



**6TH ANNUAL**

**PATIENT & FAMILY**

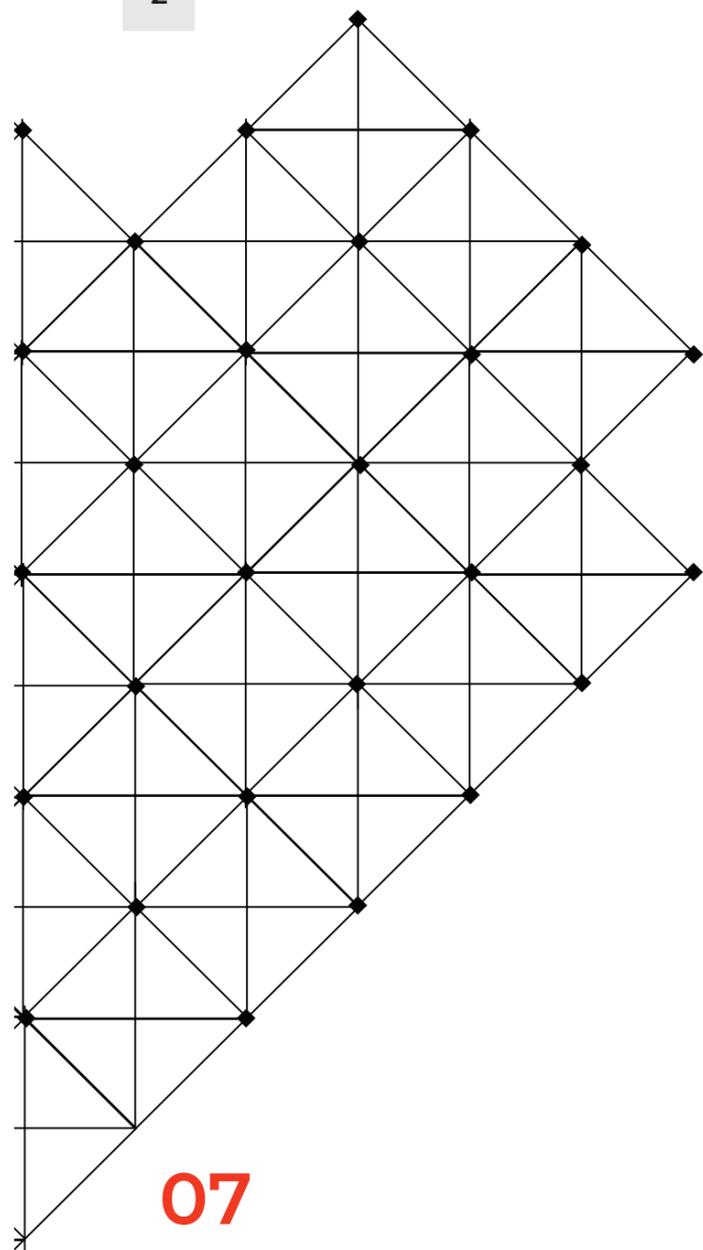
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EDUCATIONAL SYMPOSIUM

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2019

HILTON DALLAS/PLANO GRANITE PARK  
5805 Granite Parkway  
Plano, TX 75024



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**ABOUT  
US****THE SICKLE  
CELL  
CONVENTION**

The Annual Sickle Cell Disease Patient & Family Educational Symposium is the only national sickle cell convention designed, created and hosted by the sickle cell patient and family community. Now in its sixth year, the meeting has grown in size and scope. Each year the meeting is hosted by a partnership of sickle cell community-based organizations, patients and advisors. We are pleased to announce the 2019 symposium will be hosted by the Sickle Cell Association of Texas Marc Thomas Foundation, the As One Foundation, and Carol's Promise Sickle Cell Association.

Our theme this year is SICKLE SIBLINGS: BONDED BY BLOOD, focusing on our chosen families and the warrior relationships that bring us together. The 2019 agenda places heavy emphasis on becoming Expert Patients, while learning to advocate, educate, and encourage ourselves and each other. Sessions include tracks designed specifically for adults, teens and young adults, children and caregivers, and warrior men. The agenda is designed by the sickle cell community with topics identified by patients, caregivers and healthcare supporters, ranging from "Parenting Issues from Birth to Adult" and "The Science of Sickle Cell" to "Sickle Cell Mental Health" and "Sickle Cell and College Life". Fly in, register, relax with us and get to know your fellow Warrior siblings with icebreakers and evening reception. Early risers are invited to join us each morning for Yoga and morning workout sessions. A special morning workout session has been prepared for children and parents.

Registration opens Wednesday, July 24th at 3 PM. We begin festivities at 5 PM with an opening reception and ice-breakers. Early risers are invited to join us each morning at 7 AM for morning yoga and workout. The General Plenary session starts at 10 AM on each day, followed by multi-track breakout sessions, workshops, roundtable discussions and panels. We are excited to offer lunch each day accompanied by a main general session on a wide variety of topics of interest to the sickle cell warrior community. Plenty of free-time is dispersed throughout each day to explore all that Texas has to offer.

We are excited to offer several special evening sessions. Join us on Wednesday night for Warrior Game Night. On Thursday we will host Warriors After Dark Men-Only and Warrior after Dark Women-Only (age 17+/15-16 with parent permission). This session is included in full registration and is divided by gender for adults only. We will discuss a variety of adult-themed topics that are important to our warrior community. Friday afternoon has been left completely open to enable participants to enjoy the sights and tourist destinations of Texas. Then grab your ticket for the Warriors Around the World Awards Gala/Prom on Saturday night.

Join other Warriors as we learn from and encourage each other on all aspects of Warrior life, including dealing with work, school, and relationships. We have special programs for teens, parents, couples, and adults living with sickle cell. Our roundtable panels, plenary sessions, and educational lunches all have been developed for sickle cell warriors and caregivers, by sickle cell warriors and caregivers.

**OUR SPONSORS  
& SUPPORTERS**

Thank you for your unwavering support! It is because of you we are able to reach and help bring knowledge and awareness to the world concerning Sickle Cell Disease.



SILVER



BRONZE

OTHER  
SPONSORS

# AT-A-GLANCE

## WEDNESDAY, JULY 24

- ◇ Registration
- ◇ Opening Reception

## THURSDAY, JULY 25

- ◇ Wake Up Well
- ◇ Warrior Kids
- ◇ General & Breakout Sessions
- ◇ Lunch
- ◇ General & Breakout Sessions
- ◇ Dance Rehearsal- Dance Mob Video
- ◇ **ROCK THE BLOCK**

## FRIDAY, JULY 26

- ◇ Wake Up Well
- ◇ Warrior Kids
- ◇ General & Breakout Sessions
- ◇ **THE LIVE BIG PROJECT**
- ◇ General & Breakout Sessions
- ◇ Lunch

## FRIDAY, JULY 26

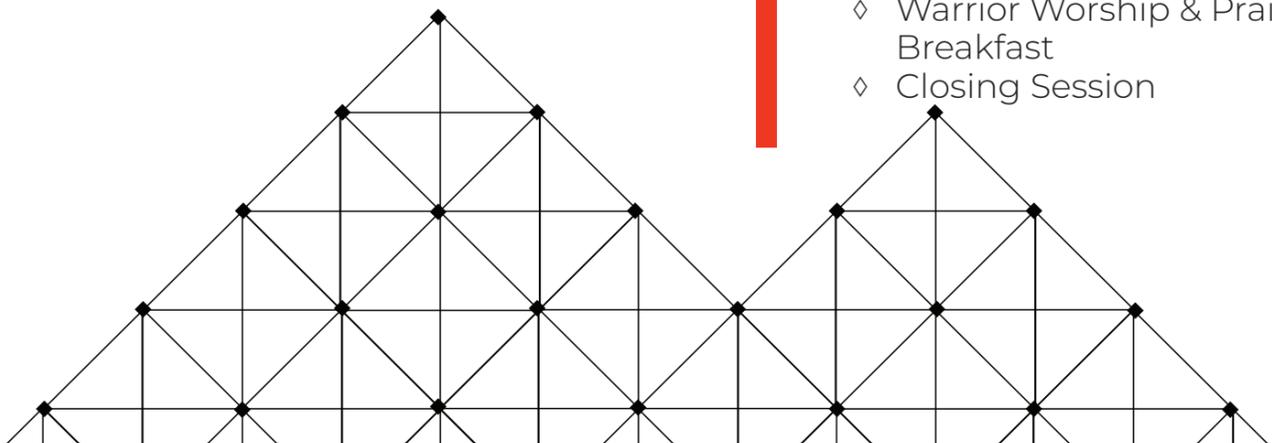
- ◇ Service Project
- ◇ **DANCE MOB**
- ◇ **WARRIORS AFTER DARK**
- ◇ **PAINT & SIP**
- ◇ **KIDS NIGHT OUT**
- ◇ Insomniac's Cafe Karaoke

## SATURDAY, JULY 26

- ◇ Wake Up Well
- ◇ Warrior Kids
- ◇ General & Breakout Sessions
- ◇ Plenary Session
- ◇ General & Breakout Sessions
- ◇ Lunch
- ◇ **ABSTRACT PRESENTATIONS**
- ◇ The Mental Health Panel
- ◇ **THE JAZMINE GLAM SQUAD**
- ◇ **GALA & PROM**

## SUNDAY, JULY 28

- ◇ Warrior Worship & Praise Breakfast
- ◇ Closing Session



# OUR HOSTS



The As One Foundation was established in 2007 as a non-profit 501(c)(3) organization to facilitate community programs both individually and in conjunction with similar organizations and to honor the memory of Devaughn Darling, who died prematurely of exertional sickling, a condition that can affect people living with sickle cell trait.



Marc noticed a desperate need in central Texas for advocacy for Sickle Cell patients. Often persons with Sickle Cell Disease in Austin, had no liaison between some doctors and themselves to explain the severity of the disease. Sickle Cell Disease often carried stigmas with which some doctors were ill informed and the level of care for Sickle Cell patients were inadequate.



Carol's Promise Sickle Cell Foundation was officially founded in 2017 to uphold a promise made by our founder to her mother, Carol to advocate on her behalf for a cure. It has since blossomed into so much more. Carol's Promise is a community-based organization that is credentialed by the Sickle Cell Community Consortium.

## SICKLE CELL CONVENTION PLANNING COMMITTEE

SHAMONICA WIGGINS - DONATIONS COORDINATOR

SHARONDA HUDSON - MEDIA AND MARKETING, PROM

MARIA RIVERA - LODGING MANAGER

VANESSA RHODES - CHILDRENS TRACK

JANEEN GREENE - HOTEL COORDINATOR & TRAVEL

YOLANDA LEWIS - WEBSITE & MOBILE APP

ALYSIAN THOMAS - SCHOLARSHIP COORDINATOR

CLAYTON ANDREWS - MENS TRACK

LISA ROSE - CHILDREN'S TRACK

KENYA K. BUCKLEY - YOUNG ADULT TRACK

DR. TOMIA WOOTEN AUSTIN - TRAIT TRACK,  
PRESENTER COORDINATION

DOMINIQUE GOODSON - ABSTRACTS & VENDORS

LAKIEA BAILEY - SPONSORS, AGENDA

SANDY MILLS - EVENT PLANNER/MANAGER

## SC3 FOUNDER



### DR. LAKIEA BAILEY

#### RECOGNITION

*Southern Regional Education Board (SREB)  
Doctoral Scholar*

#### AWARD

*Fisher Scientific Award for Overall  
Excellence in Biomedical Research*

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.

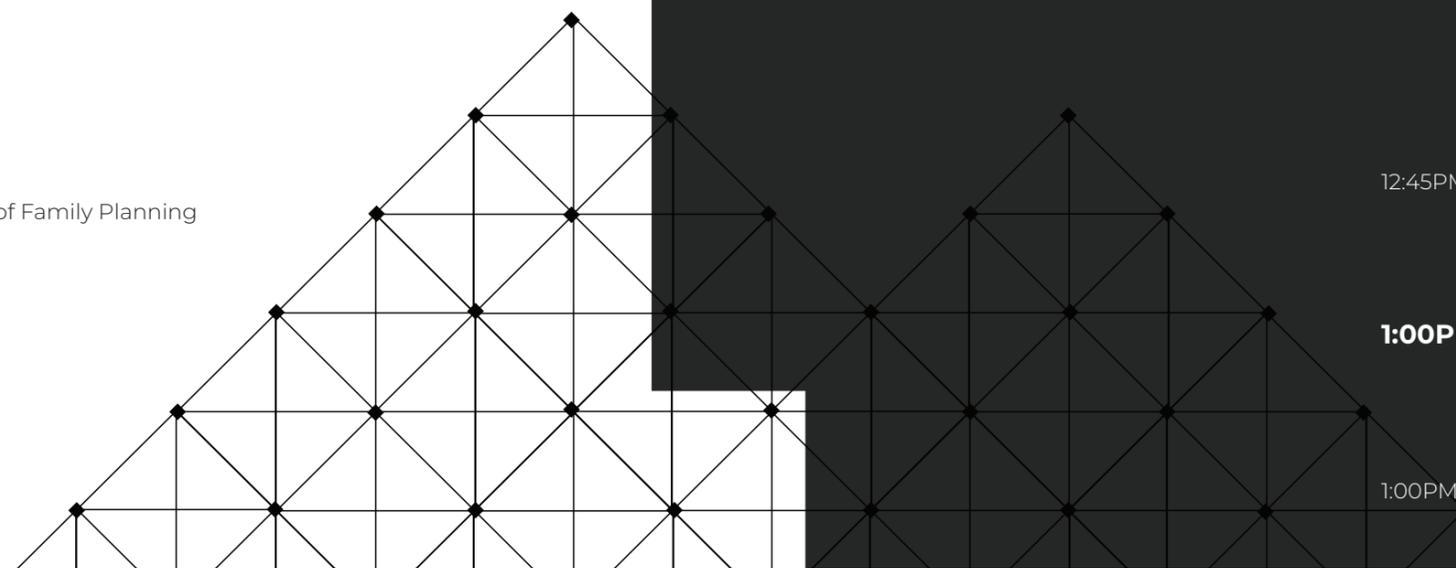
# Conference Agenda

## WEDNESDAY, JULY 24 (PRAIRIE FOYER)

- 3:00PM - Registration Opens  
Exhibit Space Opens
- 5:00PM - Kids Track Registration
- 6:00PM - Chat & Chew Mixer  
Powered By Sickle Cell Warriors, INC.
- Dance Rehearsal - Dance Mob Video

## THURSDAY, JULY 25

- 8:00AM - Wake Up Well: Morning Wellness Activities  
Kristina Ward
- Registration & Exhibit Opens
- 8:30AM - Warrior Kids - Children's Track (Bluestream 1), Kiddie Keepers  
Getting On Target
- 9:00AM - Warrior Kids - Children's Track (Bluesteam 1)  
The Language of Blood
- 10:00AM - **OPENING PLENARY**  
Warrior Kids - Children's Track (Bluestem 1)  
Sickle What? Part 1
- 11:00AM - General Session (Prairie D)  
FSCDR Update  
Dr. Lanetta Jordan
- Breakout #1 (Prairie B)  
Complications of Trait & Importance of Family Planning  
Dr. Tomia Austin  
Suzanne Gordon
- Breakout #2 (Prairie C)  
Young Adult Reception  
Carol's Promise



