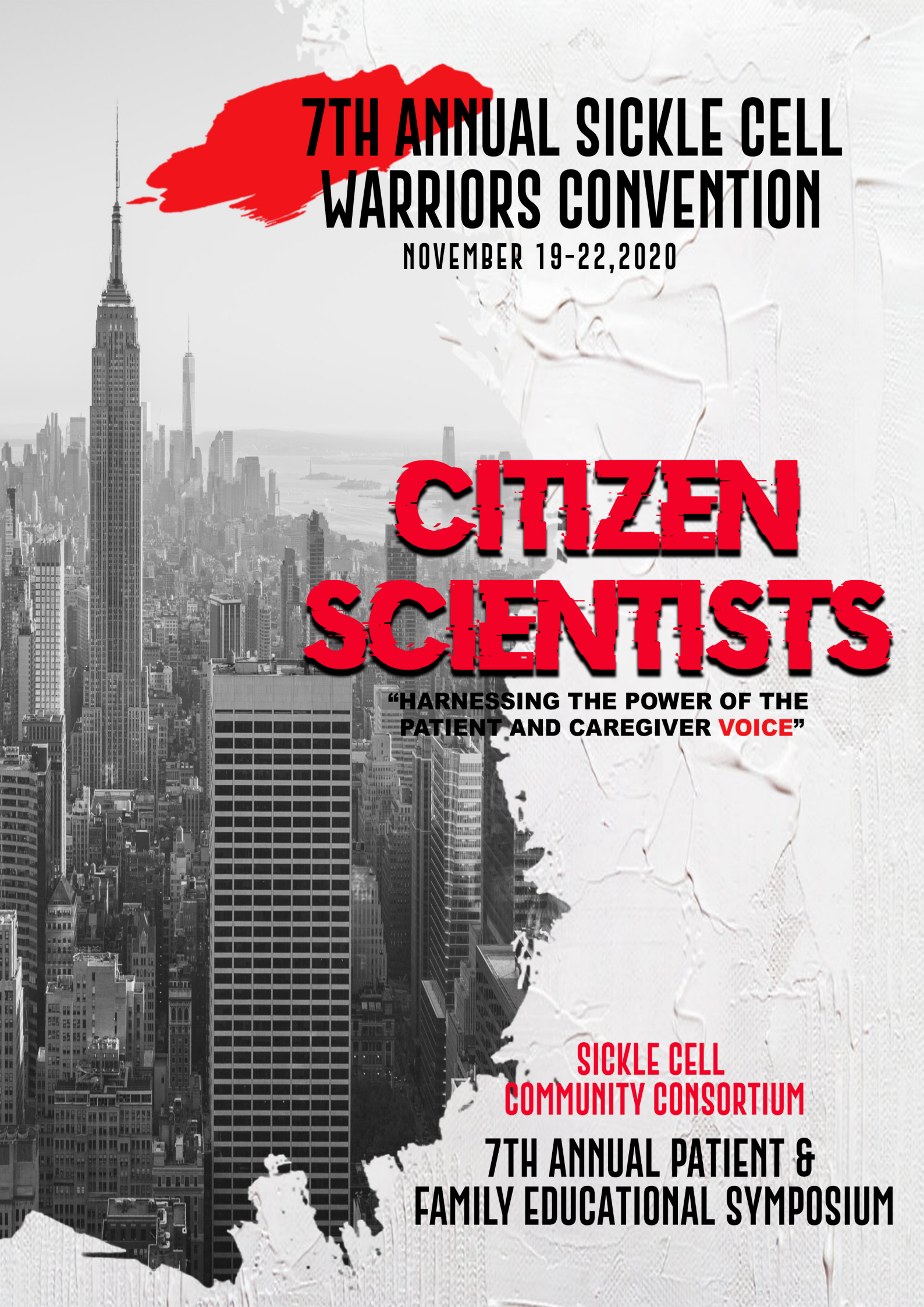


7TH ANNUAL SICKLE CELL WARRIORS CONVENTION

NOVEMBER 19-22,2020

CITIZEN SCIENTISTS

"HARNESSING THE POWER OF THE PATIENT AND CAREGIVER VOICE"

SICKLE CELL COMMUNITY CONSORTIUM

7TH ANNUAL PATIENT & FAMILY EDUCATIONAL SYMPOSIUM

Welcome.

The Sickle Cell Consortium is delighted to present the 7th Annual Sickle Cell Patient and Family Educational Symposium (aka The Warriors Convention) on November 19-21, 2020. This year we are doing things very differently. As opposed to the traditional protocol of back-to-back formal presentations, we are hosting a series of Community Conversations. Consistent with our theme "Citizen Scientists: Harnessing the Power of the Patient & Caregiver Voice", sickle cell patients and caregivers will participate in moderated, group discussions on a variety of topics ranging from "What is a Cure" to "Navigating Transition: The Caregivers Perspective". Sickle cell patients and caregivers are the experts of our own bodies and experiences. This year, we will lead discussions, share our expertise and knowledge with each other, and invite other stakeholders to join us as we share our own thoughts, feelings, and concerns. Each Community Conversation will have a moderator(s), content expert(s), and community discussion leaders. To facilitate these conversations, the Sickle Cell Classroom will open approximately one week prior to the start of the Convention. This online space will house dozens of recorded education to help inform each Community Conversation topic. We are thrilled that you have chosen to join us as we embark on this journey to "harness the power of the patient and caregiver voice".

TABLE OF CONTENTS

A Note From GBT	4
Sponsors	5
At-A-Glance	6
Meet The Founder	7
Convention Committee	8
Community Conversations	10
Tracks & Speakers	26
Speakers & Bios	31

A NOTE FROM OUR TITLE SPONSOR GBT

Global Blood Therapeutics (GBT) is a biopharmaceutical company dedicated to the discovery, development, and delivery of life-changing treatments that provide hope to underserved patient communities. Founded in 2011, GBT is delivering on its goal to transform the treatment and care of sickle cell disease (SCD), a lifelong, devastating inherited blood disorder. The company is committed to developing and delivering therapies for people with sickle cell disease. GBT's goal is to advance the care and treatment of people with SCD through science, innovative medicines and access to solutions. GBT is driven by a deep and urgent desire to improve the care of SCD patients. Beyond developing medicines, GBT is working to shine a bright light on the disparities and inequalities faced by people living with SCD.

The company has introduced Oxbryta(R) (voxelotor), the first FDA-approved treatment that directly inhibits sickle hemoglobin polymerization, the root cause of red blood cell sickling in SCD. GBT is also advancing its pipeline program in SCD with inclacumab, a P-selectin inhibitor in development to address pain crises associated with the disease, and GBT021601, the company's next generation hemoglobin S polymerization inhibitor. In addition, GBT's drug discovery teams are working on new targets to develop the next wave of treatments for SCD. To learn more, please visit www.gbt.com [1] and follow the company on Twitter @GBT_news.

Thank You Sponsors!

sickle cell community consortium
Citizen Scientists

TITLE SPONSOR

GBT

GOLD SPONSORS

VERTEX
CRISPR THERAPEUTICS
bluebirdbio
agios

TRACK SPONSORS

SANOFI GENZYME
Medunik USA
Chiesi Global Rare Diseases

GENERAL SPONSOR

NOVARTIS
BE THE MATCH

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.

At-A-Glance

WEDNESDAY, NOVEMBER 18

Pre-Con Educational Sessions
Warrior Wellness
Networking Event (Run The World)

Thursday, November 19

Morning Wellness
Digital Engagement
Opening Session
Breakout Sessions
Community Lunch & Learn
Healthy Cooking w/ Warriors
Pass The Mic - GBT

Saturday, November 21

Morning Wellness
Breakout Sessions
Community Awards
Community Lunch & Learn
Breakout Sessions
Paint & Chat
Family Game Night

Friday, November 20

Morning Wellness
Digital Engagement
Breakout Sessions
Community Lunch & Learn
Breakout Sessions
Warriors After Dark

Sunday, November 21

Close of 7th Annual Convention

MEET THE FOUNDER

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. Dr. Bailey earned a Bachelor's degree in Biochemistry and Molecular Biology in 2001 from Agnes Scott College. In 2012 she completed a Doctorate degree in Molecular Hematology and Regenerative Medicine, where she conducted research into the molecular mechanisms involved in the induction and regulation of the gamma-globin gene, provided evidence implicating cyclic adenosine monophosphate (cAMP) in gamma-globin expression in patients with beta-thalassemia, investigated the role of chemokines and cytokines in sickle-induced vaso-occlusion, and described previously unidentified human mutations in both the alpha and beta hemoglobin chains.

During the course of her education, Dr. Bailey was named a Southern Regional Education Board (SREB) Doctoral Scholar, was the recipient of multiple honors and awards, including the Fisher Scientific Award for Overall Excellence in Biomedical Research, the Medical College of Georgia Alumni Association Award, the Georgia Regents University Leadership Award and was inducted in the Alpha Upsilon Phi honor society. Dr. Bailey was one of the founding board of directors for the Family Advocacy Coalition for the Empowerment of the Sickle Cell Disease Community (FACE of SCD) and the founding vice president of Sickle Cell Warriors, Inc., serving as Research and Medical advisor for both. She was a frequent guest and resource advisor for What'z Da Count on Sickle Cell Trait BlogTalk radio show and made multiple trips to Capitol Hill where she advocated for an increase in research funding and visibility with the Sickle Cell Disease Association of America (SCDAA). In 2014 Dr. Bailey founded and began working as the Executive Director of the Sickle Cell Community Consortium, a coordinated network of sickle cell community-based organizations (CBOs), patient and caregiver advocates, community partners, and healthcare/research advisors. The Consortium functions as an organizing entity allowing this diverse group of stakeholders to identify, prioritize, develop, and execute solutions for patient-identified needs and gaps within the sickle cell community. Dr. Bailey enjoys traveling across the nation promoting sickle cell awareness. Her goal is to provide a platform to harness and amplify the power of the patient voice, ensuring that the sickle cell patient and caregiver takes a leadership role in research, policy, advocacy, legislation, and education.

