SICKLE CELL COMMUNITY CONSORTIUM

5TH ANNUAL LEADERSHIP SUMMIT

10-13 JUNE 2020

& General Assembly of Patients, Caregivers, & CBOs
Welcome to the 5th Annual Leadership Summit & General Assembly of Patients Caregivers & CBOs
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ABOUT SICKLE CELL COMMUNITY CONSORTIUM

WHO WE ARE

The Sickle Cell Community Consortium is a US-based non-profit formed in 2014 to “harness and amplify the power of the patient voice”. The Consortium is comprised of sickle cell community-based organizations (CBOs), patient and caregiver advocates, community partners and medical and research advisers. These stakeholders collectively form the General Assembly of CBOs and Advocates, the decision-making body of the Consortium. The Consortium acts as an organizing entity providing the framework for the stakeholders of the General Assembly to apply a model of Collective Impact to define problems and gaps in the sickle cell community, identify strategies to address those needs and gaps, and determine the CBO, Community, and Corporate partnerships best equipped to implement those strategies to achieve significant and sustainable change.
HISTORY

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

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

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

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

ORGANIZATION

The Consortium is organized in a manner similar to the United Nations. The General Assembly of CBOs is the decision-making body of the Consortium. It is this group that applies the model of Collective Impact to collectively identify the problems, needs and gaps in the sickle cell consortium; develop creative, collaborative solutions to these problems; and then form partnerships to execute these solutions. Committees and project managers that will then execute these solutions are determined during our annual General Assembly of CBOs. This meeting occurs every March in Atlanta, Georgia. The president of the General Assembly is elected for a two-year term. This person also sits on the Board of Directors during their term. The Board person acts as oversight for their specific area.
THANK YOU
GOLD SPONSOR

Your support enables the opportunity to raise awareness globally. THANK YOU!
RECENT PUBLICATIONS

BLOOD AND MARROW TRANSPLANT (BMT) FOR SICKLE CELL DISEASE

SICKLE CELL AND SCHOOL
A Guide to School Policy and Best Practices
Wednesday, June 10
» Reception
» Digital Engagement Hall

Thursday, June 11
» Community Engagement
» Welcome
» Opening Plenary
» Exhibit Booths
» Community Engagement
» Afternoon Plenary
» CBO & IPCA Session 1
» CBO & IPCA Session 2

Friday, June 12
» Community Engagement
» General Session
» Morning Plenary
» Exhibit Booths
» Community Engagement
» General Session
» CBO & IPCA Session 3
» CBO & IPCA Session 4

Saturday, June 13
» Community Engagement
» Digital Engagement Hall
» General Sessions
» Mental Health Initiative
» SC3 Kids
» Warrior University & Patient-Powered Resources
» SC Anthology
» ED Initiative
» Education Support
» Research
» Diversity
» Aging
» Closing Remarks

» GRADUATION

Sunday, June 14

» GRADUATION

All sessions are digital.
Meet The Founder

Dr. Lakiea Bailey

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 Reagents 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.
Doris Bailey earned her B. S. and 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.

DORIS BAILEY
ASSOC. DIRECTOR OF FINANCE

Eric Frempong is the Director of Finance for the Sickle Cell Community Consortium. Eric Frempong serves as the president of a professional firm specializing in individual income tax preparation and planning. Mr. Frempong prepares S-Corporation financial statements and income taxes.

ERIC FREMPONG
DIRECTOR OF FINANCE

Dominique Friend is an activist for Sickle Cell Disease awareness and research who currently resides in Georgia, but who grew up in Baltimore, Maryland and attended Baltimore City Public Schools. She is a mother of three wonderful children and has one beautiful granddaughter. Although her illness prevented her from graduating high school, she obtained her GED and then completed post-secondary courses in Creative Writing. Now a published author, Dominique has captured the essence of her daily struggles with the unpredictability and pain of Sickle Cell Disease in her autobiography, SICKLE, A Story of Pain, Purpose and Perseverance. Dominique’s story was written in another book entitled Uncommon Challenges; Shared Journeys. She has become an activist who is raising awareness of Sickle Cell Disease and advocating for improved treatment for people living with Sickle Cell Disease. She is the founder of the Sickles International Family Coalition, an international network of families, individuals and organizations.

DOMINIQUE FRIEND
GENERAL ASSEMBLY PRESIDENT
Meet The Staff & Board

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, 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.

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 19 year 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!
Meet The Staff & Board

Tynisha Hall was born and raised in Birmingham, Alabama and resides in Atlanta, Ga. Tynisha is a graduate and proud alumna 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. She is a mentor to girls with sickle cell disease throughout the country, and supports families of children with sickle cell. One of her biggest prides was 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.”

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.

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.
Maria Rivera has been a caregiver for over 25 years. She has volunteered her time to the SCCC for the last 5 years, advocating for Sickle Cell Warriors and Caregivers, and helping the Consortium with different projects, initiatives and events. She continues to strive to make a better life for all Sickle Cell Warriors and lend her bubbly, warmhearted spirit and helping hand to all in need. During the COVID-19 pandemic she volunteered donating her time and money to create masks for different CBO’S, partners, warriors, caregivers and their relatives.

Sharonda Sikes 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. 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.
Meet The Staff & Board

ALEXIS WARDLOW-PERRY
SPECIAL PROJECTS MANAGER

Alexis J. W. Perry is a 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.

SHAMONICA WIGGINS
MEDIA INTERN

Shamonica Wiggins is a 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. She created and is now the 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.