# Conference Agenda

## THURSDAY, JULY 25

- 11:30AM - General Session (Prairie D)  
Intervention to Improve Cognitive Function  
Dr. Anna Hood
- 12:00PM - General Session (Prairie D)  
Dealing With Medical Mistreatment: Tactics & Strategies  
Emily O'Shea
- Breakout #1 (Prairie B)  
Holistic Health and Wellness  
Dr. Tamika Bush
- Breakout #2 (Prairie C)  
Dealing With Grief & Loss  
Clay Andrews
- 12:30PM - General Session (Prairie D)  
Success in Texas: A Legislative Victory  
Tonya Price
- Breakout #1 (Prairie B)  
The Mentor: A SCCA Presentation  
Trey Brown
- Breakout #2 (Prairie C)  
Case Management: Completing the SSI/SSD Application  
Emily O'shea
- 12:45PM - Warrior Kids - Children's Track (Bluestem 1)  
Sickle What? Part 2
- 1:00PM - LUNCH**  
We Are Sickle Cell Patient Ambassador  
Dr. Terry
- 1:00PM - Warrior Kids - Children's Track (Bluestem 1)  
Self-Care Wrap Up, Day1

# Conference Agenda

## THURSDAY, JULY 25

1:30PM - Updates from Global Blood Therapeutics

2:30PM - General Session (Prairie D)  
Focus Group #1

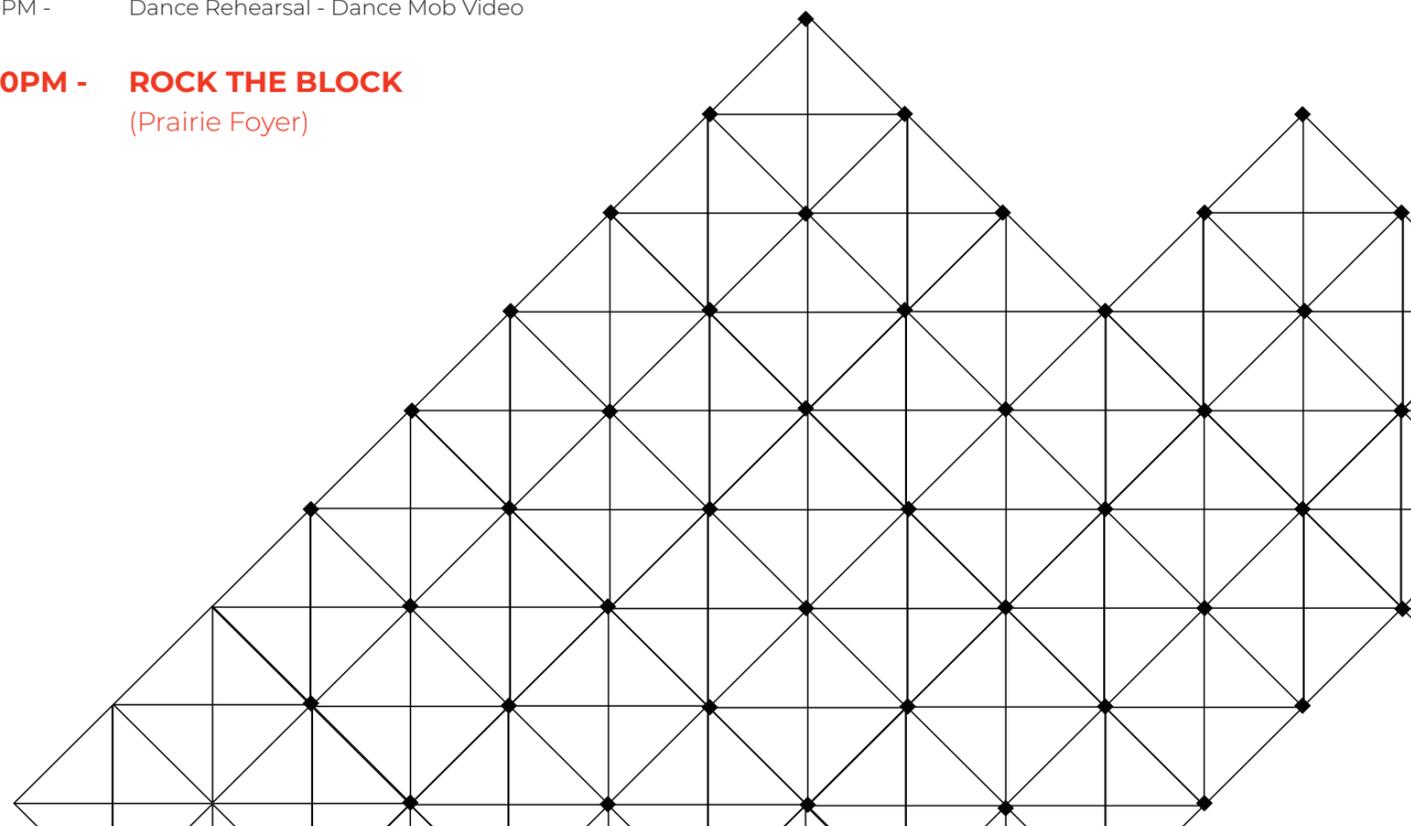
Breakout #1 (Prairie B)  
Creating a Mindset of Wealth: Fulfilling the  
Mandate of Prosperity  
Dr. Gayle Rogers

Breakout #2 (Prairie C)  
Focus Group #2

3:45PM - An Introduction to Personal Finances:  
A Warrior University Series  
Phillip Okwo

4:00PM - Dance Rehearsal - Dance Mob Video

**6:00PM - ROCK THE BLOCK**  
(Prairie Foyer)



**MY DREAMS WILL NOT BE STOPPED BY SICKLE CELL.**

Come learn more  
at the GBT booth or at  
[SICKLECELLSPEAKS.COM](http://SICKLECELLSPEAKS.COM)

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# Conference Agenda

## FRIDAY, JULY 26

8:00AM - Wake Up Well: Morning Activities  
Kristina Ward

Registration & Exhibit Space Opens

8:30AM - Breakout #1 (Prairie B)  
The Parent-to-Parent Panel  
Raising Sickle Cell Warriors  
Lisa Rose, Vanessa Rhodes, Doris Bailey  
Elle Em, Dr. Janet Ola

8:30AM - Breakout #2 (Prairie C)  
Warrior Parents: A panel on living as a sickle cell warrior  
and raising well-adjusted children.  
Clayton Andrews, Shamonica Wiggins,  
Tosin Ola, Shamaine Boswell

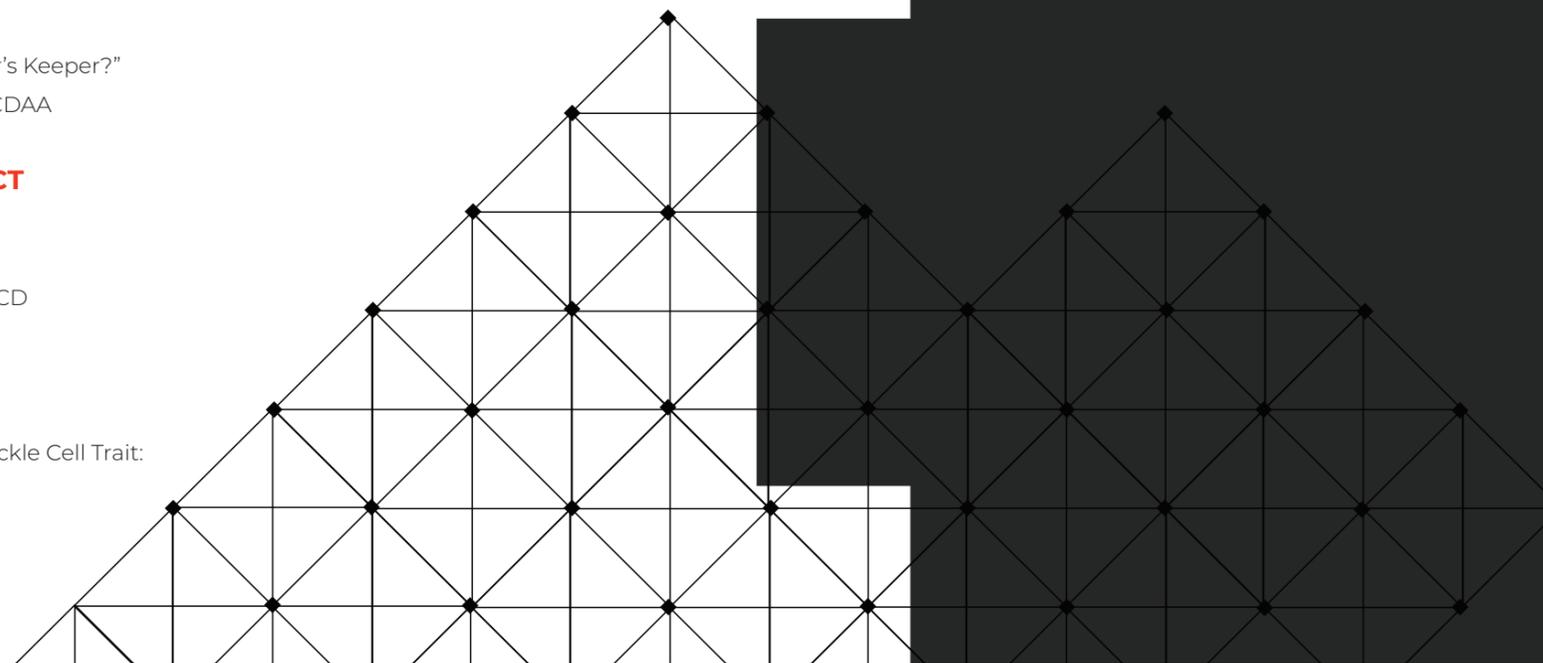
Warrior Kids - Children's Track (Bluestem 1), Kiddie Keepers  
Body Systems, Germs, My Health Passport, Infection Control

10:00AM - General Session (Prairie D)  
"Are You My Brother's/Sister's Keeper?"  
Beverly Francis-Gibson, SCDA

### 10:45AM - THE LIVE BIG PROJECT

11:00AM - General Session (Prairie D)  
Reproductive Health and SCD  
Dr. Alicia Nero

Breakout #1 (Prairie B)  
How Athletes Feel About Sickle Cell Trait:  
In Their Own Words  
Dr. Tomia Austin



# Conference Agenda

## FRIDAY, JULY 26

11:00AM - Breakout #2 (Prairie C)  
Clarity of Mind: Depression, Anxiety, & PTSD  
Dr. Gayle Rogers

Warrior Kids - Children's Track (Bluestem 1)  
Broken Crayons Still Color  
Joyce El

11:30AM - General Session (Prairie D)  
Cure Sickle Cell Initiative  
T. Mondoro

Breakout #1 (Prairie B)  
Let's talk About trait:  
Research, Screening, Prevention, Pain, Ethnicity, Mental Health  
Dr. Tomia Austin, Farron Dozier, Dr. Stephen Boateng

12:00PM - General Session (Prairie D)  
Speaking the Language: Communication in the  
E.D. Q-Source Quality Improvement  
The Adam Alliance

Breakout #1 (Prairie B)  
Priapism and Other Male Warrior Health Concerns  
Phillip Okwo, Demetrious Wyant, James Eckman

Breakout #2 (Prairie C)  
From Menstrual Cycles to Menopause: Health Concerns for  
The Warrior Woman  
Dr. Lydia Pecker



**Novartis proudly joins Sickle Cell Consortium and the 6th Annual Sickle Cell Patient and Family Education Symposium.**

**Your dedication to helping patients with Sickle Cell is applauded.**



# Conference Agenda

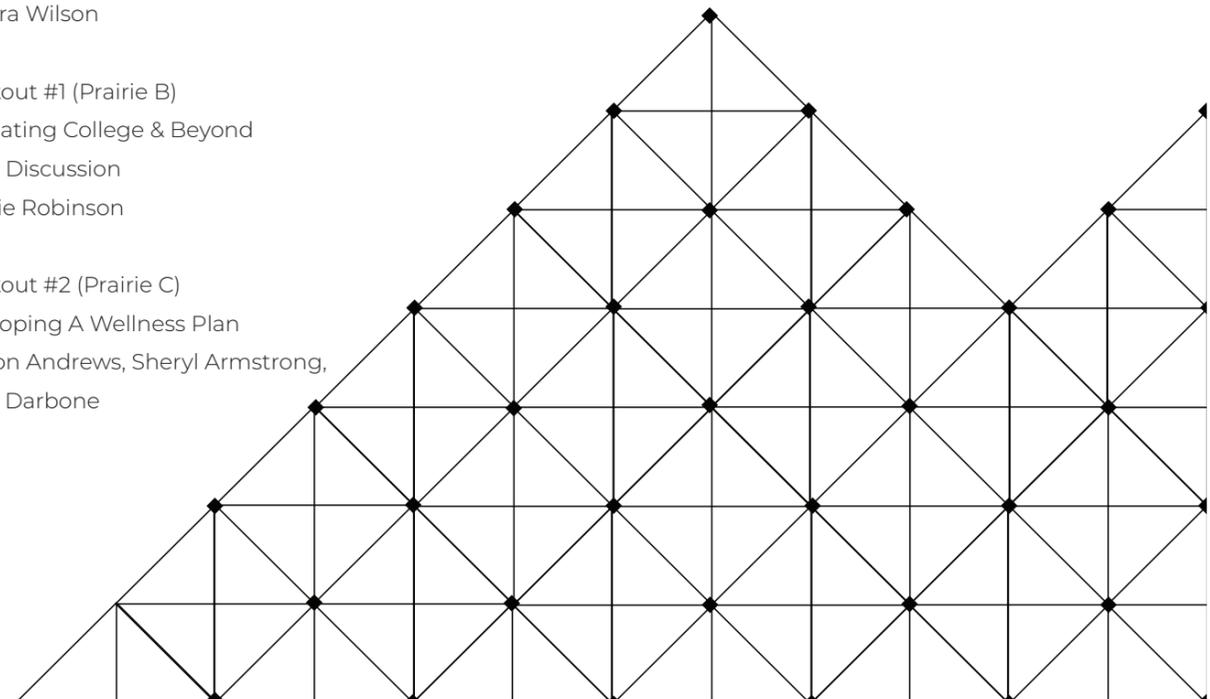
**FRIDAY, JULY 26**

- 12:30PM - General Session (Prairie D)  
Pulmonary Complications in SCD  
Liz Kings
- Breakout #1 (Prairie B)  
The Male: An Examination of the Responsibilities of The SC Male
- Breakout #2 (Prairie C)  
Spiritual and Emotional Well-being  
Sheryl Armstrong
- 1:00PM - Warrior Kids - Children's Track  
Self-Care Wrap Up, Day 2

**1:30PM - Lunch: Powered By CRISPR/VERTEX**

**WARRIOR ENGAGEMENT & EMPOWERMENT**

- 4:00PM - General Session (Prairie D)  
Focus Group: Improving ED Care - Speaking The Language  
Tamara Wilson
- Breakout #1 (Prairie B)  
Navigating College & Beyond  
Panel Discussion  
Reggie Robinson
- Breakout #2 (Prairie C)  
Developing A Wellness Plan  
Clayton Andrews, Sheryl Armstrong,  
Jewel Darbone



# Conference Agenda

## FRIDAY, JULY 26

5:00PM - Service Project  
Care Packages for the Homeless  
Get Well Cards by SC3 Kids  
School Supplies for Warriors

## 6:00PM DANCE MOB

7:00PM - WARRIORS AFTER DARK: WOMEN  
The Empowerment Center  
Maxine Colliard

WARRIORS AFTER DARK: MEN  
The Sickle Cell Champions Association  
Clayton Andrews

PAINT & SIP (TICKETED EVENT)  
Guided Painting for Caregivers

KIDS NIGHT OUT  
Kiddie Keepers  
\$20/Kid (\$50 Family Cap Out)  
\*Need-based assistance available\*

9:00PM - Insomniac's Cafe: Karaoke  
(Prairie D)

# Conference Agenda

## SATURDAY, JULY 27

8:00AM - Wake Up Well: Morning Wellness Activities  
Kristina Ward

Registration & Exhibit Opens

8:30AM - Warrior Kids - Children's Track (Bluestem 1), Kiddie Keepers  
Natural Approaches to Pain Management  
Art Therapy for Kids  
SC3 Kids Advocacy Meeting