CONVENTION COMMITTEE

CONSORTIUM EXECUTIVE LEADERSHIP

LAKIEA BAILEY
EXECUTIVE DIRECTOR
DIRECTOR@SICKLECELLCONSORTIUM.ORG

SHARONDA SIKES
DIRECTOR OF OPERATIONS
SSIKES@SICKLECELLCONSORTIUM.ORG

DORIS BAILEY
ASSOC. DIRECTOR OF FINANCE
FINANCE@SICKLECELLCONSORTIUM.ORG

SUPPORT STAFF

SANDY MILL; SANDY MILL WORKS
PROJECT MANAGER
SANDYMILLWORKS@GMAIL.COM

PATRICIA SMITH, ONLINE MEDIA INTERACTIVE
ONLINE MEDIA TECH MANAGEMENT & OVERSIGHT
PATSMITH@ONLINEMEDIAINTERACTIVE.COM

JONATHAN & LANITA SMITH
JOLA MEDIA PRODUCTIONS
SOUND PRODUCTION, IT SUPPORT,
SHIPPING/HANDLING

JOYE SMITH, 610 DESIGNS & COMPANY
VIDEO EDITING, GRAPHICS, MARKETING,
COMMUNICATION
610DESIGNSANDCO@GMAIL.COM

PARTNER PLANNING COMMITTEE

LISA ROSE - CHILDREN'S TRACK

VANESSA RHODES - CHILDREN'S TRACK

CLAYTON ANDREWS,
SICKLE CELL CHAMPIONS ASSOCIATION
MEN'S TRACK

TOSIN OLA/BROOKE PILLIFANT,
SICKLE CELL WARRIORS INC.

CONSORTIUM STAFF/VOLUNTEER SUPPORT

SHAMONICA WIGGINS - SOCIAL MEDIA

DOMINIQUE GOODSON - PRESENTERS, EXHIBITORS

MARIA RIVERA - REGISTRATION

ALEXIS WARDLOW
PATIENT, CAREGIVER, CBO VENDORS/EXHIBITORS

YOLANDA LEWIS
COMMUNICATION, PRE-CON COORDINATION

LOGAN DEAN - MEDIA/MARKETING

CHLOE ROSE - CHILDREN'S TRACK INTERN

TECH INTERN

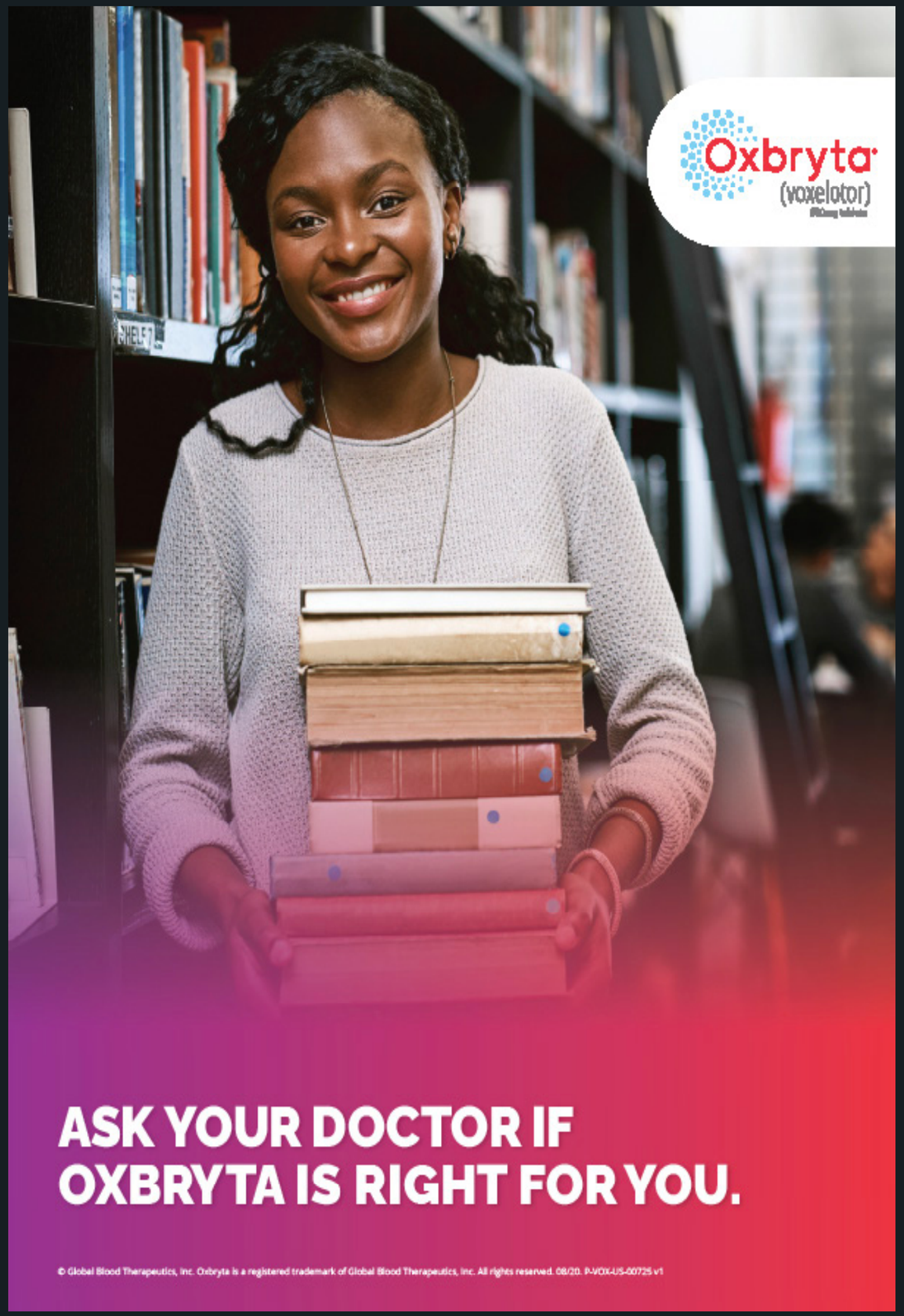
ANDREW N. LEWIS

SEAN ROSE

ON-SITE
CONSORTIUM HELP BOOTH - JANEEN GREENE,
MARIA RIVERA, SHELFINA WILKINS

CONSORTIUM BOOTH - YOLANDA LEWIS,
DOMINIQUE FRIEND, TYNISHA HALL

IT HELP BOOTH
JONATHAN SMITH
TECHTEAM@SICKLECELLCONSORTIUM.ORG



COMMUNITY CONVERSATIONS

SICKLE CELL SCIENCE: BEYOND THE RED BLOOD

What exactly is happening when we go into sickle cell crisis? We know about the sickle mutation that causes the hemoglobin to stick together causing the red blood cell to become sickle-shaped. Let's talk about this and everything else. *This will launch to a Warrior University class series to discuss the science of sickle cell.

EMERGENCY DEPARTMENT CARE

This is a big one and the sickle cell community has a lot to discuss. Join us as we share experiences and discuss current initiative to improve ED care. What does optimal ED care look like to warriors? How can we improve the ED experience for caregivers.

MENTAL HEALTH

Another big conversation. Warriors and caregivers experience higher rates of depression, anxiety, and PTSD, than the general population. It's ok to not be ok. Let's talk about it. Share our experience, coping mechanisms at home, and where to find resources to help.

WHAT IS A CURE?

What curative treatments and options are being researched? What's available now? Is it really a "cure"? What does an ideal cure look like to sickle cell warriors? What do we, patients and caregivers want to see in a cure?

COMPLIMENTARY & ALTERNATIVE METHODS OF HEALTHCARE

Many of the most effective therapies for sickle cell occur outside of the hospital and clinic setting. This Community Conversation focuses on alternative treatments and natural therapies. Join warriors and caregivers as we discuss how we treat pain, inflammation, and other disease complications without pharmaceutical intervention.

DISEASE COMPLICATIONS

This conversation will focus on sharing our experiences with some of the complications of sickle cell disease. What are the prevalent complications? How can we recognize them and what do we do about it? Patients and caregivers will share their experiences.

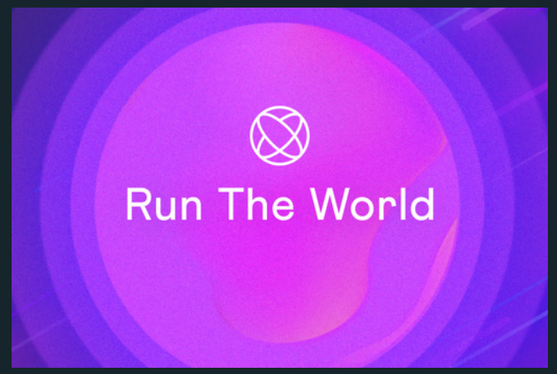
CAREGIVERS

This conversation will focus on the experiences of the Caregivers of Sickle Cell Warriors who are so important to the management of their day-to-day lives. What have they learned to make caring for their love ones easier. How do they care for themselves to make sure they are healthy and available for their Warrior?

