars. Her goal is to continue to influence sickle cell disease-related biomedical research as well as social and medical policy and to travel around the country, and the world, advocating for those living with this disease.

# SCCC Board & Staff



**Doris Bailey**  
**Associate Director of Finance**

Doris Bailey is the Associate Director of Finance for the Sickle Cell Community Consortium. She completed her B.S. in Business with a concentration in Accounting from Indiana University-Bloomington, followed by a M.S. in Accounting and Financial Management. She is the parent of a sickle cell warrior and has been a vocal advocate for over 30 years.



**Bill Cummings**  
**Director of Development**

Bill brings the perspective of a caregiver, and the experience of a bio/pharmaceutical Marketing Director to his Rare Disease Patient Advocacy role. For the cause of SCD, Bill has consulted for several companies developing new therapeutics as well as contributed to national and local Community and Faith Based Organizations as well as Government initiatives to amplify the patient voice and promote collaborative solutions. As Principal of Cummings Group, Bill operates his Patient Advocacy consultancy and also manages a financial services practice. Married to his wife of 20 years and three sons of which the eldest has SCD. He resides in Upper Saddle River, NJ.



**Kim Davis**  
**Administrative Coordinator for Georgia**

Diagnosed with Sickle Cell Anemia, type SS at the age of 11, Kimberly is a dedicated and hardworking individual who has overcome many of the challenges against sickle cell disease. With an earnest desire to increase awareness of SCD and to see marked improvement in the care and treatment of those who suffer from SCD, she seeks to inspire and provide hope for all of those who battle daily with this egregious disease.

# SCCC Board & Staff



**Raymona Lawrence DPH**  
**Director of Research**

Dr. Lawrence has dedicated her career to community engagement and the elimination of health inequities and health disparities as they relate to African Americans living in rural populations—especially those with chronic diseases such as sickle cell disease. Her research and practice focus on discovering how healthcare delivery systems, public health, formal and informal community organizations, and participants come together to more effectively address health inequities/disparities in rural areas as well as how research related to community capacity can contribute to addressing health disparities.



**Eric Nti-Frempong, CPA, MTax, PMP**  
**Director of Finance**

Eric Frempong is the Director of Finance for the Sickle Cell Community Consortium. He is president of a professional firm specializing in individual income tax preparation and planning. He also prepared S-Corporation financial statement and income taxes.



**Nikki Peterson**  
**Special Projects Coordinator**

Nikki Peterson is a sickle cell warrior living in Upper Marlboro, Maryland. With a degree in Special Education from Bennett College, Nikki has taught special education grades K through 12 and is currently the president and CEO of Tutors-R-Us, an educational service in Maryland. Nikki enjoys working with children and advocates for children with special needs as well as for patients with sickle cell disease. Nikki was among one of the first employees of the Consortium wearing multiple hats. She currently serves as Special Projects Manager and is the Consortium liaison for Special Needs Education services.

# SCCC Board & Staff



**Mutsa Seremwe PhD**  
Associate Director of Research

She earned her Bachelors of Science in Biology in 2006 and attained her Doctorate degree in Physiology in 2014 at Georgia Regents University. Dr. Seremwe is currently a clinical study coordinator on several clinical research studies at Augusta University in conjunction with Augusta University Medical Center.

## Interns



**Nathaniel Gantz**

Nathaniel is a Sickle Cell Warrior. Diagnosed at 12 with Sickle Cell Anemia Type SS Beta Thalassemia. Nathaniel is also a Cancer survivor and has been in remission of Non-Hodgkin Lymphoma since August of 2016. He is passionate about helping patients not just survive but thrive through their illness. Nathaniel is an entrepreneur having business endeavors in both the Real Estate and Retail industries. He has also committed his time to intern with the Sickle Cell Consortium.

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# Interns



## Jazmine Rivera

Jazmine Alexis Rivera is currently finishing up her senior year with hopes to obtain her Bachelor's in Business Administration with an emphasis in Marketing. She is a 24 year old sickle cell warrior living in California, working on advocating and raising awareness for sickle cell disease.

Jazmine is huge advocate for Sickle Cell Disease where she is determined to educate people on this illness. She noticed the lack of education, information, and research on Sickle Cell Disease and therefore went on to become a patient advocate, and is currently a intern with the Sickle Cell Community Consortium. She advocates for Sickle Cell Disease, through her YouTube channel, and her social media accounts. Jazmine create videos, content and manage multiple social media accounts in order to provide the education to other patients, caregivers, with hopes of continuing the education process.



## Alexis Wardlow

Alexis Joyce Wardlow 23 years old currently self-employed as an E-Nutritionist, but also works for the City of Los Angeles in Recreation & Parks. She was brought on with the Sickle Cell Community Consortium as a Patient Coordinator in October 2016. She was inspired to work with the Consortium to help better the lives of Sickle Cell Warriors and Caregivers. She strives to positively affect the nutritional aspect for Warriors, and over all, get them to have a better quality of life.

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**ADVANCING SCIENCE**

**TRANSFORMING TREATMENT**

**CHANGING LIVES**



**Global Blood Therapeutics (GBT) is committed to working closely with patients, their families and community organizations to change the lives of people living with sickle cell disease.**

GBT is currently researching and developing GBT440, a once-daily medicine that has the potential to transform the treatment of SCD.



For more information, including enrollment criteria for our upcoming clinical trial, visit us at **[www.globalbloodtx.com](http://www.globalbloodtx.com)**.

# Agenda

## THURSDAY, MARCH 16

Time	Event	Location
10:00 am – 1:00 pm	<b>Registration</b> The Registration Table is 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.	Lobby
1:00 pm – 2:00 pm	<b>Press Conference: Fair Treatment in the Emergency Department</b> The patients, caregivers and CBOs of the sickle cell community call upon all advocates, community leaders, legislative champions, and medical allies to join us as we launch “Taking Our Stand: Fair Treatment sickle cell Warriors” to address the culture of injustice, mistreatment and discrimination in hospitals and clinics throughout the United States.	Salons A, B, C
	<b>PARTNER SERVICES</b>	
9:00 am – 1:00 pm	<b>StoryCorps</b>	Augusta
10:00 am – 12:00 pm	<b>Professional headshots</b>	
2:00 pm – 4:00 pm	<b>Opening of the 2nd Session of the Sickle Cell General Assembly</b> <ul style="list-style-type: none"> <li>● 2016 Outcomes &amp; General Assembly Session I Priorities Progress Reports               <ul style="list-style-type: none"> <li>○ <b>"A Guide To Living With Sickle Cell - Patient-Powered Educational Literature"   Cassandra Trimmell</b>                    Summary of the Patient-Powered, MD-Reviewed Sickle Cell Literature Project. Presentation of the final product, and how to disseminate literature to sickle cell patients nationwide.</li> <li>○ <b>"Tackling the Transition Problem: The Transition Workgroup"   Alexis Wardlow, Jazmine Rivera</b>                    This presentation is centered specifically on the Sickle Cell Community Consortium’s efforts to positively impact the transition process of individuals with Sickle Cell Disease. It also covers the Consortium’s plans to involve social resources for Sickle Cell Warriors to grow and bond with others within their community.</li> </ul> </li> </ul>	Salons A, B, C