9:00AM - Breakout #2 (Prairie C)  
Caregiving for the Longhaul: Managing Mental and  
Emotional Health Through the Years  
Chandra White-Cummings

**10:00AM PLENARY SESSION**  
**ADM BRETT GIROIR**  
**U.S. ASSISTANT SECRETARY OF HEALTH**

11:00AM - General Session (Prairie D)  
Sickle Cell 101  
Dr. Wanda Shurney

Breakout #1 (Prairie B)  
The Truth About Sickle Cell Trait & Cancer  
Dr. Tomia Austin, Ritchie Johnson, Bridgette Lloyd  
Chloe Rose



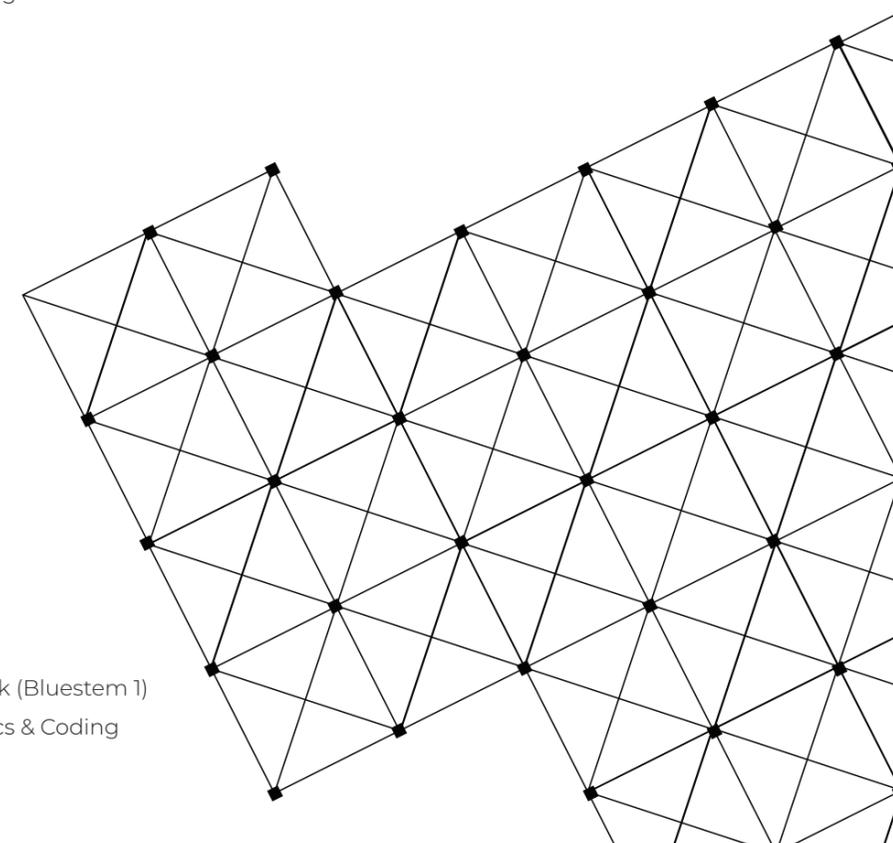
**Patients and science are at the center of everything we do.**

At Sanofi Genzyme, we are inspired to push scientific boundaries to develop specialty treatments for people with sickle cell disease and other rare blood disorders, providing hope to patients and their families.

# Conference Agenda

**SATURDAY, JULY 27**

- 11:00AM - Breakout #2 (Prairie C)  
504/IEP Accommodations  
Nikki Peterson, Tynisha Hall
- 11:30 AM - Breakout #2 (Prairie C)  
Traveling With Sickle Cell  
Mattie Robinson
- 12:00PM - General Session (Prairie D)  
What You Need To Know About Hydroxurea  
Issac Odame
- Breakout #1 (Prairie B)  
The Relationship: Social Navigation and the SC Male
- Breakout #2 (Prairie C)  
The Importance of Self Care  
Shamonica Wiggins
- 12:30PM - General Session (Prairie D)  
Clinical Trails  
Stephen Boateng
- Breakout #1 (Prairie B)  
Knowing Your Limits  
Tosin Ola
- Breakout #2 (Prairie C)  
Port Care  
Ritchie Johnson, RN
- Warrior Kids- Children's Track (Bluestem 1)  
Creative Movement:: Robotics & Coding



# Conference Agenda

## SATURDAY, JULY 27

1:00PM - LUNCH

1:30PM - Abstract Presentations

3:00 PM - The Mental Health Panel

3:30PM - The Jazmine Rivera Beauty Within  
Sickle Cell Glam Squad

7:00PM - **WARRIORS AROUND THE WORLD AWARDS GALA & PROM**  
**\*TICKETED EVENT\***

## SUNDAY, JULY 28

9:00AM - Warrior Worship & Praise Breakfast

10:00AM - Closing Session: General Meeting  
\*Vote for 2021 and 2022 Locations



TRANSFORMING  
THE LIVES OF PATIENTS  
WITH SEVERE GENETIC  
AND RARE DISEASES

INTEGRATED PRODUCT PLATFORMS  
WITH BROAD THERAPEUTIC POTENTIAL



gene therapy



cancer immunotherapy



gene editing

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# Our Speakers



## **ADM BRETT P. GIROIR, M.D.,** *U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES*

Assistant Secretary for Health (ASH) HHS Office of the Secretary

ADM Brett P. Giroir, M.D., was sworn in as Assistant Secretary for Health at the U.S. Department of Health and Human Services (HHS) on February 15, 2018. The Assistant Secretary for Health leads development of HHS-wide public health policy recommendations, oversees 11 core public health offices — including the Office of the Surgeon General and the U.S. Public Health Service Commissioned Corps, which has approximately 6,500 uniformed health officers who serve in nearly 600 locations around the world to promote, protect and advance the health and safety of our nation and our world. He also oversees three Presidential and 11 Secretarial advisory committees.

Dr. Giroir is a physician, scientist and innovator. He is a former medical school executive and biotech startup CEO, and has served in a number of leadership positions in the federal government as well as academia.

In addition, Dr. Giroir serves as Senior Advisor to the Secretary for Opioid Policy. In this capacity, he is responsible for coordinating HHS's efforts across the Administration to fight America's opioid crisis.

From 2014-2015, Dr. Giroir chaired the Veteran's Choice Act Blue Ribbon Panel to reform the U.S. Veterans Health System. During the Ebola emergency, he directed the Texas Task Force on Infectious and Disease Preparedness Response.

He was executive vice president and CEO of Texas A&M's Health Science Center from 2013-2015, having earlier served as vice chancellor of strategic initiatives (2011-2013) and vice chancellor for research (2008-2011) for the entire Texas A&M University system. A pediatric critical care physician and a former member of the American Board of Pediatrics, Dr. Giroir cared for critically ill children for 14 years, and was the first chief medical officer of Children's Medical Center of Dallas (now Children's Health). He was also a professor at the University of Texas Southwestern Medical Center from 1993-2003, and held a number of positions in academic and hospital leadership.

Dr. Giroir has had a significant federal portfolio. He directed the Defense Sciences Office of the Defense Advanced Research Projects Agency (DARPA) from 2006-2008. In this capacity, he worked regularly with the White House, Congress, and NIH, CDC, DHS and CIA leadership on national priorities, strategies and programs. He joined the office in 2004 as deputy director, and between 1998 and 2004, was a member of the Defense Sciences Research Council.

Dr. Giroir has authored or co-authored almost 100 peer-reviewed scientific publications and holds patents on a number of biomedical inventions. He is the recipient of numerous honors and awards, including the U.S. Secretary of Defense Medal for Outstanding Public Service, the American Heart Association's President Lyndon Baines Johnson Research Award and the Society of Critical Care Medicine's Annual Scientific Award. He was the nation's high school debate champion in 1978. He received a bachelor's degree in biology from Harvard University in 1982 and a medical degree from the University of Texas Southwestern Medical Center (Dallas) in 1986.



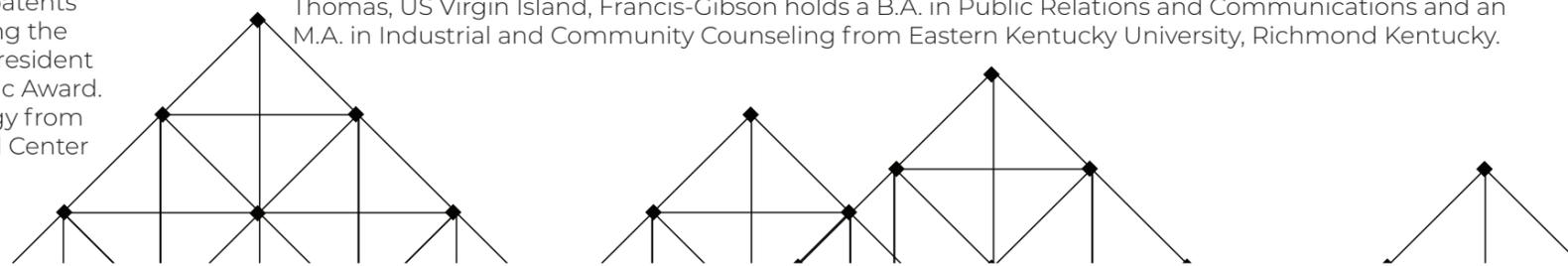
## **BEVERLEY FRANCIS-GIBSON**

Beverley Francis-Gibson is President/CEO of the Sickle Cell Disease Association of America, Inc. (SCDAA). Francis-Gibson previously served as the Executive Director of the National Alliance on Mental Illness (NAMI HC) of Howard County in Columbia, Maryland and has more than 25 years of experience serving non-profits and community foundations. She is Immediate Past Chair of the Board of Directors of Maryland Nonprofits. She is a 2009 Leadership Premiere Graduate and previous Board member of Leadership Howard County. Francis-Gibson is currently co-delegate for the Behavioral Health Work Group; member of the Child Fatality Review Team; Board Member of The Clarion Call and a member of the Local Health Improvement Coalition. She is a member of the Sickle Cell Disease Coalition and the Sickle Cell Steering Committee. She also serves on the National Minority Quality Forum's Sickle Cell Disease Working Group, and is a proud member of Delta Sigma Theta Sorority, Inc.

Francis-Gibson is the creator and co-facilitator of "Leadership Conversations" a quarterly gathering of nonprofit Executive Directors who share best practices, network and hear from engaging speakers on various topics. Currently, she mentors Executive Directors through her affiliation with the Association of Community Services.

She has been a dynamic instructor on fundraising, grant writing and philanthropy at Duke University's Nonprofit Management Program and at the University of Chapel Hill in Durham and Chapel Hill, North Carolina, respectively. She has been a popular speaker and webinar presenter at the Maryland Governor's Conference on Grant Making for several years.

Francis-Gibson brings her extensive nonprofit experience to SCDAA in the areas of management, grants, philanthropy, public speaking, fundraising/special events, advocacy and board development. Additionally, she brings her specialized expertise and exceptional professionalism to SCDAA and is excited to be joining the sickle cell family to help raise awareness of the disease across the country. A native of St. Thomas, US Virgin Island, Francis-Gibson holds a B.A. in Public Relations and Communications and an M.A. in Industrial and Community Counseling from Eastern Kentucky University, Richmond Kentucky.



# Our Speakers



## DEVARD DARLING

Devard Darling is a retired NFL veteran wide receiver and represents the 18% of professional athletes living with sickle cell trait. A native of Nassau, Bahamas, Darling was selected as the 82nd pick in the third round of the 2004 NFL draft making him one of the first Bahamian athletes to get drafted to the National Football League. Devard accomplished another boyhood dream shared by he and his late identical twin Devaughn Darling when the As One Foundation was founded in 2007. The As One 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. As the spokesperson for the foundation, Darling is devoted to ensuring his brother's death was not in vain by sharing the importance of awareness of sickle cell trait. As a #TraitWarrior - a sickle cell trait carrier and an identical genetic match to his late brother, Darling is living proof that exertional sickling is preventable and should NEVER result in death.

Darling is an entrepreneur beginning his first business experience in 2010, while still an active player in the NFL, when he started Express Pick Up and Delivery Transportation Services. As a contracted carrier of FedEx, Express P&D takes pride in delivering the "Purple Promise" and revels in the opportunity to keep its customers happy! Currently Express P&D has 10 employees and 12 trucks in its fleet. In 2012 Devard officially retired and teamed up Altruvista Wealth, a wealth management firm in Houston Texas, to develop a specific financial planning process for pro athletes. In 2014 Darling dropped his financial licenses to seek opportunities in the self storage commercial real estate industry in the state of Washington.



## ADE ADEYOKUNNU

Ade Adeyokunnu was born in Nigeria, but grew up in the Washington, D.C. area, in Maryland. I am a former technology consultant and I currently live in Austin, Texas, where I just graduated with my MBA from the University of Texas in order to pivot into a strategy role in healthcare. I've been passionate about sickle cell disease advocacy for as long as I can remember. It's what drove me to create sikcell.com in 2009, the first online community for people living with sickle cell disease because I believe building a support network of people who understand what you're going through is crucial when you're living with what can feel like an isolated and often misunderstood, chronic condition like this one.

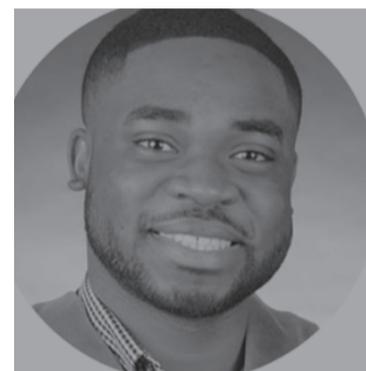
## SHERYL ARMSTRONG

Rev. Sheryl Armstrong, BA, MS, MDiv, CNPC  
Pastoral Counselor/Therapist

Presently, Reverend Armstrong is a Chaplain for Georgia Regional Hospital in Savannah Georgia. She is also founder of New Life Pastoral Care Counseling Services in Warner Robins, GA. She received her seminary training from The Interdenominational Theological Center in Atlanta Georgia.

Rev. Armstrong is also thankful for her vast experience gained at Grady Hospital, Ruby Memorial and the Department of Behavioral Health and Developmental Disabilities. She is a certified Pastoral Counselor and now has the humbling opportunity to provide care to a diverse population, and exercise the methodologies that she has been blessed to offer and share with others.

"Be prayerful and transparent while on your journey. My hope is that you are inspired to pursue your



## DR. STEPHEN BOATENG

Dr. Stephen Boateng is a passionate advocate and spokesperson for sickle cell disease and sickle cell trait. As a pharmacist by training, his passion in healthcare stems from his sister living with sickle cell disease and him being a sickle cell trait carrier.

Dr. Boateng's current research focus area is in sickle cell trait and health equity programs aimed at improving the quality of care and access for sickle cell patients globally. Outside his role as a researcher, he also provides clinical expertise as a medical writer/editor for sickle cell 101 and is the co-host of The Sickle Cell Podcast.

He has completed a clinical rotation at St. Jude Children's Research Hospital in Memphis, TN with a major focus on sickle cell and hematology.

Dr. Boateng graduated with a Doctor of Pharmacy degree from Idaho State University and is currently an Adjunct Professor at Rutgers University and a Postdoctoral Commercial Fellow at Bayer.

Dr. Boateng enjoys soccer is currently a coach at the New York Red Bulls working within the Training Programs Division in New Jersey.