AGENDA

WEDNESDAY, NOVEMBER 18, 2020

11:00 AM	Warrior Wellness Slay the Sickle Cycle
11:50 AM	Medical Records & the Power of Legislative Advocacy Strength in Sickle Cell
12:40 PM	Nutrition and Sickle Cell Disease Cayenne Wellness Center



1:30 PM	Coping with Pain in the Pandemic Practical Strategies to Manage Stress Sickle Cell Foundation of TX
2:00 PM	The Treatment of Sickle Cell Pain The Be Strong Group
3:00 PM	Networking Event (Run The World)

All Times Are In Eastern Standard Time

01

BRITTANY HIGHTOWER

SLAY THE SICKLE CELL

Warrior Wellness

DR. CAROLYN ROWLEY

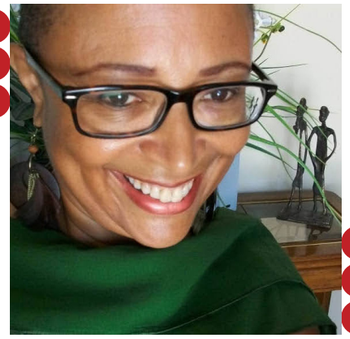
CAYENNE WELLNESS

Medical Records & the
Power of Legislative
Advocacy

ETHLEEN PEACOCK

STRENGTH IN SICKLE CELL

Medical Records & the
Power of Legislative Advocacy



SHIRLEY POWELL

STEPHANIE IBEMERE

THE BE STRONG GROUP

The Treatment of
Sickle Cell Pain

EMILY O'SHEA

SICKLE CELL FOUNDATION OF TEXAS

Coping with Pain in the
Pandemic Practical
Strategies to Manage Stress
(Bio In The Back)

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.

SANOFI GENZYME

02

AGENDA

THURSDAY, NOVEMBER 19, 2020

11:00 AM — Morning Wellness
Hosted by Carol's Promise
Sickle Cell Foundation

12:00 PM — Welcome To The 7th Annual
Warriors Convention
Dr. Lakiea Bailey

1:00 PM — Opening Session
ADM Brett Giroir

2:00 PM — Breakout Sessions

Complimentary & Alternative Methods
Sickle Cell & Pain

Young Adult Track
The Language of Pain

Trait Track
Sickle Cell Trait: Benign or Not?

3:00 PM — Community Lunch & Learn
Sponsored by CRISPR/Vertex

4:00 PM — WHAT IS A CURE?
SCD & Curative Therapies

Children's Track
Sickle Cell & The Circulatory System

5:00 PM — Healthy Cooking with Warriors

Children's Track
Sickle Cell & The Circulatory System

6:00 PM — Global Blood Therapeutics
PASS THE MIC
Virtual Karaoke Talent Show

GBT

All Times Are In Eastern Standard Time

ADM BRETT P. GIROIR, M.D,

U.S.DEPARTMEMT 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 between1998 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.

LET'S HAVE FUN!

Join The Conversation!

sickle cell community consortium
Citizen Scientists

TAMIKA MOSELEY
MODERATOR

Complimentary & Alternative Methods Of Healthcare

Bio in back

LISA ROSE
EDUCATOR

The Language Of Pain

Bio in back

VANESSA RHODES
EDUCATOR

The Language of Pain

Bio in back

DR. SANDEEP SONI
EDUCATOR

Lunch & Learn (Sponsored By Crispr/Vertex)

Bio in back

HEATHER AVANT
MODERATOR

What Is A Cure?

Bio in Back

DR. TITILOPE FASIPE
CONTENT EXPERT

What Is A Cure?

BILAN JAMA
EDUCATOR

What Is A Cure?

KAYDIENNE ROBINSON
EDUCATOR

What Is A Cure?

GENESIS JONES
EDUCATOR

What Is A Cure?

03

FRIDAY,
NOVEMBER 20, 2020

11:00 AM	Morning Wellness Hosted by Carol's Promise Sickle Cell Foundation
12:00 PM	Digital Engagement
1:00 PM	Breakout Sessions Sickle Cell Science Beyond the Red Blood Cell Young Adult Track Goal Setting Trait Track Physical Activity & Sickle Cell Trait
2:00 PM	Community Lunch & Learn Presenter Title Sponsor Global Blood Therapeutics
3:00 PM	Breakout Sessions The Mental Health Conversation Trait Track SCT & RMC: The Kidney Connection
4:00 PM	Young Adult Kickback Vision Board Party Warrior Fitness, Movement, & Bodybuilding (Foundational Fitness) Children's Track Sickle Cell & The Musculoskeletal System
5:00 PM	Jazmine Rivera Beauty Within Sickle Cell Make-up & Advocacy Gaming & Sickle Cell Coping Strategies Children's Track Sickle Cell & The Musculoskeletal System
8:00 PM	Warriors After Dark Women Only: Pajama Jam - SELF CARE Men Only: Networking & Mentoring Sponsored by: Sanofi Genzyme

AGENDA

All Times Are In Eastern Standard Time

LET'S DO THIS!

Citizen Scientists

CHARISSE FISHER
EDUCATOR

Morning Wellness

Bio in Back

LISA ROSE
MODERATOR

Sickle Science: Beyond The Red Blood Cell

Bio in Back

DR. AHMAR ZAIDI
CONTENT EXPERT

Sickle Science: Beyond The Red Blood Cell

Bio in Back

DR. JULIE KANTER
EDUCATOR

Sickle Science: Beyond The Red Blood Cell

DR. JAMES ECKMAN
EDUCATOR

Sickle Science: Beyond The Red Blood Cell

Bio in Back

OTHA MOBBS
EDUCATOR

Goal Setting
Bio in Back

JEWEL DARBONE
MODERATOR

The Mental Health Conversation

CLAYTON ANDREWS
CONTENT EXPERT

The Mental Health Conversation

Bio in Back

CARLEY COLE CAVINS
EDUCATOR

The Mental Health Conversation

Bio in Back

LAURA CRUZ
EDUCATOR

Young Adult Kick Back

Bio in Back

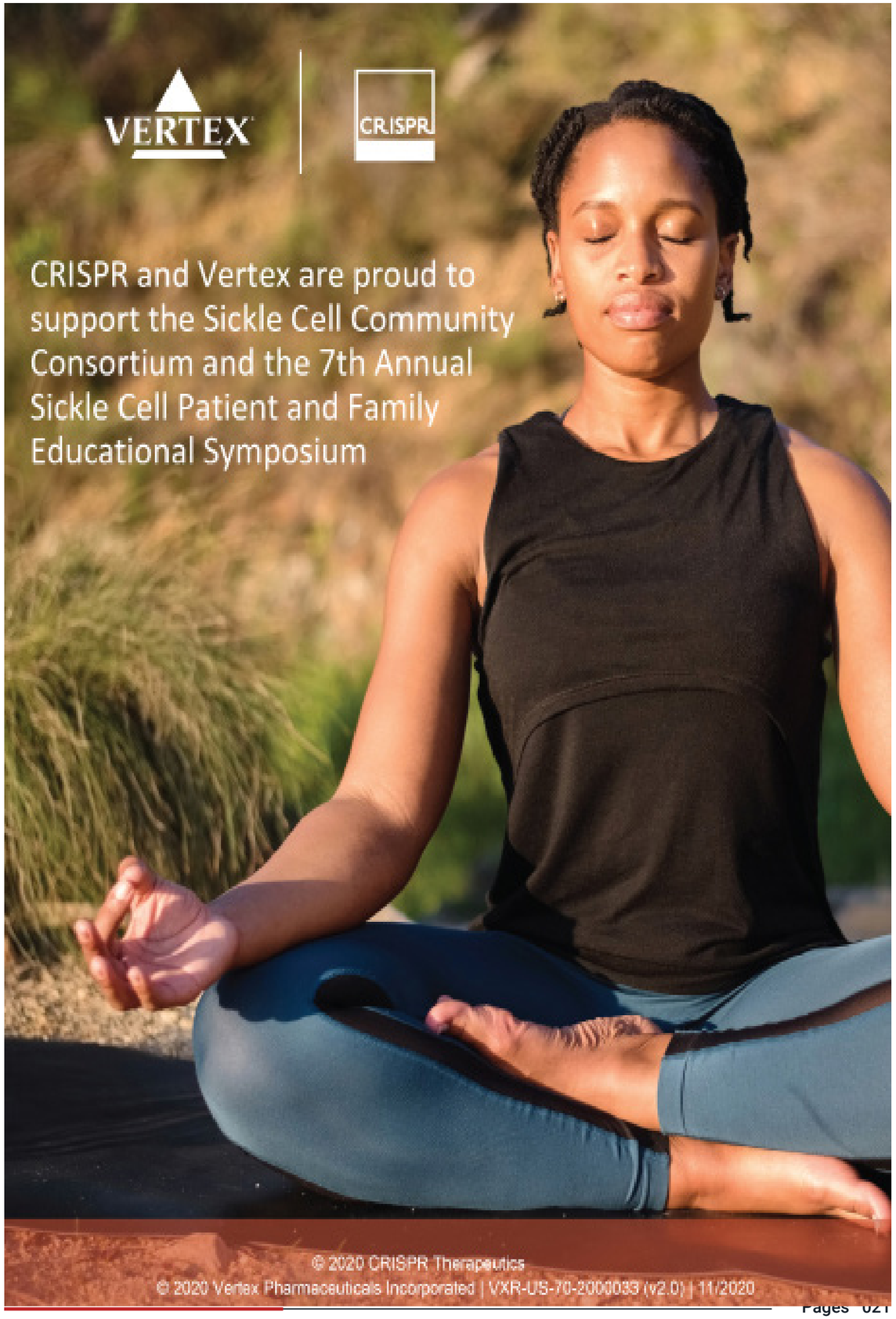
CANDYCE HEATHER
EDUCATOR

Warrior Fitness, Movement, & Bodybuilding

DR. MOUHAMED GUEYE
EDUCATOR

Warriors After Dark: Men

Bio in Back



AGENDA

SATURDAY & SUNDAY
NOVEMBER 21-22, 2020

04

11:00 AM — Morning Wellness
Hosted by Carol's Promise
Sickle Cell Foundation

Children's Track
The Nervous System

12:00 PM — Breakout Sessions

Sickle Cell Emergency Care

Men & Mental Health
An Open Forum Discussion

1:00 PM — Community Awards
Remarks By Title
Sponsor GBT

2:00 PM — Community Lunch & Learn
Sponsored By: Agios

Children's Track
The Digestive System

3:00 PM — The Caregiver Conversation
Parent-To-Parent

4:00 PM — Breakout Sessions

SCD Complications

Young Adult Track
Money Matters: Financial Literacy
For Young Adults

Trait Track
Genetics & Genotypes

5:00 PM — Paint & Chat

8:00 PM — Battle The Sexes: Sickle Cell Edition
Dating & Relationships

9:00 PM — Family Game Night

SUNDAY

1:00 PM — Close Of The 7th Annual Convention

SC3 Kids Meeting

05

All Times Are In Eastern Standard Time

sickle cell community consortium

Citizen Scientists

FAMILY TIME!