# Agenda

## THURSDAY, MARCH 16

Time	Event	Location
2:00 pm – 4:00 pm	<ul style="list-style-type: none"> <li>○ <b>“Engaging the Young Sickle Male”   Clayton Andrews</b> Addressing the impact that Sickle Cell Disease has on the already stigmatized black male (employment, motivation, status in the household and even education) as well as the need for the guidance and mentorship of the young male with Sickle Cell (helping to understand, advocate and dispel the myths and limits associated with the disease).</li> <li>○ <b>“Stigma and Sickle Cell: The Root of this Reality”   Coretta M. Jenerette, PhD, RN, CNE</b> Many individuals and families living with sickle cell face health-related stigma while seeking care for the pain. Practical solutions for both healthcare providers and individuals living with sickle cell will be discussed to help lessen health-related stigma.</li> <li>○ <b>“Social Media Priority Review”   Lakiea Bailey, PhD</b> A review of the priority identified during the 2016 General Assembly to provide training for effective use of social media for non-profits in the rare disease space.</li> <li>○ <b>“Show Up &amp; Speak Up for Sickle Cell”   Jew-El Darbone</b> The importance of showing up and speaking up about the sickle cell patient experience at different symposiums and conventions.</li> </ul>	Salons A, B, C
4:00 pm – 5:00 pm	<b>Opening Reception</b>	Presidential Ballroom
5:00 pm – 8:00 pm	<b>Best Practices I: A New Playbook: Leading the Fight Against Sickle with Digital Visual Content</b> The objective of this multi-session mini-series is to increase the media literacy of all participants by offering a solid foundation of	Salon A, B, C

# Agenda

## THURSDAY, MARCH 16

Time	Event	Location
5:00 pm – 8:00 pm	<p>basic knowledge and technique that will aid in the creation of visually appealing digital. content that is on par with industry standards, using resources already available to you. These sessions will cover media law and ethics, quality and standards, and fostering a loyal audience.</p> <ul style="list-style-type: none"> <li>○ <b>“Storytelling with High-Quality Visual Media”   e. Smalls</b></li> <li>○ <b>“Media Law and Ethics”   Jessica M Young M. Ed</b></li> <li>○ <b>“Fostering a Loyal Audience”   Evelyn from the Internet</b></li> </ul>	

## FRIDAY, MARCH 17

Time	Event	Location
9:00 am – 10:00 am	<b>Breakfast</b>	Presidential Ballroom
10:00 am – 1:00 pm	<b>Best Practices II: Capacity Building for CBOs</b>	Salons A, B, C
10:05 am – 10:35 am	<ul style="list-style-type: none"> <li>○ <b>“What's Your Passion? Your Nonprofit CAN Turn A Profit.”   Kimberly Sellars Bates .</b></li> </ul>	
10:40 am – 11:10 am	<ul style="list-style-type: none"> <li>○ <b>“Patient-Centered Outcomes Research Institute: PCORI’s Efforts within the Sickle Cell Disease Community”   Lisa Stewart, MA</b></li> </ul> <p>PCORI engages with the sickle cell community by investing in research, clinical data networks, and capacity-building projects that support individual and community engagement in research and by involving key stakeholders in the review process. During this session attendees will hear about PCORI’s existing investments and current funding initiative to support research studies focused on improving the management of care transitions for emerging adults with sickle cell disease. Information also will be shared on how to get involved in PCORI programs.</p>	

# Agenda

## FRIDAY, MARCH 17

Time	Event	Location
11:15 am – 11:45 am	<ul style="list-style-type: none"> <li>○ <b>“Hospitals are from Mars, CBOs are from Venus: Engaging CBOs in Research”   Lakshmanan Krishnamurti, MD</b> It is important to involve the community in research related to Sickle Cell Disease. Reach out to your local sickle cell clinic, make an appointment to talk with the doctors. Be prepared to discuss your role within the community and resources you may provide to benefit research. Such resources may include information regarding the sickle cell community that may be useful for researchers to know. Depending on the type of research being done, researchers enjoy engaging the community. It is an opportunity that benefits both the sickle cell community and the research community.</li> </ul>	Salons A, B, C
11:50 am – 12:20 pm	<ul style="list-style-type: none"> <li>○ <b>“A Guide to Consortium Proposals and Grants”   Lakiea Bailey, PhD</b></li> </ul>	
12:25 pm – 12:55 pm	<p><b>Be The Match</b></p> <p><b>“Increasing Access to Bone Marrow Transplant for Sickle Cell Disease”   Lensa Idossa, MPH</b> Bone marrow transplant (BMT) has been used for sickle cell disease (SCD) as a potentially curative therapy for over 20 years. Its benefits are best highlighted by a sibling-matched donor transplant in children where the cure rate is excellent. Yet, substantial barriers to accessing this advanced therapy exist. Be The Match, operated by the National Marrow Donor Program is a non-profit organization that manages the world’s largest registry of potential donors and cord blood units, connects patients to their donor matches, and educates health professionals and patients. Be The Match is committed to successfully serving all patients in need of cellular therapy. Be The Match initiatives to increase access to BMT for people living with SCD will be discussed and opportunities to partner will be highlighted.</p>	Salons A, B, C

# Agenda

## FRIDAY, MARCH 17

Time	Event	Location
1:00 pm – 2:00 pm	<b>Lunch</b> Sponsored by Global Blood Therapeutics   <b>Ken R. Bridges, MD</b>	Presidential Ballroom
2:00 pm – 5:00 pm	<b>General Assembly I</b>	Salons A, B, C
	<b>PARTNER SERVICES</b>	
5:00 pm – 9:00 pm	<b>Creative Space Opens</b>	Madison
5:00 pm – 7:00 pm	<b>Accounting Check-ups</b>	Salons A, B, C
5:00 pm – 7:00 pm	<b>Digital Content Check-ups</b>	Salons A, B, C
5:00 pm – 7:00 pm	<b>Professional Headshots</b>	Vendor Space
5:00 pm – 7:00 pm	<b>CBO Spotlights</b>	Augusta

## SATURDAY, MARCH 18

Time	Event	Location
9:00 am – 10:00 am	<b>Breakfast</b>	Salons C, D, E
10:00 am – 1:00 pm	<b>General Assembly II</b>	Presidential Ballroom
1:00 pm – 2:00 pm	<p><b>Lunch</b></p> <ul style="list-style-type: none"> <li> <b>Launch of the Sickle Cell Community Consortium Clinical Trials Initiative</b>   <b>Marie Ojiambo, Lakiea Bailey, PhD</b>            The Sickle Cell Community Consortium is excited to launch the CLINICAL TRIALS INITIATIVE at the 2017 Leadership Summit &amp; General Assembly. This initiative is launched as part, and in continuation, of the 2016/2017 Patient-Centered Outcomes Initiative (PCOI). PCOI was established to directly involve patients and caregivers in topic generation and prioritization for Patient-Centered Outcomes Research and in 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         </li> </ul>	Salons C, D, E

