

# SICKLE CELL DISEASE

## *Patient & Family Symposium*



**Wednesday to Sunday**

July 12-16, 2017

**The Westin Buckhead Atlanta**

3391 Peachtree Rd NE,  
Atlanta, GA 30326

[www.sicklecellconvention.com](http://www.sicklecellconvention.com)

*Powered By* Sickle Cell Community  
Consortium

# Welcome

We are ecstatic for you to attend the 4th Annual Sickle Cell Disease Patient & Family Educational Symposium! This annual meeting has become the Warrior Family Reunion. We look forward to enjoying this week with all of the warriors, families, healthcare providers and research scientists from all over the country.

Every July, we gather together in a city chosen by the Sickle Cell community to share experiences, learn new strategies for life improvement, and make lifelong friends. This weekend is a great time to recharge your batteries, take a break, enjoy a vacation, and meet (or reconnect) with your friends in the Sickle Cell community.

The 2017 Symposium is hosted by HOPE for SCD, Bold Lips For Sickle Cell, and Supporters of Families with Sickle Cell. Over the course of the next four days we will be joined by experts in a diverse range of fields, to provide insight into managing Sickle Cell disease. You are invited to participate in a series of presentations, breakout sessions, workshops, and panel discussions that are aimed to equip you with the tools needed to live a vibrant life.

This year we are excited to include a track designed specifically for children and caregivers hosted by HOPE for SCD, and also to introduce a new effort that will include and engage men within the Sickle Cell community. The Sickle Cell Men's Action Network (Sickle M.A.N.) has created a diverse range of subjects from the "Father-to-Father" panel, to the role of the Sickle Cell man in leading the home. These sessions will be broadcast live during the Symposium.

On Friday evening we welcome everyone to join us in The Playroom - Auction and FUNdraiser. Hosted by the Sickle Cell Champions Association, and No Pain in the Playroom, in collaboration with Playdate Atlanta, this fun-filled event is for the 16 and over crowd. It will include a vast variety of games and contests, as well as music, performances, and food. The 2017 Consortium Auction, which began this past Monday, July 10th, will end at 9PM during The Playroom. You can sign-up at [www.tinyurl.com/SCD-Auction-2017-signup](http://www.tinyurl.com/SCD-Auction-2017-signup), and then come down to Ballroom CDE to bid and challenge other Warriors at board games, video games, hula-hoop contests and much, much more!

On Saturday evening is the Bold Lips & Bow Ties Prom and Awards Gala. This elegant event is a second chance for Warriors to redo their Prom, and have the night of a lifetime, as well as for multiple organizations to be recognized for the amazing work they've done to impact Warriors' lives. The ladies of Bold Lips for Sickle Cell invite you to come and experience your prom all over again, or maybe for the very first time. It will be the Oscars of the Sickle Cell community! So pick up your prom dress or tuxedo, grab a date, and join us for a night of elegance and entertainment.

We have an eventful few days ahead of us. Remember to pace yourselves, stay hydrated, and as always be ready to teach, learn and have loads of fun!



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## BREAKFAST WITH WARRIORS



## LUNCH WITH WARRIORS



## SUPPORTERS



## WEDNESDAY, JULY 12

- ☐ REGISTRATION
- ☐ OPENING RECEPTION

## THURSDAY, JULY 13

- ☐ PLENARY: THE ANATOMY OF A WARRIOR (DR. LAKIEA BAILEY)
- ☐ BREAKOUT SESSIONS
- ☐ LUNCH
- ☐ BREAKOUT SESSIONS
- ☐ NIH FOCUS GROUPS
- ☐ KID ZONE-  
EDUCATIONAL WORKSHOPS  
OPEN SESSION (2-5 PM)
- ☐ WARRIORS AFTER DARK  
FOR MEN (CLAYTON ANDREWS)  
FOR WOMEN (MAXINE COLLIER)

## FRIDAY, JULY 14

- ☐ BREAKOUT SESSION
- ☐ ASH INITIATIVE  
(LATASHA LEE)
- ☐ RESEARCH LIGHTNING ROUNDS  
GENE THERAPY (DR. PATRICK FLIGHT)  
THE PFIZER SCD PROGRAM  
(DR. LORI LUCK)

## FRIDAY, JULY 14

- ☐ L-GLUTAMINE (DR. CHARLES STARK)
- ☐ TRANSPLANT IN SICKLE CELL  
(ANNE HAIGHT)
- ☐ LIFE AFTER BMT  
(KIRSHMA KHEMANI)
- ☐ CLINICAL TRIAL PATIENT/CAREGIVER  
ROUNDTABLE & LUNCH  
AMERICAN SOCIETY OF HEMATOLOGY
- ☐ BREAKOUT SESSIONS
- ☐ NIH FOCUS GROUPS
- ☐ PLAYROOM/KIDS NIGHT

## SATURDAY, JULY 15

- ☐ COFFEE & CONVERSATION  
(LAKISHA JOHNSON)
- ☐ BREAKOUT SESSION
- ☐ SCDA & HRSA UPDATES  
(SONJA BANKS)
- ☐ BREAKOUT SESSION
- ☐ LUNCH  
GLOBAL BLOOD THERAPEUTICS
- ☐ PROM