# Our Speakers



## TOMIA AUSTIN

Tomia Austin, Dr PH, a behavioral scientist, health educator and researcher is also the Executive Director of the As One Foundation that was established with a mission to help empower youth to unlock & unleash their full potential through athletics, education and spiritual enrichment. Since the foundation was also established to honor the memory of the founder's late brother who died of dehydration complicated by sickle cell trait, Dr. Austin authored a program – Operation Hydration - to bring awareness to sickle cell trait and promote hydration as prevention of it's adverse effects such as exertional sickling. Under Dr. Austin's leadership the new mission of the foundation became to educate and increase awareness of sickle cell trait while encouraging youth to achieve their dreams in the face of life's challenges.

Dr. Austin's nearly 20 years of dedicated work in the not-for-profit sector fuels her pursuit of health literacy for disadvantaged populations – especially young athletes of color. Her work focus and research interest areas include genetics, sickle cell anemia and sickle cell trait, dehydration, asthma, youth sports, high school, college and professional athletics, physical activity and obesity among populations of African, Caribbean, Asian, Indian, Latin, Irish, Italian, Greek, Turkish and Mediterranean descent. Dr. Austin has had experience in community settings on local, county, state, national and international levels, laying the foundation for globally impactful contributions to the research. As a telecommuter to Metro Houston, Texas in her executive role, she makes her home in Metro Atlanta with her husband, Douglas.

## HEATHER AVANT

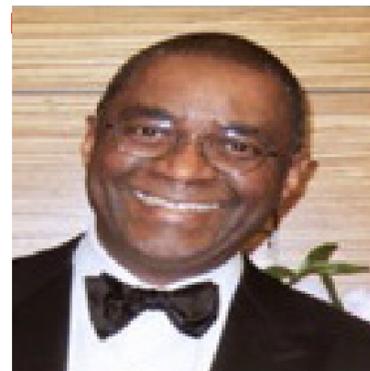
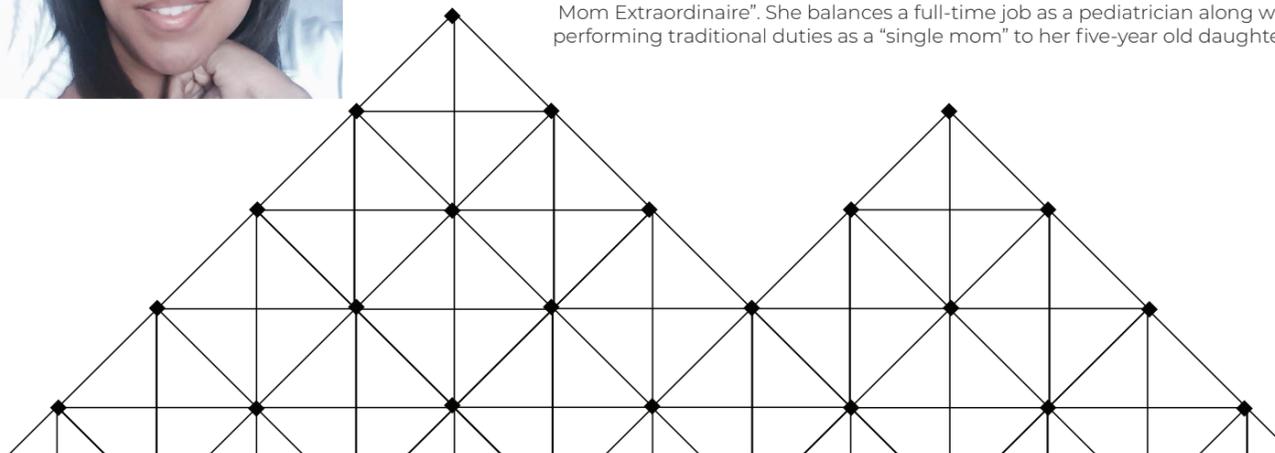
Heather is a natural light photographer, painter, crafter, sickle cell warrior, sickle cell advocate, and all around do-it-yourselfer thriving in Dallas, Texas with her husband Jason and son Jett. She was born and raised in Ypsilanti/Ann Arbor, Michigan where she went on to pursue her B.F.A in Photography at Eastern Michigan University.

She was diagnosed with sickle cell SS while in utero after her brother, then age 1, was diagnosed during a newborn screening. Heather has been advocating for sickle cell since the young age of 6, and has been an outspoken member of the sickle cell community ever since. Her photography has been published in medical journals and placed in clinics and hospitals across the US.

At a young age she unearthed a talent for storytelling and photography. With a bit of inspiration from her husband and a lot of nurturing from friends and family, Heather decided to leave corporate America and venture out on her own as a Photographer, Artist and Advocate. In 2016 Artfully Avant was born.

True to her calling as an artist, Heather is inspired daily by the world around her. From the subtle nuances of the evening sun dancing across the window curtains, to the dramatic and bold shadows greeting her on the floors in the waking light. She tries her best to live in the moment and beauty of each day because it truly is a gift.

She is currently working on a new project and getting back to her fine art roots; shooting a new series for exhibit and publication called "The Unbreakable WARRIOR Project." Her desire is to shoot the everyday sickle cell warrior and share their stories of triumph over tragedy.



## DR. KENNETH R. BRIDGES

Dr. Kenneth R. Bridges received the 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. Dr.

Bridges returned to Harvard as a member of the Hematology Division at Brigham and Women's Hospital where he achieved the faculty rank of Associate Professor of Medicine. In parallel with his laboratory investigation of iron metabolism, Dr. Bridges maintained active clinical work and established the Joint Center for Sickle Cell and Thalassemic Disorders at Brigham and Women's Hospital and Massachusetts General Hospital, emphasizing bench-to-patient translational research. Dr. Bridges published over 70 peer-reviewed articles during his academic career, as well as number book chapters. He also co-authored with Dr. Howard Pearson of Yale University a textbook on red cell disorders and anemia. Dr. Bridges left academia to work in biotechnology, initially with Hoffman La Roche followed by 3 years at Amgen where he worked on Aranesp and participated in the launch of Nplate. Dr. Bridges moved to Onyx Pharmaceuticals where he oversaw several trials involving Kyprolis (carfilzomib) for the treatment of multiple myeloma. Following the Amgen acquisition of Onyx, Dr. Bridges moved to Global Blood Therapeutics in the role of Vice President, Medical Affairs working on a treatment for sickle cell disease, voxelotor.

## DR. TAMIKA BUSH

Dr. Tamika Bush, D.O. AKA "Dr. TamikaPeds" is a highly respected and well known Board Certified Pediatrician and "Doctor Mom". Dr. Bush is an international and nationally recognized Speaker, 3x Best-Seller Author and Medical Consultant. She is also an expert on Children's Health and Natural Ways to Keep Children Healthy without the use of conventional medicine. Dr. Bush dedicates her professional career to helping children any way she can through her vast knowledge of Pediatric Medicine. She has also traveled internationally to provide Pediatric Global Health services to the impoverished and poverty stricken in need in Africa.

Due to Dr. Bush's "bubbly" personality, compassion and courteous bedside manner, no wonder she has been named one of the country's most well respected Pediatrician and known as the "Doctor Mom Extraordinaire". She balances a full-time job as a pediatrician along with consulting, while performing traditional duties as a "single mom" to her five-year old daughter as a "single mom".



# Our Speakers



## LANETTA BRONTE-HALL

Lanetta Bronté-Hall, MD, MPH, MSPH is responsible for strategic planning, scientific, and administrative oversight of the Foundation for Sickle Cell Disease Research (FSCDR). She is a leading national and international researcher and population health scientist in the field of sickle cell disease, rare blood disorders, community-based participatory research, and chronic disease management. Dr. Bronté-Hall has extensive experience in developing programs that are closely aligned with the recruitment and retention of underserved and underrepresented populations for treatment of Sickle Cell Disease and Breast Cancer, research and clinical trials. She is currently President and CEO of the Foundation for Sickle Cell Disease Research (FSCDR), Chief Health Officer (CHO) of the Sickle Care and Research Network, FSCDR, LLC, an independent full-service outpatient medical treatment and clinical trials center that offers medical care and coordinated care for underserved populations. Dr. Bronté-Hall is has a faculty appointment at the University of Miami, Miller School of Medicine as an Associate Professor in the Department of Public Health Sciences, Department of Health Services Research and Policy.

Dr. Bronté-Hall received her Bachelor of Arts in Biology and Master of Science degree in Medical Parasitology and Laboratory Practice from the University of North Carolina (UNC), Chapel Hill, Gillings School of Global Public Health. She then received a joint Doctor of Medicine and Master of Public Health with specialization in Health Policy and Administration (Health Policy and Management) from the UNC Schools of Medicine and Gillings School of Global Public Health. She completed an internship in Internal Medicine at Tulane University School of Medicine and residency in Psychiatry at the University of Miami, Miller School of Medicine. In addition, she completed a Health Research and Educational Trust/American Hospital Association Fellowship in Cultural Competence and Leadership. In February 2016, she became a Radical Wellbeing Ambassador of Deepak Chopra's Radical Wellbeing to develop expertise areas that impact the quality of life and health of people, as well as why these practices are good for business and performance. Dr. Bronte was a featured guest for the course in New York City on February 6, 2016.

Dr. Bronté-Hall spearheaded a Sickle Cell Disease and Thalassemia Registry that currently has approximately 25,000 individuals with a hemoglobinopathy. Included in this Registry is over 2,500 individuals with Sickle Cell Disease. Dr. Bronté-Hall has served in several leadership positions including the Chief Medical Officer of the Sickle Cell Disease Association of America, Senior Medical Advisor to the Centers for Disease Prevention and Control, a member of the National Institutes of Health, National Heart, Lung and Blood Advisory Council, and a member of the 2014 Expert Panel for the National Institutes of Health, National Heart, Lung and Blood.

## CARLEY "ELLE" COLE CAVINS

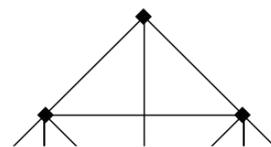
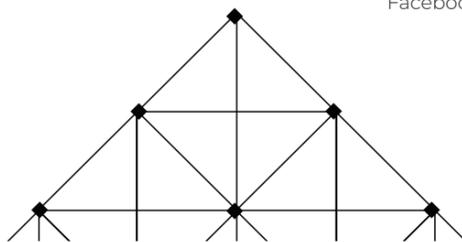


Residing in PG County Maryland with her husband and twin daughters. Elle Cole left her corporate job to become a stay-at-home mom when her daughters were only 4 months old.

She holds a B.A. degree in English and History. She is a writer and content creator who is a go-to resource on health, wellness, finances, and parenting. She is a passionate storyteller, blogger, and host of the Cleverly Changing podcast.

Elle has been featured on NPR, ABC 7, BBC World Service Radio, and a guest on several podcasts. She is also a recipient of a Bronze Congressional Award, an avid speaker, and an active community volunteer.

In addition, she serves as a health advocate for Sickle Cell Anemia and Type 1 Diabetes. She is an ambassador for St. Jude Children's Research Hospital. And it is her goal to raise awareness about Sickle Cell and help make a global impact to better the quality of life for people living with genetic disorders and autoimmune diseases. You can follow Elle's journey on Instagram and Facebook at CleverlyChanging.



## JEWEL DARBONE

Jew-EL Darbone is a 30yr old sickle cell warrior dedicated to sickle cell advocacy and empowerment. She is one of the founders and CEO of 501c3 Nonprofit organization #Boldlipsforsicklecell. #Boldlipsforsicklecell started as a social media awareness challenge for sickle cell disease, it has now turned into a full fledge organization that hosts various events within the community. #BLFSC encourages all sickle cell warriors to Be Bold and Speak Up about sickle cell as well as empowering them to live bold fulfilling lives.

As a social media consultant Jew-EL's dedication to sickle cell awareness, advocacy and empowerment will not stop. She is very vocal about the mental health issues she faces daily. She has been apart of mental health panels as well as using social media to advocate for mental health. Jew-EL is dedicated to making her sickle cell community better.

## FARRON DOZIER



SFC, Retired, US Army, Executive Director and Content Producer:  
Since the age of 5 I had pain in my left arm which doctors related it to growing pains. I found I had Sickle Cell Trait after 10 years in the Army in 1999. In 2006 after collapsing at the Master Sgt Academy completing the 2 Mille Run I experienced Rhabdomyolysis, renal failure and other joint damage. In 2009 I went into a depression dealing with physical pain and mental pain because I was found not fit for duty. All during this time one of my three daughters also inherited the gene from me and me from my dad.

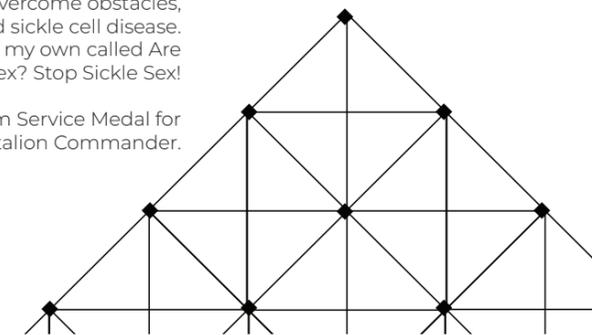
During my depression Internet radio became an outlet talking about sports highlights. Once I was made aware that people in the military and athletes have been collapsing and dying I realized that I had survived that episode and I could help make people aware through my radio program. As a result, I was able to create a Non Profit called WHATZ DA COUNT on Sickle Cell Trait Prevention. WDCONSCT.org

Host and Produced WDC Radio Show with over 422K viewers. Creator/ Curriculum writer of Sickle Cell Traits Course being taught in San Bernardino Valley Community College started in February 2015 / April 2016. It's a 1 credit / 16hr Certificate Course. 13 Students Year 1 / 26 Students Year 2.

Also the creator and Host of Trench Talk. Trench Talk is platform for our Veteran Soldiers of all branches of services (men and women) to come and share their most memorable Military stories, experiences and history. Also be a location where Veteran's services, programs and resources are shared and available for our Service Members from "Then and Now" TrenchTalk.us

The I AM WDC Achievement Award; recognition of youth and adults who overcome obstacles, adversities and challenges as a result of the sickle cell trait and sickle cell disease. He is a collaborator on Public Service Announcements raising awareness with my own called Are you having Sickle Sex? Stop Sickle Sex!

His most memorable award of his career is the Military Outstanding Volunteerism Service Medal for his Sickle Cell Trait Advocacy work recognized by his peers and his Battalion Commander.



# Our Speakers



## DR. JAMES ECKMAN

Dr. Eckman practiced academic medicine for more than 41 years establishing the Georgia Comprehensive Sickle Cell Center, the world's first 24-hour, comprehensive acute care sickle cell program, which presently serves a patient population of more than 1,000 active patients from a population of over 5,500 registered patients. His did extensive research in basic sciences, translational research, clinical research and clinical trials. His other interest is in public health services for individuals with genetic diseases. He has been active in Georgia, the Southeastern Region, nationally and internationally in improving health care for individuals with hemoglobin disorders using public health approaches.

He first focused on newborn screening and now that survival has improved, his focus is on transition and improving the adult medical home. He has been an active member of the Oversight Steering Committee for HRSA/MCHB Sickle Cell Disease Treatment Demonstration Program (SCDTDP) for both funding periods. He collaborated with the CDC RuSH and PHReSH project leading writing projects and outreach education and am committed to establishing surveillance and a registry for this population. He is participating in a HRSA project with Georgia Children's Medical Services to improve transition in youth with hemoglobin disorders. He remains active in education, mentoring young faculty, providing lectures and developing curriculum. He is presently working in Georgia to improve access to care for individuals with sickle cell disease. The focus is improving access to and utilization of a primary care medical home in adults with sickle cell disease. He is also working on methods of transitioning youth with sickle cell from pediatric centered to adult centered medical homes in Georgia that will work in many different care settings.

