

Sickle Cell Community Consortium

Leadership Summit & General Assembly of CBOs

MARCH
16-20, 2016

DoubleTree by Hilton, Buckhead
3342 Peachtree Rd. NE
Atlanta, GA 30326



sicklecellconsortium.org | facebook.com/sccconsortium

Note from Director

Welcome to the Inaugural Sickle Cell Community Consortium Leadership Summit and General Assembly of Community-Based Organizations (CBOs). We are thrilled to welcome over sixty CBO Representatives, Patient & Family Advisors, and Healthcare & Research Partners, representing 20 CBOs and 17 states to beautiful Atlanta, Georgia. You each represent a historical effort to place the destiny and future of the sickle cell community directly in the hands of sickle cell patients, caregivers and health providers. The 2016 Opening Session of the General Assembly was designed to provide the framework to apply a model of Collective Impact to tackle deeply rooted medical, social and legislative problems that have plagued our community. It has been widely acknowledged amongst the patient community that we have been placed in a position of “learned helplessness” and now WE, the patients, caregivers and providers, are determined to change this. We will collectively define problems and gaps in our communities, identify strategies to address those needs and gaps, and determine the CBO, Community, and Corporate partnerships best equipped to implement those strategies in order to achieve significant and sustainable change.

This Summit marks the launch of our 2016 Patient-Centered Outcomes Initiative (PCOI 2016). We will host the first of a series of panel discussions and patient/family meetings aimed at developing a unified effort around patient-centered outcomes. This year our PCOI focus is two-fold. We will (1) identify priorities for Patient-Centered Outcomes Research in sickle cell disease by directly involving our community in topic generation and prioritization for patient-centered research; and (2) collectively define alternative patient-focused endpoints for sickle cell disease clinical trials. During this Summit our goal is to provide an educational foundation on clinical trials, endpoints, patient-centered outcomes research, patient-centered comparative effectiveness research, and the power of the patient voice in numbers. This effort will be continued throughout the year with in-person and online patient engagement webinars and focus groups in order to educate, obtain feedback, and develop a summary on the will of the sickle cell patient in this area.

Throughout the meeting we will be joined by experts in a diverse range of fields to provide training in Best Practices to maintain effective and efficient community-based organizations, along with community leaders prepared to explain and discuss Get Connected: The SCDAA Patient-Powered Sickle Cell Registry, the FSCDR Sickle Cell Disease and Thalassemia Patient Registry, and SCDcare: The Sickle Cell Case Management Registry. On Saturday our numbers will expand considerably as we are joined by the Sickle Cell Foundation of Georgia to host the 3rd Annual Southeastern Sickle Cell Symposium. This Symposium, titled “The Power of Knowledge: Living With Sickle Cell”, will provide valuable information on medical, policy, research, self-care and youth matters for those living with sickle cell.

We have a LONG few days ahead of us. Pace yourself, stay hydrated and get ready as we harness the power of our collective voices to create a new and better future for those living with sickle cell disease.

Thank you for joining us!



Dr. Lakia J Bailey
Executive Director

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Thank You to Our Sponsors & Supporters



At-A-Glance

Wednesday, March 16

- ❑ **Business Meeting** (1:00pm – 5:00pm)
This session will provide a general overview of the organizational structure of the Consortium, along with a line-by-line review of the Bylaws, rules and regulations that govern the organization. Committee chairs will be elected, subcommittees formed and proposed amendments discussed.

Thursday, March 17

- ❑ **Best Practices I** (10:00am – 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** (1:00pm – 2:00pm)
- ❑ **General Assembly I** (2:15pm – 5:45pm)
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.

Friday, March 18

- ❑ **General Assembly II** (10:00am – 12:45pm)
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

Friday, March 18 (cont'd)

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.

- ❑ **An Introduction to Gene Editing** (12:45pm - 1:15pm)
- ❑ **Lunch** (1:15pm – 2:15pm)
- ❑ **OUR VOICE** (2:30pm – 5:00pm)
This afternoon session is dedicated to engaging CBO leaders in a discussion about the power of the patient voice and patient-centered outcomes research. This is the beginning of a multi-step process, continued at the 10th SCD Research & Educational Symposium in April, two online patient-engagement meetings and culminating at the 3rd Annual Sickle Cell Warriors, Inc. Patient and Family Gathering & Education Symposium (July 14-18, 2016).
- ❑ **Dinner** (5:15pm)

Saturday, March 19

- ❑ **Sickle Cell Foundation of Georgia 3rd Annual Symposium** (9:00am – 4 :00pm)
Designed to reach medical personnel and nursing students to choose the path of sickle cell disease. Presented by the Sickle Cell Foundation of Georgia. Hosted by the Sickle Cell Community Consortium. Lunch provided.
- ❑ **Georgia Collaborative Quarterly Meeting** (4:00pm – 6:00pm)
Quarterly Collective Impact meeting of the Sickle Cell Community Consortium, Sickle Cell Foundation of Georgia, Atlanta S.C.A.R., Titus Huissman Sickle Cell Foundation of Augusta, Lockhart-Morgan Foundation, Morehouse College Sickle Smart and the Sickle Cell Champions Association.