# Agenda

## SATURDAY, MARCH 18

Time	Event	Location
1:00 pm – 2:00 pm	<p>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.</p> <ul style="list-style-type: none"> <li> <b>Patient Safety: The Most Important Aspect of Every Clinical Trial   Jeffrey Keefer MD, PhD</b>            As SCCC launches our clinical trials initiative, it is important to have a discussion on patient safety. Many laws and practices are in place to ensure that those living with sickle cell, are kept safe at all times.         </li> </ul>	
2:00 pm – 3:00 pm	<p><b>Clinical Trials Roundtable   Jeffrey Keefer, MD, PhD; Kate Lewis, MA; Mark Brezzell; and Ken R. Bridges, MD</b></p> <p>This session features a roundtable discussion with industry representatives for active clinical trials and a clinical trial patient safety expert. The roundtable discussion will be followed by a question and answer session with patient, caregiver and CBO Summit participants.</p>	Presidential Ballroom
3:30 pm – 5:00 pm	<p><b>Business Meeting</b></p> <p>This session serves as the business meeting for Consortium infrastructure, main committees and the financial report. All partners are requested to attend and to join at least one Main Committee, in addition to at least one priority project committee.</p>	Presidential Ballroom

# Agenda

## SATURDAY, MARCH 18

Time	Event	Location
	<b>PARTNER SERVICES</b>	
5:00 pm – 9:00 pm	<b>Creative Space Opens</b>	Madison
5:00 pm – 7:00 pm	<b>Accounting Check-ups</b>	Salons A, B, C
5:00 pm – 7:00 pm	<b>Digital Content Check-ups</b>	Salons A, B, C
5:00 pm – 7:00 pm	<b>Product Placement &amp; Branding Photography</b>	

## SUNDAY, MARCH 19

Time	Event	Location
9:00 am – 10:00 am	<b>Working Breakfast</b> <ul style="list-style-type: none"> <li>• <b>Collaborating with your Healthcare and Academic Partners on Grant Applications: Why and How</b>   Ify Osunkwo, MD</li> </ul>	Salons A, B, C
10:00 am – 11:45 pm	<b>Best Practices III: Digital Content Workshop</b> <ul style="list-style-type: none"> <li>• <b>“Snapchat Talkback”</b>   Evelyn from the Internet, e. Smalls</li> </ul>	Madison
10:00 am – 11:45 am	<b>Best Practices IV: The Business of Running a CBO</b> This session will focus on proposal development, budgets and requests for funds (RFFs).	Salons A, B, C
10:05 am – 10:35 am	<ul style="list-style-type: none"> <li>• <b>“The Importance of Digital Transformation in the Non-Profit Space”</b>   Patricia Wilson-Smith            How becoming a digitized, data-driven organization helping non-profits gain the capability to attract funding faster and do more with less, with a focus on how smaller CBOs can easily begin to automate and leverage cloud, social, analytics, and mobile to transform their organizations for the future.</li> </ul>	
10:40 am – 11:10 am	<ul style="list-style-type: none"> <li>• <b>“Creating Sponsor Packages &amp; RFFs”</b>   Lakiea Bailey, PhD</li> </ul>	
11:15 am – 11:45 am	<ul style="list-style-type: none"> <li>• <b>“Effective Accounting Practices for Non-profits”</b>   Eric Frempong, CPA</li> </ul>	
11:45 am – 12:00 pm	<b>Closing of the 2nd Session of the General Assembly of CBOs, Patients &amp; Caregivers</b>	Salons A, B, C



bluebirdbio®

## TRANSFORMING THE LIVES OF PATIENTS WITH SEVERE GENETIC AND RARE DISEASES

bluebird bio is committed to individuals and families affected by severe genetic diseases and cancer, including severe sickle cell disease, transfusion-dependent  $\beta$ -thalassemia, also known as  $\beta$ -thalassemia major, cerebral adrenoleukodystrophy and multiple myeloma.

Thank you Sickle Cell Community for all you that you do for those living with sickle cell disease.

Please visit us at [www.bluebirdbio.com](http://www.bluebirdbio.com) to learn more.



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/bluebirdbio

# Partner Services

We are pleased to offer a variety of services to our partners. The services vary by day and time. Availability is in order of sign-up. Time slots are limited. All partners are encouraged to sign-up at registration. Please arrive promptly, prepared for the chosen service.

## **Headshots with Jamie Starr of Xcintric Media, LLC**

A headshot is a good opportunity to make a lasting impression in a professional manner. Jamie Starr of Xcintric Media will be on site to capture headshots photography for each partner. The image will be available to save on your Consortium flash drive the following day. Sign-up at the registration table. Please contact Kimberly Davis (kdavis@sicklecellconsortium.org) for details.

## **Sickle Cell Voices with StoryCorps**

StoryCorps Atlanta as part of the Consortium Sickle Voices Initiative. The mission of StoryCorps is to preserve and share humanity's stories in order to build connections between people and create a more just and compassionate world. This project will continue throughout the year. Contact Tynisha Hall at tynishahall@yahoo.com.

## **Accounting Consultations with Director of Finance Eric Frempong, CPA**

Sign-up for a 30 minute one-on-one session with the Consortium's Director of Finance. Come prepared to ask specific questions related to your CBOs. Non-profit 990s are due soon. This is an excellent opportunity to get your questions answered.

## **Digital Content Check-Ups with Pat Smith of Online Media Interactive**

These 30 min one-on-one consultations with Patricia Smith will review your website and/or social media profiles to ensure full optimization and utilization, and how to best cater to your web-based audience.

## **Product Placement and CBO Branding Photos with Jamie Starr of Xcintric Media, LLC**

Bring your CBO merchandise and models to obtain professional photography for your websites, publications and social media profiles. We will not be providing hair and make-up during these photography sessions. Come ready to shoot and go.

## **CBO Spotlights with Minimarie Andrews**

Minimarie Andrews of Purpose-Filled Mommy will be on-site to capture CBO profile videos. Copies of these videos will be available for CBO use and may appear as a spotlight in Consortium media projects. Sign-up for your spotlight interview at registration.

## **Creative Content Laboratory Open Space**

Lights. Camera. Action! Participants of the Digital Content Workshop will have access to the lights, cameras and backdrops in the Creative Content laboratory. Use of this space will be explained during the opening digital content best practices session. Contact project manager essiata Smalls at: swankk.e.smalls@gmail.com

# DIGITAL VISUAL CONTENT WORKSHOP & CREATIVE SPACE LAB

## A New Playbook: Leading the Fight Against Sickle with Digital Visual Content

**Project Lead:** e. Smalls

Whether it's business or personal, during a time when technology is necessary for survival, understanding tech and media is a linchpin to thriving in a saturated digital space.

The objective of this multi-session mini-series is to increase the media literacy of all participants by offering a solid foundation of basic knowledge and technique that will aid in the creation of visually appealing digital content on par with industry standards, using resources already available.