SHELFINA WILKINS
PARTNERS COMMUNICATION LIAISON

As the spouse of a person with sickle cell disease, I was a caregiver, sickle cell advocate, and care coordinator for my husband, Warren. During that time, he was on chronic transfusions, experienced iron overload, congestive heart failure, avascular necrosis, acute chest syndrome, renal failure, and end organ damage. I was his case manager, care coordinator, and emotional barometer. When Warren was placed in hospice, the depression and mental strain was almost unbearable, but it gave me a unique perspective into the all aspects of caring for a person with sickle cell disease; the stigma, the stereotypes, the inadequacy of the emergency room, the bias of healthcare professionals, and the lack of education of employers and the public. While, it was something I would not wish on anyone, it gave me a firm foundation as a sickle cell advocate and has allowed me to help others with the disease.
Nikki Peterson was a sickle cell warrior living in Princess Anne, Maryland. Nikki had a bachelor’s degree from Bennett College in Special Education and a master’s degree in School Administration and in Special Education from University of North Carolina A&T. She was certified to teach all subjects and areas of special education from Birth to the twelfth grade. Nikki was 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 had been with consortium since the idea of a patient ran non-profit organization was a dream on Dr. Lakia Bailey. Nikki served as special projects manager and as the educational specialist and liaison.
Knowing my numbers helps me take care of myself.

Hear our stories and learn more at sicklecellspeaks.com
Agenda
Wednesday & Thursday
June 10 - 11, 2020

WEDNESDAY

2:00 PM - 6:00 PM
DIGITAL ENGAGEMENT HALL

4:00 PM - 6:00 PM
DIGITAL OPENING RECEPTION
Princess Walls & DeMitrious Wyant

THURSDAY

10:00 AM - 10:30 AM
COMMUNITY ENGAGEMENT ACTIVITIES

10:30 AM - 11:00 AM
WELCOME – Dr. Lakiea Bailey

11:00 AM - 11:55
MORNING PLENARY WITH CRISPR/VERTEX
Sandeep Soni

12:00 PM - 2:00 PM
DIGITAL ENGAGEMENT HALL

1:30 PM - 1:50 PM
COMMUNITY ENGAGEMENT ACTIVITIES

2:00 PM - 2:50 PM
AFTERNOON PLENARY WITH NOVARTIS
Savita Nandal, MD
Jincy Paulose
Laurie Debonnette

3:00 PM - 3:30PM
BREAKOUT #1 - CBO WORKSHOP
Developing your research advisory board
Speaker: Georgene Glass

BREAKOUT #1 - EXPERT ADVOCATE WORKSHOP
The Art of Expert Patient Advocacy
Speaker: Shamonica Wiggins

3:30 PM - 4:00 PM
BREAKOUT #2 - CBO WORKSHOP
Digital Techniques for CBO Branding & Self-Promotion
Speaker: Patricia Wilson-Smith

BREAKOUT #2 - EXPERT ADVOCATE WORKSHOP
Growing Your Advocacy Resume
Speaker: Heather Avant

*THIS SCHEDULE IS SET ACCORDING TO EASTERN STANDARD TIME
Novartis proudly joins Sickle Cell Consortium and the 5th Annual Leadership Summit & General Assembly of Patients, Caregivers and CBO’s.

Your dedication to helping patients with Sickle Cell is applauded.

At Novartis, our mission is to discover new ways to improve and extend people’s lives. We use science-based innovation to address some of society’s most challenging health care issues. We discover and develop breakthrough treatments and find new ways to deliver them to as many people as possible.

We are passionate about what we do and the impact we have on society, especially patients, including those living with Sickle Cell. We are Novartis, and we are reimagining medicine.
CRISPR and Vertex are proud to support the Sickle Cell Community Consortium’s 5th Annual Sickle Cell Leadership Summit & General Assembly
Agenda

Friday

June 12, 2020

10:00 AM
COMMUNITY ENGAGEMENT ACTIVITIES

10:30 AM
GENERAL SESSION
Sickle Cell Travel
Speaker: Dr. Coretta Jenerette

11:00 AM
OPENING OF THE 5TH GENERAL ASSEMBLY OF
PATIENTS, CAREGIVER, & COMMUNITY
BASED ORGANIZATIONS
Dr. Lakiea Bailey

12:00 PM - 2:00PM
DIGITAL ENGAGEMENT HALL

1:30 PM
COMMUNITY ENGAGEMENT ACTIVITIES

2:00 PM
AFTERNOON PLENARY WITH GLOBAL BLOOD
THERAPEUTICS (GBT)
Dr. Ken Bridges

3:00 PM - 3:30 PM
BREAKOUT #3 - EXPERT ADVOCATE WORKSHOP
Race, Class, and Healthcare in America
Speaker: Dr. C. Chic Smith

3:00 PM - 3:30 PM
BREAKOUT #3 - SC3 KIDS
Speakers: Lisa Rose/Sophia Rose

3:30 PM - 4:00 PM
BREAKOUT #4 - CBO WORKSHOP
Guiding the direction of Community-Engaged Sickle
Cell Research (COMPASS)
Speaker: Dr. Raymona Lawrence

*THIS SCHEDULE IS SET ACCORDING TO EASTERN STANDARD TIME*
Agenda
Saturday & Sunday
June 13 -14 2020

SATURDAY

10:00 AM
COMMUNITY ENGAGEMENT ACTIVITIES

10:00 AM - 3:00PM
DIGITAL ENGAGEMENT HALL

10:30 AM - 11:00 AM
GENERAL SESSION: EDSC3
Emergency Department Sickle Cell Care Coalition
Dr. Patricia Kavanagh & Dr. Caroline Freiermuth

11:00 AM - 11:15 AM
GENERAL SESSION: CURESCI
Dr. Edward Benz

GENERAL ASSEMBLY OF PATIENTS, CAREGIVERS, & CBOS

The General Assembly is the decision-making body of the Consortium and is made up of credentialed CBOs, sponsored patient groups, patient and caregiver advocates, community partners and medical/research advisers. This group meets annually to apply the framework of Collective Impact to DEFINE and PRIORITIZE the top needs, gaps and problems within the sickle cell community, and then collectively DEVELOP and EXECUTE patient-powered solutions to these community-identified concerns. Working in partnership with community partners and healthcare/research advisers, patients and caregivers lead the teams dedicated to tackling each priority.