“HARNESSING THE POWER OF THE PATIENT & CAREGIVER VOICE”

sickle cell community consortium

Citizen Scientists

KENYA BUCKLEY
EDUCATOR

Morning Wellness

Bio in Back

DOMINIQUE FRIEND
MODERATOR

Sickle Cell
Emergency Care

Bio in Back

DR. JAMES ECKMAN
CONTENT EXPERT

Sickle Cell
Emergency Care

Bio in Back

DR. LAKIEA BAILEY
EDUCATOR

Sickle Cell
Emergency Care

Bio in Front

TYNISHA HALL
EDUCATOR

Sickle Cell
Emergency Care

Bio in Back

TOSIN OLA
EDUCATOR

Sickle Cell
Emergency Care

Bio in Back

DR. CORETTA JENERETTE
EDUCATOR

Sickle Cell
Emergency Care

Bio in Back

DEMITRIOUS WYANT
EDUCATOR

Sickle Cell Disease
Complications

Bio in Back

DR. CHRIS BOWDEN
EDUCATOR

Lunch & Learn
(Sponsored By Agios)

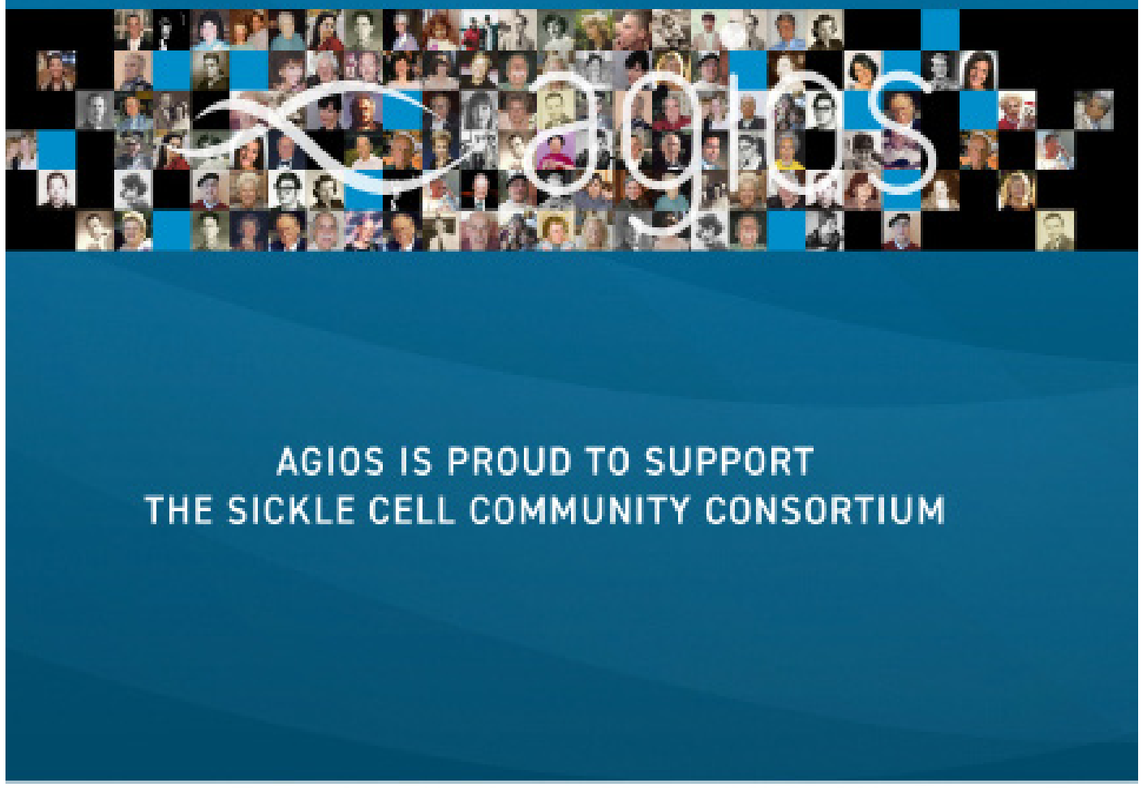
Bio in Back

DR. TOM WINKLER
EDUCATOR

Lunch & Learn
(Sponsored By Agios)

Bio in Back

Agios is passionately committed to transforming the lives of people living with sickle cell disease through our scientific leadership in PKR activation.

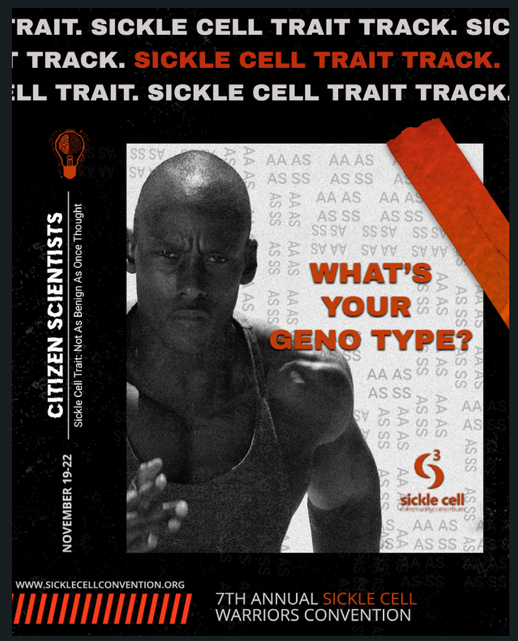


AGIOS IS PROUD TO SUPPORT
THE SICKLE CELL COMMUNITY CONSORTIUM

agios

www.agios.com

TRAIT TRACK



DR. TOMIA AUSTIN
COORDINATOR

Bio in Back

DEVARD DARLING
EDUCATOR

Athletes, Laborers, Caregivers
Bio in Back

DR. ALEX WASHINGTON
EDUCATOR

Physical Activity & SCT
Bio in Back

JAMIEE ROQUE
EDUCATOR

Athletes, Laborers, Caregivers

RITCHIE JOHNSON
EDUCATOR

Trait & RMC: The Kidney Connection
Bio in Back

FARRON D. DOZIER
EDUCATOR

SCT: Benign or Not?
Bio in Back

LISA ROSE
EDUCATOR

SCT: Benign or Not?
Bio in Back

HOSTED BY:

As One FOUNDATION

YOUNG ADULT TRACK

SPONSORED BY:

Chiesi
Global Rare Diseases

SHAMONICA WIGGINS
COORDINATOR

Bio in Back

OTHA MOBBS
EDUCATOR

Goal Setting
Bio in Back

LISA ROSE
EDUCATOR

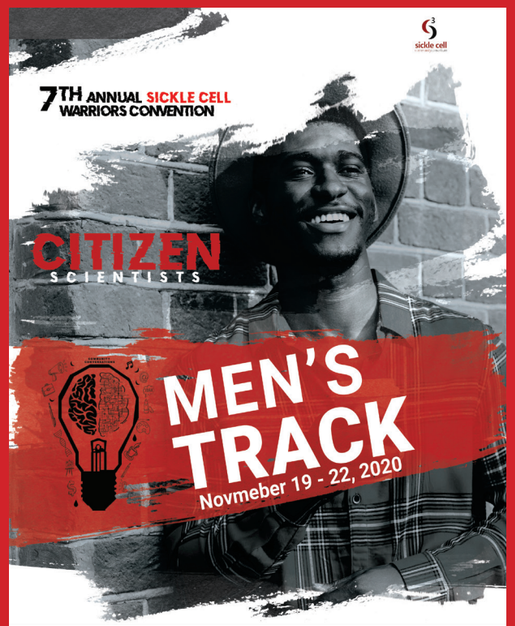
The Language of Pain
Bio in Back

VANESSA RHODES
EDUCATOR

The Language of Pain
Bio in Back

PHILLIP OKWO
EDUCATOR

Financial Planning



MEN TRACK

SPONSORED BY:

SANOFI GENZYME

CLAYTON ANDREWS
COORDINATOR
Bio in Back

DEMITRIOUS WYANT
EDUCATOR
Bio in Back

DR. MOUHAMED GUEYE
EDUCATOR
SANOFI GENZYME
Bio in Back

MARCUS MCKINLEY
EDUCATOR

CHARLY BLAKK
EDUCATOR
Bio in Back

CHILDREN'S TRACK

LISA ROSE
COORDINATOR
Bio in Back

VANESSA RHODES
EDUCATOR
Bio in Back

SPEAKERS & BIOS

PRE-CON
WEDNESDAY, NOVEMBER

STEPHANIE IBEMERE

EDUCATOR, THE TREATMENT OF SICKLE CELL PAIN

Stephanie Ibemere, PhD, RN is a postdoctoral fellow in the Duke School of Nursing. Dr. Ibemere received her PhD in Nursing Research from the University of Cincinnati. Dr. Ibemere is a registered nurse with experience in global health capacity building and clinical education related to sickle cell disease and other chronic diseases. Her research program focuses on building healthcare provider capacity to deliver high quality and effective care for chronic disease symptom management. Dr. Ibemere is passionate about addressing healthcare disparities in partnership with communities to co-create feasible and sustainable healthcare interventions for and with patients.

TAMIKA MOSELEY

MODERATOR, COMPLIMENTARY & ALTERNATIVE METHODS OF HEALTHCARE

Tamika Moseley, Founder of Everything Health LLC, US Veteran, Herbalist, published author, global speaker, sickle cell advocate, health & wellness consultant.

She's a member of the Holistic Chamber of Commerce and the project manager for Healing Blends Global, a company whose focus is to improve the quality of health and life for individuals, families, and communities around the globe.