Sunday, March 20

- ❑ **Brunch/Best Practices II** (10:00am – 12:00pm)
This session will offer additional best practices for developing and growing strong non-profits.
- ❑ **Adjournment**

About the Sickle Cell Community Consortium

In February of 2014, during the FDA Patient-Focused Drug Development Initiative, a group of community-based organization leaders and patient advisors met to lay the foundation of what would become the Sickle Cell Community Consortium. Organized by Dr. Lakiea Bailey, this group made the collective decision to join efforts to create a unified platform to bring the sickle cell patient to the forefront of all matters regarding health, research, advocacy, education and awareness.



Over the span of the 18 months that followed, Dr. Bailey, Velvet Brown-Watts and Kena Drew would build upon this foundation to develop a cohesive, 501(c)(3) not-for-profit, created to harness and amplify the sickle cell patient voice.

Organized in a manner similar to the United Nations, Consortium Partner CBOs from all over the Country retain their individual autonomy, while uniting to apply a model of Collective Impact to tackle deeply rooted social, medial 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 problems identified by the collective sickle cell community.

Joined by a diverse Board and Staff of patients, caregivers and supporters, the Consortium provides the infrastructure to coordinate the activities of strategic partnerships, provide training and support to Partner CBOs, and push forward collective Consortium platforms and initiatives. Last year, 2015, was focused on organizing and providing support for patients and families to “Show Up and Speak Up” at sickle cell and/or rare patient meetings and conferences. In 2016 we will build upon this by also working to actively further sickle cell research and clinical trials through our Patient-Centered Outcomes Initiative (PCOI 2016).



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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 β -thalassemia, also known as β -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 to learn more.



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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



Kena Drew

Executive Administrator

She is a 48 year old Sickle Cell survivor and was declared disabled in 1999 due to complications with Sickle Cell. During this time, she assisted other survivors as an Advocate aiding them in their needs concerning Doctors, Hospitals, and in conjunction with Social Workers. Kena worked in the Administrative field for 13 years with ACSI, Thomas Raffa & Associates, Department of State and the Washington Redskins. She attended Prince Georges Community College and Parks College in pursuit of a Bachelor's in Business Administration.



Nikki Peterson

Special Projects Coordinator

Nikki Peterson is a 42 year old 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.



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.

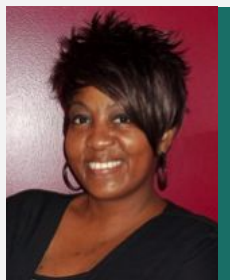


Doris Bailey

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.

SCCC Board & Staff



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.



Bill Cumming

Director of Development

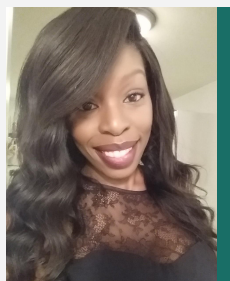
Bill brings the perspective of a caregiver, and the experience of a bio/pharmaceutical Marketing Director to his Rare Disease Patient Advocacy role. For the cause of SCD, Bill has consulted for several companies developing new therapeutics as well as contributed to national and local Community and Faith 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.



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.



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.

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WEDNESDAY, MARCH 16, 2016

- ❑ **Business Meeting (1:00pm – 5:00pm)**

THURSDAY, MARCH 17, 2016

- ❑ **Best Practices I (10:00am – 12:45pm)**

- ❑ **Today's Fundraising Climate: How to Position Yourself for Success** - *Wade Zamechek, MS*
- ❑ **CBO Branding, Marketing & Messaging** - *Patricia Wilson-Smith, MS*
It's more important now than ever for non-profits and social enterprises to learn how to harness the power of digital marketing. In this workshop, Patricia Wilson-Smith introduces a very simple framework for a community engagement strategy, and then shows you how to align that strategy with a digital marketing plan that helps make that engagement more efficient and effective.
- ❑ **Successful Grant Writing & Forming SMART Objectives** - *Yvonne Carroll, RN, JD*
Examples of objectives that are specific, measurable, attainable, relevant, and timely to CBOs and their members.
- ❑ **Navigating Corporate Partnerships** - *Wade Zamechek, MS*

- ❑ **Lunch (1:00pm – 2:00pm)**

- ❑ **SCDcare: Sickle Cell web Case Management Registry** - *Allen Tien, MD*
Many emergency departments (ED) visits occur when patients need acute care for a clinically known recurring event; unfortunately, there is often a 'problem pattern' in which existing key medical information is not effectively communicated or available to ED staff. Our program lead case is painful vaso-occlusive crisis (VOC) in sickle cell disease (SCD), in which the cascading consequences of care coordination failure are delay and under-treatment, suffering, higher rates of complications, and avoidable hospital admissions costing the American health care system millions of dollars per year. The patient-led precision medicine 'solution template' we have developed is a combination of organizations, education, technology, and science.

Our focus is on education linked to action. The two main goals are: 1) reducing and eliminating the substance abuse stigma that is unfortunately associated with SCD patients seeking ED treatment for VOC pain; and 2) increasing actionable knowledge of a newly available web tool, www.scdcare.com,

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that enables ED staff to rapidly access each patient's individual treatment plan from their primary provider, in accordance with the 2014 Evidence Based Guidelines issued by the National Heart Lung and Blood Institute (NHLBI).