## CARLEY "ELLE" COLE CAVINS

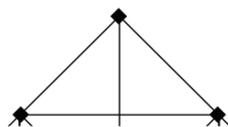
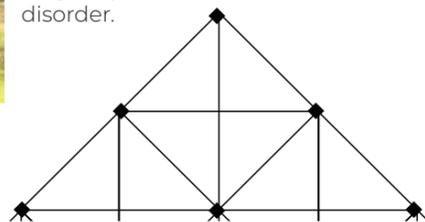
Founder/CEO  
GA, FLA, Africa  
Self Advocacy Training/Workshops  
Medical Humanitarian Missions (worldwide)  
Yellow Rose Mentoring Group (girls)  
Expressive Art Therapy (Film, Crafts, and Writing)



## KADEEM GAYLE

Kadeem Gayle was born in Boston, MA, at an early age Gayle was diagnosed with sickle cell disease. Gayle is a graduate candidate at DREW University, he holds a BA from American International College and an MFA from Adelphi University. He has found writing to be a positive outlet especially when coping with SCD.

Kadeem is an active and impactful advocate in the Sickle Cell Community. Kadeem is also the acting Secretary for the Sickle Cell Champions Association (S.C.C.A.). He diligently advocates for the advanced treatment and care of those living with this disorder.



## SUZANNE GORDON

SUZANNE GORDON is a mother of 4. Her 2 older children carry the sickle cell trait and her 2 younger children are afflicted with sickle cell disease (Hgb SS). After the birth of her second child, she left her career as a paralegal to raise her children. Suzanne was co-founder of FACE Foundation, a non-profit organization geared at increasing awareness and providing more resources for the sickle cell community. Suzanne is a strong advocate for her children and a proponent for increased awareness about sickle cell disease.

## ULYSSE GUERRIER

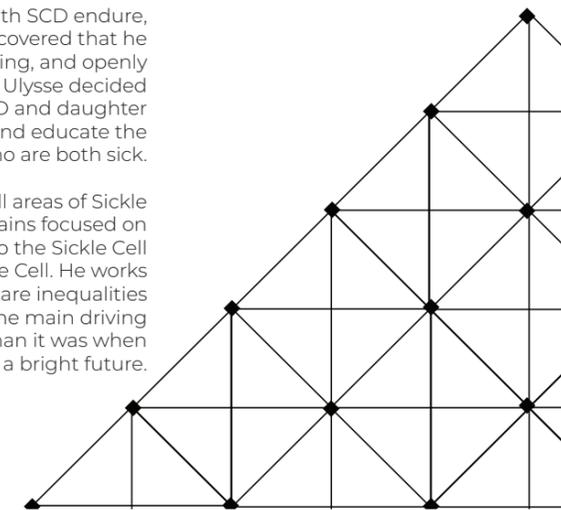
Ulysse is the Coordinator of the Sickle Cell Program out of TAIBU Community Health Centre where he runs a support group for adults living with the disease. He began the Sickle Cell Program in 2011 as a research project to gather data and to show the many needs of individuals living with SCD.

Since the age of 16, Ulysse has been on multiple boards and currently sits on multiple committees within the SC community in Canada and the US. He is one of the founding members of UJIMA Sickle Cell Patient Emergency Fund, an initiative to fund raise in order to support individuals living with Sickle Cell in urgent need of financial aide.

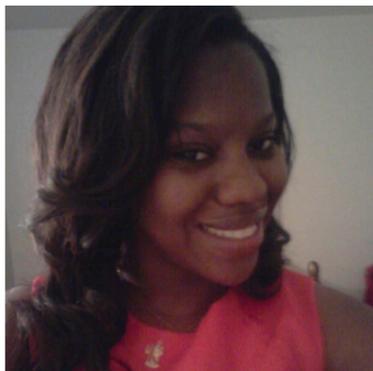
He himself is a Sickle Cell Warrior living with Sickle hemoglobin SBeta Thalassemia which is a rear and more serious form of the disease. He has endured many complications, including strokes, acute chest syndrome, Avascular Necrosis which left him with a replaced hip, and lives with chronic pain every day of his life.

Ulysse believes that if people truly could see and understand what people living with SCD endure, that we would see a shift in the way the Sickle Cell community is treated. Ulysse discovered that he could reach a wider audience to educate people about SCD through film, storytelling, and openly sharing his life and its challenges. Harnessing his creativity and passion for advocacy, Ulysse decided to put his life story on YouTube. Along with his spouse Shelly-Ann whom also has SCD and daughter Arianna they created the channel "Our Sickle Life". They hope to raise awareness and educate the public by showing the challenges they face as a couple who are both sick.

He is a patient advocate, a mentor for others living with SCD, and an advisor in all areas of Sickle Cell. Ulysse strives to ensure that the voice and scope of Sickle Cell always remains focused on the individuals with the disease and their families. His passion and dedication to the Sickle Cell community has always helped him to overcome the challenges of living with Sickle Cell. He works to inspire others to join the cause and the mission of addressing the many healthcare inequalities of those affected by SCD. His life's mission is to make this invisible disease visible. The main driving force behind all his hard work is to leave the sickle cell community in a better state than it was when he came into the world. With him championing the cause, Sickle Cell has a bright future.



# Our Speakers



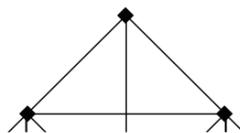
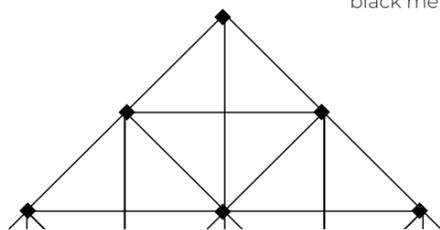
## TYNISHA HALL

Tynisha Hall 30 years old born and raised in Birmingham, Alabama and resides in Atlanta, Ga. Tynisha is a graduate and proud alumnus of Delaware State University with a Bachelors degree in Broadcast Journalism. She serves as the communications/community outreach director for Sickle International Family Coalition Inc., serves in her community where she is on the media ministry at her church, she is a mentor to girls with sickle cell disease throughout the country, and supports families of children with sickle cell. While in college she held many positions in leadership from treasure in RHA, Vice President Jenkins hall, Miss Mass Communications, Director of Production at the radio station and TV station where she helped bring in new ideas and new sets and created budgets and plans to get the equipment for the department. One of her biggest prides were helping her infirmary on campus cater to the needs of sickle cell patients and speaking for those who didn't want to speak up she knew she could be that face and voice for them. "I dedicate my time so I can raise awareness for sickle cell and help those with this disease go to college and be successful in completing college for post graduation is her goal when she goes out into her community."

Tynisha has served as college advocacy coordinator for Sickle International Family Coalition Inc., she presented senator Carper with an award on behalf of the William E Proudford Foundation in Baltimore at the SCDAAC convention, Sickle Cell activist at Kent General hospital in (Dover, DE.), she is a Sickle cell community consortium partner as well as new elected Secretary for the Sickle Cell Community Consortium, Sickle International Family Coalition senior video campaign manager, Sickle Cell Ambassador 2015, sickle cell camp new hope counselor which she enjoys giving back. One of her many sayings are "I too have sickle cell and I've learned to have a voice now." It has been ten years of advocating and traveling to speak across the U.S., with a passion to take that international. She proudly was apart of the first ever HBCU sickle cell college tour, and Tynisha has worked with many people in the sickle cell community who are positive activist and advocates. Tynisha knows this has helped her in several ways just to learn how to listen to the pain that so many say is invisible is really a pain that speaks volume. Tynisha says often to her fellow warriors, let your passion be your career whatever you may be interested in do that and turn it into a way for you to give back and you will be sure to be successful and learn the things in life that no classroom can teach you. My favorite quote is "Without data you're just another person with an opinion" by W. Edward Deming.

## ANDRE HARRIS

André Marcel Harris is a Bachelor of Social Work (BSW) student and a Ronald E. McNair Scholar at Fayetteville State University in Fayetteville, North Carolina. Upon completion of his BSW, Mr. Harris aspires to pursue a Master of Social Work/Master of Public Health (MSW/MPH) and a PhD in Social Work/Sociology. André's professional goals include him working to influence health equity for Sickle Cell patients, providing quality resources to address disparities in black men's health and providing psychosocial support for male sexual assault survivors. Mr. Harris would like to one day be the Director of a Community Based Organization or a Nonprofit Organization that supports these programs. André's research interest focuses on social determinants of health, black men's health, and black male sexual assault survivors.



## DR. ANNA HOOD

Anna Hood, PhD, is a Sickle Cell Disease Postdoctoral Fellow in the Division of Behavioral Medicine and Clinical Psychology at Cincinnati Children's Hospital Medical Center. She is the recipient of pre-doctoral (F31) and postdoctoral (F32) training grants from the National Heart, Lung, and Blood Institute (NHLBI) to fund research focused on the cognitive and psychological challenges faced by children and young adults with sickle cell disease. Specifically, she aims to 1) promote self-management, patient engagement, and medication adherence and 2) to identify interventions and the underlying neural mechanisms to improve cognitive outcomes. Dr. Hood has given presentations at regional and national meetings, and authored or co-authored peer-reviewed articles, book chapters, and community-focused reports. In addition to her research, Dr. Hood has also worked clinically with children with sickle cell disease for the past 6 years. She is currently a clinical supervisor for community health workers working with young adults with sickle cell disease transitioning from pediatric to adult care.

## RITCHIE JOHNSON

Ritchie Johnson is a Mother, Registered Nurse, Author, Speaker and Advocate. She is the Founder and President of the Chris "CJ" Johnson Foundation, Inc., a 501(c) 3 non-profit charity organization located in Sugar Land, Texas. She holds a BSN from Texas Woman's University in Denton, Texas. She obtained her MBA from California College for Health Services in Salt Lake City, Utah. She has 6 years experience in organizing fundraisers and raising awareness for Renal Medullary Carcinoma (RMC). The majority of her experience as a nurse was in Women's Health and Healthcare Leadership. She has 47 years experience as a registered nurse, 26 years in Healthcare Leadership, 18 years in organizing and developing Customer Service Workshops for hospital employees.



As an advocate for RMC, she has been featured in the New York Times, Fort Bend Herald, Fort Bend/Southwest Star, Fox 26 KRIV Houston, KPRC 2 Houston, CW39 Houston and several neighborhood magazines. She is a published author of "Mama I'm Tired" A Mother's Journey Through Her Son's Cancer Battle with Renal Medullary Carcinoma.

She resides in Sugar Land, Texas and because of her youngest son's death from RMC, she has dedicated her life to advocating for at risk adolescents and young adults who carry sickle cell trait (SCT). She is committed to raising RMC awareness in both the public and medical communities. Last, but not least, she has organized fundraiser events to support advance research at MD Anderson Cancer Center.

## KENYA BUCKLEY



Kenya Buckley is the Founder and President of Carol's Promise Sickle Cell Foundation. Carol, her mother, passed away from complications of Sickle Cell Disease in 2005. It has been her mission to tell her mother's story and the motivation behind her creating Carol's Promise Sickle Cell Foundation. The foundation holds her mother's namesake and is fulfilling the "promise" that Kenya made to her mother that she would help find a cure and advocate on her behalf, so no one would have to suffer the way that she did. Carol's Promise was birthed in 2017 to improve the quality of life in individuals living with Sickle Cell. The organization does this by Support, Advocacy, Raising Awareness, and Education. Carol's Promise provides services and resources to families in Tarrant County. Kenya pours her heart and soul into being an advocate for Sickle Cell and being a voice for those who have been silenced by the disease. Kenya is also a Storyteller for the GenerationS campaign that is being highlighted by Novartis.

Kenya completed her Bachelor's degree in Accounting from Sam Houston State University and currently works Full-Time for the City of Arlington as an Accounting Analyst. Kenya is also a devoted wife to Ray and mother to 2 handsome boys, Grant (11) and Raymond III (2). Kenya, along with her 2 children live with Sickle Cell Trait.



# Our Speakers



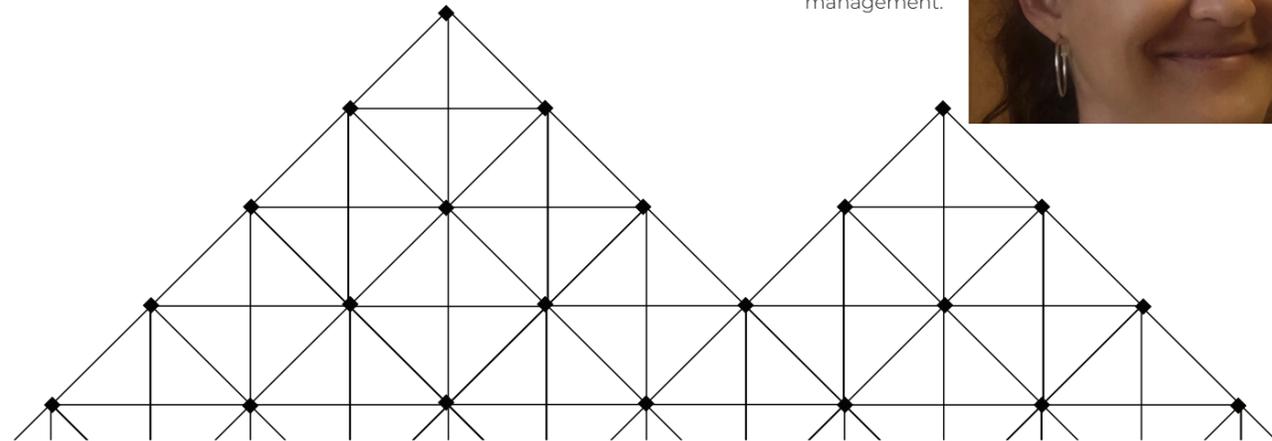
## DR. ELIZABETH KLINGS

Center for Excellence in Sickle Cell Disease, Boston Medical Center  
Associate Professor of Medicine and the Director

Dr. Elizabeth Klings is an Associate Professor of Medicine and the Director of the Center for Excellence in Sickle Cell Disease, which cares for over 500 adult and pediatric patients, at Boston University School of Medicine/Boston Medical Center. She received her BA and MD degrees from New York University and completed her training in Internal Medicine, Pulmonary and Critical Care at Boston City Hospital/Boston Medical Center/Boston University School of Medicine. She joined the faculty at Boston University School of Medicine in July 2000. Her clinical and research interests have focused on the pulmonary vascular complications of sickle cell disease, and she has published over 60 papers and book chapters on the subject. She led the development of the Clinical Guidelines for the Diagnosis and Treatment of Pulmonary Hypertension in Sickle Cell Disease published in the American Journal of Respiratory and Critical Care Medicine in 2014 and continues to lead efforts to better understand this condition. She became the Director of the Pulmonary Hypertension Center at Boston Medical Center/Boston University School of Medicine in July 2018 where she leads a multi-specialty program devoted to clinical management, research and education in pulmonary hypertension. Her current research interests are in the roles of pulmonary vascular modulators, particularly sleep-disordered breathing and venous thromboembolism in the development of pulmonary hypertension in sickle cell disease. The pain that so many say is invisible is really a pain that speaks volume. Tynisha says often to her fellow warriors, let your passion be your career whatever you may be interested in do that and turn it into a way for you to give back and you will be sure to be successful and learn the things in life that no classroom can teach you. My favorite quote is "Without data you're just another person with an opinion" by W. Edward Deming.

## EMILY O'SHEA

Emily O'Shea is a licensed clinical social worker based out of the Austin Texas area. She became interested in social justice issues when she started studying at the University of Arizona. She was able to further her education at the University of Texas at Austin and graduated in 2001 with a Masters of Science in Social Work. Since 2001 Ms. O'Shea has been working in the Austin area at the county, state, and federal level. Her experience includes work around abuse/neglect, severe mental illness, homelessness, and addiction. Since 2016 Ms. O'Shea has been employed through the Sickle Cell Association of Texas as a case manager, advocate, and health educator. Ms. O'Shea is passionate about working towards solutions to improve sickle cell disease treatment and management.