This program is designed to be a panel presentation and a multi-session workshop that takes place throughout our 2017 Leadership Summit and General Assembly.

The presentation portion is designed to focus on the creation of digital visual content and is broken up into three umbrella topics: media law and ethics, storytelling with high-quality visual media, and fostering a loyal audience.

Participants will also have access to the Creative Content Lab for hands-on experience with studio-quality film and photography equipment.

<p><b>Thursday, March 16</b> 5 pm - 8 pm</p> <p>Salons A, B, C</p> <p>Digital Visual Content Best Practices: Guidelines for Creating Professional content that is authentic, accessible, and relatable</p> <ul style="list-style-type: none"> <li>• Storytelling with High-Quality Visual Media e. Smalls, Taelord Existence</li> <li>• Fostering a Loyal Audience Evelyn Ngugi, Evelyn from the Internet</li> <li>• Media Law and Ethics Jessica Young, Jessica Young Films</li> </ul>	<p><b>Friday, March 17</b> Creative Space Open Lab 5pm - 9pm</p> <p><b>Saturday, March 18</b> Creative Space Open Lab 5pm - 9pm</p> <p><b>Sunday, March 19</b> Creative Space Open Lab 6am - 9 am</p> <p>Digital Video Content Best Practices Wrap-Up 10am - 12pm</p>	<p>Madison</p> <p>Madison</p> <p>Madison</p> <p>Madison</p>
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# Clinical Trials Initiative

## Improving Patient Participation & Engagement in Clinical Trials

### Clinical Trials Initiative Workgroup:

**Project Lead:** Marie Ojiambo, PharmD.

- Alexis Wardlow
- Marie Ojiambo
- Kentina Moore
- Shamika Williams Minisee
- Nurudeen Muhammad Nurudeen

SCD is the most common genetic disorder worldwide affecting 1 in every 365 Americans, 1 out of every 16,300 Hispanic-Americans and with some African countries reporting prevalence of as high as 45% of their population.

With over 100 years since its discovery, sickle cell disease does not yet have a FDA approved cure. However, the data from the costs of hospitalization, mortality and morbidity rates associated with having disease increase every year.

Currently, there is only one clinically approved pharmacotherapeutic agent used to manage sickle cell disease. Treatment with hydroxyurea shows patient-to-patient variability in response, as well as a range of moderate to severe adverse effects leading to gross underuse of this medication. Patient's living with the disease are reaching dangerously desperate levels for the need to have new treatment options and possibly a cure.

So why do very few, if any patients suffering the disease enroll in clinical trials?

What can we do to make clinical trials more accessible to patients, advocates, caregivers and the community? What is the blockage that prevents patients from participating in trials that will in the long run benefit them or those who come after them?

Our patient-powered clinical trials initiative will apply the collective power of the Patient, Caregiver and CBO General Assembly to define patient-identified barriers to minority participation in clinical trials.

Collectively, we will work to:

- Define and understand patient-identified barriers to minority participation in clinical trials.
- Address and help bridge these barriers so as to:
  - Increase enrollment of patients suffering the disease in clinical trials.
  - Better communicate the importance of participating in clinical trials.



# Online Media Interactive Web Site Solutions

## Owning a Website is Not Enough!

Meeting the constantly changing needs of your constituents means having a *web solution* that is extensible, manageable, and supports your CBO's future growth goals.

Let OMI build the perfect web site for your organization, using the latest in industry standard content management systems to ensure easy updates and maintenance for you and your staff!



For Sickle Cell CBOs!

## Ten Page e-Commerce Website, Starting at \$1500.00 – Includes Logo!

We build beautiful, functional sites using  **WORDPRESS**

- Custom Web Design
- CMS Design/Customization
- Graphic Design
- Hosting Services
- Content Management
- SEO Services

### About OMI:

*Online Media Interactive, LLC is a web design and digital marketing agency.*

*Founded in 2009, we provide web development, mobile development, search marketing and other professional services to businesses of any size.*

### Contact Us:

2140 McGee Road, Suite C-310  
Snellville, GA 30078  
[www.onlinemediainteractive.com](http://www.onlinemediainteractive.com)  
678.395.5874  
[sales@onlinemediainteractive.com](mailto:sales@onlinemediainteractive.com)





# Speaker Profiles



## **Clayton Andrews**

### **President, Sickle Cell Champions Association**

A 34 year old patient with Sickle Cell Disease, residing in Augusta GA. Andrews is a Troy University graduate with a Master of Science in Counseling and Psychology, and eight years of experience with working with a variety of people and behavioral patterns. His ultimate objective is to become a positive influence and and mentor to my peers in the Sickle Cell Community, especially in serving and advocating young males with this disease. As an Advocacy Coordinator, he is responsible for the day-to-day support to CASA volunteers, ensuring that children receive professional advocacy and early permanency planning.

Andrews is currently in the process of obtaining his licensure as a counselor, as well as pursuing his Doctorate to further expand his effectiveness.



## **Coretta M. Jenerette PhD, RN, CNE**

### **Associate Professor, School of Nursing; University of North Carolina**

Coretta M. Jenerette, PhD, RN, CNE, earned a PhD and MSN in nursing from the University of South Carolina and her BSN from Clemson University. She completed a certificate in nursing education at The University of North Carolina at Chapel Hill and is a certified nurse educator. She also completed post-doctoral fellowships at both Yale University and The University of North Carolina at Chapel Hill. Her program of research is aimed at enhancing self-care and family management in vulnerable populations such as individuals with sickle cell disease. Specifically, she uses both qualitative and quantitative methods to identify vulnerability factors in order to intervene by enhancing self-care and family management resources with the goal of improved health outcomes.

# Speaker Profiles

**Lakiea Bailey, PHD**

**Executive Director, Sickle Cell Community Consortium**

See bio in 'SCCC Board & Staff'



**Jew-El Darbone**

**Co-founder and CFO, Bold Lips for Sickle Cell**

Jew-EL Darbone Founder/CFO of #Boldlipsforsicklecell she is a 28 year old sickle cell warrior dedicated to sickle cell advocacy and empowerment.

**e. Smalls**

**Patient Advocate**

an artist + advocate writing to improve the visibility + representation of coloreds + queers and fighting for the improved quality of life + liberation of all oppressed peoples, with a spotlight on Black mental health, chronic illness, and invisible disability.

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# Speaker Profiles



**Jessica M Young M.Ed**  
**CEO, Jessica Young Films, LLC**

A native of Charlotte, NC, Jessica has resided in Atlanta, GA since 2006. She began producing for J Young Media in 2007 with the highly successful music video, "Pray for me", which premiered on BET's video gospel. She then made her directorial debut with the Bronze Lens Premiere, Telly Award winning documentary, Second Time Around. Jessica's keen eye for creativity and dedication to excellence, propelled her to launch Jessica Young Films, where she is the CEO and Executive Producer for ground breaking film and video projects. She is a sought after motivational speaker that has graced both corporate, educational, and non-profit sectors on the value of pursuing your purpose with passion! Her company has led very successful prevention based social media campaigns, which have made an impact in the Atlanta community. Jessica operates under the belief that the greatest investment, one can ever make, is in the lives of others!