## SUNDAY, JULY 16

- ☐ PRAYER BREAKFAST
- ☐ MEET ME IN THE CORNER OF  
FAITH & SCIENCE

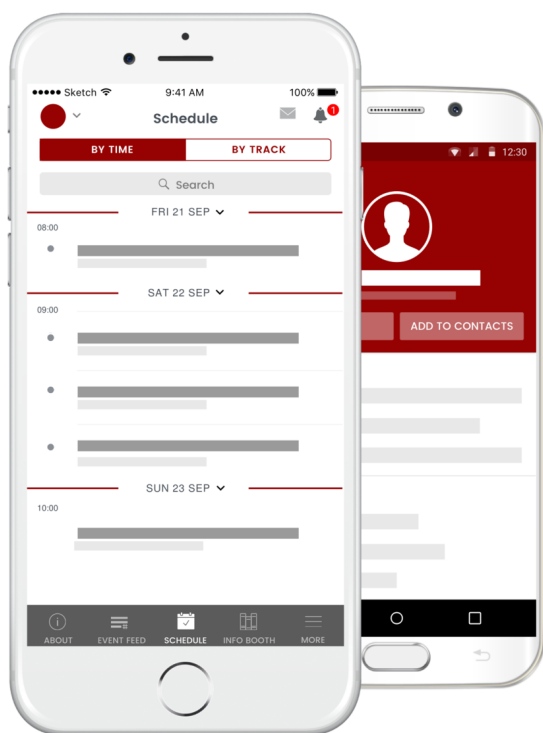


# 4th Annual SCD PFE Symposium

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# About the Hosts



## HOPE FOR SCD

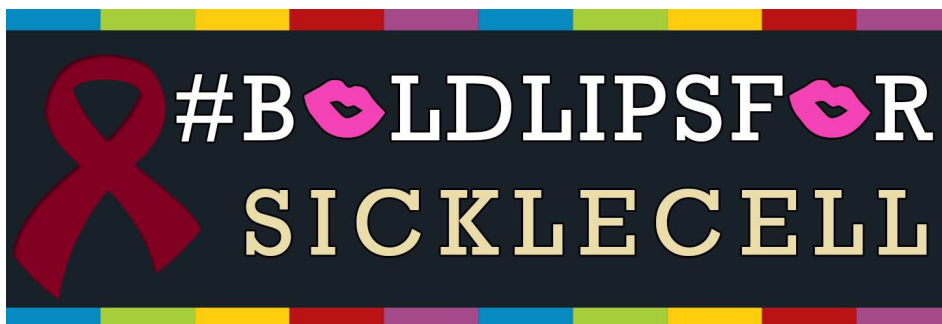
Hope for SCD is a Health Literacy NPO that was started by parents of a child with Sickle Cell Disease. Based in Raleigh, NC, we work with consumers, medical providers, and the pharmaceutical industry to increase international access to research based medical education materials.

Our mission is to bridge the gap between providers and the lay community through research based health literacy tools and programs. As our background lies in education, our focus remains solely on the learning connected to this chronic illness from birth through adult. Every person, regardless of educational background should feel empowered to speak up, spread the word, and educate in their community. Accurate, user-friendly literature is key to this if we want to increase the visibility of Sickle Cell Disease.

## BOLDLIPSFORSICKLECELL

#BoldLipsForSickleCell is a 501(c3) non profit organization geared towards spreading awareness for sickle cell disease and empowering individuals who have the illness. They have become a fresh and relevant movement, intended to put a bold and flattering spotlight on this disease and it's community. We plan to continue to build a network of supporters and allies who will help make this disease as well known and positively endorsed such as the ones of breast cancer and other high profile diseases.

The mission of #BOLDLIPSFORSICKLECELL is to educate and raise awareness for sickle cell disease through it's 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.



# About the Hosts



## SUPPORTERS OF FAMILIES WITH SICKLE CELL DISEASE

Supporters of Families with Sickle Cell Disease (Supporters), Inc., was founded in Tulsa in 2004 as a family support group and incorporated in 2007. Supporters is the only comprehensive 501(c)(3) nonprofit organization committed to exclusively serving families living with sickle cell disease and related conditions in Oklahoma. The initial goal was to support the Oklahoma Chapter of the Sickle Cell Disease Association of America and the families they serve.

However, when the Association lost funding in 2009 due to state budget cuts and dissolved; Supporters' became the center of contact and community resource provision for the more than 40,000 Oklahomans with sickle cell trait and over 1,500 Oklahoman families living who struggle daily with the crippling effects of sickle cell, thalassemia, cc disease and traits. Supporters promotes a community-based approach to SCD education and care management that empowers individuals and families who live with the debilitating condition, so they can enjoy the best quality of life possible.

## Hosts' Contact Information



Email: [info@hopeforscd.org](mailto:info@hopeforscd.org)  
Website: [www.hopeforscd.org](http://www.hopeforscd.org)  
Youtube:  
[www.youtube.com/hopeforscdorg](http://www.youtube.com/hopeforscdorg)  
Twitter:  
[www.twitter.com/hopeforscd](http://www.twitter.com/hopeforscd)  
Facebook:  
[www.facebook.com/hopeforscd](http://www.facebook.com/hopeforscd)



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Sickle Cell Disease, Inc.  
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(918) 619.6174  
[www.sicklecelloklahoma.org](http://www.sicklecelloklahoma.org)



Website:  
[www.boldlipsforsicklecell.com](http://www.boldlipsforsicklecell.com)  
Twitter: @Boldlips4scd  
FB: Bold Lips For Sickle Cell  
Instagram: Boldlipsforsicklecell

# Planning Committee

## 4TH ANNUAL SICKLE CELL PATIENT & FAMILY EDUCATIONAL SYMPOSIUM PLANNING COMMITTEE

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### **Teonna Woolford**

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# Planning Committee

## BOLD LIPS & BOW TIES AWARDS GALA AND PROM

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### **Corin Wilson**

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#BoldLipsForSickleCell

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## THE PLAYROOM AUCTION FUNDRAISER

### **Angeline Hiley**

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Sickle Cell Community Consortium

### **Diamond Edmundson**

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### **Sharonda Sikes-Hudson**

Founder, President

The Red Chair Project

### **Rae Bailey**

Project Manager

Sickle Cell Community Consortium

### **Omeka Edwards**

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# *Planning Committee*

## **SICKLE CELL MEN'S ACTION NETWORK (SICKLE M.A.N.)**

### **Jeremiah Watts Sr.**

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### **Marcus Mckinley**

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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.**

The GBT HOPE study, a Phase 3 global clinical research study for adults and adolescents living with SCD, is currently underway. To see if you or a loved one may qualify, please visit **[GBTsicklecellstudy.com](https://GBTsicklecellstudy.com)**.





# Agenda

## WEDNESDAY, JULY 12

Time	Event	Location
11 AM	<b>Expo Set Up</b>	Ballroom A
2 PM	<b>Registration Opens</b>	Pre-Function
5 PM	<b>Reception</b>	Pre-Function

## THURSDAY, JULY 13

9 AM	<b>Expo Opens</b>	Ballroom A
10 AM	<b>Welcome to the 4th Annual Sickle Cell Patient &amp; Family Symposium: The Anatomy of a Warrior</b> (Dr. Lakiea Bailey)	Ballroom B
	<b>BREAKOUT SESSIONS</b>	
11:00-11:30 AM	<b>Patient Rights in the Workplace</b> (Dr.Yvonne Carroll)	Ballroom B
	<b>Young Adult Mixer</b> Host: Marcus Mckinley, Monique Mckinley, Teonna Wolford	Habersham
	<b>Navigating Pediatric Healthcare</b> (Dr.Tandua Washington)	Tuxedo
	<b>BREAKOUT SESSIONS</b>	
11:35 AM - 12:15 PM	<b>Understanding Clinical Trials &amp; Patient Safety</b> (Dr. Marie Ojiambo)	Ballroom B
	<b>The College Experience</b> (Kallie Hargrove, Jazmine Rivera, Clyde Rhodes, Marquitta Gaines)	Habersham
	<b>IEP/504 Primary School</b> (Nikki P.)	Tuxedo