## MARCUS MCKINLEY

I am Marcus McKinley, a 34 year old male entrepreneur living with, advocating, and conquering sickle cell disease. I am originally from a small Mississippi Delta city of about 40,000 inhabitants named Greenville. Greenville is where I was diagnosed with sickle cell type SS at the age of two. This was my first crisis that required hospitalization. I have endured many, many hospitalizations, blood transfusions, and medical procedures due to sickle cell. I currently reside in Oklahoma City, Oklahoma where I own a mobile auto detailing and a towing business. I also hold various positions within community based organizations dedicated to sickle cell. I am a passionate advocate for those living with and affected by sickle cell. My life is and always will be committed to advocating and finding advanced treatment and a possible cure for this genetic blood disorder. I love traveling around the country to lend my voice and a helping hand to those living with and/or affected by sickle cell disease. I am a family man and a man full of integrity and leadership.

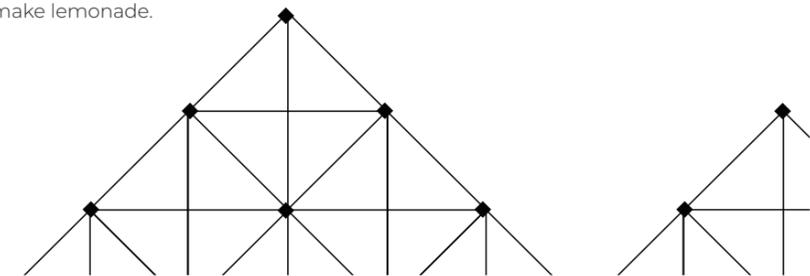
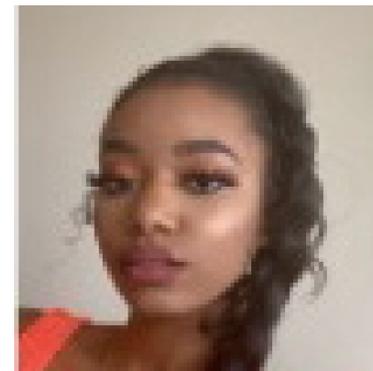
## MONIQUE MCKINLEY

Hi! I'm Monique Deloris McKinley! I'm 31 years old and from Oklahoma City, Oklahoma. The second oldest of four children, Monique loves being around her family whenever she can. Monique's heart melts for the little people. She has even gone to further her education with a Mastery in Child Development. She loves the kids and is planning on opening a child development center in Oklahoma City in the next couple of years. Monique married her sickle cell warrior, Marcus McKinley, on June 25, 2016 and has been advocating for sickle cell since 2009.



## SHERIKA PRINCESS

My name is Sherika Princess and I am supercalifragilisticexpialidocious. I was born and raised in Houston, Texas. I came to the DFW area to continue my education at Texas Woman's University. Initially I came to pursue an education and Health Studies and Health Informatics it hopes of becoming a Hematologist. That's still on the agenda. Unfortunately I suffer from a blood disorder called Sickle Cell. I have Sickle Cell Anemia genotype SS. I have good and bad days, it was on a bad day that inspired me to write "Super Cells". I was at work one day and got a piece of receipt paper and just started writing down ideas. It was no representation of children with sickle cell. So I created my own lane. Not to sound cliché, but I do believe that the children are our future. Super Cell is set to be released sometime in September. This was literally a dream, I had no idea that I would take it this far. I could not have done this alone, with the help of Deavonte who brought the main character to life. Sickle is my passion it is my purpose in life. I'm Sickle Cell gave me lemons, but life taught me how to make lemonade.



# Our Speakers

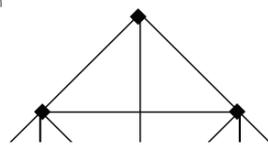


## TOSIN OLA

Tosin Ola, RN, BSN Founder & President, Sickle Cell Warriors, Inc. Tosin Ola, BSN, RN knows firsthand the challenges of living with sickle cell disease. The practicing registered nurse and mother of twin toddlers, launched the Sickle Cell Blog in 2005 to bond with others and share her experience living with this debilitating and deadly disease. The term "sickle cell warrior" was coined by Tosin in 2005, when she wrote a post that resonated with millions around the world rejecting the word "sickler" and the negative associations with it. To some, it's just words, but people like Tosin recognize that change happens because of words. Many patients adopted this term and it spread into all echelons of the sickle cell community. Her words shifted the dynamics of the provider-patient relationship, restoring dignity and respect in situations where one is often most vulnerable. A short two years later in 2007, the sickle cell advocate created an online platform – the Sickle Cell Warriors website – to broaden the discussion and give the patient community a much-needed voice. The educational site is the largest collection of articles (over 600) written by Sickle Cell Warriors, those affected directly by sickle cell disease. The Sickle Cell Warriors website is designed to raise public awareness of this complex chronic medical condition, and empower patients a greater level of self-care management, discuss the serious complications of the disease, provide expert advice to patients, share latest research news, spotlight videos, promote SCD events, increase patient engagement and so much more. Also, the portal highlights "Warriors in the Spotlight" - people living with sickle cell disease who share their personal experiences and are a source of inspiration for others. To complement these efforts, the Sickle Cell Warriors Facebook Page located at [www.facebook.com/sicklecellwarrior](http://www.facebook.com/sicklecellwarrior) supports and encourages members to engage with others going through the same daily struggles. The leading social media channel has connected almost 24,000 members, making it the largest online group of people affected by this disease. Sickle Cell Warriors, Inc. also runs social media channels on YouTube, Twitter, and Instagram.

Tosin strives to create a community where people can feel comfortable asking (and getting answers to), their most pertinent and personal questions related to sickle cell disease. There has not been a topic that Tosin shies away from or is afraid to address. She is dedicated to presenting positive and uplifting messages about sickle cell to the society, as well as empowering sickle cell patients to take control of their disease and think differently about life with sickle cell. She believes that sickle cell does not define you, and that one can have a beautiful and fulfilling life regardless of sickle cell. Tosin has worked as a registered nurse in healthcare for over 16 years, squashing the myth that those with sickle cell cannot physically thrive in a professional setting. She has experience in the trauma ICU, telemetry, CCU, oncology, and surgical setting, with leadership in multiple arenas. She also worked for a pharmaceutical company for 3 years on the EPIC-study, a clinical research study for sickle cell disease. Although it did not meet the clinical endpoint, the EPIC study ended up enrolling 388 patients, the largest phase III study ever conducted in sickle cell disease. Tosin has been a public speaker and educator at over 50 sickle cell advocacy events and programs. She is currently in high demand as an accomplished speaker, inspiring teacher, experienced advocate, and passionate community activist for sickle cell disease. Tosin has partnered with many governmental agencies like the FDA to advance treatments and support for those with sickle cell disease. She has also collaborated with pharmaceutical and research entities to push for advanced cures, provide educational support for numerous clinical trials and fiercely advocate for patients living with sickle cell disease. Sickle Cell Warriors is one-third of the only three national sickle cell disease patient advocacy groups to be a part of the Sickle Cell Disease Coalition [www.conquerscd.org](http://www.conquerscd.org) and one of the founding member partners of the Sickle Cell Community Consortium SC3 [www.SickleCellConsortium.org](http://www.SickleCellConsortium.org). Part of her accomplishments include the co-creation of the only national patient conference, the Sickle Cell Patient and Family Conference (aka the SCD Warriors Convention) which is now producing its Sixth Edition in the summer of 2019. Visit their website at [www.sicklecellconvention.org](http://www.sicklecellconvention.org). This conference is the first national conference powered by the Sickle Cell Community Consortium [www.scccommunityconsortium.org](http://www.scccommunityconsortium.org) with three revolving patient advocacy organizations annually co-hosting the conferences. The conference is the only national conference that focuses specifically on education for patients and caregivers living with sickle cell disease. This growing national 5-day Conference has been held in the Bahamas (cruise), Atlanta (x2/years), Los Angeles, and Memphis, TN. Visit older editions, 2012-2018 years and including the strategic planning year of 2014 live here at [www.scdconference.org](http://www.scdconference.org). The year 2019 will be in Texas, and 2020 will be in Las Vegas, NV.

Tosin co-developed the VOICE Crisis Alert app, the first sickle cell disease app available in the United States for patients and caregivers living with SCD. The app stores all its data locally on your phone, so its private. In addition to being a crisis pain tracker tool storable for 90 days with an in-app pain diary to share with your health care provider and the ED, the Voice Crisis Alert app has an avatar expression of the pain scale, complete with personalizations. The app has a medical history section and is also a crisis alert notifier to three specified emergency contacts in your phone. In addition to numerous awards for her advocacy work in the sickle cell community including the nomination in 2011 for Nurse of the Year for the State of Oregon, activist of the year by WegoHealth and patient advocacy award from Wellsphere, Tosin has lent her expertise and been a source for print publications like ESSENCE, Glamour, Minority Nurse, True Shine; online media like the New York Times, U.S. News & World Report, WEGOHealth, Wellsphere, BlogTalkRadio, BioCentury, SF Bay News, Buffalo Times, and many more. Tosin was also featured in 2017 by the National Lung, Heart, Blood Institute in Today's Faces of Sickle Cell Disease. Tosin got her Associate's Degree in Nursing from Oakwood University in Huntsville, AL. In 2018, she was honored to give the commencement address to the nursing graduating class. She has a Bachelor's Degree in Nursing from the University of Phoenix. Currently, Tosin is working on her Master's Degree in Nursing and Master's Degree in Business Administration with an emphasis in Healthcare Management. She serves as an authoritative speaker, sickle cell community educator, professional advocate, rare disease expert, and a reliable source to all media and book authors. Tosin lives in Encinitas, California with her toddler twins and husband. Visit the Sickle Cell Warriors website, or email Tosin directly [Tosin@SickleCellWarriors.com](mailto:Tosin@SickleCellWarriors.com) or [SickleCellWarrior@gmail.com](mailto:SickleCellWarrior@gmail.com)



## VANESSA RHODES

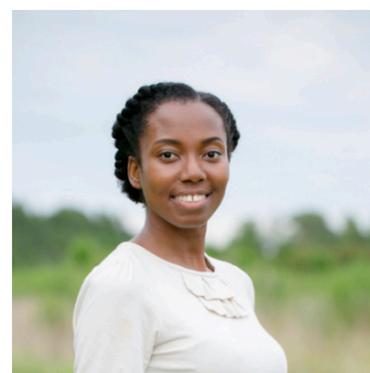
HOPE for SCD  
Director of Outreach and Communication  
Vanessa is a mother of a warrior, advocator, and an educator. She is a self proclaimed lover of the educational process as evidenced by the variety of positions she has held over the past 31 years. She served as a teacher, curriculum writer, principal,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

## FRANCES RICHARDSON



As the Qsource project lead for a Centers for Medicare & Medicaid Services (CMS) initiative to improve health care for adults with Sickle Cell Disease (SCD), Frances Richardson works closely with providers, health plan navigators, and patients and families to increase education and care guidelines around SCD. Richardson has over 30 years of experience as a Registered Nurse, including 20+ years' experience in healthcare quality improvement (QI), 10 years of QI management experience/project management, team and partnership building, and process flow development. She is a Certified Professional in Healthcare Quality (CPHQ) with specialized knowledge in Continuous Quality Improvement (CQI) principles. Richardson is well-versed in regulatory medical case review and utilization review, data abstraction and quality data reporting, as well as self-management education for patients and trainers. She is passionate about bridging the gap between patients and providers to improve care for SCD through patient identification, patient and provider education and reducing stigmas. Richardson received her Bachelors in Nursing from the University of Tennessee, Memphis, TN.

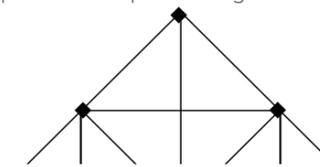
Qsource is a nonprofit, 501(c)(3) healthcare quality improvement and information technology consultancy headquartered in Tennessee since 1973. Qsource provides a wide range of programs and services to assist states, organizations, patients, and providers in improving community health, improving healthcare quality and delivery, and achieving improved patient outcomes and costs savings.



## MATTIE ROBINSON

MicroMattie Consulting

Mattie Robinson, MS MA has earned graduate degrees from Johns Hopkins University and the University of Florida. Ms. Robinson has over 7 years of biomedical research experience spanning the fields of Human Genetics and Molecular Biology, Microbiology, and Chemistry. She is the President of Micromattie Consulting Inc., a firm specialized in facilitating knowledge transfer between stakeholders in rare disease research and clinical practice. Services provided have strengthened initiatives at Sanford Health and other medical centers, pharmaceutical companies, professional organizations, and US-based regulatory agencies. Under Ms. Robinson's leadership, Micromattie Consulting Inc. serves as a guide and liaison to ensure that new therapeutic developments align with patient needs.



# Our Speakers



## DR. GAYLE ROGERS

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. In the ministry arena, her primary focus is equipping, coaching and training leaders to facilitate wholeness and healing, while carrying a Kingdom message to the nations. Dr. Gayle leads conferences nationally and internationally with a strong apostolic/prophetic and healing anointing.

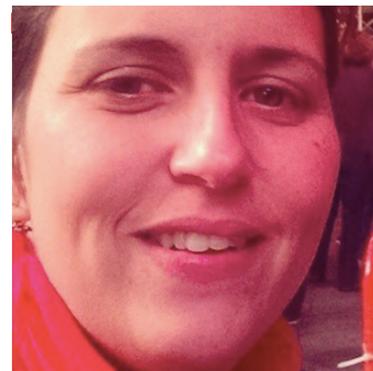
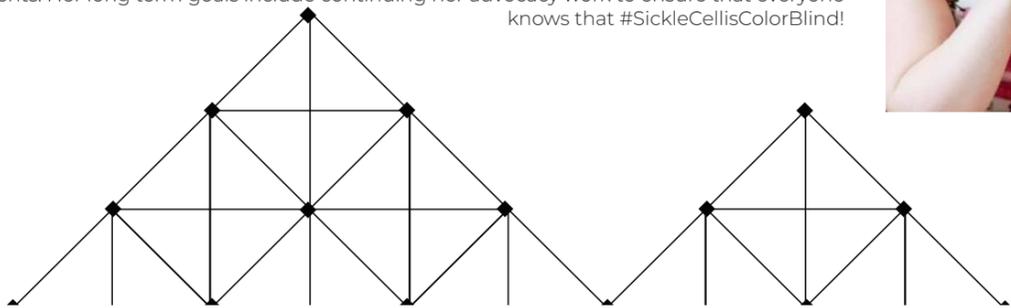
In addition to her worldwide traveling ministry activities, Dr. Rogers is a mental health professional with a Master's Degree in Psychology, and a Ph.D. in Women's Studies. Her focus is integrating a clinical therapeutic approach, using cognitive behavioral therapy and a spiritual discipline. Dr. Gayle's primary goal is to bridge the gap between spiritual and psychological modalities. Her clinical expertise includes post traumatic stress disorder, depression/anxiety issues, personality disorders, sexual trauma, and domestic violence. She focuses on mind/brain/body healing through her extensive training of how to practically change toxic thought patterns, ridding the body and mind of toxic emotional trauma. After years of scientific research, Dr. Gayle believes as much as 90 to 95% of illness is directly related to issues plaguing the mind. Her practice includes individual and group therapy, teleconferencing, and Skype/web-based therapy. She and her husband Ed of 35 years have three daughters and seven grandchildren. She has authored several books, including the most recent, *The Whole Soul-- Rescripting Your Life for Personal Transformation*. This book focuses on embracing your authentic identity, and changing mindsets with the authority to take control over negative thought patterns. Dr. Gayle is a Board Certified Pastoral Counselor through American Association of Christian Counselors, a certified "Train the Trainer" through the University of Oklahoma, and has previously been a certified clinical treatment specialist in both domestic violence and sexual offense.