- ❑ **Get Connected: The SCDAAs Patient-Powered Registry** - *Marian "Asabi" Jeter*
The 1st National Sickle Cell Patient Powered Registry - A Patient Powered Registry gives the Sickle Patient objectives on choosing what news feeds are of interest to them. Allows the SCDAAs to have a more accurate number of sickle cell patients and their phenotype. The registry will allow the patient to keep track of and access their doctor visits, history on their hospitalizations, transfusions and other areas pertaining to their medical history. All information is stored in a secured database at the SCDAAs. The registry is federally regulated in accordance to HIPPA.

- ❑ **General Assembly I (2:15pm – 5:45pm)**

FRIDAY, MARCH 16, 2016

- ❑ **General Assembly II (10:00am – 12:45pm)**
- ❑ **An Introduction to Gene Editing (12:45pm – 1:15pm)**
- ❑ **Lunch (1:15pm – 2:15pm)**
 - ❑ **FSCDR Sickle Cell Disease & Thalassemia Registry** - *Lanetta Jordan, MD, MPH, MSPH*
 - ❑ **Sickle Options: The Sickle Cell Education Portal** - *Diana Ross, MSN, RN*
- ❑ **Our Voice (2:30pm – 5:00pm)**
 - ❑ **Patient-Centered Outcomes Initiative 2016** - *Lakiea Bailey, Ph.D.*
 - ❑ **Clinical Trials and Endpoints** - *Jennifer Helfer, Ph.D.*
 - ❑ **Patient-Reported Outcomes** - *Nitya Bakshi, MD*
 - ❑ **Comparative Effectiveness Research** - *Lakshmanan Krisnamurti, MD*

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- ❑ **PCOI 2016 Survey** - *Raymona Lawrence, DPH*
- ❑ **Dinner (5:00pm) Sponsored by Bluebird Bio**

SATURDAY, MARCH 19, 2016

- ❑ **Annual Southeastern Sickle Cell Symposium (Sickle Cell Foundation of Georgia) (9:00am– 4:00pm)**
 - ❑ **Medical**
 - ❑ **Policy & Research**
 - ❑ **Self-Care**
 - ❑ **Youth Matters**

SUNDAY, MARCH 20, 2016

- ❑ **Best Practices II (10:00am – 12:00pm)**
 - ❑ **Non-Profit Accounting & Fiscal Responsibilities** - *Eric Frempong, CPA*
 - ❑ **Consortium Collaborative Project Management** - *Cassandra Trimnell*

How to start and complete a project in correspondence with SCCC. This includes: writing a proposal, creating a budget, developing a timeline (task tracking) and creating and completing deadlines. Project Management also requires creating a good environment for collaboration, which includes good communication, and work accountability.
 - ❑ **Social Media Engagement** - *Jew-EL Darbone*

How you can utilize social media to promote your community based organization. As well as create a network of community based organizations through different social media platforms, which will aid in spreading sickle cell awareness especially to the younger generation through social media.
 - ❑ **Developing a Partnership with Your State** - *Velvet Brown-Watts*

Empowering your community through collective partnership, will focus on forming effective partnership with community. governmental agencies, and stakeholders. Developing key partners increases organization support. Empowering the community you serve through greater awareness, education, and support.

Speaker Profiles



Wade Zamechek, MS

Presentations: Today's Fundraising Climate: How to Position Yourself for Success; Navigating Corporate Partnerships

Wade Zamechek is a Director at Changing Our World. Wade has been involved with fundraising for nearly a decade with a focus on healthcare philanthropy. He has experience in major giving, corporate partnerships, event planning, government relations, managing volunteer leadership, and web design/digital strategy.

Prior to joining Changing our World, Wade was the Director of Development and Volunteer Leadership for the New York Blood Center where he relaunched and led the organization's fund development department. In addition to fundraising, he oversaw New York Blood Center's Volunteer Leadership Team which included the organization's most important external clients as well as managed and designed digital content.

Wade earned his Bachelor's Degree in History from New York University and a Master's Degree in Non-Profit Management from the New School University.



Patricia Wilson-Smith, MS

Presentation: Digital Tactics in Community Engagement Marketing

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.

Speaker Profiles

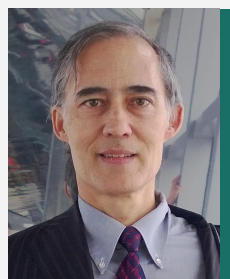


Yvonne M. Carroll, RN, JD

Presentation: S.M.A.R.T. Objectives: The First Step to Better Grant Writing

Yvonne is currently Director of Patient Services in the Department of Hematology at St. Jude Children's Research Hospital. Yvonne graduated with a Bachelors of Nursing Degree from the University of Tennessee and a Law degree from the University of Cincinnati. Yvonne served in the United States Navy as a Staff Judge Advocate. She joined SJCRH in 1999 in the Department of Hematology and served in several positions before becoming the Director of Patient Services.