Join us for a review of a few of the active community-led and prioritized projects, platforms, and initiatives.

SC3 KIDS SCHOLARS - Sophia Rose
MENTAL HEALTH - Clayton Andrews

CLOSING REMARKS
CLASS OF 2020 GRADUATION!!!
4:00 PM - Kindergarten/6th/8th Grade
6:00 PM - High School

SUNDAY

4:00 PM - College & Beyond Commencement

*THIS SCHEDULE IS SET ACCORDING TO EASTERN STANDARD TIME
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.
MEET OUR SPEAKERS

CLAYTON ANDREWS
Speaker

Clayton Andrews is a 35-year-old Sickle Cell Warrior, husband, and father of four residing in Augusta GA. Clayton is the Chair and co-founder of the Sickle Cell Champions Association (SCCA), a mentoring organization geared and designed for the guidance and empowerment of young males with SCD for their transition into adulthood. Since graduating Troy University with a Master of Science in Counseling and Psychology, his primary focus has been to sustain and develop the self-sufficiency of mental health. Clayton’s ultimate objective is to become a positive influence and mentor to his peers in the SC Community, and advocating for young males with this disease.

HEATHER AVANT
Speaker

Heather is a sickle cell warrior, sickle cell advocate, photographer, painter, crafter, and all around do-it-yourselfer thriving in Dallas, Texas with her husband Jason and three-year-old 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.

She is currently, the Chairperson for the Community Input Panel for the NHLBI Cure Sickle Cell Initiative. Heather also serves as a mentor to young women living with sickle cell. Her newest project is 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.
Edward J. Benz Jr., MD is the President and CEO Emeritus at Dana-Farber Cancer Institute and the Richard and Susan Smith Distinguished Professor of Medicine, Genetics, and Pediatrics at Harvard Medical School. Dr. Benz began his faculty career at Yale University in 1979, rising to the rank of Professor of Medicine and Human Genetics in 1987. He served as Chief of the Hematology Section and Vice Chair of the Department of Internal Medicine from 1987-1993, after which he served as the Jack D. Meyers Professor and Chair of the Department of Medicine at the University of Pittsburgh (1993-1995) and Sir William Osler Professor, Director of the Department of Medicine and Physician in Chief at Johns Hopkins University (1995-2000). He was President of Dana-Farber from 2000-2016. Dr. Benz is an internationally recognized hematologist who is an active National Institutes of Health-funded Investigator. He is an expert in inherited anemias. His laboratory studies focus on the molecular regulation and functions of membrane cytoskeletal proteins that were originally discovered in the red blood cell. He has authored more than 300 peer reviewed articles, reviews, chapters, and abstracts. He is Co-editor of “Hematology: Principles and Practice,” which received the First Place Award for Textbooks from the British Medical Journal and of the “Oxford Textbook of Medicine,” for which he and his colleagues received the Royal Society of Authors Textbook Award. He was an Associate Editor of the New England Journal of Medicine from 2002 – 2016. He currently serves as the Executive Director of the NIH sponsored Cure Sickle Cell Initiative.

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.
MEET OUR SPEAKERS

Georgene Glass is the Founder/Executive Director at Dreamsickle Kids Foundation, the 1st SCD organization in Nevada, created in 2018. She is also a Certified Community Health worker in Nevada with a BS in Criminal Justice, and a Community Manager for a new application created specifically for SCD patients. The mother of two, Raven, her oldest and her youngest daughter Gia, who has Sickle Cell Disease (SS) are inseparable. Frustrated with the lack of Awareness and quality medical treatment for people in Nevada affected by SCD, she created Dreamsickle Kids Foundation to support children and families impacted by this rare Disease. Since the creation of Dreamsickle Kids in 2018, she has been apart of getting the 1st SCD bill in Nevada passed AB254, she has also testified in support of lowering medication cost in NV. In 2019, Georgene was awarded the Community Advocate of the year by Sickle Cell 101 and was appointed the Rare Ambassador for the state of NV to advocate for all rare disease communities in the state and nationwide. The goal is to #MakeSickleCellPopular through awareness events and campaigns and also inspire those parents to make the changes they long for by showing them no matter their background or where they are they can make changes to help their loved ones and others. Her children’s book about Sickle Cell Disease is set to be released in September for Sickle Cell Awareness Month.

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

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!
MEET OUR SPEAKERS

Patricia Wilson-Smith is an author, technology executive, educator, and the President and CEO of Online Media Interactive, LLC, a local technology consulting firm and digital marketing agency, and has over 20 years of experience in delivering technology solutions for a variety of industries. She earned a Bachelor’s in Computer Information Systems from DeVry University, and later a Master’s of Information Technology from Southern Polytechnic State University, where she earned a 4.0 GPA and was honored as “One of The Outstanding Women of SPSU”, and “Graduate Student of the Year” in 2003.