Because she has faced multiple chronic health conditions in her life involving herself and her son, she has a huge passion to help others become healthy and overcome their illnesses. She wants to share her amazing story with the world, especially those who suffers from sickle cell disease. After watching her son suffer with so much pain, she realized it was a better way; and through her extensive research, knowledge and expertise using natural herbs, and proper nutrition, her son has not had a crisis in 10 years.

Tamika's current focus is aiding the sickle cell battle in Africa, where the disease is so prominent, also bringing awareness to other chronic diseases and educating on how to manage, prevent and reverse health challenges. Her main goal is to provide education, guidance and useful information on the importance of natural herbs and nutrition and how they can help sustain our health while living on this earth. Tamika, her husband Rodney, and their three beautiful

EMILY O'SHEA

EDUCATOR, COPING WITH PAIN IN THE PANDEMIC
PRACTICAL STRATEGIES TO MANAGE STRESS

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.

DR. CAROLYN ROWLEY

EDUCATOR, NUTRITION & SICKLE CELL DISEASE

Dr. Rowley holds a Bachelor's and Master's degree in Psychology from Loyola Marymount University, a Ph.D. from Southern Illinois University at Carbondale, a nutrition certificate from Trinity College and is working on obtaining a Doctor of Naturopathic Medicine (ND) degree.

Dr. Rowley has teaching experience from Southern Illinois University at Carbondale (SIU-C), CSU Channel Islands, Alliant University, and currently teaches at UCLA Extension. Dr. Rowley has devoted 50% of her clinical psychology practice to the needs of children, adults, and their families with sickle cell disease. She is a committed environmentalist and vegan and has brought an understanding of the importance of nutrition in dealing with sickle cell disease. She has served as a panel member for a number of forums for the general public and for medical professionals regarding successful living with sickle cell disease.

Dr. Rowley was also a regular guest host on an award-winning cable show - Talk About Parenting with Shirlee Smith. In her efforts to bring about awareness about sickle cell disease, Dr. Rowley is spearheading 'The Faces of Sickle Cell Disease: An Educational Traveling Photo Exhibit' which encompasses photographing 500 persons with sickle cell disease across the United States. In 2007, Dr. Rowley was awarded Person of the Year for the at the NIH (National Institute of Health) / Sickle Cell Disease Association of America, Inc. 35th Annual Convention held in Washington, D.C.

As a result of travels to Kenya, Dr. Rowley desires her legacy to be a collaboration with the U.S. and Kenya to create a surveillance program, newborn screening, access to treatment, and best practices for the management and treatment of sickle cell disease.

THURSDAY, NOVEMBER 19

DR. TOMIA AUSTIN

COORDINATOR OF TRAIT TRACK

Tomia Austin, DrPH, 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 health effects such as exertional sickling. Under Dr. Austin's leadership a new mission to empower families globally, delivering life-saving sickle cell education now describes the organization's intentional provision of comprehensive sickle cell trait and sickle cell disease educational tools, curriculum, events and programming.

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

MODERATOR, WHAT IS A CURE?

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.

ANNA DESALVO

EDUCATOR (BE THE MATCH)

Anna is a board certified and licensed genetic counselor and Senior Clinical Trials Patient Navigator with the Clinical Trials Search and Support program which is operated by the National Marrow Donor Program (Be The Match). Before joining Be The Match, Anna worked in multiple different clinical settings including general genetics and oncology. She is a part of the Sickle Cell Disease Coalition Research & Clinical Trials Working Group and the American Cancer Society Clinical Trial Eligibility Workgroup. Anna received her Masters of Science in Genetic Counseling from the Icahn School of Medicine at Mount Sinai in New York, NY.

FARRON D. DOZIER

EDUCATOR OF TRAIT TRACK

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. 2010 the Medical Board process started and in 2013 I was Medical Retired from the United States Army due to Exertional Sickling with Rhabdomyolysis and Arthritis.

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. Creator/ Curriculum writer of Sickle Cell Traits Course being taught at 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. 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. The 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.

Graduate of both Radio and Television Academy at the Academy of Radio and Television Broadcasting in Huntington Beach, CA 2016 & 2019.

Owner of the Oxnard Orcas Professional American Basketball Association Team dedicated to bring Awareness to Sickle Cell Trait, Sickle Cell, Veterans and Youth Critical Thinking Skills

CHARISSE FISHER

MORNING WELLNESS

Charisse started her healing journey in 2008 primarily volunteering her time to those in need and eventually creating a nonprofit to extend her healing energy and give to those fighting homelessness. After observing human behavior and studying history, Charisse started her journey to study mental wellness.

Charisse has become a Spiritual Life Coach minoring in psychology and pursuing her degree to become a Licensed Professional Counselor, LPC. Her journey has led her to heal the mind+body+soul with a holistic approach.

Spiritual Journey

Charisse's spiritual journey started after her third eye was opened to the truths of the universe and her intuitive abilities. Since then she has experienced a tremendous amount of success and support. In 2020 she created Vibe Tribe as a platform to offer a spiritual and sacred space for those searching for their soul tribe and holistic wellness needs. Although Charisse has a focus on the Black Community she sends Love and Light to all of humanity. She is a healer to

CANDYCE HEATHER

EDUCATOR, COMPLIMENTARY & ALTERNATIVE METHODS OF HEALTHCARE

Candyce Heather is native of New York, born with Sickle Cell Disease. Doctors told her mother that she would not live past a year old. Her fighting spirit, perseverance, and fortitude proved otherwise! As a little girl her mother enrolled her in dance and her passion for dance blossomed into a fruitful career spanning over a decade. Touring the world with various recording artist she faced many health challenges which inspired her to become a certified holistic health coach and personal trainer.

She became her very first client and through years of experience and turning her obstacles into adversity she found her purpose. Her mission is to be able to help empower others to live life powerfully and THRIVE through her holistic approach to fitness, nutrition, and mindset coaching.

BILAN JAMA

EDUCATOR (BE THE MATCH)

Bilan Jama is Patient Navigator in the Patient Support Center at Be The Match, and has been with the organization for 5 years. She works one-on-one with patients, caregivers, and health professionals to identify barriers to care and works to alleviate them for the patient by referring them to internal and external resources. While at Be The Match, Bilan has worked to improve programs including the Caregiver Companion Program, BMT Survivorship Chats, and Patient Grants Program. Bilan graduated from the University of Minnesota with a Masters in Social Work.

DR. RAYMONA LAWRENCE

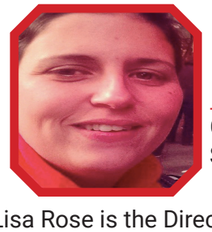
EDUCATOR, MORNING WELLNESS, & COOKING W/ WARRIORS; PRE-RECORDED

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.

VANESSA RHODES

EDUCATOR; CHILDREN'S TRACK

Vanessa is a mother of a warrior, an advocate, 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 home-schooled her children when they were young. Currently she consults schools and homeschooling families about curriculum development. This is Vanessa's 5th year as co-teacher for the Children's Track.



LISA ROSE

CHILDREN'S TRACK COORDINATOR, MODERATOR, SICKLE SCIENCE: BEYOND THE RED BLOOD CELL

Lisa Rose is the Director of Curriculum and Design for The As One Foundation, an organization focused solely on providing research based medical education around Sickle Cell Trait and Disease. She has a Master's Degree in Education as well as a Bachelor's Degree in Social Work and Psychology. Lisa has been developing curricula and trainings for a myriad of companies for over 15 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. Formerly with HOPE for SCD, Lisa's work has reached international audiences within 73 countries. Her professional passion lies in developing educational materials for those both within and beyond the sickle cell community in an effort to make sickle cell as household name. Lisa is also the mother of two sickle cell warriors- 11 year old Sophia and 1 year old John Patrick. These two have been and will always be the driving motivation for Lisa and her work in sickle cell education.

DR. LAMETRA SCOTT

EDUCATOR, COMPLIMENTARY & ALTERNATIVE METHODS OF HEALTHCARE

Dr. Scott is the Founder/CEO of the non-profit organization Breaking The SSickle Cell Cycle Foundation, Inc., a pharmacy consultant, and mother of a child with sickle cell disease. Dr. Scott has worked in pharmacy for 20 years. Over the last 10 years, she has worked in managed care pharmacy assisting organizations with developing strategies to provide cost-effective pharmaceutical care and improving patient outcomes. As a caregiver and healthcare professional, Dr. Scott understands the challenges associated with treating complex conditions like sickle cell disease. In 2015, Dr. Scott decided to leverage her experiences in managed care and community pharmacy and founded a non-profit for sickle cell disease which focuses on promoting community awareness, education, and prevention of sickle cell disease. Dr. Scott has led numerous outreach efforts to educate the community and other healthcare professionals about sickle cell disease.

Dr. Scott has been recognized for her involvement in sickle cell advocacy. She was featured in the in-augural edition of PharmaSis Magazine- a magazine that celebrates women in pharmacy, featured on the CDC's website " Real Stories from People Living with Sickle Cell Disease" and she is also a Power Moves Award recipient, an honor that is awarded to "Ordinary people doing EXTRAordinary things" in the community. Dr. Scott contributes to student pharmacist academic development and conducts didactic presentations on sickle cell disease at both the University of TN and Lipscomb College of Pharmacy.

Dr. Scott obtained her Doctorate of Pharmacy degree (PharmD) from the University of Tennessee College of Pharmacy and she also holds a Bachelor of Science degree in Biology from the University of Memphis. She believes patient engagement and inclusion is key to developing best practices for providing care to sickle cell patients. Her contributions have been published in the Journal of Health Care for the Poor and Underserved.

DR. SANDEEP SONI

EDUCATOR (CRISPR/VERTEX)

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 YI 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.

