

4TH ANNUAL

SICKLE CELL COMMUNITY CONSORTIUM LEADERSHIP SUMMIT & GENERAL ASSEMBLY OF CBOS



DOUBLE TREE BUCKHEAD 3342 PEACHTREE RD. NE, ATLANTA, GA 30326

MARCH 13 - MARCH 17, 2019

Unity - Commitment - Progress

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Unity Commiment Progress

Sickle Cell Community Consortium

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FOUNDER



Dr. Lakiea Bailey

Dr. Lakiea Bailey is a sickle cell disease advocate, educator and research scientist. Diagnosed with sickle cell disease at age three, she has become a passionate advocate for those living with rare diseases and is committed to serving as a voice of encouragement and empowerment within the sickle cell community.

Despite the devastating symptoms of sickle cell, Dr. Bailey was determined to complete her educational goals, earning a Bachelor degree in Biochemistry and Molecular Biology in 2001 and a Doctorate degree in Molecular Hematology and Regenerative Medicine in 2012. During the course of her education, Dr. Bailey was named a Southern Regional Education Board (SREB) Doctoral Scholar, was the recipient of multiple honors and awards, including the Fisher Scientific Award for Overall Excellence in Biomedical Research, the Medical College of Georgia Alumni Association Award, the Georgia Reagents University Leadership Award and was inducted in the Alpha Upsilon Phi honor society. She believes that through hard work, diligence, patience and faith, even the seemingly most impossible obstacles can be overcome.

Dr. Bailey recognizes that her success is due to the strength and commitment of many amazing advocates and supporters in her life and is determined to provide the same support and encouragement to others in the sickle cell community. She is therefore committed to serving as a resource for the sickle cell patient population as an advocate, educator, mentor and public speaker. Dr. Bailey is the Executive Director of the Sickle Cell Community Consortium, a coordinated network of sickle cell disease community-based organizations throughout the United States, a contract consultant with bluebird bio, has served as a patient engagement consultant with Pfizer Pharmaceuticals and sits on the Research Advisory Board for the Foundation for Sickle Cell Disease Research. Dr. Bailey enjoys traveling across the nation promoting sickle cell awareness and education and is available for sickle cell and health-related community events, conferences and seminars. Her goal is to continue to influence sickle cell disease-related biomedical research as well as social and medical policy and to travel around the country, and the world, advocating for those living with this disease.

ABOUT THE SICKLE CELL COMMUNITY CONSORTIUM



The Sickle Cell Community Consortium was founded in February 2014 by a core group of patients and caregivers while attending the FDA Patient-Focused Drug Development meeting. For several years many in the community expressed a need to create a unified platform to support the many CBOs (both large and small) throughout the country as they work to ensure that the voice of the sickle cell patient and caregiver was central in all areas of research, legislation, advocacy, education and policy. Realizing that several of the key players in this discussion would be in Maryland for the FDA meeting, Dr. Lakiea Bailey convened the first meeting to lay the foundation for what would become the Sickle Cell Community Consortium. Over the course of the year that followed, she, along with Velvet Brown-Watts, Kena Drew, Douglas Deveaux, Laveda Wallace-Page, Nikki Peterson and a host of other patient and caregiver advocates, worked to establish the Consortium as a US-based not-for-profit collective of sickle cell stakeholders and opinion leaders. The Consortium's first official act was to organize and support the attendance of Warriors and Caregivers to 2014 (and 2015) SCDAA Advocacy Day on Capitol Hill. The Consortium became an official 501(c)3 designated non-profit in August 2015 and held the first Leadership Summit and General Assembly of CBOs in March 2016.

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

Although we are a young organization, by working collectively, Consortium partners have accomplished a great deal in a very short amount of time. In 2016, we provided over \$50,000 in travel, lodging and registration for patients and caregivers to #SpeakUp and #ShowUp for sickle cell and helped to coordinate patient/caregiver participation in sponsored meetings and focus groups throughout the country. The July Sickle Cell Patient and Family Education Symposium, co-hosted by Sickle Cell 101, IASCNAPA and Sickle Cell Warriors, Inc., was attended by over 100 patients, caregivers, researchers and providers. All workshops, panels and education session topics were chosen by sickle cell patients and caregivers. We launched our Patient-Centered Outcomes Initiative and formed the Mental Health Workgroup, the Sickle Cell Mens Action Network (M.A.N.) and the Transition Workgroup. The first project in the Patient-Powered Educational Literature series was developed, funded and completed. The final product "A Guide to Living with Sickle Cell" was written for sickle cell warriors by sickle cell warriors and is now available.

Together, the patients, caregivers and supporters of the Consortium have worked to define and alter the landscape of the sickle cell community for current and future generations. All projects are created and completed directly by our community. We are only able to succeed by working as a collective unit and invite all warriors, caregivers and CBOs to work with us as we equip and empower the sickle cell community to become full participants and lead the charge in sickle cell advocacy, education, research, legislation and policy.