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

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 cliche, 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.
Barbara Jean Wilson served as an Executive Coordinator in the Legal Division of Freddie Mac for fifteen (15) years and retired on March 31, 2020.


Barbara has been featured as guest speaker at numerous events across the U.S. to include the United Nations. These events focus heavily on bringing awareness to the challenges of human trafficking, sexual, physical and mental abuse, and the overwhelming impact of the individual and to the community.

In addition to receiving numerous awards for her hard work and dedication at Freddie Mac, Barbara was nominated as Woman of the Year by the Women’s Interactive Network (WIN). During this event, Barbara was a featured panelist along with the Prince William County Chief of Police, to discuss Human Trafficking and Sexual abuse.

DeMitrious Wyant is a patient/advocate from Des Moines IA, who currently resides in Orlando FL. DeMitrious has Sickle Cell Disease type SS and has battled with the disease his whole life. Despite being in and out of the hospital with countless surgeries and blood transfusions, DeMitrious is a business owner and operator of YOUNG BLACK AND TALENTED LLC. With special services as a Personal Chef and Catering with “Your Best Taste Catering” in Orlando FL. DeMitrious is a man of many talents; with music in rotation on ITunes, Apple Music, Spotify, and Amazon, expressing his life with Sickle Cell.

Mr. Wyant also has an educational documentary on his battle with Priapism (a symptom in males caused by sickle cell) on YouTube titled “A Day In The Life Of A Sickle Cell Souljah: Priapism Edition”. DeMitrious plans to continue to be a voice for Sickle Cell and educate the world on the disease, while encouraging his fellow warriors to take care of themselves and keep fighting! “Pray without ceasing and have Faith, I Swear that’s all it takes. Never Give Up!” -SCSouljah

#SouljahStrong#Sickletember
Dr. Zaidi is a classical hematologist who cares for chronic and acquired hemolytic anemias, and hemoglobinopathies, primarily, sickle cell disease (SCD). His research interests are focused on the intersection of technology and disease, as well as on healthcare outcomes and novel biomarker development. He is also a tireless advocate for sickle cell disease and firmly believes that advocacy and patient education can be achieved using social media as a tool to interact with patients and physicians.

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.
Translational Research: pre-clinical development of cell/gene therapy trials, vector development, large scale manufacturing of gene-modified human stem cells, gene-editing using Crispr-Cas9, safety-monitoring, pharmacovigilance, CD34+ selection, design and conduct of Phase I clinical trials according to GCP standards, IND process and interactions with regulatory bodies (FDA, EMA).

Clinical: 16 years’ experience in management of patients undergoing SCT, with focus on hemoglobinopathies and bone marrow failure as niche areas of expertise. Recipient of many awards for compassionate care. Experienced in design, management and regulatory requirements for multi-center gene and cell therapy trials and Phase I studies. Well acquainted with immune effector cell therapies, and alternative donor HSCT options (cord blood, alpha/beta depleted haplo-identical transplants).

Organizational Roles: Involved in ASTCT, ISCT and FACT for immune effector cell and gene-therapy policymaking committees. Current co-chair of ISCT immune cell and gene therapy committee. COG Y1 mentor-mentee program participant (mentor 2006-2013); ISCT Early Stage Professional Mentorship Program (2018-current); mentor for junior faculty for cell/gene therapy clinical trials. ISCT 2020 Conference Organizing committee.

I am a Pediatrician and attended Medical School at University of Illinois and completed my Pediatric residency training at Rush Presbyterian St. Luke’s Medical Center in Chicago during which time I had the privilege of treating Sickle Cell Disease patients and developed a passion for working with these patients. I practiced General Pediatrics in the Chicago area for 10 years prior to joining Novartis in 2002 as part of the Respiratory/Dermatology field medical team working as a Medical Science Liaison.

In 2007 I relocated to East Hanover as Medical Director in US Medical Affairs continuing to work in Respiratory/Dermatology and subsequently moved to Global Development.

I have been working in Global Medical Affairs for 3 years, as Global Medical Director in sickle cell disease and have the pleasure of working with physicians, patients and colleagues in many countries including US, Europe, the Middle East and Sub Saharan and South Africa.
MEET OUR SPEAKERS

SAVITA NANDAL, MD
Novartis
Speaker

Savita is MD with more than 15 years of experience in academia and industry. She worked as principal investigator for multiple studies in early phase unit and worked as Head of clinical affairs with Johnson & Johnson until 2011. Subsequently, she joined as Medical Director in academic setting for the collaboration of Duke University- North Carolina. She joined Novartis in 2013 and is presently Executive Medical Director for Sickle cell disease in United States.

JINCY PAULOSE
Novartis
Speaker

Jincy Paulose is currently the Medical Director for the Iron Overload and Sickle Cell Disease program in US Medical and supports the Benign Hematology Integrated Disease Management Team (IDMT).

Jincy has over 10 years in various positions in the pharmaceutical industry, including Safety and Medical Information. Jincy’s contributions in her roles have resulted in successful innovative activities for HCP engagement, and clinical trial recruitments such as Oncology Medical Information (oMI) On-Demand, and utilization of virtual reality (VR) as a platform for education.