Yvonne is active in Hematology and the sickle cell disease community and serves on the Governor's Genetic Advisory Committee for the State of TN and as President of the International Association of Sickle Cell Nurses and Physician Assistants (IASCNAPA). Throughout the years, Yvonne has been a Principal Investigator and Program Manager on numerous sickle cell related grants and has spoken locally, regionally, and nationally on sickle cell disease and trait. Yvonne has developed partnerships with numerous community organizations and rural healthcare workers to improve awareness and treatment for people with sickle cell disease.



Allen Tien, PhD

Presentation: SCDcare: The Sickle Cell Disease Web Case Management Registry

Dr. Allen Tien is the founder of Medical Decision Logic, Inc. ("mdlogix"), with long-term visionary involvement in health science software purpose, architecture development, interface design, evaluation, and evolution. He is also an Adjunct Associate Professor in the Division of Health Science Informatics (DHSI) at Johns Hopkins School of Medicine and participates with ongoing informatics and multi-level scientific conceptualization, grant preparation, and technological considerations with mdlogix partners and clients.

Based on over a decade of academic health research spanning public mental health and clinical neuroscience, Dr. Tien's strategic approach to contribute to health and care is to enhance and expand the development and application of health science informatics and information technologies. His software implementation approach is user-centered to assure usability and utility, and designed to enable continuous data, information, and scientific knowledge (DISK) based improvements, organized as software user roles, rules, and workflows. In multiple complementary ways, bringing together biomedical and public health science with software architecture and continuous engineering processes, provides a foundation for an accelerated and robust ongoing process for health system innovation.

Speaker Profiles

Marian"Asabi" Jeter

Presentation: Get Connected: A Patient Powered Registry

Prior to being a Communication Specialist, Marian worked in the television, radio and telecommunications industry for 20+ years. Since her transition from the industry, she decided to follow her passion and advocate for Sickle Cell Disease. She is currently pursuing a Master's Degree in the Public Health arena due to living the life of a Sickle Cell patient and the desire to help others.



Brian R. Robinson, MD

Presentation: An Introduction to Gene Therapy

Brian Robinson joined bluebird bio in June 2015 to lead the Medical Affairs function. He is responsible for driving medical strategies and tactics that support successful product development and guide education, research and communication about bluebird bio's innovative therapies. His team works with numerous stakeholders, including physicians, scientists, advocates, patients, and caregivers. Dr. Robinson has over 12 years of experience in biotechnology Medical Affairs. Most recently, he was the Global Medical Lead for the hemophilia program at Biogen. Prior to Biogen, Dr. Robinson held similar Medical Affairs roles at GE Healthcare, Pfizer, and Abbott Laboratories. Before joining the drug development industry, he engaged in basic science and clinical research at Harvard University and MIT. Dr. Robinson completed an internship in surgery and subsequent training in otolaryngology at the Tufts New England Medical Center. He received a B.A. in anthropology from Yale University and a Doctorate of Medicine from Tufts University School of Medicine.



Lanetta B. Jordan, MD, MPH, MSPH

Presentation: FSCDR Sickle Cell Disease and Thalassemia Patient Registry

An Associate Professor of the Department of Epidemiology and Public Health Sciences at the University of Miami, Miller School of Medicine. She is President of the Foundation for Sickle Cell Disease Research that aims to support care and innovative research in sickle cell and disease and hemoglobinopathies. She serves as Editor-in-Chief for the Journal of Sickle Cell Disease and Hemoglobinopathies, an online peer reviewed journal. Of note, she is a former Senior Medical Advisor, Centers for Disease Control and Prevention. She established and consequently directed the Department of Sickle Cell Services at Memorial Healthcare System for twelve years, with its "Sickle Cell Day Hospital" being the first of its kind in the nation to receive "Disease-Specific Certification" from The Joint Commission.

Speaker Profiles

Diana Ross, RN, MSN

Presentation: Sick Cell Options - A sickle cell disease learning tool

Diana Ross is a Senior Research Coordinator at Emory University. Her expertise is in Hematology, Nursing Science and Clinical Trials.

Lakiea Bailey, PhD

Presentation: Patient-Centered Outcomes Initiative 2016

Jennifer Helfer, PhD

Presentation: Overview of Therapeutic Approval Process – USA Clinical Trials

Jennifer joined bluebird bio in December of 2015. In her patient affairs role she is responsible for 1) connecting with sickle cell disease and beta-thalassemia patients, caregivers, and advocates; 2) establishing partnerships with these communities to address issues critical to improving health; and 3) developing strategies to integrate, increase, and advance patient and caregiver perspective throughout bluebird bio.

Before joining bluebird bio, Jennifer was Associate Director of Scientific Operations at the National Brain Tumor Society, the largest nonprofit organization dedicated to the brain tumor community in the United States. Jennifer remains active in the brain tumor community by serving as the Massachusetts State Co-Lead Advocate and as a Boston Brain Tumor Bike Ride Committee Member.

Jennifer received a B.A. in Psychology from the University of North Carolina Wilmington, an M.A. in Behavioral Neuroscience from the University of Delaware, and PhD in Biology (Neuroscience) from the University of Victoria.