# Agenda

## THURSDAY, JULY 13 Continued

Time	Event	Location
	<b>BREAKOUT SESSIONS</b>	
12:20 PM- 12:55 PM	<b>Psychological &amp; Psychosocial Impact of SCD: Dispelling the Myths Related to Mental Illness</b> (Dr. Gayle Rodgers)	Ballroom B
	IEP/504 Secondary School (Nikki P.)	Tuxedo
1:00 PM	<b>Lunch Presentation: Results of the Sickie Option Study</b> (Dr. Krishnamurti/Diana Ross) Emory University	Ballroom CDE
2:15 PM- 2:45 PM	<b>The Science of Sickie Cell</b> (Dr. Julie Kanter)	Ballroom B
	<b>KID ZONE: Therapeutic Recreation &amp; Educational Workshops</b>	Tuxedo
2:50 PM-3:20 PM	<b>Herbal Remedies &amp; Sickie Cell Disease</b> (Dr. Marie Ojiambo)	Ballroom B
	<b>NIH Focus Group #1</b> Caregiver	Habersham
3:25 PM-3:55 PM	<b>Taking Our Stand: Fair Treatment in US Hospitals &amp; Clinics</b> (Dominique Friend)	Ballroom B
4:00 PM - 4:30 PM	<b>Chronic Pain and the Opioid Connection</b> (Dr. Julie Kanter)	Ballroom B
4:35 PM - 5:05 PM	<b>Be Well with Sickie Cell: Food and Lifestyle Presentation</b> (T.J. Brown)	Ballroom B
7:00 PM	<b>Warriors After Dark</b> For Men: (Clayton Andrews) For Women: (Min.Maxine Collier)	Habersham Tuxedo

# Agenda

## FRIDAY, JULY 14

Time	Event	Location
8:00 AM	Registration Opens	Pre-Function
9:00 AM	Expo Hall Opens	Ballroom A
9:00 AM	<b>National Consortium Parent-to-Parent Initiative</b> (Vanessa Rhodes, Adrienne Bell Cours, Lisa Rose)	Ballroom B
	<b>The Warrior Husband &amp; Leading the Home</b>	Tuxedo
10:00 AM	<b>ASH Multi-Faceted Sickle Cell Disease Initiative</b> (LaTasha Lee)	Ballroom B
<b>RESEARCH LIGHTENING</b>		
<b>GROUP #1</b>		
11:00 AM-11:20 AM	<b>Gene Therapy</b> (Dr. Patrick Flight, bluebird bio)	Ballroom B
11:25 AM-11:45 AM	<b>The Pfizer Sickle Cell Disease Program</b> (Dr. Lori Luck, Pfizer)	Ballroom B
11:50 AM-12:10 AM	<b>Endari: L-glutamine</b> (Dr. Charles Stark, Emmaus)	Ballroom B
<b>GROUP #2</b>		
12:15 PM - 12:35 PM	<b>Transplant in Sickle Cell: The Short Story</b> (Ann Haight)	Ballroom B
12:40 PM - 1:00 PM	<b>Life After Transplant</b> (Kirshma Khemani)	Ballroom B
1:15 PM	<b>Clinical Trial Patient/Caregiver Round Table (SPONSORED &amp; HOSTED BY: The American Society of Hematology)</b>	Ballroom CDE
<b>BREAKOUT SESSIONS</b>		
2:30 PM-2:55 PM	<b>Sickle Cell Patients Score with Congress: A Case Study &amp; Time to Do It Again</b> (Saira Sultan)	Ballroom B



# Agenda

## FRIDAY, JULY 14

Time	Event	Location
	<b>BREAKOUT SESSIONS</b>	
2:30 PM - 2:55 PM	<b>NIH FOCUS GROUP #2 (PATIENT)</b>	Habersham
3:00 PM-3:25 PM	<b>Caregiver Burnout and Guilt</b> (Velvet Brown Watts)	Tuxedo
	<b>L-Glutamine &amp; The FDA</b> (Dr. Charles Stark)	Ballroom B
	<b>The homeschool alternative</b> (Lisa Rose/Vanessa Rhodes)	Tuxedo
3:30 PM-3:55 PM	<b>Sickle Cell &amp; Mental Health: Impact, Coping, Recovery</b> (Clayton Andrews)	
4:00 PM-4:25	<b>Mental Health Panel</b> (Clayton Andrews, Shamonica, Jewel, Gayle Rodgers)	Ballroom B
	<b>Motherhood &amp; Self Care: Purpose-Filled Families within Sickle Cell</b> (Minimarie Andrews)	Tuxedo
4:30 PM-5:00 PM	<b>Life Coaching Children with Sickle Cell</b> (Duchess Joy-EL)	Tuxedo
7:00 PM	<b>THE PLAYROOM - AUCTION &amp; FUNDRAISER</b> Hosted by in collab with NO PAIN IN THE PLAYROOM, & SICKLE CELL CHAMPIONS ASSOCIATION	

## SATURDAY, JULY 15

8:00 AM	Registration Open	Pre-Function
8:00 AM	Coffee & Conversation with Lakisha Johnson	Ballroom CDE
9:00 AM	Expo Hall Opens	Ballroom A

# Agenda

## SATURDAY, JULY 15 Continued

Time	Event	Location
	<b>BREAKOUT SESSIONS</b>	
9:00 AM	<b>Mother-to-Mother Panel</b> (Velvet Watts, Doris Bailey, Lisa Rose, Vanessa Rhodes)	Ballroom B
	<b>Young Adult Panel</b> (Clyde Rhodes, Marcus Mckinley, Teonna Woolford, Marquitta Gaines)	Habersham
	<b>Father-to-Father Panel</b> (Bill Cummings, Jeremiah Watts)	Tuxedo
10:00 AM	<b>Sickle Cell Association of America: Community Updates &amp; HRSA Grant</b> (Sonja Banks, President, SCDA)	Ballroom B
11:00 PM- 11:55 PM	<b>Sickle Cell and Women's Health</b> (Dr. Ify Osunkwo)	Ballroom B
	<b>NIH Focus Group #3 Caregiver</b>	Habersham
	<b>Sickle Cell &amp; Men's Health</b> (Dr. James Eckman)	Tuxedo
12:00 PM - 12:25 PM	<b>Sickle Cell Complications, Stress Prevention and Pain Management</b> (Dr. Eckman)	Ballroom B
	<b>Financial Health &amp; Stability</b> (Erika McKay)	Tuxedo
12:30 PM- 12:55 PM	<b>GET CONNECTED</b> (Sonja Banks)	Ballroom B
	<b>After Transition: Navigating the Adult Sickle Cell World</b> (Dr. Ify Osunkwo)	
1:00 PM	<b>SPONSORED LUNCH, GLOBAL BLOOD THERAPEUTICS (GBT): PIONEERING NEW TREATMENTS FOR SICKLE CELL DISEASE</b>	
2:00 PM-4:00 PM	NIH Focus Group #4 Patient	Habersham