Jincy earned her Doctor of Medicine degree (M.D.) from Saint James School of Medicine.
Sickle cell disease (SCD), while considered a rare disease, is the most common genetic blood disorder and affects approximately 100,000 Americans, primarily of African and Hispanic descent. Individuals with SCD can experience multiple life-threatening problems during their lifetime. Much of their acute care is delivered in the emergency department (ED), yet patients often relate poor experiences in this setting. In recognition of the need to improve the care offered to patients with SCD in the ED, the American College of Emergency Physicians in collaboration with multiple public, private and professional partners have created the Emergency Department Sickle Cell Care Coalition (EDSC3). Its purpose is to provide a national forum dedicated to the improvement of the emergency care of patients with SCD in the United States. The EDSC3 primary objective is to promote evidence-based emergency care and optimize provider-patient-family communication in the delivery of the emergency care for patients with SCD.

The Cure Sickle Cell Initiative is a collaborative, patient-focused research effort designed to accelerate promising genetic therapies to cure sickle cell disease. The Initiative considers non-traditional ways to advance research and brings together the sickle cell disease (SCD) community—patients, advocates, caregivers, providers, researchers, industry, and others.
Dr. Schlenz received her B.A. in Psychology from the University of Colorado in 2006 and her Ph.D. in Clinical-Community Psychology from the University of South Carolina in 2014. She completed her internship and post-doctoral fellowship at the Medical University of South Carolina. Dr. Schlenz was previously a faculty member in Developmental Pediatrics as well as an embedded pediatric psychologist for the Pediatric Sickle Cell Clinic at the Medical University of South Carolina from 2015-2019. She recently joined the faculty at the University of Colorado School of Medicine, and she continues to provide clinical care through Developmental Pediatrics and the Pediatric Sickle Cell Clinic at Children’s Hospital Colorado. Dr. Schlenz’s research and clinical interests are focused on improving the quality of life of children with sickle cell disease, particularly children who are affected by neurological complications and pain. She is currently a co-investigator on an NIH-funded study (DISPLACE) focused on improving the implementation of stroke prevention guidelines in pediatric sickle cell disease.

Dr. Phillips received her BSN from the University of North Florida in 1999 and her PhD from the Medical University of South Carolina in 2013. Prior to joining the faculty at the Medical University of South Carolina in 2013, Dr. Phillips was a nurse in the Pediatric Intensive Care Unit (PICU). During this time, she developed a passion for improving care for children with complex chronic conditions and their families and was inspired to pursue a PhD. Her research interests focus on improving access to care and services in individuals with sickle cell disease and using technology-based approaches for self-management of symptoms in children with sickle cell disease and their families. She is a past recipient of a KL2 Career Development Award from the South Carolina Clinical and Translational Research Institute and a current recipient of a K23 Patient-Oriented Research Career Development Award from the National Institute of Nursing Research. She is Co-Investigator on the National Heart, Lung, and Blood Institute-funded study, DISPLACE, which is designed to improve the implementation of stroke prevention guidelines in children with sickle cell anemia.
I’m a strategist who enjoys studying human behavior through the lens of communication. My research interests are in Communication/Rhetoric, Culture, & Women’s Studies. My doctoral research examined the use of African American English Vernacular in mainstream discourse by those outside of the African American community. I am always intrigued by the messages people send and the dynamics at play that create those messages. My work in Washington, DC in politics and various federal agencies/initiatives, served as a wonderful foundation for examining messages from various ideological viewpoints. As co-founder and Vice President of Urban-Think Tank Institute, the nation’s first think tank developed by and for members of the hip hop community, I enjoyed connecting generations and communities on the significance of politics and policymaking. I am a member of the National Communication Association, American Popular Culture Association, & Rhetorical Society of America.

I teach courses on Rhetoric and encourage students to examine the socio-political and cultural aspects of a message. I look forward to working with students as they create their unique plans for success.

OTHER SPEAKERS

Dr. Lakiea Bailey
Dominique Friend
Dominique Goodson
Dr. Raymona Lawrence
Sickle Stroke Screen
Alexis Wardlow-Perry
Junior CBOs

BEAUTIFUL GEMS SICKLE CELL FOUNDATION
Hampton, VA

Spread awareness about Sickle Cell Disease, Sickle Cell trait through education, community health fairs, motivational speaking, and advocating locally. To also make connections with other community organizations, schools and health facilities.

Contact: Raven Cassidone | Email: raven.cassidone@icloud.com

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SICKLE CELL CHAMPIONS ASSOCIATION
Savannah, GA

This program is created and implemented to make sure the S.C.C.A. does everything within its capability to ensure that we place focus on the empowerment, motivation, mentorship and overall growth of adolescent males living with Sickle Cell Disease.

Contact: Clayton Andrews | Email: sicklecellchampionsassociation@gmail.com

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MY SICKLE FAMILY FOUNDATION
Royal Palm Beach, FL

To support the sickle cell community while advocating for other sickle cell warriors; bringing knowledge and wellness to the community through health initiatives and financial literacy.

Contact: Etta Flanagan | Email: mysicklefamily@gmail.com
**Strength in Sickle Cell**  
**Milwaukee, AL**

This community raises awareness to prevent Sickle Cell disease from spreading to the next generation.

Strength in Sickle Cell is a platform for people living with Sickle Cell to interact, express their feelings, find a mentor or mentor someone and make suggestions on things the medical community should do for them, to have better treatment and care.

Contact: Ethleen Peacock | Email: ethleenpeacock@gmail.com

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**The Sickle Cell Mommies Club**  
**Tampa, FL**

A place for moms who have children with SC or mothers with SC or mothers with SC who are actively trying to conceive. Judgement free zone where we can talk and share about the victories and achievements and sometimes pitfalls of our type of motherhood.