DR. ALEXANDRIA WASHINGTON

EDUCATOR OF TRAIT TRACK

Dr. Alexandria Washington is the Founder and Chief Strategist of Change The Narrative, LLC; a health education and advocacy company specializing in creating culturally relevant health products. As an award-winning health advocate, her work has been featured in Tallahassee Democrat, Capital Outlook, and Forbes. Her dedication to her local community also resulted in her receiving a Golden ACE from the Tallahassee Network of Young Professionals and being named one of Tallahassee's 25 Women You Need to Know. A tried and true rattler, Dr. Washington received her Bachelor of Science degree in Health Science, Master of Public Health, and Doctor of Public Health degree from Florida Agricultural and Mechanical University.

DEMITRIOUS WYANT

EDUCATOR, COOKING W/ WARRIORS, BATTLE OF THE SEXES, SCD COMPLICATIONS

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

Novartis Oncology

Novartis proudly joins Sickle Cell Community and the 7th Annual Warriors Convention

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.

NOVARTIS

Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936-1080 | [illegible] Novartis | 7/[illegible] | T-[illegible]

SPEAKERS & BIOS

CONTINUED

FRIDAY, NOVEMBER 20

CLAYTON ANDREWS

COORDINATOR OF MEN'S TRACK, EDUCATOR

Clayton Andrews is a 38-year-old mental health professional, living with Sickle Cell Disease, residing in Savannah GA. An advocate, mentor and father of four, Clayton is a Licensed Professional Counselor 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 Champions Men's Action Network (SC M.A.N.), formerly the Sickle Cell Champions Association (SCCA), a mentoring organization geared and designed for the guidance and empowerment of young males with Sickle Cell Disease into their transition into adulthood. SC M.A.N. places 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, especially 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 five years as a Forensic Behavioral Health Counselor and Treatment Team Facilitator with the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD). Currently, he is a Clinical Supervisor with Spectrum Health Systems, where he is accountable for the provision of guidance and supervision for the facilitation of substance abuse counseling for clients within the prison population. He is currently in the process of pursuing his Doctorate to further expand his effectiveness. Clayton also serves as the project coordinator of the Sickle Cell Mental Health Initiative.

Clayton is the proud father of three daughters, all of whom have Sickle Cell Trait and a teenage 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 role in co-organizing with No Pain in the Playroom for The Playroom Talent Showcase and Online Auction at the 2017 SCD Family and Patient Educational Symposium, involvement in the S.C.C.A. "Mentoring Workshop" in 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)."

DR. KENNETH BRIDGES

GBT, TITLE SPONSOR
FRIDAY LUNCH & LEARN

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.

STEPHANIE BROUSSARD

EDUCATOR, THE MENTAL HEALTH CONVERSATION

Sharing time and space with individuals and families during their most difficult days has given Stephanie a sincere and unique perspective of life. This is evident in her rare ability to aide individuals as they navigate the complexities of living life while simultaneously providing support to others during their final days. Stephanie shares her passion for life and the pursuit of purpose at every available opportunity.

Stephanie Broadnax Broussard is a Licensed Clinical Social Worker(LCSW), Advanced Certified Hospice and Palliative Care Social Worker(ACHP-SW), and a Certified Advanced Care Planning Facilitator and Trainer. A proud Louisiana native, she is a graduate of Louisiana Tech University and continued to the University of Texas at Arlington, where she received her Master's degree. Stephanie is the Director of Palliative Care and Social Work in a Community Oncology practice and a therapist in a Private Practice.

While others avoid uncomfortable moments, Stephanie enjoys educating the community and other clinicians on the importance of communication and having difficult conversations while equipping them with the necessary skills. Recognizing the impact and the weight of life's transitions and being saddened by seeing others miss the opportunities of beauty and hope even within those most challenging times inspired Stephanie to speak and share intentional, powerful messages about purposeful living.

CARLEY "ELLE" COLE CAVINS

EDUCATOR; THE MENTAL HEALTH CONVERSATION, PRE-RECORDED

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 Cleverly Changing.

LAURA CRUZ, SPEAKER

GBT, TITILE SPONSOR
YOUNG ADULT KICK BACK

Laura Cruz is the Vice President of Marketing at GBT. She has spent her career focused on communicating health information to healthcare providers and patients. Prior to joining GBT, she launched numerous pharmaceutical products in HIV, Dermatology, and Cardiovascular Disease. She has held senior positions at Pfizer, Gilead Sciences and most recently GBT. Her passion is empowering communities of color with the right information to allow them to champion their health care choices and live healthier lives. "Communities of color disproportionately experience a burden of health challenges due to social, financial, language, and other barriers that have a lasting impact on families and future generations. This needs to change."

Laura lives in Colorado with her husband and enjoys the mountains, skiing, cooking, and spending time with family and friends. She considers it a privilege to work with the amazing team at GBT and to serve the Sickle Cell community.

DEVARD DARLING

TRAIT TRACK; PHYSICAL ACTIVITY & SICKLE CELL TRAIT

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.

DR. JAMES ECKMAN

EDUCATOR, CONTENT EXPERT; SICKLE SCIENCE: BEYOND THE RED BLOOD CELL; SICKLE CELL EMERGENCY CARE; DISEASE COMPLICATIONS, PRE-RECORDED

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.

DR. MOUHAMED GUEYE

EDUCATOR; WARRIORS AFTER DARK, MEN

Dr. Mouhamed Gueye is currently the Vice-President Global Medical Head, Rare Blood Disorders at Sanofi Genzyme, a Fortune 500 Company and one of the leading pharmaceutical organizations in the world. Prior to joining Sanofi Genzyme, Mouhamed lived in Switzerland and was the Medial Head of Europe for Hematology and Rare Disease with another pharmaceutical giant Roche.

Mouhamed earned a Pharm.D. from Texas Southern University, and an MBA from Boston College. He currently lives in Milton, MA with his family and in his spare time, he enjoys chasing after his three children, watching the real football (soccer), cooking Sunday brunch, and practicing Karate. He is also a proud member of Kappa Alpha Psi Fraternity Inc.

CHESTER HALL

TRAIT TRACK; EDUCATOR

Growing up, Dom Ali was very active in sports and martial arts. Dom was diagnosed in 2011 with having Sickle Cell Trait by his adult primary care physician. Ten years ago he created the Sickle Cell Trait Journal on Facebook to locate more people with sickle cell trait with the same experiences. Dom enjoyed playing adult amateur football for a decade in Wisconsin and previously coached in high school football, college club football, a youth fundamental football camp for the Green Bay Packers and men's adult amateur football and women's adult amateur football. While seeing his 4th hematologist-oncologist he was retested and diagnosed with having a positive test for Hb Beta Chain-related Hemoglobinopathy (Including Beta Thalassemia and Sickle Cell Disease) a carrier at risk for symptoms. Today he's a human rights defender.

RITCHIE JOHNSON

TRAIT TRACK; SCT & RMC: THE KIDNEY CONNECTION

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 Heath 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.

DR. CHARLES JONASSAINT

EDUCATOR; PRE-RECORDED

Dr. Jonassaint's overarching career goal is to eliminate health disparities by designing, developing and disseminating, trial tested, evidence-based behavioral interventions to underserved populations. More specifically, his research will lead to a better understanding of the psychological and biobehavioral factors that underlie socioeconomic and racial health disparities, and the design of mobile technology-based behavioral interventions that can be used to reach underserved populations. His specialties include mHealth, health psychology, behavioral medicine, sickle cell disease, minority health, personality, and stress & coping.

DR. PETER LANE

EDUCATOR, PRE-RECORDED

Peter A Lane, MD is a pediatric hematologist with expertise in newborn screening and treatment of sickle cell disease. Dr. Lane received his undergraduate degree from Columbia University in New York City and his MD from the University of Cincinnati. After completing residency and fellowship training at the University of Colorado and University of California-San Francisco, he worked for 15 years at the University of Colorado School of Medicine in Denver, where he served as Director of the Colorado Sickle Cell Treatment and Research Center. In 2002, Dr. Lane joined the faculty at Emory School of Medicine, where he is currently Professor of Pediatrics and Director of Sickle Cell Disease Program at Children's Healthcare of Atlanta, the largest pediatric sickle cell program in the country.

Dr. Lane has provided consultation about newborn screening and about approaches to improving the quality of healthcare for patients with SCD to the American Academy of Pediatrics, the federal Maternal and Child Health Bureau, and to public health agencies in the U.S. and abroad. Dr. Lane has been a member of the Medical and Research Advisory Committee of the Sickle Cell Disease Association of America, and former Chair of Sickle Cell Disease Advisory Committee at the National Institutes of Health. He is currently one of the co-leads in Georgia for southeast regional HRSA EMBRACE Network, that has partnered with the Sickle Cell Community Consortium to provide this summer's series of Warrior University's Educational Webinar Courses.

MARCUS MCKINLEY

EDUCATOR; MEN'S TRACK

I am Marcus McKinley, a 34 year old male entrepreneaur 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 hospitilization. I have endured many, many hospitilizations, 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.

OTHA MOBBS

EDUCATOR, YOUNG ADULT TRACK; GOAL SETTING

As a confident trailblazer Otha Mobbs, uses not only his education but personal experiences and passions to assists his clients in identifying what they truly want in their lives. He takes a relationship based approach in his coaching, focusing on each client's assets and unique values to help them understand what is and isn't lining up with those values. Using creative techniques, he supports his clients in creating goals and strategies for living a life that is genuinely meaningful and purposeful.

Otha stands tall as a living example of success through persistence and sacrifice. An advocate for Sickle Cell awareness, he shares is triumphs as a survivor himself and uses his personal journey through losing both parents at a young age to empower and motivate his clients to remain dedicated to their dreams despite life's uncontrollable challenges. Through his involvement with performing arts, he has also supported many artists in developing projects that reflected their unique voice and vision. As a masterful speaker, Otha uses the arts to capture the attention of youth and also implements his skills as a financial advisor to support more mature and professional audiences as well. Remaining versatile, he promotes belief and passion that one must follow their hearts and realize their strengths and creative abilities led him to pursue a career in life coaching. Otha instills the belief that each person who lives authentically and passionately offers their unique gifts to the world, allows us all the opportunity to purposeful living and a meaningful legacy.