Nitya Bakshi, MD, MS

Presentation: Patient Reported Outcomes and the SCD Patient

Nitya Bakshi is a practicing Pediatric Hematology-Oncology doctor with Emory University. She is a member of the American Society of Hematology, American Society of Pediatric Hematology-Oncology, American Pain Society, and the International Association for the Study of Pain.

Speaker Profiles



Lakshmanan Krishnamurti, MD

Presentation: The Role of the SCD Patient in Comparative Effectiveness Research

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.

Raymona Lawrence, D.P.H

Presentation: PCOI 2016 Survey

Eric Niti-Frempong, CPA

Presentation: Non-Profit Accounting & Fiscal Responsibilities



Cassandra Trimnell

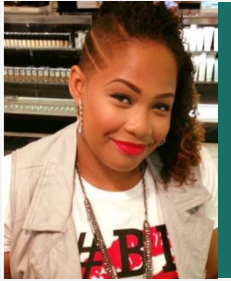
Presentation: Consortium Project Management

As Founder and President of Sickie Cell 101, Cassandra is an active educator and advocate within the sickle cell community. Her passion for sickle cell stems directly from her living with the disease, hgb SS. Cassandra received a B.A. in Global Studies: Social, Political, and Economic Development from Sonoma State University.

In 2014, Cassandra received her sickle cell education certificate, issued by the Department of Public Health. Cassandra is responsible for developing and creating the educational material and curriculum presented by Sickie Cell 101.

As a sickle cell educator, Cassandra provides education and awareness through social media platforms such as Instagram, Facebook and Twitter. Other education platforms include community settings such as: Continuing Education Unit trainings for healthcare professionals, health fairs, sickle cell camp kids and teens, and events. Cassandra also volunteers for various sickle cell organizations.

Speaker Profiles



Jew-EL Darbone

Presentation: Social Media Engagement

A Manhattan, New York native that now lives in North Carolina. Jew-EL graduated from Mount Tabor High School in 2006, and got accepted into Johnson and Wales University in Charlotte. Her education got cut short due to health complications.

She doesn't allow the wheelchair to stop her, she is now Founder and CFO of #Boldlipsforsicklecell. Sickle cell advocacy is her passion and she is determined to better her community in every way possible.



Velvet Watts-Brown

Presentation: Empowering Your Community through Collective Partnership

As Founder/Chairperson of Supporters of Families with Sickle Cell Disease, Inc. Supporters Through her leadership, Supporters of Families with Sickle Cell Disease, is working with the State of Oklahoma Medicaid Agency and was awarded a contract with the Oklahoma Health Care Authority to conduct consultation and services for those impacted by SCT/SCD. Supporters has formed the first Oklahoma Sickle Cell Collective Impact Team to address gaps in the sickle cell community. She is the wife of minister, Jeremiah Sr. and mother of four children of whom Jeremiah Jr. is impacted by sickle cell disease.

Velvet has spent over 20 years in social services. She has conducted several workshops for various agencies throughout Oklahoma on impact of SCD/SCT. Velvet is a member of the National Association of Social Workers, a member of Phi Alpha Honor Society and a member of Oklahoma Sickle Cell Disease Association of America Patient Advocacy Committee. Velvet holds an AA in Liberal Arts from Tulsa Community College, a Bachelor's Degree in Social Work from Northeastern University and Master of Social Work in Administration from University of Oklahoma. Velvet is case management certified for the state's Advantage Program. She works as a Mentor Coordinator with women, and as a Medical Social Worker with hospice and home health patients. Velvet is passionate about serving in the Oklahoma community and empowering others.



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Meeting Participants

CBO Partners

Advancing Sickle Cell Advocacy Project, Inc (A.S.A.P)

A.S.A.P.'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 on sickle cell anemia as well as sickle cell trait. Our vision is to become a leader in advocating for better protocols, raising awareness, developing a wide range of support, educational and networking services designed to improve the quality of life for people living with SCD. We serve as a voice for those who have had no voice.

Representatives: Kemba O. Gosier, President; Paul Braxton, Alma Brown, Monique Favors, Jeffrey Durandis
Website: www.asapbeinformed.org | **Contact:** (954) 951-1108

#BoldLipsForSickleCell

We are a community based organization dedicated to spreading sickle cell awareness by bringing attention with bold colored lipstick as well as empowering sickle cell warriors to live bold fulfilling lives. We use our social media as a empowerment platform dedicated to showing that there is beauty in our pain associated with sickle cell.

Representatives: Shamonica Wiggins, Co-Founder/CEO; Jew-EL Darbone, Co-Founder/CFO
Website: www.boldlipsforsicklecell.com | **Contact:** (336) 749-8373

Cedric Sickle Cell Support Group 4 Kids (CSC)

A non-profit organization for kids with Sickle Cell Disease. The mission of CSC Support Group 4 Kids is to provide advocacy, awareness, education, outreach, referrals, financial support, and aid in research to children diagnosed with Sickle Cell Disease. CSC will reach over 300 sickle cell people in the community through social media and different events that we look forward to having. This organization was created because we deal with communities that have a lack of knowledge and information in the Middle Georgia Area.