# Agenda

## SATURDAY, JULY 15 Continued

Time	Event	Location
2:00 PM- 3:00PM	<b>Transition App Focus Group</b> What should be in the app? What should it look like?	Tuxedo Ballroom B
7:00 PM	<b>Bold Lips &amp; Bow Ties Award Gala &amp; Prom</b>	Ballroom CDE

## SUNDAY, JULY 16

8:00 AM-10:00 AM	<b>Prayer Breakfast: Faith-Based Empowerment &amp; Encouragement</b> (Lakiea, Nathaniel, Min.Remy, Alexis Jarrett)	Ballroom CDE
10:00 AM-11:00 AM	<b>Meet me at the Corner of Faith &amp; Science</b> (Lakiea Bailey)	
11:00 AM-12:00 AM	<b>Close of the 4th Annual Sickle Cell Patient &amp; Family Educational Symposium</b>	

# NIH wants your thoughts on **Gene-Editing!**

Currently recruiting participants for this study.

## The purpose of this study is to:

Evaluate the effectiveness of a video-based educational tool on improving understanding of a new gene-editing technique

Better understand the knowledge, views, and beliefs of patients with sickle cell disease, parents of patients with sickle cell disease, and providers towards gene-editing and new developments within this space



## You may be able to participate if:

- You have sickle cell disease, are a parent of someone with sickle cell disease, OR a physician who cares for patients with sickle cell disease
- You are over 18 years of age

## What you can expect:

- Compensation will be provided for your time (\$75 Target gift card)
- Completion of three brief questionnaires
- Watching a short educational video on a new gene-editing technology
- Participation in a 60 to 90-minute focus group discussion

For more information, contact us at 301-451-3997  
[SCDVoices@mail.nih.gov](mailto:SCDVoices@mail.nih.gov)



National Human Genome  
Research Institute



# Speaker Profiles

## Alexis Jarrett

**CEO of Grace Media LLC.**



Alexis M. Jarrett is a young woman who has a love and zeal for life that is contagious. She is a powerful prophetess, preacher, teacher and friend. Alexis was born with Sick Cell Disease and is an advocate for educating the public on the disease and donating blood. Her motto: "I have Sick Cell, but it does NOT have me!" While in college she accepted the call on her life to minister The Gospel, and is currently enrolled at The Pentecostal Theological Seminary to complete her Masters Degree in Pastoral Counseling. She has a B.A. in Mass Communication from Columbus State University, and currently owns her own business called Grace Media LLC, a marketing and branding company. She is the author of "Back to the Father's Heart," a book that tells the story of her overcoming sickle cell and her painful past. Alexis is currently the President and Founder of The Radiant Ones, a ministry for girls and women, ages 15-30.

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

## Ann Haight



Dr. Haight grew up in Louisiana and trained in the Southeast, attending Rhodes College in Memphis for her BA in Biology, medical school in Augusta at MCG, completing pediatric internship and residency at Arkansas Children's Hospital, and a fellowship in pediatric hematology/oncology/transplant and gene therapy at St. Jude. She joined the faculty at Emory University School of Medicine in 2001 and has been a bone marrow transplant physician at Children's Healthcare of Atlanta, Aflac Cancer and Blood Disorders Center since then. With special expertise in BMT for sickle cell, she is committed to the success of well designed, well executed collaborative trials improving clinical outcomes for children, and enjoys educating staff and patients/families about the

complexities of blood and marrow transplant, creating strong partnerships for optimal care of BMT patients at all points in the journey. She started and leads the "Ex-sickle clinic," a long-term follow up program for those transplanted for sickle cell. Her other interests lie in supportive care in BMT as well as bioethics, and she serves as Vice Chair for Emory's Institutional Review Board, which oversees protection of human research subjects.



# Speaker Profiles

## Bill Cummings

### Sickle Cell Community Consortium



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.

## Charles Stark, Pharm D.

### Senior Vice President of Research and Development



Mr. Stark has served as Emmaus' Senior Vice President of Research and Development since 2013, bringing more than 30 years of experience in medical affairs, research and academia. Previously, Dr. Stark was Director of Clinical Development at Bavarian Nordic, an immunotherapeutic company, and prior to that, the Associate Director of Medical Affairs for the Dendreon Corporation, also an immunotherapeutic company. He has served as, Director, Medical Science Liaisons (cardiovascular, metabolic, and oncology) at Pfizer, Inc., a pharmaceutical company. Dr. Stark has served as the Director

of Investigational Drug Services and Clinical Research at LABioMed at Harbor UCLA and at the Health Research Association at USC Medical Center. He has also served as a faculty member at the University of Southern California School of Pharmacy. Dr. Stark received his Pharm.D. from the University of Southern California and completed his residency at the Veteran's Affairs Medical Center in West Los Angeles.

# Speaker Profiles

## Clayton Andrews

### Co-Founder Sickle Cell Champions Assn.



Clayton Andrews is a 34-year-old Sickle Cell Warrior, husband, and father of four residing in Augusta GA. Clayton is the Chair and co-founder of the Sickle Cell Champions Association (SCCA), a mentoring organization geared and designed for the guidance and empowerment of young males with SCD for their transition into adulthood. Since graduating Troy University with a Master of Science in Counseling and Psychology, his primary focus has been to sustain and develop the self-sufficiency of mental health.

Clayton's ultimate objective is to become a positive influence and mentor to his peers in the SC Community and advocating for young males with this disease.

## Dominique Friend

### Founder of Sickle International Family Coalitions, Author, Sickle Cell Advocate



Dominique Friend is an activist for Sickle Cell Disease awareness and research who currently resides in South Central Pennsylvania, but who grew up in Baltimore, Maryland. She is a wife, the mother of five wonderful children and has one beautiful granddaughter. Although her illness prevented her from graduating high school, she obtained her GED and then completed post-secondary courses in Creative Writing. Now a published author. Dominique has captured the essence of her daily struggles with the unpredictability and pain of Sickle Cell Disease in her autobiography, *SICKLE, A Story of Pain, Purpose and Perseverance*.