Dr. Gayle is an apostolic/prophetic intercessor and serves as Consultant and Team Director with AIN, a professional marketplace intercessory group, serving clients in seven countries. In addition, she is a member of several ministry networks, including International Breakthrough Ministries, Dallas TX, & A.P.E.C.T. Network, Columbia SC. Dr. Gayle is a former Executive Council member of Kingdom Congressional International Alliance (KCIA), and International Society of Deliverance Ministers.

## SOPHIA ROSE

SC3 Kids Initiative

Sophia Rose is a rockstar 10 year old artist and speaker who just happens to also have Sickle Cell. She comes from a super fun family of 9 kiddos and she loves snuggling with her mom, who also happens to be her teacher. Sophia is the current program manager for the SC3 Kids Initiative, a national group of patients and family members ranging in age from 8-17. Their focus is on creating programs, solutions, and opportunities for pediatric patients, with a strong emphasis on those that are inpatient or in a longer day treatment/infusion setting. Sophia feels very passionate about inspiring other kids to speak up and speak out about their needs as pediatric patients. Her long term goals include continuing her advocacy work to ensure that everyone knows that #SickleCellisColorBlind!



## LISA ROSE

HOPE for SCD

Lisa Rose is the Executive Director for 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 including The University of Colorado Hospital, The Children's Hospital of Colorado, The National Circles Campaign and The National Long Term Care Ombudsman Program.

In addition, she has authored a book for newly diagnosed families entitled, "Sickle What?" which breaks down intense medical topics into Adult Learner friendly modules. Although her work with HOPE for SCD has reached international audiences within 157 countries, she continues to push national hospitals and organizations to focus on presenting educational materials in a way that meets both the needs of the audience while ensuring all necessary information is conveyed. Her current focus is on Adult Education and the gaps related to this within the medical field for patients and families. Lisa is also the mother of two children living with Sickle Cell- 10 year old Sophia and 5 month old John Patrick. Her children have been and will always be the driving motivation for Lisa and her work through HOPE for SCD.

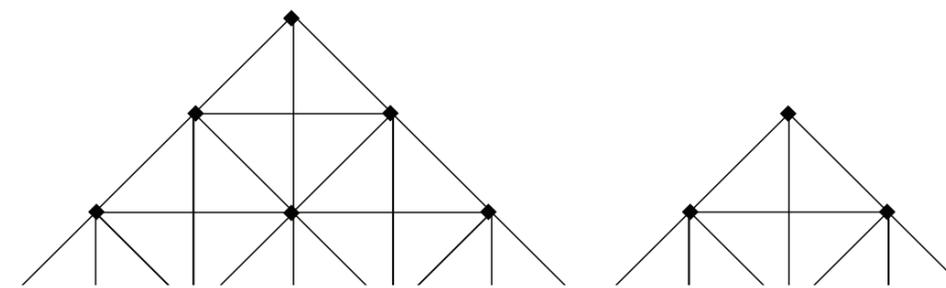
## NIA SUMPTER THOMAS

Nia graduated from Saint Louis University with a Bachelors of Arts in African American Studies and a minor in Medical Humanities. As a student, I served on the Student Government Association as the Senator for the College of Arts and Sciences. Before graduation, I was offered the distinguished position of being an AmeriCorps VISTA working along side Saint Louis University's Vice President of Diversity and Community Engagement and other faculty to develop and employ pragmatic solutions to increase equitable outcomes for SLU and the surrounding St. Louis community. I became a member of Sigma Gamma Rho Sorority Incorporated during the Spring of 2017. I am a board member for the Charles Drew Committee through the American Red Cross. I am an avid volunteer with the Sickle Cell Association of St. Louis. I was selected for the Kristina Jordan Sickle Cell Scholarship and awarded the Top Student Abstract Award in Public Policy from the Sickle Cell Disease Association of America. I alongside my committee members of Charles Drew Committee received the Spirit Award for our dedication to awareness for the need of diversity in blood donation in July 2018. I was selected to attend the Summer Anatomy Institute at Johns Hopkins and I was also chosen to attend the Focus on Your Future Summer Scholars Program with Illinois College of Optometry.



## KIDDIE KEEPERS

Kiddie Keepers come to your event to entertain the kids, while adults party in peace. We provide services for weddings, conventions, conferences and more!



# Our Speakers



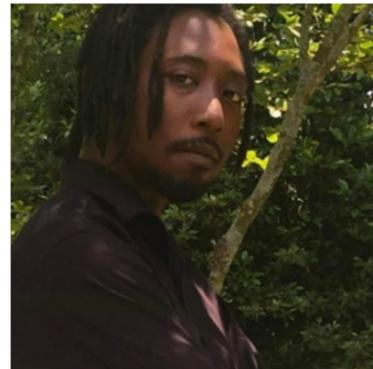
## LINDA THOMAS WADE

Marc Thomas Foundation

Linda Thomas Wade is the President, CEO and Co-Founder of the Sickle Cell Association of Texas Marc Thomas Foundation which started in 1997 by Marc Thomas, her late husband and Linda. Linda is a former United States Health and Human Services (Patient Advocate) Advisor on Blood Safety and Availability Committee in Washington, D.C. appointed under the Bush Administration and served one term under President Obama's Administration. Linda served several years on the Genetics Regional Mountain States Collaborative. In 2009, Linda had an exclusive White House Oval Office invitation where she met with former President Barack Obama in his first 100 days in office to discuss the challenges of sickle cell disease. She met with former Governor George W. Bush at the Governor's Mansion to discuss the state challenges of sickle cell disease. She was also invited to Imo State Nigeria, where she was hosted by the Government to educate about sickle cell disease, dispelling myths and misconceptions. Linda has served hundreds of clients by providing: certified hemoglobinopathy education to patients, patient advocacy, health care professional education, medical home placement, notified hundreds of parents that their newborn has sickle cell trait through the Texas Department of State Health Services Newborn Screening Program, Linda was instrumental in getting legislation passed for newborn sickle cell trait testing in the State of Texas. Linda has assisted and established partnerships and relationships with the City of Austin, City of Houston, Sickle Cell Houston Collaborative, Department of State Health Services, Austin Travis County Health and Human Services Department, SCDAA and HRSA among others. Linda currently oversees three office locations in Houston, San Antonio and Austin with 14 staff members and serves more than 750 sickle cell disease patients and their families through awareness, case management, education and support.

## CLAYTON ANDREWS

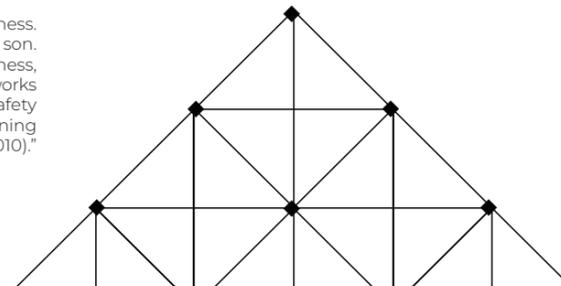
Sickle Cell Champions Association



Clayton Andrews is a 36-year-old patient with Sickle Cell Disease, residing in Augusta GA. An advocate, mentor and father of four, Clayton is an LAPC and graduate from Troy University with a Master of Science in Counseling and Psychology. His primary focus is the enablement and development of self-sufficiency, development and growth of mental health. Clayton is the Chair and co-founder of the Sickle Cell Champions Association, a mentoring organization geared and designed for the guidance and empowerment of young males with Sickle Cell Disease into their transition into adulthood. Additionally, he is helping to spearhead the overall Men's Initiative, Mans Action Network (MAN), which will place a more all-encompassing focus on the many facets and challenges that the Sickle Cell Male faces. Clayton's ultimate objective is to become a positive influence and mentor to his peers in the Sickle Cell Community and advocating for young males with this disease. Clayton has seven years of combined experience as a Child Protection Investigator and Child Advocacy Coordinator with the State of Georgia and an additional three years as a Forensic Behavioral Health Counselor and now Treatment Team Facilitator with the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD). He is accountable for providing guidance and facilitating behavioral health practice for clients facing criminal issues. He is currently in the process of obtaining his license as a counselor, as well as pursuing his

Doctorate to further expand his effectiveness.

Clayton is the proud father of three daughters, all of whom have Sickle Cell Trait and a 13 year-old son. Additionally, Clayton is certified in the Wellness Recovery Action Plan (WRAP) for mental health wellness, recovery and maintenance and is also a member of the Walden University Psi Chi Chapter. Clayton's works include his involvement in the S.C.C.A. "Mentoring Workshop" in August 2016, Panel Presentation of the "Safety Response System, Phase I" for Georgia Department of Human Services in 2013 and self-designed training presentation of "The Proper Acquisition and Assessment of Safety Resources in Child Protective Services (2010)."



## DOMINIQUE GOODSON

Dominique Goodson was born and raised in Newark, NJ. After graduating from Rutgers University with a degree in Sociology and Anthropology, Dominique began working as research assistant to professors at different universities. During one of her breaks between research projects, she worked as a Business Development Specialist at Eagle Detective Agency, where she worked to gain numerous contracts including the NFL Super Bowl NY/NJ 2014 contract. Dominique resigned from Eagle Detective Agency in 2014, to focus on her passions writing and advocating for Sickle Cell Anemia. Having Sickle Cell Anemia herself, Dominique works with many other Sickle Cell Community Based Organizations to help not only get information to people about Sickle Cell Anemia, but also to help Sickle Cell Anemia patients and caregivers. She has been using her social media platform Sickle Cell Disease Community Forum for the last year equipping, empowering and encouraging the community.

## SHAMONICA WIGGINS

Shamonica Wiggins is a 30-year-old sickle cell warrior and a native of Dallas, TX. Although she has sickle cell SS, which is commonly referred to as the most critical form of the illness, she rarely allows it to get in the way of her chasing her dreams. This is evident in the work she did as creator and former CEO of the non-profit organization, #BoldLipsForSickleCell. Shamonica was awarded the 2018 National Sickle Cell Advocate of the Year by Sickle Cell 101. Ms. Wiggins is a trailblazer in the sickle cell community and strives to be a voice of one, speaking for many. When she's not busy fulfilling her passion of spreading sickle cell awareness you can find her on the sidelines of the soccer field cheering on her 8-year-old daughter Roree. Shamonica prides herself as a mother and her daughter is a big reason why she refuses to give up. She hopes that her advocacy work leads to a big breakthrough for the sickle cell community and she's not going to stop being a voice for her people until she sees the changes that sickle cell warriors so desperately needs.



## MARLENE PETERS-LAWRENCE

Marlene Peters -Lawrence is a Clinical Trials Specialist in the Division of Blood Diseases and Resources, Blood (DBDR), Epidemiology and Clinical Therapeutics Branch at the National Heart Lung and Blood Institute (NHLBI). Ms. Peters-Lawrence has been with NIH for twenty years, and currently co-leads multicenter domestic and international sickle cell disease programs. She oversees' clinical studies management, community engagement outreach events, and evaluation of NHLBI funded projects.

Ms. Peters-Lawrence' commitment to caring for individuals with sickle cell disease stems from working as a Respiratory Therapist in critical care medicine and as a Research Nurse in the bone marrow transplant, hematology unit. Her passion for her work has been acknowledged by the numerous awards she has received over the years, including Nurse Chief Award for Exemplary Clinical Research, NHLBI Director's Award for Diversity in Population Recruitment and the Excellence in Mentorship award. Marlene, is the stakeholder, engagement and outreach specialist for the Blood Division and serves as Co-chair of The Department of Health and Human Services, Sickle Cell Stakeholder Engagement Workgroup in the Office of Minority Health, Office of the Assistant Secretary of Health. She is a member of the American Nurse Association and is passionate about finding strategies to increase minority participation in clinical research.

Ms. Peters-Lawrence received her Bachelor of Science in Nursing from Jacksonville University and a Cardiopulmonary Science degree from Valencia College. She is currently pursuing her graduate degree in education and business administration.



# Our Speakers



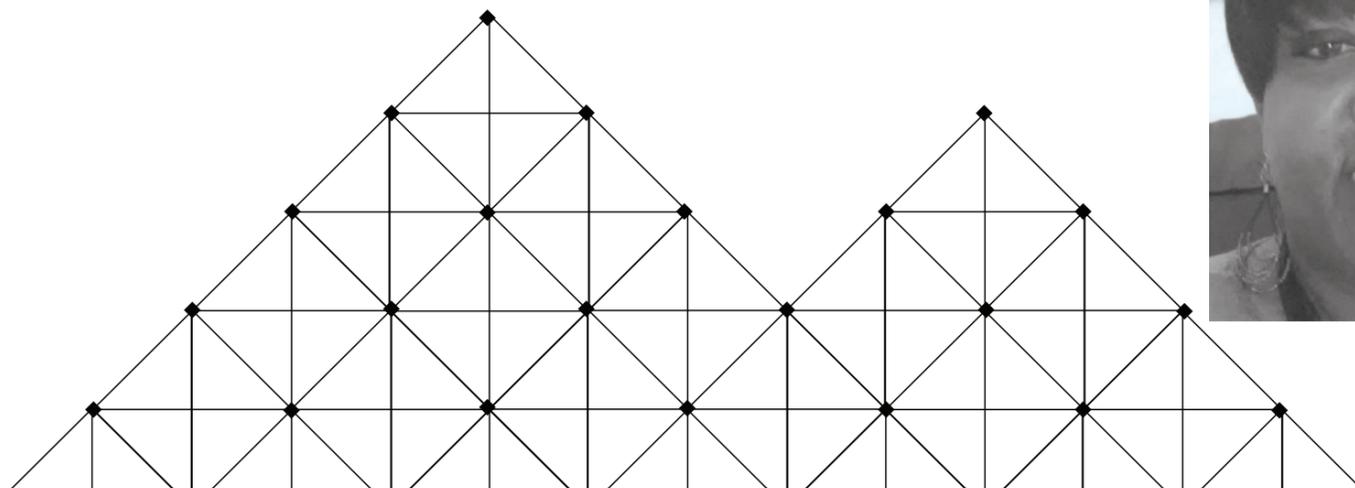
## DR. LYDIA H. PECKER

Lydia H. Pecker is the Director of the Young Adult Clinic at the Sickle Cell Center for Adults at Johns Hopkins in Baltimore, Maryland. Dr. Pecker is a Brooklyn native, and trained in the Bronx and Washington D.C. before settling in Baltimore. Dr. Pecker is supported by awards from the American Society of Hematology, the Johns Hopkins Building Interdisciplinary Research Careers in Women's Health program and the National Institutes of Health to study fertility and reproductive intentions in girls and women with sickle cell disease. She hopes this work will help provide more concrete information to girls and women with sickle cell disease as they make consequential reproductive- and treatment-decisions.

### MORE SPEAKERS

- SHAMAINE BOSWELL
- MAXINE COLLARD
- BENJAMIN MORALES
- ISAAC ODAME
- PHILIP OWKO
- DR. TERRY
- KRISTINA WARD
- DR WANDA WHITNEY-SHIRNEY
- DEMETRIOUS WYANT

- BRITTANY CLERKLEY
- T. MONDORO
- DR. ALICIA NERO
- JANET OLA
- TONYA PRINCE
- COREY WARD
- SICKLE CELL WARRIORS, INC.
- TAMARA WILSON



# Our Staff



## DORIS BAILEY, MFIN

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.

## 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.



## KIMBERLY M. 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 faced by those fighting the battle 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, including her 12 year old niece. She seeks to inspire and provide hope for all of those who battle daily with this egregious disease. Kimberly is committed to the idea of being the change that she wants to see.