Representatives: Vanessa Harvey, Founder & President; Demetrice Spencer
Website: www.cscsupportgroup4kids.org | **Contact:** (478) 225-4624

Meeting Participants

CBO Partners

The Cilly Cell Project

The Cilly Cell Project is an advocacy agency for adults and specializes in support of children. We visit adults and children in the hospital during their hospital stay. Our children's book entitled "Jeffrey's Story: A Time of Sickle Cell Crisis" educates on Sickle Cell Disease. We spread awareness through social media and campaigns like I Choose Red 4 Sickle Cell, which has received international support. We will be hosting benefit concerts starting June 19th, along with our I Choose Red Awards Banquet in December 2016.

Representatives: Angel Woods, Founder; Courtney Woods, Timothy Henderson, Jennifer Williams

Website: thecillycellproject.weebly.com | angelcillycellwoods.selz.com | **Contact:** 404-919-2355

Hope For SCD

We are a health literacy NPO started by parents of a child with Sickle Cell Disease. Although we are based in Denver, Colorado, 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.

Representatives: Lisa Rose, Executive Director; Sean Rose, Director of Outreach & Communications

Website: www.hopeforscd.org | **Contact:** (303) 929-3378 | info@hopeforscd.org

Inspiring More Minds Inc.

Inspiring More Minds, Inc. is a nonprofit organization headquartered in Greenbelt, Maryland. We aim to inspire the minds and enhance the lives of individuals with Sickle Cell Disease (SCD). We achieve these goals through providing students with SCD scholarships to help with finances for college, trade and vocational schools and educational pursuits after high school. We also provide supportive services for individuals with SCD locally and nationally and provide educational advocacy and various help.

Representatives: Bronwyn C. Scott, President; Cyntra D. Scott

Website: www.inspiringmoreminds.com or www.helpimm.org | **Contact:** (301) 534-6205

Meeting Participants

CBO Partners

International Association of Sickle Cell Nurses and Physician Assistants

IASCNAPA is committed to strengthening the relationship between nurses and physician assistants who care for patients with sickle cell disease. Nurse and physician assistants make significant contributions that further the depth of knowledge about sickle cell disease. Our cooperative efforts allow us to play vital roles in clinical research as demonstrated by our participation in NIH studies that have defined the natural history of sickle cell disease and proven the efficacy of prophylactic penicillin for children with the disease.

Representative: Yvonne M. Carroll, RN, JD, Director; Nadine Matthie

Website: www.iascnapa.org | **Contact:** (901) 595-5684

Kids Conquering Sickle Cell Disease Foundation Inc.

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. provides 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.

Representatives: Carla Lewis, Executive Director; Demitrious Wyatt

Website: www.kidsconqueringscd.org | **Contact:** (407) 844-2474 | kidsconqueringscd@yahoo.com

Melanie Dartest Chapter Sickle Cell Foundation

The Melanie Dartest Sickle Cell Foundation was founded to help Sickle Cell patients and their family understand the seriousness of the disease. Also to advocate for the patient with the medical community so that they are of all the medical breakthroughs that are available to them. The foundation will also educate the public on the need to know the seriousness of knowing about Sickle Cell Trait.

Representatives: Dave Andrea Wright, Founder/CEO

Website: www.melanie-dartest-chapter-sickle-cell-foundation.org | **Contact:** (281) 433-1836

Meeting Participants

CBO Partners

Sickle Cell 101 (SC101)

A 501(c)3 non-profit organization that specializes in sickle cell education *within* the sickle cell community and the general public via social media and other platforms. Our slogan is, "education + awareness" because we believe these two factors are vital contributors to the progression of the disorder. Our certified sickle cell educators equip those affected by sickle cell with a comprehensive understanding of the disorder. Equally, by raising awareness our goal is for sickle cell to become a household name, encouraging research efforts.

Representatives: Cassandra Trimnell, Founder/President; Brandy Morgan

Website: www.sc101.org | **Contact:** info@sc101.org

Sickle Cell Awareness Ride, Inc (S.C.A.R)

S.C.A.R.'s purpose is to deliver an energetic and upbeat riding event that reflects the spirits of those with Sickle Cell Disease. This annual event serves, inspires, and empowers those affected by Sickle Cell, and also educate the public on the pressing issue that is Sickle Cell Anemia. Whether it be through pamphlets, conversations with those affected, or testing for the trait, the word of the illness shall be spread. S.C.A.R. wishes to accomplish a greater understanding of the disease amongst the community.

Representative: Lisa Dean-Touray, Founder/Executive Director

Website: www.atlantastar.com | **Contact:** (404) 784-5781 | atlantascar@gmail.com

Sickle Cell Champions Association (S.C.C.A)

S.C.C.A. was formed to bring a male perspective to not only the youth, but also for new parents, and to enlighten the communities of what Sickle Cell Disease is, how it affects the body, and what a child may possibly encounter within their lives. We strive to be an effective voice, for the SCD patient, family member and male community. The program ("Champions Mentoring") was created and implemented to ensure that we place focus on the empowerment, motivation and overall growth of adolescent males living with SCD.