## DIANA ROSS, RN, MSN

### Senior Research Coordinator- Emory University

Diana Ross is a Senior Research Coordinator at Emory University. Her expertise is in Hematology, Nursing Science and Clinical Trials. Over 30 years experience as a registered nurse with 10 years experience in research and 5 years experience working with the sickle cell population.

# Speaker Profiles

## Duchess Joyce El

**CEO of Journeys by Grace Global Missions, Inc.**



Joyce El has many titles within the SCD community but she is best known as "Duchess" due to her compassion and commitment to wellness for others. As the founder and CEO of Journeys by Grace Global Missions, Inc; Administrator/Advocate of Shawn's Testimony/I-Testify & Founder/Owner of Journeys Advocates, she is a passionate community advocate and visionary, who helps individuals bring self realization and hope to their lives through faith and perseverance from life circumstances. Duchess is a "Life Line" and an Advocate for the adult community facing "substance

abuse/recovery" and children with special medical needs such as SCD. She is committed to the cause of healing & recovery within her community by creating media projects that feature guests from various walks of life that share experiences, advice, and testimonies.

## Erika Mckay

**Financial Consultant**



Erika McKay is a financial consultant and business coach. She is a graduate of Emory University and travels internationally empowering people to achieve financial success. Erika teaches people how to push through challenges to create a powerful life.



# Speaker Profiles

## Dr. Gayle Rogers

### Founder/President of Forever Free Inc. & A.C.E. Network



Dr. Gayle Rogers is founder and president of Forever Free, Inc., & A.C.E. Network, a coaching for empowerment group located in Dana Point, California. Dr. Rogers is a mental health professional with a Master's Degree in Psychology, and a Ph.D. in Women's Studies. Her focus is integrating a clinical therapeutic approach, using cognitive behavioral therapy and a spiritual discipline, and to bridge the gap between spiritual and psychological modalities. Within the ministry, her primary focus is to equip, coach, and train leaders to facilitate wholeness and healing. She leads conferences worldwide with apostolic/prophetic anointing while carrying a Kingdom message to the nations.

## Dr. Ify Osunkwo

### Medical Director, Adult Sickle Cell Program Carolinas Healthcare System

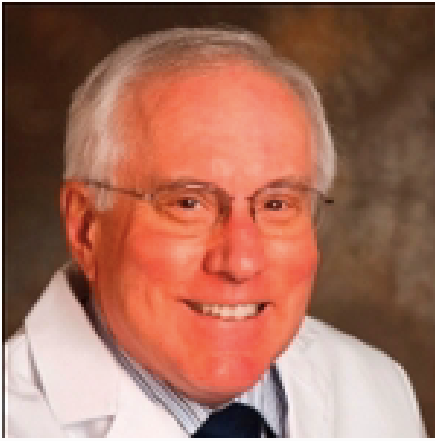


Dr. Ify Osunkwo, a specialist in hematology and Sickle Cell Disease at Levine Cancer Institute in Carolinas HealthCare System (Charlotte NC), had made it her mission to improve the quality of life for Sickle Cell patients. After obtaining her medical degree from the University of Nigeria, she obtained a Masters in Public Health from Johns Hopkins University in Baltimore, MD and completed a fellowship in Pediatric Hematology/Oncology at Columbia University in New York, NY. With over two decades of clinical experience in sickle cell disease, Dr. Ify leads the Transition/Care Coordination working for the Southeastern Regional Genetics Collaborative, and serves as the Secretary for the National Sickle Cell Adult Provider Network. She currently leads a team of dedicated and passionate providers and staff striving to establish a comprehensive, multi-

disciplinary system of care for all adults living with SCD in the Charlotte Metro area. This care model involves critical components such as the prominent role of the PCP, multi-faceted care navigation, case management and community support networks and is guided by a robust Community Advisory Board and system led Oversight Committee.

# Speaker Profiles

## Dr. James Eckmann



Dr. Eckman received his medical training and was appointed to the faculty of University of Minnesota Medical School before being recruited to Emory in 1978. He is the Emeritus Professor of the Department of Hematology and Medical Oncology and held appointments as Professor of Medicine and Adjunct Professor of Pediatrics in Medical Genetics at Emory University School of Medicine. He was committed to establishing a sickle cell program at Grady Memorial Hospital, and after intensive state lobbying for funding in 1984, became Medical Director of the world's first 24-hour

comprehensive acute care sickle cell center. James Eckman, MD, has championed newborn screening for sickle cell disease on a local and national level. His work has saved the lives of many sickle cell children, and through his efforts, Georgia instituted universal mandatory sickle cell screening for newborns in October of 1998. Dr. Eckman's other interest is in public health services for individuals with genetic diseases, and he acts as an advocate to continue awareness and support of these programs.

## Jazmine Rivera

### Intern/ SCD Advocate



Jazmine Alexis Rivera is a 24 year old sickle cell warrior living in California, and is a current intern with The Sickle Cell Community Consortium. She obtained her Bachelor's of Science in Business Administration with an emphasis in Marketing in May 2017.

Jazmine is advocate for Sickle Cell Disease where she is determined to educate people on this illness. Jazmine decided to become an advocate because of her battles with Sickle Cell Disease. She noticed the lack of education, information, and research on Sickle Cell Disease and therefore went on to become a patient advocate, and an intern with the Sickle Cell

Community Consortium. She is highly motivated to continue advocating for Sickle Cell Disease, and she does this through her YouTube channel BeautywithinSickleCell, and her social media accounts. Jazmine loves to create videos, create content and manage her multiple social media accounts in order to provide the education to other patients, caregivers, and those who are not aware of Sickle Cell Disease, with hopes of continuing the education process.



# Speaker Profiles

## Jeremiah L. Watts Sr.



Jeremiah went to Northeastern State University and obtained a Bachelor's in General Studies where he earned minors in Social Work, Psychology and Criminal Justice.

Jeremiah received a Master of Human Relations degree in Organizational Leadership from University of Oklahoma - Tulsa. Jeremiah is an ordained and licensed minister, husband of Minister Velvet Brown-Watts and father of 4 and father figure to many others. Jeremiah became involved with Sick Cell when his youngest child was diagnosed with SCD at the age of 6 months. Jeremiah is the Development Director for Supporters of Families with

Sickle Cell Disease, Inc., in Oklahoma which is a 501(c)3 nonprofit organization, and the chair of the Sick Cell 5K event, which raises funds for sickle cell disease. He works with the youth through the peer to peer program. Jeremiah enjoys being able to impart leadership and educate the community about sickle cell and what individuals impacted by SCD go through. He believes in empowering young people especially in the Sick Cell Community.