**Kimberly Sellars-Bates**  
**Founder, KSTB Enterprises, LLC**

A native Atlantan and a product of the Atlanta Public and Fulton County school systems. Upon graduating from Alabama State University with a Bachelor of Arts in Psychology, she returned to her hometown and began working at Spelman College. While at Spelman, Mrs. Sellars-Bates was introduced to the world of development as a researcher.

Continuing her successes as a research and grant writing professional, Kimberly is currently responsible for over \$20 million in grants and contracts. KSTB Enterprises, LLC. development consulting firm was founded in 2007, KSTB establishes organizations as 501c3's and analyzes and implements action plans for all ongoing fundraising initiatives including: individual, corporate, and foundation prospect research, annual fund appeals, grant proposal writing and board solicitation and training. KSTB also works with organization's executive and program staff as well as the Board of Directors to ensure successful fundraising efforts.

# Speaker Profiles



**Lisa Stewart, MA**  
**Engagement Officer, PCORI**

Lisa Stewart, MA, is an Engagement Officer at the Patient-Centered Outcomes Research Institute (PCORI). She acts as a liaison between the Engagement and Science programs, helping to manage the organization's research portfolio and supporting the engagement of patient and other stakeholders throughout the course of research studies.

Prior to joining PCORI, she led patient and stakeholder teams as a co-investigator on patient-centered research projects. She began working in health systems as a patient/family navigator in pediatric care, providing peer support to families of children with complex medical conditions and serving as a consumer representative on system-level quality improvement initiatives. She co-led Children's National Health System's patient and family advisory council and the community advisory board for its NIH Clinical and Translational Science Award. She was formerly a member of the DC-Baltimore Research Center for Child Health Disparities and a qualitative researcher for the District of Columbia's Community Health Needs Assessment. Before becoming active in health care, she worked for many years in the arts field as a grant-maker and performance curator.

Stewart earned a BA in business administration, marketing and finance from Florida A&M University and a MA in sociocultural anthropology with a concentration in medical anthropology from the University of Virginia.



**Lakshmanan Krishnamurti, MD**  
**Chair of Blood and Marrow Transplant, Aflac Cancer and Blood Disorders Center Children's Healthcare of Atlanta/Emory University**

Dr. Krishnamurti is the Director of the Bone Marrow Transplant program and a practicing Pediatric Hematology-Oncology doctor at Emory University. He is a member of the American Society of Bone Marrow Transplantation, the American Society of Hematology, and the American Society of Pediatric Hematology Oncology.

# Speaker Profiles

## **Ken Bridges, MD**

### **Vice President, Medical Affairs Global Blood Therapeutics**

Dr. Kenneth R. Bridges received the MD degree from Harvard Medical School, and subsequently trained in internal medicine and hematology, at Massachusetts General and Brigham and Women's Hospitals. Following medical subspecialty training, he worked on the biology of cellular iron metabolism for three years at the National Institutes of Health in Bethesda, Maryland. Dr. Bridges returned to Harvard as a member of the Hematology Division where he achieved the faculty rank of Associate Professor of Medicine. He maintained active clinical work and established the Joint Center for Sickle Cell and Thalassemic Disorders at Brigham and Women's Hospital and Massachusetts General Hospital, emphasizing bench-to-patient translational research.

Dr. Bridges published over 70 peer-reviewed articles during his academic career, as well as number book chapters. He also co-authored with Dr. Howard Pearson of Yale University a textbook on red cell disorders and anemia. Dr. Bridges left academia to work in biotechnology, initially with Hoffman La Roche followed by 3 years at Amgen where he worked on Aranesp and participated in the launch of Nplate. Dr. Bridges moved to Onyx Pharmaceuticals where he oversaw trials involving Kyprolis (carfilzomib) for the treatment of multiple myeloma. He moved to Global Blood Therapeutics in the role of Vice President, Medical Affairs working on the new treatment for sickle cell disease, GBT440.



## **Lensa Idossa, MPH**

### **Program Analyst, Be the Match**

Lensa Idossa, MPH is a Program Analyst for Diverse and Medically Underserved Populations at the National Marrow Donor Program (NMDP) / Be The Match. She provides expertise in health literacy, cultural competence, language access, medical under-service and translation of research into programs to increase access to blood and marrow transplant (BMT) for all patients in need. She is a co-Investigator on PCORI funded study, Individualized Care Plans for Hematopoietic Cell Transplant Survivors.

She holds a Master's degree in Public Health with a concentration on vulnerable populations/global health from Mailman School of Public Health, Columbia University, and a B.A in Psychology with a minor in Leadership from the University of Minnesota.

# Speaker Profiles

## **Marie Ojiambo**

### **Founder, Sickle Strong Initiative**

Trained at St John's University, College of Pharmacy and Health Sciences in New York, Marie Ojiambo is a Formulation Scientist by profession specializing in drug research and development. She is also a Sickle Cell warrior and a global advocate. Diagnosed at the age of 1, Marie her knowledge and to raise awareness about sickle cell disease (SCD).

Currently consulting with Pfizer Inc. and SCDA, Ojiambo uses her experiences to inform researchers, advocates and various stakeholders within the SCD space on strategies to advance the healthcare and treatment options available to sickle cell warriors.

In 2013, Marie founded the Sickle Strong Initiative, a Kenyan based NGO whose mandate is to raise awareness around SCD and to advocate for better health care opportunities for patients in Kenya. Through SSI, she has been able to host medical training and awareness campaigns for patients in Kenya. Marie is also the proprietor of the annual sickle cell public awareness forum, Ongea ('speak out!' in Swahili). This annual summit that takes place every June in Kenya to commemorate World Sickle Cell Day, and provides a platform for sickle cell warriors to speak out about their condition, and interact with each other. It also provides an opportunity for patients to challenge the government, the pharmaceutical industry, insurance companies, the public on what is being done to improve the health care and environment that they are exposed to. Her initiative hosted the third edition of Ongea on the 18<sup>th</sup> of June 2016, which brought together an estimated 300 warriors and their families.

## **Kentina Moore**

Kentina Moore is a 25 year old mother and Sickle Cell Patient Advocate. She has sickle cell genotype SC disease, and uses her pain and struggles to inspire hope and triumph in anyone she can reach. Through her social media efforts via Instagram, Facebook, and YouTube she tries to bring an ere of positivity and perseverance while also spotlighting the lows and mistreatment patients experience. She also creates graphics and jewelry through her business "Katie Kat Jewelry". She hopes to expand her business to include a sickle cell awareness line called "Precious Cells".

She is currently working alongside Shabreon Howard and Shamaine Charelle to bring their vision of the "A Warrior's Life Docuseries" (a series that follows the daily lives of Sickle Cell patients) to life. She studied Business Administration at Kaplan University.