TOSIN OLA

EDUCATOR; SICKLE CELL EMERGENCY CARE, PRE-RECORDED

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, first launched the Sickle Cell Blog in 2005 to bond with others and subsequently created the Sickle Cell Warriors website, a clearinghouse of education designed to raise public awareness, empower patients, 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 much more.

Tosin has worked as a registered nurse in healthcare for over 16 years, with 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.

Ms. Ola is honored to have been the recipient of numerous awards, honors, and recognition for her relentless and dedicated advocacy for patients and families living with sickle cell disease, including Top Advocate in SCD by the NHLBI, Nurse of the Year by the State of Oregon, Activist of the Year by WegoHealth, and Patient Advocacy Award from Wellsphere.

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. In 2020, despite COVID19 interruption of plans, Tosin graduated with a Master's Degree in Nursing and Master's Degree in Business Administration with an emphasis in Healthcare Management. Tosin 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 San Diego, California with her spouse and twin boys.

DR. GAYLE ROGERS

EDUCATOR; THE MENTAL HEALTH CONVERSATION, PRE-RECORDED

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.

JAMIE ROQUE

EDUCATOR; TRAIT TRACK

Jaimee Roque is a mother of two sons with Sickle Cell Hemoglobin E Disease (SE) and a daughter with Hemoglobin E trait. She has been active in the Sickle Cell community since 2015 and is the founder of DFW Sickle Cell Kids Crew, an organization in the Dallas Ft Worth area that aims to create an environment that fosters relationships with others who understand life with Sickle Cell, recognizes siblings and children of Warriors as champions of awareness in the making, while providing parents with tools, resources, education, and support to build up the next generation of advocates.

MIKAYA WARREN

MAKE-UP ARTIST; BEAUTY WITHIN SICKLE CELL

Mikaya D. Warren – a woman of many talents, who holds many titles, is a woman on a mission! As a wife, mother of 4, model, public speaker, image consultant, model development coach and makeup artist, Mikaya has faced many challenges in life and has dealt with her share of obstacles, fear and feelings of low self-worth. From just a young child, Mikaya always displayed a love for all things beauty. She enjoyed styling hair, playing in makeup, and exploring style and fashion!

For the last decade, Mikaya Dionne has been an inspiring, game changing staple in her hometown community- Tallahassee, FL and beyond. Beginning her career as a model at age 12, Mikaya has walked the runway for countless high fashion shows including New York Fashion Week and designers including world renowned Nino Lettieri, Archana Kocchar and several others. Mikaya is the first model with alopecia to grace the New York Fashion Week stage. Mikaya has posed for countless photographers and has been published in several magazines, books, media, and news outlets. Throughout her career and her history of overcoming trying times with her experience with hair loss, she has since embraced her passion for empowering women to feel and look their best in total confidence.

Mikaya established an organization (My B.A.L.D. Is Beautiful, Inc.) in support and promotion of self-confidence and acceptance among women in the hair loss community. Living with hair loss, her journey to find herself and her confidence, independent of her hair and regardless of society's thoughts, incited a strong passion to help women do the same. Because of the culmination of these career and life experiences, Mikaya is well grounded and possesses an undeniable ability to connect with and empower women in the areas of self-image, beauty, and self presentation. Mikaya is also owner and CEO of Mikaya Dionne Enterprises-a boutique consulting firm offering makeup artistry and instruction, skincare education, image consulting, wardrobe styling, confidence coaching and women's empowerment. Most recently, Mikaya established a modeling agency- The Mikaya Dionne Agency where she trains and develops models and helps to facilitate sustaining careers in the modeling industry.

DR. AHMAR ZAIDI

EDUCATOR; SICKLE SCIENCE: BEYOND THE RED BLOOD CELL, SICKLE CELL EMERGENCY CARE; PRE-RECORDED

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.

SATURDAY, NOVEMBER 20

DR. CHRIS BOWDEN

EDUCATOR; LUNCH & LEARN, AGIOS

Dr. Bowden joined Agios as chief medical officer in May 2014. He has more than 18 years of experience in clinical drug development, including the approval of several cancer medicines. Prior to joining Agios, Dr. Bowden was vice president product development oncology, franchise lead (Signaling Group) at Genentech, Inc., a member of the Roche Group. During Dr. Bowden's eight years at Genentech, he was responsible for the successful development of a number of novel targeted oncology medicines, including Zelboraf™ for patients with BRAF V600E positive melanoma and Tarceva™ for patients with EGFr activating mutation positive, non-small cell lung cancer. From 2003 to 2006, Dr. Bowden was the executive director for EMEA (Europe, Middle East, Africa) regions for Bristol-Myers Squibb. In this role, he led medical affairs strategies for cancer, immunology and pain medicines. Earlier, Dr. Bowden held positions of increasing responsibility in oncology clinical development, Phases I-III at Pharmacia Corporation and Janssen Pharmaceutical, Inc. Prior to his industry experience, Dr. Bowden was on the oncology faculty at the University of Virginia Health Science Center where he participated in numerous industry and cooperative group trials. Dr. Bowden received his medical degree from Hahnemann University School of Medicine in Philadelphia followed by internal medicine training at Roger Williams Medical Center and the Providence VA Medical Center, Rhode Island. He completed his medical oncology fellowship at the National Cancer Institute Medicine Branch. Dr. Bowden is board certified in internal medicine and medical oncology, and he serves on the board of directors at miRagen Therapeutics and Ziopharm Oncology.

KENYA BUCKLEY

MORNING WELLNESS, CAROL'S PROMISE

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.

ANDREA CRENSHAW

MORNING WELLNESS

Andrea Crenshaw is a Strategic Finance professional turned Wellness Champion, after experiencing and evaluating the impact that wellness has on quality of life and personal peak performance. Her zeal for wellness led her to become a NASM Certified Personal Trainer and Certified Nutrition Coach.

She believes that to truly stimulate and sustain an achievable state of wellness, one must consider a holistic approach. Through her own experiences, science and fact-based research, and connections with others, Andrea has uniquely combined elements of mental, physical, and relational components in her solutions.

She is passionate about the power of mindset, nutrition & fitness techniques as it relates to improving immunity and building resilience in personal wellness and peak performance.

Andrea loves to effect positive change to not only improve performance personally, but also institutionally, in business and in life. One of her proudest accomplishments was creating a Supplier Diversity program for a Fortune 500 company in order to promote corporate responsibility and stimulate economic growth in underserved communities.

What brings her the most energy is "kindly" challenging people to try nutritious foods and simplistic resourceful tactics to outperform themselves in their personal health journey. She's known to turn into "Coach Bink" when running high intensity fitness challenges, as she's relentless in serving you an experience of your own transformation. Her goal over the next year is to bring awareness to the power of simple techniques to drive massive momentum in quality of life and wellness performance through her actionable strategies.

DR. CORETTA JENERETTE

EDUCATOR; PRE-RECORDED

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.

DR. LYDIA PECKER

SICKLE CELL DISEASE COMPLICATIONS, PRE-RECORDED

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.

DR. SHANNON PHILLIPS

EDUCATOR; SICKLE CELL DISEASE COMPLICATIONS, PRE-RECORDED

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.

CHARLY "BLAKK" RICHARD

MEN'S TRACK & BATTLE OF SEXES

Charly (BlaKk) Richard, artist, advocate, & entrepreneur was born and raised in Miami, Florida. As a kid growing up, he dreamed of playing in the NBA. Due to having early complications of Sickle Cell Anemia, it permitted him from pursing his ultimate goal. In 2008, he relocated to Atlanta, Georgia and began his life there. Awarded with the National Honors Technical Society and placed on the Dean's list, he graduated from Fortis College with an IT degree. He started his career at an IT firm where his role in the company was to remotely diagnose Lenovo products. He eventually discovered a passion in music and decided to use his talents to advocate in the sickle cell community. With his song, "Sickle Cell Suvivor" he was able to become that beacon of light for many lives who didn't have anyone to advocate for them. It grew so much traction where he was blessed with opportunities to perform the song. In March of 2020, he started his own company "C. Richard Enterprises". As CEO, his motto is to build a franchise where it can impact so many lives who are facing financial hardships by educating them in credit repairing and offer up tips on starting an entry level profession. His ultimate goal is to show people that there's no limitations when it comes to finding purpose in life. One of his favorite quotes are, "Just because we're sick in our health, doesn't mean we're sick in our minds!"

MIA ROBINSON

PAINT & CHAT

Mia Robinson is a 37 year old Atlanta, GA native who lives with Sickle Cell Hemoglobin C disease. Mia has been a devoted mentor and advocate for people with Sickle Cell disease for nearly 20 years. She is the co-founder of a non-profit called, Sickle Cell Awareness 365 (SCA365). They work closely with the Children's Healthcare of Atlanta and the Sickle Cell Foundation of GA on multiple projects including participating in transition workshops that teach teens and their parents about going into adult care and the creative arts classes at the annual camp for children with Sickle Cell disease. We also host events such as our Paint Away The Pain events which mimic sip and paint sessions. Mia uses many different forms of art to express herself and distract her from pain. The Paint Away the Pain session introduces people to this self-care technique to implement when they aren't feeling their best whether it's physical or emotional pain or just feeling creative.

TAYO TOGBA

EDUCATOR, PRE-RECORDED

Tayo Togba born in the city of New York, raised in Atlanta Ga. and is currently Co-owner and COO of JHC Healthcare a family home healthcare service. At birth she was diagnosed with Sickle Cell Beta Thal, inspired by her journey with sickle cell and her experience in the healthcare field. She became active in the wellness community and became a Certified Mindful Practitioner and created Selfish Joy, an organization committed to helping others gain knowledge of the importance of self care with chronic illness while normalizing conversations about Mental Health. Tayo Togba adds a unique perspective, strong faith, and inspirational work ethic to her community. She began to pour back into the community through her work with the Sickle Cell Foundation of Georgia where she served on the Leadership Development Team for over 8 years. Tayo has been recognized with the 21st Century Leadership award, Sickle Cell Foundation, "Volunteer of the year", Lockhart Morgan Foundation "Strong enough to live" it award, Morehouse School of Medicine "Effective SP" award, and serves as a Civic Leader with Hands on Atlanta " she continue to serve her community through various activity.