Contact: Shamir Jubert | Email: thescmc@gmail.com
CBOs

**1212 FOUNDATION INC.**
Texas
Contact: Samyika Anderson
Email: samyika.anderson@gmail.com

1212 Foundation is an organization designed to provide support and assistance to single parents living with a chronic illness and/or have children living with a chronic illness.

**ADVANCING SICKLE CELL ADVOCACY**
Florida
Contact: Kemba Gosier
Website: asapbeinformed.org
Email: kgosier@asapbeinformed.org

The mental health initiative that was launched helped our organization, as we hold monthly support group sessions as well as workshops. The tools given were helpful to share. Also the awareness campaign to educate the general public on SCD.
The As One Foundation empowers families globally by delivering life-saving sickle cell education.

All As One Foundation events and activities acknowledge sickle cell trait and sickle cell disease as factors existing not independent of each other but because of each other. Sickle disease births are prospectively the result of procreation between two sickle cell trait positive parents and any combination of at least one sickle cell disease parent will certainly result in a sickle cell trait birth at best. In order to increase quality health care and directly address disparities associated with chronic and acute blood conditions, we seek to fill knowledge gaps of patients, caregivers, family and community members and even health care providers. All-embracing information is provided through in-person and digital delivery methods to empower those of living with, affected by or are caregivers of people of varying sickle cell genotypes.

“Education and advocacy for the sickle cell community (patients, families, caregivers, providers and researchers. Our pillar events are co-chairing the annual California Sickle Cell Education Meeting (past 5 years), the community media based program - The Sickle Cell Experience. Hourly podcast - The Axis Advocacy hour. Point of Care advocacy. The annual Sickle Cell Arts and Film Festival. Legislative and policy advocacy nationally and state. Support of research for quality care, new treatments and stem cell research.”
BOLD LIPS FOR SICKLE CELL
North Carolina
Contact: Jewel Darbone
Email: jeweldarbone.blfsc@gmail.com

The Mission of #BoldLipsForSickleCell is to educate and raise awareness for sickle cell disease through it advocates wearing bold lipstick colors to symbolize them being bold and speaking up for sickle cell. We host various events geared towards spreading education and awareness. Founded in 2014 we have become a new and vibrant force in the sickle cell community. We wish to change the stigma of sickle cell while showing our supporters we all can live bold and fulfilling lives.

BREAKING THE SSICKLE CELL CYCLE
Tennessee
Contact: Dr. Lametra Scott
Email: btsscycle@gmail.com

Breaking The SSickle Cell Cycle Foundation, Inc. seeks to promote sickle cell disease awareness, education, and prevention through community education and service.
CAROL’S PROMISE
Texas
Contact: Kenya Buckley
Website: carolspromise.org
Email: info@carolspromise.org

To increase the quality of life for individuals living with Sickle Cell Disease by awareness, support and education.

CAYENNE WELLNESS CENTER
California
Contact: Dr. Carolyn Rowley
Website: cayennewellness.org
Email: carolyn@cayennewellness.org

To increase the quality of life for individuals diagnosed with sickle cell disease in California by ensuring expert, unbiased, and comprehensive care.

This mission is part of a broader vision of (1) a medical system which effectively addresses the unique needs of individuals with sickle cell disease and (2) patients who are empowered and equipped to advocate for themselves.

DREAMSICKLE KIDS FOUNDATION
Nevada
Contact: Georgene Glass
Website: dreamsicklekids.org
Email: ginaglass@dreamsickle.org

Our mission is to #MakeSickleCellPopular by increasing Awareness, educating, and advocating for long term changes for the SCD population of Nevada to improve Equity and access to care for those affected by SCD while also addressing health disparities.
CBOs

HEART OF GOLD
Virginia
Contact: Melanie Hurley
Website: heartofgold.org
Email: melanie.hurley@heartofgold.org

It is our mission to serve as an advocate for adults and children in the Northern Virginia area. Heart of Gold Foundation is structured to educate, mentor, and support those that battle with Sickle Cell Disease.

IASCNAPA
South Carolina
Contact: Dora Clayton-Jones
Website: iascnapa.org
Email: dora.clayton-jones@marquette.edu

International Association of Sickle Cell Nurses and Professional Associates provides a platform for nurses, nurse practitioners, physician assistants, social workers, sickle cell advocates, and other healthcare professionals caring for individuals with sickle cell disease to improve the care of people with sickle cell disease through advocacy, standardized practice, and education.
LOCKHART MORGAN FOUNDATION
Georgia
Contact: Gwen Morgan
Website: lockhartmorganfoundation.org
Email: gwendmorgan@yahoo.com
Lockhart Morgan Foundation is an Atlanta Based organization which is focused on bringing awareness to our community, providing assistance to families in need and providing scholarships for Sickle Cell Students continuing their education.

MISSISSIPPI SICKLE CELL FOUNDATION
Mississippi
Contact: Jeanne Tate
Website: mssicklecellfoundation.org
Email: mssicklecellfnd@yahoo.com
The mission of the Mississippi Sickle Cell Foundation is to enhance the quality of life for individuals living with sickle cell disease through the support of research, public activities and awareness, and patient/family education.

SICKLE CELL AWARENESS RIDE S.C.A.R.
Georgia
Contact: Lisa Touray | Logan Dean
Website: atlantascar.com
Email:atlantascar@gmail.com
Atlanta S.C.A.R. Sickle Cell Awareness Ride, is a grassroots organization with the goals of educating Georgians about Sickle Cell Trait (SCT) and Sickle Cell Disease (SCD), while also raising money to bring communal aid to those who are afflicted with the disease.
CBOs

SICKLE CELL ALLIANCE FOUNDATION
Ohio
Contact: Lisa Meatchem
Website: scafcincy.org
Email: lisa@scafcincy.org

Our mission is to bring awareness, inspire hope and advocate for families coping within the many facets of Sickle Cell Disease.