# Speaker Profiles



## **Nurudeen Muhammad Nurudeen**

Nurudeen Muhammad Nurudeen is an HBSC warrior diagnosed at age 3. He received a Bachelor's in Anatomy from the University of Ilorin in Nigeria. He facilitated prompt and effective treatment of patients (particularly those reporting manifestations of sickle cell anaemia). He also enhanced the doctor-patient connection through tactical counselling of patients (warriors specifically) in adhering to the doctor's line of treatment.

Nurudeen is currently a member of the Sickle Cell Aid Foundation Nigeria and the Ilorin Sickle Cell Support Club to pursue his zeal towards playing active roles in health education and awareness through free genotype testing and advocating for blood donation. He is a postgraduate student at the University of Lagos with an unflinching interest in sickle cell disease research.



## **Jeffrey Keefer, MD, PhD** **QuintilesIMS**

Jeff is a board-certified pediatric hematologist/oncologist with 12 years of academic faculty experience at the Johns Hopkins University School of Medicine in the Division of Pediatric Hematology. His research and clinical focus was in sickle cell disease. Jeff was involved in phase 1-3 clinical trials, including serving on the executive steering committee for a large phase 3 study. He was also the PI of an effort to study and improve the transition of care from pediatric to adult care providers. Jeff's clinical practice included a large population of children, adolescents and young adults with sickle cell disease. He joined QuintilesIMS almost 2 years ago where he serves as a Medical Director in Hematology and Oncology within the Therapeutic Science and Strategy Unit.

He received his MD and PhD degrees from Vanderbilt University School of Medicine where his graduate work was in Pharmacology. He completed his residency in Pediatrics and served one year as Chief Resident at the Johns Hopkins Hospital. He continued on there for Fellowship in Pediatric Hematology and Oncology before joining the faculty.

# Speaker Profiles



**Kate Lewis, MA**

**Senior Director of Scientific Communications, Bluebird bio**

Kate Lewis, MA, is Senior Director of Scientific Communications at bluebird bio. Over the past twenty years, she has worked with both academic and biotechnology industry researchers to share information about unmet needs and groundbreaking research in the biomedical sciences, with a focus on rare and genetic diseases. At bluebird bio, she leads communication about the results of clinical studies and educational efforts about gene therapy and hemoglobinopathies for healthcare providers.



**Ify Osunkwo, MD**

**Medical Director, Adult Sickle Cell Program; Carolinas Healthcare System  
Associate Professor, University of North Carolina at Chapel Hill**

Dr. Ifeyinwa (Ify) Osunkwo is a lifespan hematologist and provides care for adults with sickle cell disease (SCD) in Charlotte NC. She is the medical director for the Carolina's Healthcare System (CHS) Sickle Cell Disease Enterprise that provides comprehensive culturally sensitive coordinated health care for individuals living with SCD across the CHS system. She loves to teach, has a passion for fostering health literacy and patient empowerment and has engaged numerous community based organizations in collaborative research, clinical outcomes and community engagement projects over her 25 year career. She graduated medical school from the University of Nigeria, did residency at the University of Medicine and Dentistry of NJ in Newark NJ and completed her fellowship training at Columbia University in NY. She has a masters degree in Public Health from Johns Hopkins University. Her loving husband David and 3 children have been her strong support to give of her time and talent to the betterment of the sickle cell community.

# Speaker Profiles



**Patricia Wilson-Smith, MS**  
**President & CEO, Online Media Interactive, LLC**

Patricia Wilson-Smith is an author, technology executive, educator, and the President and CEO of Online Media Interactive, LLC, a local technology consulting firm and digital marketing agency, and has over 20 years of experience in delivering technology solutions for a variety of industries. She earned a Bachelor's in Computer Information Systems from DeVry University, and later a Master's of Information Technology from Southern Polytechnic State University.

Ms. Smith is also a political activist and radio talk show host, who has appeared on the nationally syndicated television show, Democracy Now!, as an Oscars red-carpet correspondent at the 2007 Academy Awards, and has written for countless news media outlets, including the New York Times, the Huffington Post, and the Atlanta Journal Constitution. As Executive Director of Black Women for Obama, Wilson-Smith blazed a trail in local and national politics that earned her a seat on the National Women for Obama Leadership Team, and a spot in the Georgia DNC Delegation in 2008. As the owner of Online Media Interactive, Ms. Smith leads a team of resources who are developing new technologies, and helping companies across the country better leverage technology to meet their business goals.

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# Your Passion Is your Purpose

Join Me For Daily

Daily Inspiration

Empowerment

Motivation

Helpful Tips

Purpose Filled Mommy  
with Minimarie

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# CBO Partners

**Advancing Sickle Cell Advocacy Project** | e: [info@asapbeinformed.org](mailto:info@asapbeinformed.org); w: [asapbeinformed.org](http://asapbeinformed.org)

Advancing Sickle Cell Advocacy Project, Inc. (A.S.A.P.) is a nonprofit organization based in Hollywood FL, comprised of sickle cell warriors, sickle cell trait carriers, caregivers and those who have a passion for the sickle cell community.

ASAP's mission is to educate and advocate on behalf of sickle cell clients and their families in Miami-Dade, Broward, and Palm Beach counties. Also, we are dedicated educating the general public about sickle cell anemia and sickle cell trait. ASAP wants to see patients live longer and more pain free lives by maintaining good health emotionally, mentally, and physically. We are dedicated to breaking the stigma associated with sickle cell anemia and invoking change in treatment within the healthcare community. We serve as a voice for those who have had no voice.

**As One Foundation** | e: [Tomia@asonefoundation.org](mailto:Tomia@asonefoundation.org); w: [asonefoundation.org](http://asonefoundation.org) | [@AsOneFoundation](https://www.instagram.com/AsOneFoundation)

The As One Foundation was established in 2007 by NFL wide-receiver and FBISD Stephen Austin Alum, Devard Darling in honor of his identical twin, Devaughn, who died prematurely and tragically of exertional rhabdomyolysis due to sickle-cell trait & dehydration during Spring football practice at FSU on February 26, 2001. The As One Foundation empowers young people through two main programs: 1. Operation Hydration, a sickle cell trait awareness program that promotes awareness of sickle cell trait through education about the importance of proper hydration and recovery time as prevention of athletic/fitness related death (ARD/FRD) throughout all schools of Fort Bend Independent School District (FBISD); 2. The Devard & Devaughn Darling Scholarship Awards, that annually awards ten \$1000 scholarships to eligible FBISD high-school seniors based not solely on academic merits, but also on demonstrated resiliency to Devard's turning tragedy into triumph through the work of the As One Foundation.

**AXIS Advocacy** | e: [info@axisadvocacy.org](mailto:info@axisadvocacy.org); p: +1(626) 350-8239

Grassroots organization dedicated to improving the lives of people living with Sickle Cell Disease through Advocacy, Education, Research and Legislation.