## Jew-EL Darbone

### Co-Founder/CFO of Bold Lips for Sick Cell



Jew-el is a Manhattan, New York native that now lives in North Carolina. She graduated from Mount Tabor High School in 2006, and was accepted into Johnson and Wales University in Charlotte. Her education was cut short due to health complications, but She doesn't allow a wheelchair to stop her, she is now Founder and CFO of #Boldlipsforsickcell. Sick cell advocacy is her passion and she is determined to better her community in every way possible.

# Speaker Profiles

## Jimmie L. Williams

### Councilman



Councilman Jimmie L. Williams, III was re-elected in November 2013 to a four-year term in Council Seat #4, which includes the Southwest area of Florida. He was first elected as a Homestead council member in that seat in 2009.

## Dr. Julie Kanter

### Medical University of South Carolina

### Director of Lifespan Comprehensive Sickle Cell Center



Dr. Julie Kanter is the current director for SCD research at the Medical University of South Carolina. She treats patients with sickle cell disease of all ages with the heart of a pediatrician. Dr. Kanter is actively involved in clinical research to identify new therapies for affected patients, and new point of care methods of diagnosis. She is also passionate about improving equal access to care for all individuals living with sickle cell disease. Dr. Kanter is an advocate, a doctor, and a mother.

# Speaker Profiles

## Lakshmanan, Krishnamurti, MD

### 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.

## Dr. Kenneth R. Bridges



Dr. Kenneth R. Bridges received his MD degree from Harvard Medical School, and subsequently trained in internal medicine and hematology in Boston, at Massachusetts General and Brigham and Women's Hospitals, respectively. Following medical subspecialty training, Dr. Bridges worked on the biology of cellular iron metabolism for three years at the National Institutes of Health in Bethesda, Maryland. 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. 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, and eventually moved to Global Blood Therapeutics in the role of Vice President, Medical Affairs working the new treatment for sickle cell disease, called GBT440.

# Speaker Profiles

## Dr. Lakiea Bailey

**Executive Director, Sickle Cell Community Consortium**

**[director@sicklecellconsortium.org](mailto:director@sicklecellconsortium.org)**



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. 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 on patient panels, a disease expert with Pfizer, Novartis, FDA, NHLBI and sits on the Research Advisory Board for the Foundation for Sickle Cell Disease Research.

## LaKisha M. Johnson

**Min., Author, SC Advocate**



LaKisha M. Johnson is mom, advocate, trainer, author, motivational speaker, minister and teacher. She is the executive director of Sickle Cell Support Services in Arkansas. She is the host of Coffee and Conversations on "facebook live" Monday-Friday at 5:00 am central standard time and Sundays at 7:00 am central standard time. She hosts a pajama party for women, "Pillow Talk" several times throughout the year, walking them through God inspired truths, while providing a place of vulnerability and transparency to talk. (To find out more information on her log on to [lakishamjohnson.com](http://lakishamjohnson.com) and follow her on social media @justbeinglmj)



# Speaker Profiles

## LaTasha H. Lee, PhD, MPH

**LaTasha H. Lee, PhD, MPH**

**Manager, Sickle Cell Disease Policy and Programs**

**American Society of Hematology**



LaTasha H. Lee, PhD, MPH is the Manager of Sickle Cell Disease Policy and Programs at the American Society of Hematology where she is responsible for the day-to-day management and implementation of activities related ASH's Call to Action on Sickle Cell Disease (SCD), as well as the Sickle Cell Disease Coalition ([www.scdcoalition.org](http://www.scdcoalition.org)).

She also provides input into the overall strategy of ASH's SCD Initiative, legislative/regulatory issues related to SCD, and provides oversight for the global and research aspects of the initiative. Dr. Lee works very closely with Congress and federal agencies to monitor biomedical research and access to care policy related to SCD.

She also provides input into the overall strategy of ASH's SCD Initiative, legislative or regulatory issues related to SCD, and provides oversight for the global and research aspects of the initiative. A knowledgeable, skilled and energetic scientist and public policy advisor with experience on Capitol Hill, Dr. Lee previously worked as a health policy advisor for U.S. Members of Congress, including Representative Alcee Hastings (D-FL) and Senator Sherrod Brown (D-OH). She also serves as an Adjunct Professor at The George Washington University School of Medicine and Health Sciences where she teaches graduate level courses in genetics, molecular biology and epidemiology.

## Lisa Rose

**Executive Director of HOPE for SCD**



Lisa Rose is the Executive Director of HOPE for SCD, an organization focused solely on providing research based medical education around Sickle Cell Disease and areas of complimentary interest. She has a Master's Degree in Education and has been developing curricula and trainings

for a myriad of companies for over 10 years. Her collaborating efforts include research studies spanning both medical and educational settings. Her current focus is on Adult Education, and the gaps related, within the medical field for patients and families. She has also authored a book for newly diagnosed families entitled, "Sickle What?", which breaks



# Speaker Profiles

## Lisa Rose

down intense medical topics into Adult Learner friendly modules. Although her work with HOPE for SCD has reached international audiences, she continues to push national hospitals and organizations to focus on presenting educational materials in a way that meets the needs of the audience, while ensuring all necessary information is conveyed. Her daughter Sophia has SCD, and will always be the motivation for Lisa to continue her work within the community.

## Lori Luck, MD

**Medical Director, SCD, Global Medical Affairs, Pfizer, Inc.**



Lori Luck, M.D. is a pediatric hematologist and joined Pfizer in January as the Medical Affairs Director for Sickle Cell Disease. Prior to Pfizer, Dr. Luck worked in Oncology at Genzyme and Leadiant (formerly Sigma Tau) in Field Medical Affairs. She completed her pediatric residency at Children's Hospital of Michigan and pediatric hematology-oncology fellowship at Children's Hospital Los Angeles. Dr. Luck credits her mentors, Sharada Sarnaik, MD and Punam Malik, MD, for her intense desire to improve the lives of individuals living with sickle cell disease and, under their tutelage,

had been awarded the Sheldon Brenner Resident Research Award and Post-Doctoral Fellowship Award, bestowed by the Sickle Cell Disease Association of America, Inc. After fellowship, Dr. Luck moved to Philadelphia, Pennsylvania and joined the Marian Anderson Comprehensive Sickle Cell Center at St. Christopher's Hospital for Children. During her five-year tenure at SCHC, Dr. Luck had acted as local Principal Investigator for the Baby HUG study. Dr. Luck realizes the broad impact that can be achieved through her work in Global Medical Affairs at Pfizer, however, she admits to missing the rewarding interactions with her beloved "little patients"

## Marcus McKinley



Marcus McKinley is a 31 year old male entrepreneur and SC advocate living with and conquering sickle cell disease. Originally from Greenville, Mississippi Delta is where he was diagnosed with sickle cell type SS at the age of two. He has endured many hospitalizations, blood transfusions, and medical procedures due to sickle cell. He currently resides in Oklahoma City, Oklahoma where he owns a mobile auto detailing and a towing business. He also holds various positions within community based organizations that are dedicated to sickle cell. He vows to always be committed to advocating and finding advanced treatments and a possible cure for this genetic blood disorder.