Our vision is to change the life expectancy for patients living with Sickle Cell Disease.

SICKLE CELL ANEMIA AWARENESS
California
Contact: NeDina Brocks-Capla
Website: scaasf.org
Email: crisis@scaasf.org

Our mission is to bring about a greater awareness of this disease and advocate for Sickle Cell patients. In addition, bring awareness of one's own Sickle Cell status, issues regarding healthcare and treatment as well as new medical treatment therapies and centers.
**SICKLE CELL ASSOCIATION OF ONTARIO**

Canada  
Contact: Ulysse Guerrier  
Website: sicklecellontario.ca  
Email: chair@sicklecellontario.ca  

Our Programs and Services are geared towards supporting those who are currently living with Sickle Cell Disease and the people who support them.  

We use a CARE model towards providing this needed support:  
Counselling | Advocacy | Raising Awareness | Education

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**SICKLE CELL ASSOCIATION OF TEXAS MTF**

Texas  
Contact: Linda Wade  
Website: sicklecelltx.org  
Email: lwade@sicklecelltx.org  

We provide numerous services to children, adults and families in Central Texas, San Antonio, the Texas Gulf Coast, and other affected with sickle cell disease and those carrying sickle cell trait. We provide education, research awareness, outreach, support group meetings, assistance and numerous other services.

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**SICKLE CELL FOUNDATION OF ALBERTA**

Canada  
Contact: Jean Walrond  
Website: ourscfa.org  
Email: jean.walrond@ualberta.ca  

The SCFA teaches patients coping skills for pain management, advocates for funding of SCD research and provides its members with access to the most current scientific research and information. It is led by a board of directors, consisting primarily of sickle cell patients, health professionals, patients’ parents and caregivers.
SICKLE CELL FOUNDATION OF MINNESOTA

Minnesota
Contact: Rae Blaylark
Website: sicklecellmn.org
Email: sicklecellmn@gmail.com

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

SICKLE CELL FOUNDATION SUPPORT GROUP, INC.

Georgia
Contact: Parnel Abraham
Website: thesicklecellsupportgroupyolasite.com
Email: parnel.abraham@emoryhealthcare.org

The Support Group addresses the psychosocial/nutritional issues in coping with Sickle Cell Disease.
SICKLE CELL WARRIORS
California
Contact: Tosin Ola
Website: sicklecellwarriors.com
Email: sicklecellwarriors@gmail.com
Sickle Cell Warrior’s Inc., is a non-profit charitable organization dedicated to education, empowerment, and awareness about sickle cell disease. Our mission is to inspire those affected by sickle cell. As of this minute, you are no longer alone. You have us and we have you. Welcome to the family.

SICKLE CELL WARRIORS OF WISCONSIN
Wisconsin
Contact: Tokara Henry
Email: sicklecellwarriorsofwisconsin@gmail.com
The Sickle Cell Warriors of Wisconsin (SCWWI) is an organization committed to not only bringing awareness and education to the community on sickle cell disease but also improving the quality of life for individuals and families affected by the disease.

SICKLE INTERNATIONAL FAMILY COALITION
Georgia
Contact: Dominique Friend
Website: sifc.us
Email: dominiquefriend.author@gmail.com
SIFC will use the power of its united, worldwide membership to advocate for improved care and treatment of patients with sickle cell disease. A patient-centered approach will be used to provide clinical education to medical professionals and to avail patients of the best possible care and quality of life.
CBOs

SUPPORTERS OF FAMILIES WITH SICKLE CELL DISEASE

Oklahoma
Contact: Velvet Brown
Website: www.sicklecelloklahoma.org
Email: swithsicklecell@att.net

Supporters’ mission is to increase self-efficacy, improve the overall quality of life for individuals living with sickle cell disease and its inherited disorders and traits - children, adults and their families within the State of Oklahoma; through systemic changes in patient care, disability policies, education, family support, nutrition, economic self-sufficiency, awareness, and advocacy.

THE B STRONG GROUP

South Carolina
Contact: Brenda Green
Website: thebstronggroup.org
Email: thebstronggroup@gmail.com

The B Strong Group was created to support those with sickle cell disease and their caregivers in the Columbia area. We advocate for, empower and uplift our sickle cell warriors by spreading awareness of the disease, educating the community and engaging volunteers.
THE CHILDREN’S SICKLE CELL FOUNDATION
Pennsylvania
Contact: Michael Matthews
Website: cscfkids.org
Email: mmatthews@cscfkids.org

The mission of The Children’s Sickle Cell Foundation, Inc. is to provide quality programs for children with sickle cell disease and their families to help them face the educational, social and economic challenges caused by the disease across the life span. Our commitment to advocacy, community education and support for research are natural extensions of this mission.

THE MARTIN CENTER SICKLE CELL INITIATIVE
Indiana
Contact: Gary Gibson
Website: themartincenter.org
Email: ggibson@themartincenter.org

The Martin Center Sickle Cell Initiative exists to aid and enhance the lives of those affected by Sickle Cell and associated disorders by providing services, education, and advocacy. We are committed to providing essential programs and services to benefit individuals and families affected by Sickle Cell. We also educate clients as well as community members by providing access to quality educational experiences.