# CBO Partners

**Bold Lips For Sickle Cell** | e: [boldlipsforsicklecell@gmail.com](mailto:boldlipsforsicklecell@gmail.com); w: [boldlipsforsicklecell.com](http://boldlipsforsicklecell.com)

#BoldLipsForSickleCell is a 501 C3 non profit organization geared towards spreading Sickle Cell awareness and empowering individuals who has the illness. They have become a fresh and relevant movement, intended to put a bold and flattering spotlight on this disease and its community. We plan to continue to building a network of supporters and allies who will help make this disease as well-known and positively endorsed as the likes of breast cancer and other high profile diseases.

The mission of #boldlipsforsicklecell to educate and raise awareness for sickle cell disease through its advocates wearing bold lipstick colors. They are making a loud and boisterous statement which in turn gains attention along with conversations being sparked. They want to infiltrate surrounding communities by hosting events that are geared towards educating and building awareness for SCD.

**Cayenne Wellness Center & Children's Foundation** | e: [info@cayennewellness.org](mailto:info@cayennewellness.org);  
w: [cayennewellness.org](http://cayennewellness.org)

Dedicated to health promotion and disease prevention in children, adolescents, adults and their families diagnosed with sickle cell disease. Their mission is to improve the nutritional and mental health of the public and those diagnosed with sickle cell disease. We achieve this mission through education (our Annual SCD Educational Seminar; our upcoming Provider Inservice Training program), research, and public awareness initiatives and community outreach programs (i.e., our Canvassing program that educates the public). We practice the science of helping people make changes in their lifestyle to improve their overall health and quality of life emotionally, physically, and spiritually.

**The Committee on Better Racial Assurance** | e: [cobraagency@bellsouth.net](mailto:cobraagency@bellsouth.net); w: [cobraagency70.com](http://cobraagency70.com)

We assist those served to achieve a better quality of life. Sickle Cell Disease services are provided to patients, their families and the public: case management, patient assistance, education, screening, hemoglobinopathy counseling, referrals and follow-up. The Community Relations services improve and create channels of communication between individuals and entities - governmental bodies, agencies and organizations-which govern or serve them.

# CBO Partners

**Hope for SCD** | e: [lrose@hopeforscd.org](mailto:lrose@hopeforscd.org); w: [hopeforscd.org](http://hopeforscd.org)

We are a health literacy NPO started by parents of a child with SCD. Although we are based in Raleigh, NC, we provide international access to research based medical education materials. Our mission to bridge the gap between providers and the lay community through research based health literacy tools and programs.

**IASCNAPA** | w: [iascnapa.org](http://iascnapa.org)

The International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA) is the only organization consisting solely of nurses, physician assistants, and other health care professionals who provide care and advocacy for individuals with sickle cell disease. IASCNAPA recognizes its responsibility to maintain high standards in the provision of quality and accessible health care services for individuals with sickle cell disease. IASCNAPA is committed to strengthening the relationship between nurses, healthcare providers, and people with sickle cell disease to ensure a patient-driven multi-disciplinary approach is used to provide comprehensive care for people with sickle cell disease.

**Kids Conquering SCD Foundation, Inc.** | e: [info@kidsconqueringscd.org](mailto:info@kidsconqueringscd.org); w: [kidsconqueringscd.org](http://kidsconqueringscd.org)

To dedicate with compassion to provide education, awareness, advocacy and outreach to improve the quality of life for individuals and families living with sickle cell disease and other hemoglobin disorders. Kids Conquering SCD, Inc. joins the fight against Sickle Cell and other hemoglobin diseases. We provide awareness, educate and support families, educate the community, promote testing for hemoglobin gene, support research of treatments, and collaborate efforts worldwide. Our mission will not be complete until a universal cure is found for sickle cell & other blood diseases.

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# CBO Partners

**Lockhart Morgan Foundation** | e: [gwendmorgan@yahoo.com](mailto:gwendmorgan@yahoo.com); w: [lockhartmorganfoundation.org](http://lockhartmorganfoundation.org)

Lockhart Morgan Foundation is Atlanta Based organization which is focused on bringing awareness to our community, providing assistance to families in need and providing scholarships for Sickle Cell Students continuing their education.

**Martin Center Sickle Cell Initiative** | e: [info@themartincenter.org](mailto:info@themartincenter.org); w: [themartincenter.org](http://themartincenter.org)

Martin Center, Inc. is a human services agency founded in 1969 by the late Rev. Boniface Hardin, O.S.B., and Dr. Raymond Pierce. Martin Center has remained dedicated to providing a “holistic approach” to clients battling the effects of Sickle Cell in our community for over 40 years. Martin Center assumed the name Martin Center Sickle Cell Initiative (MCSCI) in September 2012 in order to have its name more directly reflect its mission.

Martin Center Sickle Cell Initiative exists to aid and enhance the lives of those affected by Sickle Cell and associated disorders by providing services, education, and advocacy.

We are committed to providing essential programs and services to benefit individuals and families affected by Sickle Cell. We also educate clients as well as community members by providing access to quality educational experiences. MCSCI works with educators, medical professionals, schools and caregivers in the provision of our services and we strive to build public awareness about Sickle Cell Disease, Sickle Cell Trait and other abnormal hemoglobin conditions that primarily impact African-Americans, Arabs, Asians and Latinos. Building public awareness of Sickle Cell Disease, Sickle Cell Trait and associated disorders is necessary in the fight against Sickle Cell.

**SCDAA - Philadelphia/Delaware Valley Chapter** | e: [scdaa.pdvc@verizon.net](mailto:scdaa.pdvc@verizon.net);  
w: [sicklecelldisorder.com](http://sicklecelldisorder.com)

The mission of SCDAA/PDVC is to serve as a vehicle and resource center for the psychosocial and social service needs of children, adolescents, adults and families affected by sickle cell disease. SCDAA/PDVC seeks to develop, manage and allocate resources in partnership with hospitals, charitable organizations community based organizations and social service agencies.

# CBO Partners

**Sickle Cell 101** | e: info@sc101.org; w: sc101.org

Sickle Cell 101 (SC101) is a 501(c)(3) non-profit organization educating all people affected by sickle cell through the use of social media. The SC101 team consists of certified sickle cell educators and expert physicians within the field of hematology.

SC101's main outlets include their social media platforms, website (sc101.org), and online newsletter. SC101's information is liked, commented on, shared, and reposted, and any given one of their posts can reach up to 50,000 users. Their information is accessed by followers from over 72 countries on six continents.

SC101's "social media education" program, is comprised of quick sickle cell facts with supporting graphics, perfect for those looking to learn more about sickle cell in a quick and condensed manner. Additional programs include "Ask Dr. Q, the Sickle Cell & Thalassemia Expert Physician", which is a popular resource to patients who don't have access to a sickle cell doctor; and the Sickle Cell Advocate of the Year Awards, which recognizes sickle cell advocates making a difference in the sickle cell community.

In addition to the web-based programs, SC101 also provides sickle cell education in local schools, sickle cell camps, seminars, CEU courses, and within the workplace.