# Speaker Profiles

## MARIE OJIAMBO

**Founder, Sickie Strong Initiative**

**Clinical Trials Initiative, Program Manager- Sickie Cell Community Consortium**



Marie Ojiambo trained at St John's University, College of Pharmacy and Health Sciences in New York, Marie is a Formulation Scientist by profession, specializing in drug research and development. She is also a Sickie Cell warrior and a global advocate. Diagnosed at the age of 1, Marie uses her knowledge and to raise awareness about 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 health care and treatment options available to sickie cell warriors. In 2013, Marie founded the Sickie 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 SC Public Awareness forum, Ongea ('speak out!' in Swahili). This annual summit that takes place every June in Kenya to commemorate World Sickie Cell Day, and provides a platform for sickie 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.

## Min. Maxine Collier

**Founder/President of C.S.I. Network, Life Point Outreach, & Platinum Streaks**



Maxine Collier, affectionately known as "Pastor Max", is a wife, mother, Minister and mentor. She is a Community Activist and a volunteer for Women Outreach Organizations. She currently Pastors with her husband, W. Bernard Collier, at The Empowerment Center in Macon, GA while working full time at The Department of Homeland Security as a Telecom Specialist. She is the Founder and President of the C.S.I. (Covenant Sisters' International) Network, Life Point Outreach and Platinum Streaks. She travels extensively across the country preaching, teaching, hosting empowerment conferences and retreats and partnering with other community outreach organizations.

# Speaker Profiles

## Minimarie Andrews

### Founder of Purpose Filled Mommy



Minimarie Andrews is an inspirational speaker, coach, host, and founder of Purpose Filled Mommy. She is a graduate of Paine College with a Masters in Mass Communications. She has worked in media and radio beginning in high school, as well as with local radio stations (WKZK/WTHB), guest featured on national broadcasts, and national respected podcast such as StoryCorp. She is the host of her own show, "Girl Talk With Purpose", in addition to sharing daily inspirational videos and articles from her celebrated blog Purpose Filled Mommy. She is a sought after speaker on

empowerment, Youth Motivation, Family, and her passion living for purpose. She also is a trained and respected performance art teacher with over 17 years of experience and expertise in dance, music, and drama. Minimarie is a devoted wife to her husband Clayton Andrews, and mother to her four active children Pierce, Paige, and twins Paris and Payton.

## Nikki Peterson

### President/CEO of TutorsRUs



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 TutorsRUs, 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.



# Speaker Profiles

## Patrick Flight, Ph.D.

### Associate Director of Medical Affairs



Patrick Flight received a BS in Biology from Duke University and a PhD in Ecology and Evolutionary Biology from Brown University. Dr. Flight has over five years of experience in various roles related to the pharmaceutical and biotechnology industry. Dr. Flight joined Bluebird Bio in March of 2016, as part of the Medical Affairs Organization. Most recently, he was the scientific lead for the spinal muscular atrophy medical training program at Biogen. As Associate Director of Medical Affairs, he is responsible for driving medical strategies and tactics that support successful product development, as well as to guide education, research, and communication about Bluebird Bio's innovative therapies. They work with numerous stakeholders, including physicians, scientists, advocates, patients, and caregivers.

## Shamonica Wiggins

### Co-Founder, CEO, #BoldLipsForSickleCell



Shamonica Wiggins is a 27 year old with Sickle Cell SS, diagnosed at 2 weeks of age. After high school, she attended Texas Tech University pursuing a degree in Newspaper-Editorial Journalism. Growing up as a Dallas native, she has always been supported by her family and medical team to strive to be the best. This is not a luxury that every Sickle Cell Warrior is told, so this has always driven her to inspire others like her. That drive is what led to the founding of #BoldLipsForSickleCell in 2014, which is now a 501(c)(3) non-profit, that speaks up about this disorder and spreading Sickle Cell awareness.

# Speaker Profiles

## Shaunii Rawls

### Miss Black Georgia USA 2017



Rawls was born and raised in Savannah, GA where she developed a passion for empowering youth and women through confidence and overcoming adversity. Her first experience with the power of confidence came in middle school where she was ridiculed by peers about her full body birthmark which caused discoloration on her skin. Despite the taunting, Rawls decided to start modeling which turned into back-to-back castings and a new found confidence. Today, she uses that experience to uplift Savannah's youth through motivational speaking, to grow her career in multimedia, and

model for the likes of HP, Belk, Anthropologie, Savannah Magazine, and more. Her socialite personality and good reputation led her to become the face of Savannah. Her platform is "Strut for Sickle Cell" which brings awareness to the struggle of Sickle Cell Disease Warriors through fitness, food, and fashion. Rawls has watched her sister suffer, yet mentally overcome the deficiencies and pain that come with the disease. Since she has seen first-hand the strength that it takes to be a sickle cell warrior, she is driven to shine a light on the disease and the people who endure through it.

## Sonja L. Banks, MPA, MBA

### President/Chief Operating Officer for SCDA



Sonja L. Banks is the newly elected President and Chief Operating Officer for the Sickle Cell Disease Association of America, Inc. She is primarily responsible for the administrative activities of the organization which serves over fifty-five sickle cell community based organizations throughout the United States. Ms. Banks is an accomplished management professional with over 17 years of executive level experience and an established background in nonprofit leadership and operations. Prior to her current position, Ms. Banks served at St. Vincent's Health System in Birmingham, Alabama, as Director of Community Services, Outreach and Adult Indigent Services. Her previous professional experience also includes leadership roles within the United Negro College Fund,

United Way of Central Alabama and City of Birmingham. Ms. Banks' academic credentials include a Bachelor's degree from the University of Alabama and a Master's Degree in Public Administration and Business, and she is presently pursuing her doctorate of education in Organization Leadership & Nonprofit Management. Her focus has been, and will continue to be to vigorously advance and further develop the strategic direction of SCDA while remaining keenly focused on patient care, service delivery, education, research, funding and core legislative goals.