# Our Staff



## RAYMONA LAWRENCE, DPH, MPH, MCHES

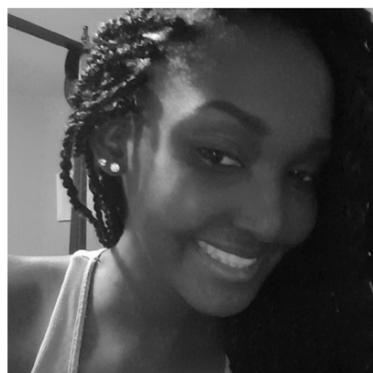
### DIRECTOR OF RESEARCH

Dr. Raymona H. Lawrence is an Associate Professor of Community Health Behavior and Education in the Jiann Ping Hsu College of Public Health at Georgia Southern University. Her main research focus is community engagement in rural, hard to reach populations-especially those with Sickle Cell Disease. Her approach to research is primarily qualitative. Dr. Lawrence has been an investigator on numerous rural health and sickle cell disease-related grants. Dr. Lawrence is currently a dual principal investigator with Dr. Ify Osunkwo on a \$9.7 million Patient Centered Outcomes Research Institute (PCORI) grant entitled, Comparative effectiveness of peer mentoring versus structured education based transition programming for the management of care transitions in emerging adults with sickle cell disease. Dr. Lawrence also serves as the Director of Research for the Sickle Cell Community Consortium and as the Editor in Chief for the Journal of the Georgia Public Health Association.

## ALEXIS WARDLOW-PERRY

### PROGRAMS MANAGER

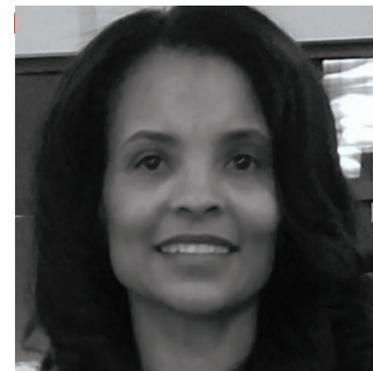
Alexis J. W. Perry is a 25 year old young adult, living in Los Angeles, California that was diagnosed with Sickle Cell SS at birth. She has been dealing with many health issues since, including being diagnosed with 2 other chronic disorders. After high school, Alexis decided to follow her passion and attend Culinary school, and went on to graduate with honors. Shortly after working for stars in Hollywood, CA, she became an online E-Nutritionist, helping other individuals manage their chronic disorders through balanced dieting. She now works with the Sickle Cell Consortium as the Director of Programs, working on projects and initiatives to benefit the Sickle Cell Community as a whole.



## NIKKI PETERSON

### SPECIAL EDUCATION SERVICES

Nikki Peterson is a sickle cell warrior living in Princess Anne, Maryland. Nikki has a bachelors degree from Bennett College in Special Education and a masters degree in School Administration and in Special Education from University of North Carolina A&T. She is certified to teach all subjects and areas of special education from Birth to the twelfth grade. Nikki is the founder and CEO of Tutor's-R-Us. Tutor's-R-Us was created originally just as a tutoring company. Currently Tutor's-R and Us helps students and their parents with homework, with creating 504 plans and IEP's, and advocating for them in the classrooms, school systems and in the court rooms when needed. They also educated the parents on what 504 plans and IEP's are and what IDEA is and the laws of special education and the importance of having their child identified as a person with special needs. Nikki has been with consortium since the idea of a patient ran non-profit organization was a dream on Dr. Lakeia Bailey. Currently Nikki serves as special projects manager and as the educational specialist and liaison.



## JANEEN GREENE

### EVENTS COORDINATOR

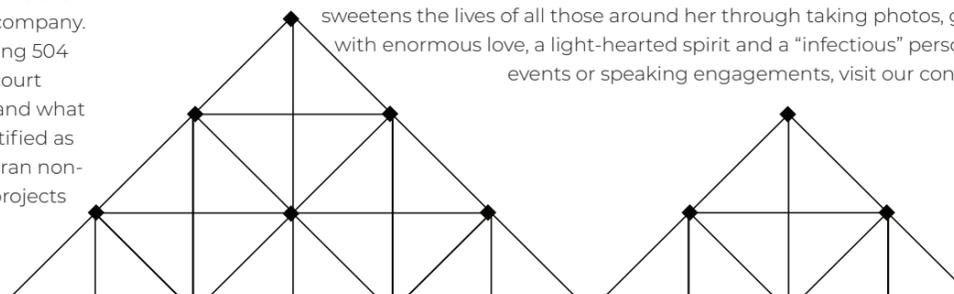
A 28year career in the flight industry Janeen is grateful to have survived 9/11/2001 and a company merger. Janeen is even more Thankful that God has enabled her to work and raise a family through it all. Skilled in safety and systems negotiation Janeen has developed a discerning ability to assess situations and people and carefully guide the space where thy intersect. She is also First Aid and CPR certified and has a Federal Aviation Administration Security clearance.

Janeen is living with Sickle Cell Thalassemia disorder. Two of her children also carry the sickle trait. At 2 years old she began to fall and always wanting to be carried,what many thought was spoiled turned out to be Sickle Cell. After years of flare-ups and hospitalizations, this diagnosis was finally confirmed for her while a 19year old college student living in a dormitory. It was God's grace that a Mediterranean physician recognized the symptoms and knew which medical test to order. Grace again. Janeen is a member of the Sickle Cell Community Consortium under the leadership of Dr. LaKiea Bailey. She has represented the Consortium and provided information in her local community as well as on Capital Hill. Janeen says an "ounce of prevention is worth a pound of cure". She tells everyone as soon as you meet a potential partner, asks what's their sickle cell status. If they have the trait and you have the trait you can only be friends for life.

## SHARONDA HUDSON

### MEDIA & MARKETING MANAGER

Sharonda Hudson is the Founder and Lead Advocate at The Red Chair Project. Founded in February of 2014, the organization provides Support, Education and Empowerment for Sickle Cell Warriors, their families and their communities. Through her work with The Red Chair Project, Sharonda received the 2015 Philanthropy Award from DFW Teen Fashion Week. She also hosts concerts, photo shoots and other "projects" to continue to forward the movement for Sickle Cell awareness. A photographer by trade, Sharonda learned her craft organically and almost by chance. After an unexpected layoff from her job, Sharonda began taking pictures of her nephews both to help her sister capture those first precious years and as a personal form of therapy. Over time, she developed quite an eye for taking quality photos and began volunteering and apprenticing under other photographers to continue to develop her skills. Some of her clients have included gospel artists such as Candy West, Kirisma Evans, JaRa' & The Lineage, Cedric Rives and BET "Sunday's Best" Winner, Amber Bullock. She has shot photos for magazine publishers Be You! Girl Magazine and Elisia Magazine as well as nonprofits The Society of Women Who Love Shoes and Minnie's Food Pantry. Singer, actor and personal friend Cedric Rives once nicknamed her "Cupcake" because Sharonda was "the sweetest person he'd ever met." True to her name, Sharonda "Cupcake" Sikes sweetens the lives of all those around her through taking photos, giving back and living every day with enormous love, a light-hearted spirit and a "infectious" personality. For sickle cell awareness events or speaking engagements, visit our contact page here [trcpcinfo@gmail.com](mailto:trcpcinfo@gmail.com).



# Our Staff



## MARIA RIVERA

### SPECIAL PROJECTS COORDINATOR

Maria Elena Rivera is a caregiver living in California, working as an Administrative Assistant for the Sickle Cell Community Consortium, and she became involved after being a caregiver to a daughter with Sickle Cell Disease. Her daughter is a 25 year old patient, who is currently undergoing the bone marrow transplant process. Maria is deeply passionate about raising awareness for sickle cell disease and being a supportive caregiver to her daughter as well as to other caregivers. Both my daughter and I love to help out the Sickle Cell Community Consortium in any way that we can. Maria has helped the Consortium by managing the registration tables at their various events, helping with any Spanish translations that may have been needing, and helping Dr. Lakeia Bailey with any requests. Maria is always inspired to help and work with the Sickle Cell Community and the Consortium, in raising awareness for sickle cell disease, and to help improve the lives of Sickle Cell warriors and other Caregivers.

## YOLANDA LEWIS

### WEBSITE MAINTENANCE

Yolanda Lewis is an advocate at heart who uses her diverse background to minister, mentor and educate within her multiple spheres of influence. Her heart for people extends into a role as a mentor mom for an international organization, as well as providing one-on-one encouragement to those experiencing transitions in life. Yolanda's advocacy is really on display within the Sickle Cell Disease community. Yolanda has created a series of educational videos for Conquerors. Yolanda is currently providing web content update support, social media presence (Parent 2 Parent Initiative) and limited administrative support to the Sickle Cell Consortium. As a wife, mother of four, and caregiver of a child with SCD, Yolanda stays very busy by volunteering. Yolanda believes that by advocating on behalf of others, the connection between care providers and caregivers is the key to sustained positive care.



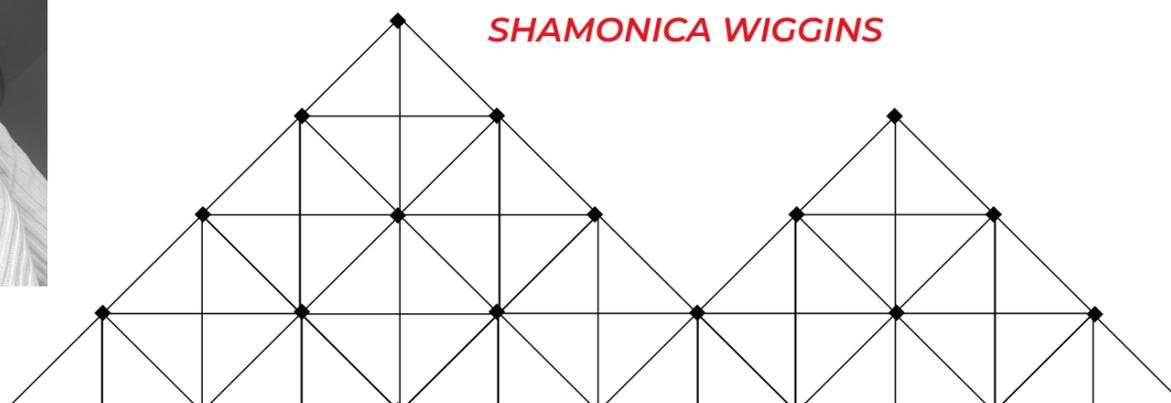
## SHAYLA WALKER

### EXECUTIVE ASSISTANT

## DR. LAKEIA BAILEY

### PRESIDENT

## SHAMONICA WIGGINS



# Sickle cell disease has MET ITS MATCH.

**Sickle cell disease can be cured** by a blood or marrow transplant. Our Patient Support Center can help answer your questions about sickle cell disease, transplant as a treatment option and connect you with another SCD patient through our *Peer Connect* program.

Visit [BeTheMatch.org/SCD](https://BeTheMatch.org/SCD) to learn more  
OR call **1 (888) 999-6743**  
to contact our Patient Support Center.



# Sickle Cell Anthology

## **BREAKING THE STIGMA**

We are seeking narratives that highlight the sickle cell warriors and caregivers experience. What challenges have you faced with sickle cell disease?

### Eligible Submissions

Poetry

Visual Art (PDF Format)

Personal Narratives

Essays (300 - 2000 word count)

Individuals may submit up to three pieces in any genre contained within a Microsoft Word Document. Please include a short bio along with your submission

Submit Works To  
[sicklecellanthology@gmail.com](mailto:sicklecellanthology@gmail.com)

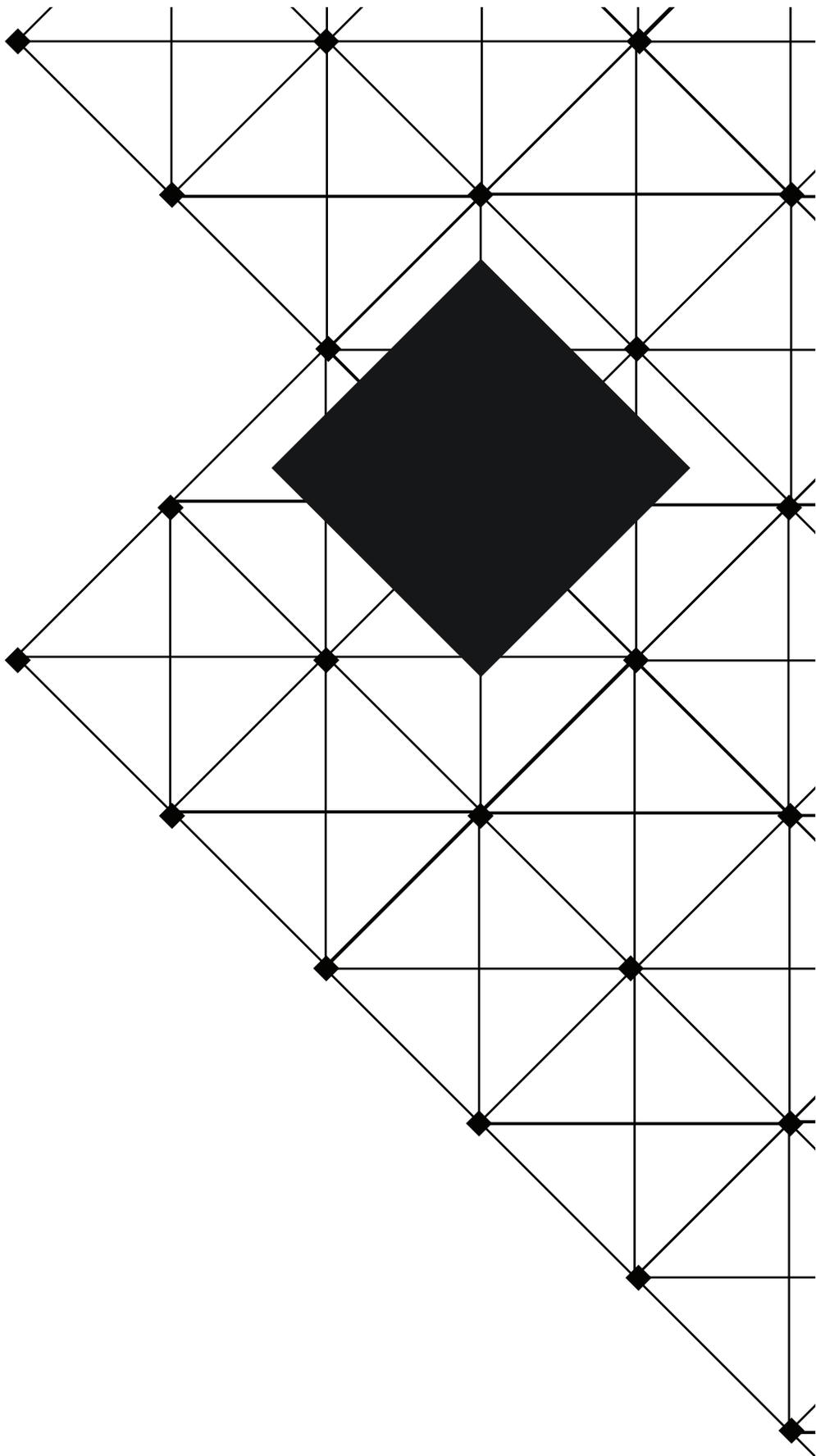
**Deadline: September 29, 2019**

Powered By: The Sickle Cell Consortium

We proudly support the great work of our partners at the Sickle Cell Consortium and the 6<sup>th</sup> Annual Patient and Family Education Symposium



Dedicated to Helping Patients with Sickle Cell Disease



# CONTACT US



**Sickle Cell Community  
Consortium**

135 Auburn Ave.  
Atlanta, GA 30303  
706.204.9269

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