Representatives: Clayton W. Andrews, Chair; Lamar Gathers, Secretary

Contact: (470) 231-9287 | sicklecellchampionsassociation@gmail.com

Meeting Participants

CBO Partners

Sickle Cell Natural Wellness Group Inc. (SCNWG)

A 501c3 non-profit organization founded in 2010. Our mission is to support health advocacy and build global awareness for Sickle Cell Anemia. Our organization advocates using natural modalities such as plant-based nutrition and holistic methods to alleviate Sickle Cell pain crisis. We are the only organization dedicated to truly treating Sickle Cell, without risking side effects. Our dedication is to better the lives of those living with Sickle Cell Anemia and Sickle Cell trait through education and healthy lifestyle choices.

Representatives: TJ Brown, President; Stephanie Zapata

Website: www.scnwg.com | **Contact:** (561) 929-4454

Supporters of Families With Sickle Cell

Supporters of Families with Sickle Cell Disease, Inc., is committed to comprehensively addressing the needs of the Oklahoma Sickle Cell community; as we are the only community based 501[c]3 organization assisting those impacted with sickle cell/thalassemia disease and trait. Supporters is dedicated to increase self-efficacy; improving the overall quality of life through education, family support, economic self-sufficiency, awareness, and advocacy.

Representatives: Velvet Brown-Watts, CM, MSW; Founder/Chairperson, Jeremiah Watts, Sr. MHR

Website: www.sicklecelloklahoma.org | **Contact:** (918) 619.6174 | swithsicklecell@att.net

Lockhart-Morgan Foundation

To promote awareness of sickle cell anemia through education, fundraisers, and social events.

Representatives: Gwen Morgan, Edwin Morgan

Website: www.lockhartmorganfoundation.org | **Contact:** lockhartmorganfoundation@yahoo.com

Meeting Participants

Patient & Family Advisors

Janeen JV Greene, Patient

State: New York | **Email:** inflight344@gmail.com

Judy Johnson

Kadeem Gayle, Patient

State: Massachusetts | **Email:** kadeem.gayle@gmail.com

LaVeda Page

State: Georgia

Marcus McKinley, Patient

State: Oklahoma | **Email:** mckinleymarcus@yahoo.com

Marian “Asabi” Jeter, Patient

State: Georgia | **Email:** ajeter@sicklecellga.org

Marquita Gaines, Patient

State: Georgia | **Email:** marquita0215@gmail.com

Nicole L. Harvey, Patient

State: Kansas | **Email:** nicole64127@yahoo.com

Nita Thompson

State: California | **Email:** aa4scdawareness@aol.com

Tina Kay Hughes, Patient

State: Alabama | **Email:** tkay2006@gmail.com

Ulysse Guerrier, Patient

Canada | **Email:** uguerrier@me.com

Meeting Participants

Other CBOs

As One Foundation

A non-profit 501(c)(3) organization that facilitates community programs. Our mission is to educate and increase awareness of sickle cell trait while encouraging youth to achieve their dreams in the face of life's challenges. Our vision is to support and enhance youth development by providing youth-centered activities and opportunities to develop character, values, sportsmanship, responsibility and positive relationships.

Representative: Tomia Austin

Website: www.asonefoundation.org | **Contact:** (832) 308-9984 | info@asonefoundation.org

Foundation for Sickle Cell Disease Research

A comprehensive, non-profit organization that provides a platform for researchers, healthcare providers, individuals and their families living with sickle cell disease and supporters to work collaboratively in identifying barriers that are limiting creation, adoption and adherence to evidence-based screening recommendations, new therapeutics and best practices that help in the management of sickle cell disease. Our mission is to support innovative research in Sickle Cell Disease.

Representative: Lanetta Jordan, MD

Website: www.fscdr.org | **Contact:** (954) 397-3251 | info@fscdr.org

Sickle Cell Association of Houston

A Community Partner Program providing support and resources to families & communities affected by sickle cell disease. Our mission is to create and support Sickle Cell awareness through education and provide treatment information and research updates.

Representatives: Tonya Prince, President; Quannecia McCruse

Website: www.sicklecellhouston.org | **Contact:** (832) 930-7224

Sickle Cell Foundation of Orange County

Founded in response to the ever increasing disparities among Orange County youth and adults living with SCD. We are committed to increasing the public's awareness of sickle cell disease; through educational seminars, community based workshops, educational activities, and other support programs. Our goal is to provide continuous education about the disease, its management, and its myriad of issues.