# Speaker Profiles

## TANDUA WASHINGTON, MD

**TSPMG, General Pediatrician**

**Facebook.com/doctwash**

Dr. Tandua Washington is a General Pediatrician in the Atlanta area who has Sickle Cell Disease. A New York native, Dr. Washington graduated Hofstra University with a BS in Biology. She graduated from the Medical College of Virginia with honors and completed her residency at Albert Einstein Medical Center in Philadelphia. She has been practicing Pediatrics for 16 years, with a special interest in caring for children with Sickle Cell. She has received many awards and accolades for her achievements in her field. Dr. Washington is married and has 2 sons who also have Sickle Cell Disease. The family is very committed to advocacy work in the Sickle Cell Community.

## Dr. Terry Richardson

**Sr. Pastor of First Baptist Church**



Rev. Dr. Terry Richardson has served as the Senior Pastor of the First Baptist Church, South Orange, NJ since 1997. Their vision is to "Impact the World." Dr. Richardson graduated Temple University with a BA in Business Administration.

Focusing in Metro-Urban Ministry, He earned both his Masters of Divinity and Doctorate of Ministry degrees from New Brunswick Theological Seminary (NBTS), New Brunswick, NJ, graduating with high honors. Dr. Richardson has worked as an Adjunct Professor at Essex County College, teaching Introduction to Sociology, Social Problems, and World Religion.

Dr. Richardson is a Visionary. His relentless passion for justice

and equality has led him to create the "Knowledge Is Power" after school supplemental education, "Eternal Light" community outreach, and the Metro-Urban Ministry Solution 501 (c) (3) programs. Dr. Richardson constantly seeks out ways to bring institutions and organizations together to collaborate their efforts and work together to create a new normal, a new reality; a world of what "should be" instead of settling for a "world that is". Dr. Richardson has also been recognized and honored by the Essex County Prosecutor's Office and the National Organization of Black Law Enforcement Executives at their 6th Annual "Black History Month Awards Celebration" for his outstanding work in community. Dr. Richardson is married to NaDeen Richardson. Together they are the proud parents of Deven, Kayla and Jeremiah Richardson.

# Speaker Profiles

## Vanessa Rhodes

### SC Warrior, Educator, & Advocate



Vanessa is a mother of a warrior, an advocator, and an educator. She is a self proclaimed lover of the educational process as evidenced by the variety of positions she has held over the past 31 years. She served as a teacher, curriculum writer, principal, Educational Administrator, mentor of new teachers, PTA President and cheerleading coach in both public and private schools and universities. In addition, she homeschooled her children when they were young, and she currently consults for schools and homeschooling families about curriculum development.

## Velvet L. Brown-Watts

### Founder/Chairperson of SFSCD, Inc.



Velvet is the Founder-Chairperson of Supporters of Families with Sickle Cell Disease, Inc. Supporters (as it is affectionately known) is an IRS 501(c)(3) designated nonprofit agency, and community-based Oklahoma nonprofit organization that has assisted families living with sickle cell diseases since 2004. Supporters is the only comprehensive grassroots family support and advocacy organization in Oklahoma that serves as a center of contact and referral service for community resources to assist individuals with sickle cell and related diseases. Supporters promotes self-care management, testing, education, research and development, and economic self-sufficiency

as key approaches to empowerment and effective management of sickle cell disease. Velvet received the Social Justice Award from University of Oklahoma Women Gender Studies for her work with sickle cell disease and women, in 2010, and was also named graduate student of the year by the Oklahoma Chapter of National Association of Social Workers for her advocacy and awareness work with Sickle Cell Disease in the state of Oklahoma. Velvet is an inspirational voice in the sickle cell community, a pioneering executive, social worker, and community activist. She is the wife of Pastor Jeremiah Sr., and mother of four children, of which, Jeremiah Jr., was diagnosed with sickle cell disease in 2004.

# Speaker Profiles

## Yvonne M. Carrol

**Director of Patient Services- SJCRH**

**President of IASCNAPA**



Yvonne M. Carroll, RN, JD is the 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. She joined SJCRH in 1999 in the Department of Hematology and served in several department positions, culminating as the Director of Patient Services. Yvonne is an active SC community member, and a member of the Governor's Genetic Advisory Committee regarding newborn screenings. She is also president of the International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA) and a liaison with the American Society of Hematology Sickle Cell Coalition, while also raising awareness of SCD throughout the U.S. She is passionate about her commitment to sickle cell disease and continues to develop and participate in projects to further research and improve care for people with the disease.



# 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 eventually 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, that was 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, together form the decision-making body of the Consortium, which is tasked with forming mutually beneficial partnerships. They also have the responsibility 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. In the year 2015, the Consortium 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).







**Bioverativ is committed to performing research to develop treatments in the hopes of having a meaningful impact in the lives of people with sickle cell disease and other rare blood disorders by:**

- Striving for progress when and where people need it most
- Advancing innovative programs to address serious unmet needs
- Challenging the status quo at every step with focus, urgency, and integrity
- Applying state-of-the-art research to address the specific needs and concerns of the sickle cell disease community

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# Thank You from the Hosts

We, the Hosts, would like to sincerely thank you for attending the 4th Annual Sickle Cell Disease Patient & Family Symposium. The hosts (Hope For SCD, Supporters of Families with Sickle Cell, and #BoldLipsForSickleCell) extend gratitude to all those who were apart of each and every planning committee that worked together to put on this amazing Warrior Convention. Many members of the planning committees have Sickle Cell, but regardless of that, they volunteered much of their time, energy, and expertise in hopes of delivering a memorable experience.

To all the Sickle Cell Warriors in attendance, we thank you for dedicating your time to this cause with us. Let's not forget we are all here in honor of you all! To our lovely Caregivers and Advocates, we thank you for being the support that those with Sickle Cell, truly need. We hope you all learned something new, made some amazing memories, and enjoyed the company of your fellow Sickle Cell community from across the country. We'd also like to express our appreciation to all the dedicated physicians, researchers and healthcare professionals in attendance. The Sickle Cell community is indebted to trailblazers, such as yourselves.

We would like to give a special thank you to all of our sponsors, (Bluebird Bio, Pfizer Pharmaceuticals, Be the Match, Global Blood Therapeutics, St. Jude Children's Hospital, and Prolong Pharmaceuticals), for your continued support of Sickle Cell awareness, advocacy, and empowerment. Without your willingness to give, we could not have put together this amazing event. Once again, we thank you!

Finally, we send our gratitude and respect, to the Sickle Cell Community Consortium, and Executive Director, Dr. Lakiea Bailey, for bringing us all together for this wonderful symposium. Dr. Bailey, your hard work, dedication, commitment never goes unnoticed! We, the Hosts, appreciate all of you, and we look forward to seeing you all next year!





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Ines, marrow transplant recipient  
for SCD