THOMAS WINKLER

EDUCATOR; LUNCH & LEARN, AGIOS

Dr. Winkler joined Agios in May 2018 after spending more than 10 years as a physician scientist at the National Institutes of Health (NIH), Bethesda, MD, focusing on basic and clinical studies to improve the treatment of patients with various blood diseases, including sickle cell disease. Following a clinical fellowship at the University of Cape Town, South Africa and a research scholarship at the Dana-Farber Cancer Institute, Harvard Medical School, Boston, MA, Dr. Winkler received his medical and doctoral degree from Hanover Medical School in Germany, where he also completed his training in Internal Medicine as well as in Hematology and Oncology before joining the NIH as a postdoctoral fellow in 2007. During his training and faculty appointments, Dr. Winkler, participated in and led numerous industry, cooperative group or investigator initiated trials.

CONVENTION PARTICIPANTS

DR. BIREE ANDERMARIAM
COVID-19,
PRE-RECORDED

DR. MICHAEL DEBAUN
SICKLE CELL
EMERGENCY CARE,
PRE-RECORDED

ASHLEY DEOMINGUE
MAKE-UP ARTIST
BEAUTY WITHIN
SICKLE CELL

BLAZE EPPINGER
HEALTHY COOKING
W/ WARRIORS

DR. TITILOPE FASIPE
PRE-RECORDED

DR. CAROLINE FREIERMUTH
SICKLE CELL
EMERGENCY CARE,
PRE-RECORDED

JEL GLASS
MAKE-UP ARTIST
BEAUTY WITHIN
SICKLE CELL

DR. PATRICIA KAVANAUGH
SICKLE CELL
EMERGENCY CARE,
PRE-RECORDED

KIARRA ROSEBURGH
MAKE-UP ARTIST
BEAUTY WITHIN
SICKLE CELL

ADRIENNE SHAPIRO
PRE-RECORDED

CHRIS SMITH
WARRIOR FITNESS

MARISSA VEGA
PAINT & CHAT

MEET THE TEAM

STAFF & COMMITTEE

DORIS BAILEY
ASSOC. DIRECTOR OF FINANCE

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.

ERIC FREMPONG
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.

DOMINIQUE FRIEND
GENERAL ASSEMBLY PRESIDENT

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 Sickle International Family Coalition, an international network of families, individuals and organizations.

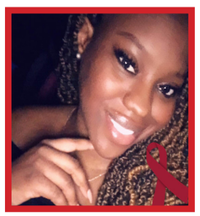
DOMINIQUE GOODSON
DEAN OF WARRIOR UNIVERSITY

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 few years equipping, empowering and encouraging the community. She has also been working with many Sickle Cell Community Based Organizations to lend a voice and bring about a much needed change.

JANEEN GREENE
EVENTS COORDINATOR

A 28 year 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!



TYNISHA HALL
GENERAL ASSEMBLY SECRETARY

Tynisha Hall was 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. 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."

YOLANDA LEWIS
ADMINISTRATOR

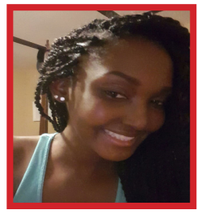
Yolanda Lewis is an advocate at heart who uses her diverse background to minister, mentor and educate within her multiple spheres of influence. Her heart for people extends into a role as a mentor mom, as well as providing one-on-one encouragement to those experiencing difficulties in life. Yolanda's advocacy is really on display within the Sickle Cell Disease community as she provides support and embraces the opportunities of connecting with her local political representatives. Yolanda has created a series of educational videos for parents of children with sickle cell. Yolanda is currently the Executive Administrator for the Sickle Cell Consortium. She also serves as Secretary of the Black Ministers Conference of Montgomery, Maryland. As a wife, mother of four, and caregiver of a child with sickle cell anemia, 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 and quality of life.

MARIA RIVERA
SPECIAL PROJECTS COORDINATOR

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
DIRECTOR OF OPERATIONS

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.



ALEXIS 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
SOCIAL MEDIA MANAGER

Shamonica Wiggins is a 31-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. Currently, Ms. Wiggins is the Media-Marketing Intern for the Sickle Cell Community Consortium. 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 9-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. Shamonica refuses to stop being a voice for her people until she sees the changes that sickle cell warriors so desperately need.

SHELFINA WILKINS
PARTNERS COMMUNICATION LIASON

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 lace 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.

ANDREW LEWIS
IT INTERN

Andrew Lewis is currently pursuing an Associate Applied Science Degree in Cyber Security at a local community college. His experience includes a year and a half of employment as a customer service representative at Micro Center Computers & Electronics. This allowed him the opportunity to learn more about the different technologies that are available commercially. In addition, it provided him with an avenue to expand upon the previous knowledge and experience pertaining to computers, tablets, mobile devices and more. In his free time Andrew has moderated for a small Twitch stream, with viewership ranging from 40-100+ participants, as well as multiple Discord servers. Andrew is also a caregiver of a sibling living with Sickle Cell Anemia.

CHOLE ROSE
CHILDREN'S TRACK INTERN

Chloe is a Trait warrior that enjoys working on all things related to film and technology. She has a passion for baking, comedy, and set design and is currently studying the latter in school. She is the children's track intern this year and is assisting with all set up and prep work leading up to convention day. She is also the sister of two sickle cell warriors, Sophia and John Patrick and loves to sing to them when they are not feeling well.

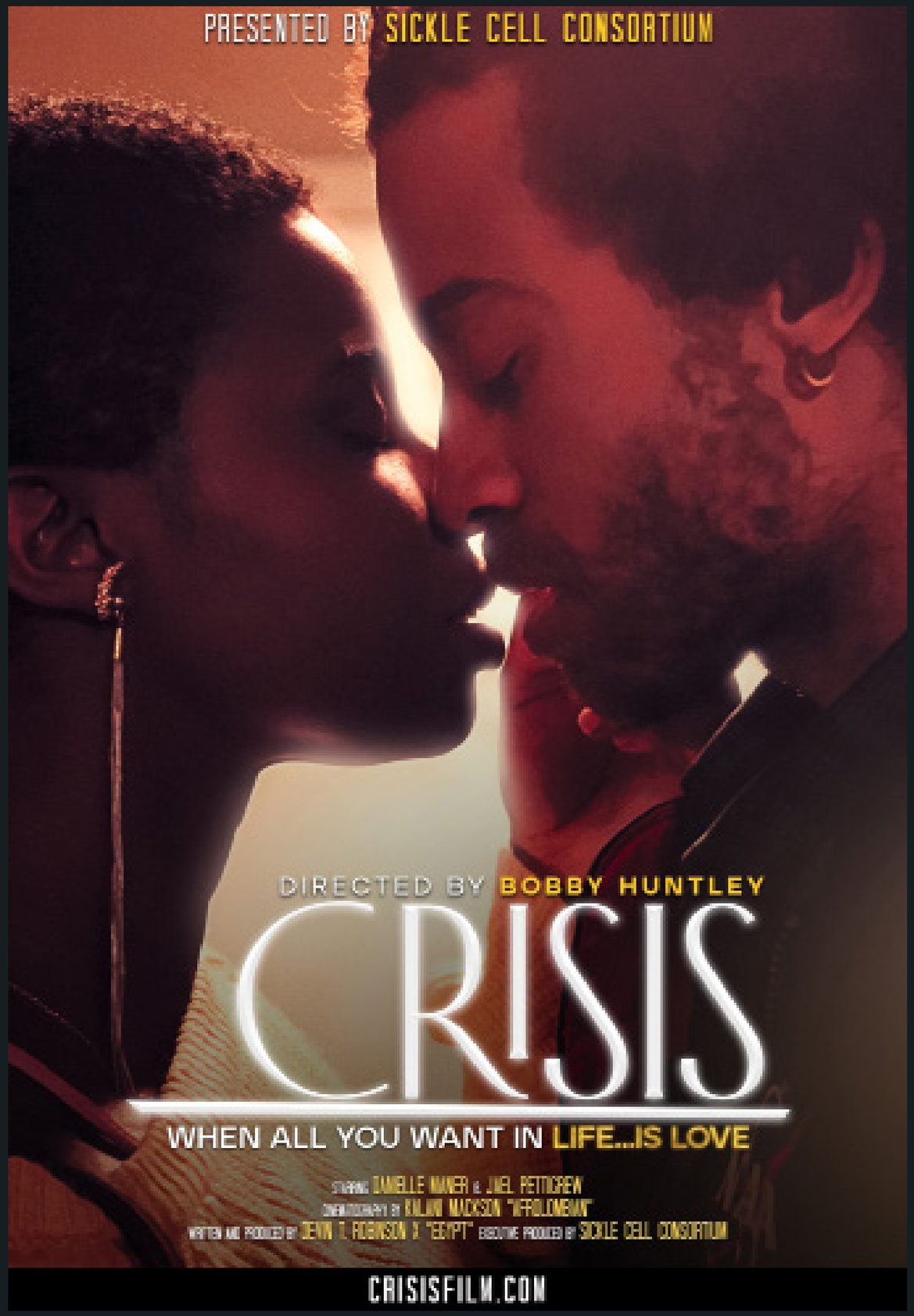
SANDY MILLS
PROJECT MANAGER

JONATHAN SMITH
IT SUPPORT

LANITA SMITH
TECH ADMINISTRATOR

PATRICIA SMITH
ONLINE MEDIA TECH MANAGEMENT & OVERSIGHT

THANK YOU FOR JOINING US!



SICKLE CELL COMMUNITY CONSORTIUM
WWW.SICKLECELLCONSORTIUM.ORG

HARNESSING THE POWER OF THE
PATIENT & CAREGIVER VOICE