Representatives: Star Simmons, President & Founder

Website: www.scdfoc.org | **Contact:** (949) 331-8121 | ssimmons@scdoc.org



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**Sickle Cell Foundation
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“The Power of Knowledge, Living with Sickle Cell”

MEDICAL

- ☐ The Medicine Cabinet: Hydroxyurea & New Developments in Treatment
- ☐ Transfusion Pros & Cons
- ☐ The Significance of Sickle Cell Trait

POLICY & RESEARCH

- ☐ Medical Cannabis and More
- ☐ Advocacy: Fighting For What You Need

SELF-CARE

- ☐ Caring For The Total You
- ☐ Paying For Your Care: Examining The Options
- ☐ TAKING CHARGE OF YOUR HEALTH: NEW TOOLS
- ☐ “Get Connected” National Registry

YOUTH MATTERS

- ☐ 10 Must-Do: Transitioning From Pediatric to Adult Care
- ☐ What Section 504 Is: How It Can Help Your Child



Participants by Locations

ALABAMA

Tina Kay - Patient Advisor

CALIFORNIA

(CA) Cassandra Trimmell, President – Sickie Cell 101
(CA) Brandy Morgan – Sickie Cell 101
(CA) Nita Thompson – Patient Advisor
(CA) Star Simmons, President – Sickie Cell Foundation of Orange County

COLORADO

(CO) Lisa Rose, Executive Director – Hope for SCD
(CO) Sean Rose, Director of Outreach & Communications – Hope for SCD

FLORIDA

(FL) Kemba Gosier, President – Advancing Sickie Cell Advocacy Project, Inc.
(FL) Paul Braxton – Advancing Sickie Cell Project, Inc.
(FL) Alma Brown – Advancing Sickie Cell Project, Inc.
(FL) Monique Favors – Advancing Sickie Cell Project, Inc.
(FL) Carla Lewis, Executive Director – Kids Conquering Sickie Cell Disease Foundation
(FL) Demitrious Wyatt – Kids Conquering Sickie Cell Disease Foundation
(FL) T.J. Brown, President – Sickie Cell Natural Wellness Group, Inc.
(FL) Stephanie Zapata – Sickie Cell Natural Wellness Group, Inc.
(FL) Lanetta Jordan – Foundation for Sickie Cell Disease Research

GEORGIA

(GA) Nitya Bakshi – Speaker
(GA) Diana Ross – Speaker
(GA) Lakshmanan Krishnamurti – Speaker
(GA) Raymona Lawrence, Director of Research – Sickie Cell Community Consortium
(GA) Mutsa Seremwe, Assoc. Director of Clinical Research – Sickie Cell Community Consortium
(GA) Gwen Morgan – Lockhart-Morgan Foundation
(GA) Edwin Morgan – Lockhart-Morgan Foundation
(GA) Lakiea Bailey, Executive Director – Sickie Cell Community Consortium
(GA) Doris Bailey, Assoc. Director of Finance – Sickie Cell Community Consortium
(GA) Kimberly Davis, Administrative Coordinator for Georgia – Sickie Cell Community Consortium (SCCC)
(GA) Vanessa Harvey, President – Cedric Sickie Cell Support Group 4 Kids
(GA) Demetrice Spencer – Cedric Sickie Cell Support Group 4 Kids
(GA) Angel Woods, President – The Cilly Cell Project
(GA) Courtney Woods – The Cilly Cell Project
(GA) Timothy Henderson – The Cilly Cell Project
(GA) Jennifer Williams – The Cilly Cell Project
(GA) Lisa Dean-Touray, Executive Director – Sickie Cell Awareness Ride, Inc.
(GA) Clayton W. Andrews, Chair – Sickie Cell Champions Association
(GA) Lamar Gathers, Secretary – Sickie Cell Champions Association
(GA) Eric Frempong, Director of Finance – Sickie Cell Community Consortium
(GA) Marian “Asabi” Jeter – Patient Advisor
(GA) Marquita Gaines – Patient Advisor
(GA) Patricia Wilson-Smith – Speaker

ILLINOIS

(IL) Elijah Powell – Sickie Cell Champions Association

KANSAS

(KS) Nicole Harvey – Patient Advisor

MARYLAND

(MD) Kena Drew, Executive Administrator – Sickie Cell Community Consortium
(MD) Nikki Peterson, Special Projects Coordinator – Sickie Cell Community Consortium
(MD) Allen Tien – Speaker

MASSACHUSETTS

(MA) Kadeem Gayle – Patient Advisor
(MA) Jennifer Helfer – Speaker

NEW JERSEY

(NJ) Bill Cummings, Director of Development – Sickie Cell Community Consortium

NEW YORK

(NY) Janeen JV Greene – Patient Advisor
(NY) Wade Zamechek – Speaker

NORTH CAROLINA

(NC) Jew-El Darbone, CFO – #BoldLipsForSickieCell

OKLAHOMA

(OK) Velvet Brown-Watts, Chair – Supporters of Families with Sickie Cell
(OK) Jeremiah Watts – Supporters of Families with Sickie Cell
(OK) Marcus McKinley – Patient Advisor

TENNESSEE

(TN) Yvonne M. Carroll, Director – International Association of Sickie Cell Nurses & Physician Assistants

TEXAS

(TX) Shamonica Wiggins, CEO – #BoldLipsForSickieCell
(TX) Andrea Wright, CEO – Melanie Dartest Sickie Cell Foundation
(TX) Tomia Austin – As One Foundation
(TX) Tonya Prince – Sickie Cell Association of Houston
(TX) Quannecia McCruse – Sickie Cell Association of Houston
(TX) Andrell “Ty” – Sickie Cell Champions Association

VIRGINIA

(VA) Browyn C. Scott, President – Inspiring More Minds, Inc.
(VA) Cyntra D. Scott – Inspiring More Minds, Inc.

CANADA

Ulysse Guerrier