THE SICKLE CELL FOUNDATION OF TENNESSEE
Tennessee
Contact: Reginald French
Website: sicklecelltn.org
Email: rfrench@sicklecelltn.org

To increase the public awareness of sickle cell disease by supporting awareness and education regarding this life threatening disease.
TOTALLY HEALED NETWORK INTERNATIONAL INC.

Georgia
Contact: Angel Woods
Website: totallyhealednetwork.org
Email: totallyhealed17@gmail.com
Our mission is to bring health, hope and healing to the diseased community by using faith healing and holistic medicine as an alternative to modern medicine.

TRANSITION WITH POWER

Pennsylvania
Contact: Tahirah Austin
Email: transitionwithpower@gmail.com
Transition With Power is committed to empowering teens and young adults with Sickle Cell Disease by providing the necessary tools and resources to ensure a successful journey into adulthood while improving their quality of life.
TUNMICRO SICKLE CELL FOUNDATION

Alabama
Contact: Ola Ogundemi
Website: tunmicro.org
Email: ola.ogundemi@tunmicro.org

TunMicro Sickle Cell Foundation, is a UK based charity organisation with the primary goal of creating awareness and education on sickle cell disease. We provide FREE sickle cell/genotype testing for the management of sickle cell disease.

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INDEPENDENT PATIENT & CAREGIVER PARTNERS

Ade Ejiofor  Caregiver  jkoguns4@gmail.com
Alexis Wardlow Perry  Patient   awardlow@sicklecellconsortium.org
Andre Harris  Patient   andremarcelharris@gmail.com
April Ward  Patient   bh092188@gmail.com
Brittany Hightower  Patient   blazeofck@gmail.com
Blaze Eppinger  Caregiver   cleverlychanging@gmail.com
Carley Cole-Cavins  Caregiver   astromom1124@yahoo.com
Carla Sanders  Patient   sicklecell87@gmail.com
Carolyn Boose  Patient   wclundy@gmail.com
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Chris Lundy  Patient   sanderscottney2@gmail.com
Chrysycynthia Carter  Patient   darius_rhodes@yahoo.com
Cortney Sanders  Patient   christiandavinna@aol.com
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DeMitrious Wyant  Patient/Staff   edavis218@gmail.com
Dominick Hall  Patient   fsbaker@gmail.com
Dominique Goodson  Caregiver   heather.l.avant@gmail.com
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Francine Baker  Patient   jamesgriff3@yahoo.com
Heather Avant  Patient/Staff   travel@sicklecellconsortium.org
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LaShanna Nekia Ritchie  Patient   mckinleymarcus@yahoo.com
Latashe Sanders  Patient   mariavra15@yahoo.com
Latrice Peterson  Caregiver   coolinblue07@yahoo.com
Marcus McKinley  Patient/SC3 Kids   ml4sicklecell@gmail.com
Maria Rivera  Patient   melissa4thh@gmail.com
Mariam Toure  Caregiver   rjonjaz@yahoo.com
Matalia Liptrot  Patient   neka405@yahoo.com
Melissa Hernedez  Caregiver   niasumpter@icloud.com
Moises Rivera  Patient   nicolesicklecelladvocate@gmail.com
Monique McKinley  Patient   nortoria@gmail.com
Nia Sumpter  Patient   nortoria@gmail.com
Nicole Surjit  Patient   nortoria@gmail.com
Nortoria Jones  Patient   nortoria@gmail.com
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<thead>
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<tr>
<td>Pam Moore</td>
<td>Patient</td>
<td><a href="mailto:pmoore4684@yahoo.com">pmoore4684@yahoo.com</a></td>
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<tr>
<td>Paul Braxton</td>
<td>Patient</td>
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<tr>
<td>Revee Agyepong</td>
<td>Patient</td>
<td><a href="mailto:mysickledcells@gmail.com">mysickledcells@gmail.com</a></td>
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<td>Shamika Minisee</td>
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<td>Shamonica Wiggins</td>
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<td>Sharonda Sikes</td>
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<td><a href="mailto:iamlinsgirl@gmail.com">iamlinsgirl@gmail.com</a></td>
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<tr>
<td>Shelfina Marshall(Wilkins)</td>
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<td><a href="mailto:annaye33@gmail.com">annaye33@gmail.com</a></td>
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<td>Stacey Johnson</td>
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<td><a href="mailto:oneasim@yahoo.com">oneasim@yahoo.com</a></td>
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<td><a href="mailto:lrose@hopeforscd.org">lrose@hopeforscd.org</a></td>
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<td><a href="mailto:suzanne.gordon@yahoo.com">suzanne.gordon@yahoo.com</a></td>
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<td>Tiffany Brown</td>
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<td><a href="mailto:tbrown61988@gmail.com">tbrown61988@gmail.com</a></td>
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<tr>
<td>Titilope Fasipe (Ishola)</td>
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<td><a href="mailto:titilope.ishola@gmail.com">titilope.ishola@gmail.com</a></td>
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<tr>
<td>Versetta Brown-Eaddy</td>
<td>Patient</td>
<td><a href="mailto:veebabee04@gmail.com">veebabee04@gmail.com</a></td>
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<td>Vivian Washington-White</td>
<td>Patient</td>
<td><a href="mailto:asiaug@gmail.com">asiaug@gmail.com</a></td>
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<tr>
<td>Yolanda Lewis</td>
<td>Caregiver/Staff</td>
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GOT NOTES
MY FUTURE IS: UNSTOPPABLE

Class of 2020

CONGRATULATIONS!