**Sickle Cell Foundation of Minnesota** | e: sicklecellmn@gmail.com; handle: @SickleCellMN

The Mission of The Sickle Cell Foundation of Minnesota is to improve the quality of life for individuals and communities in Minnesota who are affected by sickle cell disease and sickle cell trait. SCFMN is the only active community-based organization that exists to create education, awareness, and support for the Minnesota sickle cell community. We are passionately dedicated to carrying out this work through education, activities, programs and approaches that provide life skills and patient advocacy for equitable and affordable access to health care that improves life for today's generation and those to come.

# CBO Partners

**Sickle Cell Foundation Support Group, Inc.** | e: [parnel@sicklecellsupportgroup.org](mailto:parnel@sicklecellsupportgroup.org)  
w: [thesicklecellsupportgroup.yolasite.com](http://thesicklecellsupportgroup.yolasite.com)

The Support Group addresses the psychosocial/ nutritional issues in coping with Sickle Cell Disease.

**Sickle Cell Natural Wellness Group** | e: [sccantstopme@gmail.com](mailto:sccantstopme@gmail.com); w: [scnwg.org](http://scnwg.org)

Sickle Cell Natural Wellness Group Inc. is dedicated to spreading sickle cell awareness while promoting a healthy and creative lifestyle by way of hosting events, arts, music, poetry, food, fashion and education. Our mission is to show the importance of living a creative and healthy lifestyle. We give back by visiting churches, homes, schools & hospitals providing wellness education and delivering health and wellness supplies.

A healthy community is important to advance its economic growth. Our dedication is to better the lives of those living with Sickle Cell and raise awareness through events that focus on engaging with the community.

Sickle Cell Natural Wellness Group Inc. is a pioneer when it comes to bringing ground breaking Events and concepts to the community. Specializing in events, outreach, educational workshops and giving back, Our board members, volunteers, sponsors and staff, are dedicated to delivering the type of activities that are not only advancing knowledge of the arts and wellness, and Sickle Cell but making sure our audience always has fun leaves inspired and wanting more.



# C B O Partners

**Sickle Cell Support Services** | e: [arsicklecell@yahoo.com](mailto:arsicklecell@yahoo.com); w: [arscss.org](http://arscss.org)

Since incorporation, SCSS has provided supportive assistance and services to over hundreds of families affected by Sickle Cell Anemia Disease. In 2008, they launched Sickle Cell Enrichment Camp for children who were born with Sickle Cell Disease ages 7-16. They have been successful to establish community partnerships and collaborations with organizations such as UAMS LIVING Well with Sickle Cell, Little Rock Alumnae Chapter of Delta Sigma Theta, Arkansas Children's Hospital, Arkansas Minority Health and several other organizations.

In 2009, their founder and CEO was appointed as Chairperson of the Legislative Taskforce on Sickle Cell Disease. This successful process led to the sickle cell bill passed to support an adult clinic in the state of Arkansas. Their organization continues to advocate, support, provide and help individuals and families impacted by sickle cell anemia disease throughout the state of Arkansas.

**Sickle Kan Cic** | e: [sicklekan.info@yahoo.co.uk](mailto:sicklekan.info@yahoo.co.uk); w: [sicklekan.com](http://sicklekan.com); handle: @sicklekan\_

We are a UK community charity that helps to raise awareness and support to your community. We were recently featured on The BBC News in London, Helping to raise awareness and showing members of the public the struggles that we are currently facing here in the UK. We help to support Families and Children within our community by helping to spread awareness about Sickle Cell.

**Sickle Strong Initiative Kenya** | e: [sicklestronginitiative.kenya@gmail.com](mailto:sicklestronginitiative.kenya@gmail.com)

A non-governmental organization registered in Kisumu, Kenya. Its mandate is to raise awareness around the control and management of Sickle cell disease and advocate for better health care options for patients suffering the disease.

# C B O Partners

**Supporters of Families with Sickle Cell Disease** | e: swithsicklecell@att.net;  
w: sicklecelloklahoma.org

Supporters of Families with Sickle Cell Disease, Inc., is a grass root comprehensive community based family support and advocacy nonprofit entity in the State of Oklahoma. Supporters is the only community based organization contracted with the Oklahoma Health Care Authority to provide awareness, education and outreach. We are committed to assisting all Oklahomans impacted by Sickle Cell, Thalassemia, and CC Disease and Traits.

Supporters believes self-care management, testing, education, and research and development, economic self-sufficiency are key approaches to empowerment. Our vision is to break the cycle of fear-based dependency and increase self-efficacy, and improve the overall quality of life, for children, adults, and families living with these conditions in Oklahoma.

**The Red Chair Project** | e: theredchairprojectinfo@gmail.com ; w: trcp@info.com

It is our mission to support, educate and empower warriors and their families through hosting events, visiting warriors and telling their stories.

# Junior C B O Partners

**No Pain in the Playroom** | e: nopainintheplayroom@gmail.com; IG: @NoPainInThePlayroom

No Pain In The Playroom: A Sickle Cell Awareness organization which focuses on the use of distraction as a form of alternative pain management has been in operation 2011 and is lead by Sickle Cell Anemia Survivors Diamond Ray Edmundson and Omeka Edwards. Together they continue fight for awareness and education for sickle cell using their various social media platforms, their Sickle Cell themed clothing lined and making in person appearances speaking to children ranging from preschool to high school.

# Junior CBO Partners

**Sickle Cell Champions Association** | e: sicklecellchampionsassociation@gmail.com;  
**handle:** @sicklecellchampionsassociation

Sickle Cell Champions Association (S.C.C.A.) have come together as a group of advocates who endure the pain and discomfort of living with SCD.

The S.C.C.A. affiliate advocates represent a male voice and bring awareness to this disease, in order to inform the patient, family, and community. We have come together, to mentor and guide the youth that have been stricken with this blood disorder. We have designed a positive mentoring program to guide the youth through their transitioning years into adulthood.

**Sickle International Family Coalition** | e: dominiquefriend.author@gmail.com;  
**FB:** Sickle International Family Coalition

The vision of the Sickle International Family Coalition (SIFC) is to work with families affected by Sickle Cell Disease and Sickle Cell Trait worldwide to reduce the burden of living with these chronic conditions that show no outward symptoms.

**Tillo Cilly Cell Foundation International** | e: tccfoundationintl@gmail.com ;  
**w:** tillocillycellfoundationintl.com

A community support organization for children and adults born with Sickle Cell Disease They offer hospital visits, food, clothing, prayer and funds for small bills when they are available. They do spread awareness through social media and their weekly talk show. They do awareness and fundraiser events called "IT'S A RED AFFAIR".

They place a lot of focus on the children and education through their children's books and cartoon characters created specifically for Sickle Cell.

# Other Organizations

**Sickle Cell Disease Association of Illinois (SCDAI)** | e: talanahughes@scdai.org; w: scdai.org,

Sickle Cell Disease Association of Illinois' (SCDAI) primary mission is to enhance the quality of life for individuals with sickle cell disease and their families. To effectively achieve this goal, SCDAI acts as an advocate for improved healthcare and services for sickle cell patients by educating and informing the community through outreach and educational programs.

# Patient & Caregiver Advocates

## Patient Advocates

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# Patient & Caregiver Advocates

## Patient Advocates

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