RECOGNITION

Southern Regional Education Board (SREB) Doctoral Scholar

AWARD

Fisher Scientic Award for Overall Excellence in Biomedical Research

AT-A-GLANCE

TUESDAY, MARCH 12

Special Leadership Council

SC3 Programs, Platforms & Initiatives Lunch - Collective Impact and the Power of Patient Voice **Overcoming the Access Barrier**

THURSDAY, MARCH 14

Leadership Summit & General Assembly of Patients, Caregivers, and CBOs

Opening of the General Assembly Research Review - Hope On The Horizon Lunch Consortium Partner Onboarding Creative Content Workshop & Lab

SATURDAY, MARCH 16

Leadership Summit & General Assembly of Patients, Caregivers, and CBOs

Breakfast Public Policy & Advocay Track A: Community-Based Organizations Track B: Independent Patient/Caregivers Lunch - Infrastructure Committees Business Meeting SC3 Kids Leadership Team Creative Content Closing of the 4th General Assembly of Patients, Caregivers, & CBOs

MONDAY, MARCH 18 Special Best Practices Traning Sessions

DAY 2 - GRANT WRITING TRAINING - Vision, Design, Capacity Grant Workshop: Office of Minority Health **Resource Center**

Lunch - SMART Objectives and Skills Building

VERTEX.

THE SCIENCE of POSSIBILITY

b NOVARTIS

bluebirdbio GBTS

OUR SPONSORS & SUPPORTERS





CRISPR

THERAPEUTICS

WEDNESDAY, MARCH 13

Leadership Summit & General Assembly of Patients, Caregivers, and CBOs

Registration **Opening Reception & Partner Meet-n-Greet Creative Content**

FRIDAY, MARCH 15

Leadership Summit & General Assembly of Patients, Caregivers, and CBOs

Breakfast General Assembly Strategy Session Lunch General Assembly Strategy Session II Creative Content Workshop & Lab

SUNDAY, MARCH 17

Special Best Practices Training Sessions

Grant Writing Training Lunch - Navigating Online Grant Portals

DAY 1 - Vision, Design, Capacity Grant Writing Workshop: Office of Minority Health Resource Center

PARTNERS **SERVICES**

We are pleased to offer a variety of services to our partners. The services vary by day and time. Availability is in order of sign-up. Time slots are limited. All partners are encouraged to sign-up at registration. Please arrive promptly, prepared for the chosen service.

Headshots with Sharonda Hudson of 610 Designs & Company

A headshot is a good opportunity to make a lasting impression in a professional manner. 610 Designs will be on site to capture headshots photography for each partner. The image will be available to save on your Consortium flash drive the following day. Sign-up at the creative content workshop. Please contact Sharonda Hudson @ 610designsandco@gmail.com

Accounting Consultations with Doris Bailey, Asst. Director of Finance

Sign-up for a 30 minute one-on-one session with the Consortium's Asst. Director of Finance. Come prepared to ask specific questions related to your CBOs. Non-profit 990s are due soon. This is an excellent opportunity to get your questions answered.

Digital Content Check-Ups with Pat Smith of Online Media Interactive

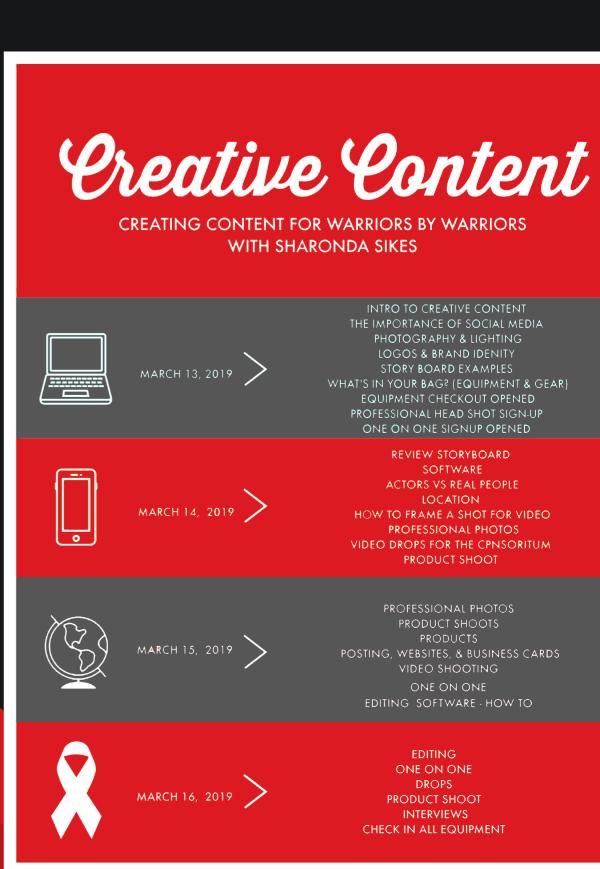
These 30 min one-on-one consultations with Patricia Smith will review your website and/or social media profiles to ensure full optimization and utilization, and how to best cater to your web-based audience.

Product Placement and CBO Branding Photos with 610 Designs & Company

Bring your CBO merchandise and models to obtain professional photography for your websites, publications and social media profiles. We will not be providing hair and make-up during these photography sessions. Come ready to shoot and go.

Creative Content Laboratory Open Space

START NOW! Creating with what you have!!! Participants of the Creative Content Lab. The use of this space will Be explained during the overview. If you have any questions or concerns please email Sharonda at media-marketing@sicklecellconsortium.org



INTRO TO CREATIVE CONTENT THE IMPORTANCE OF SOCIAL MEDIA PHOTOGRAPHY & LIGHTING LOGOS & BRAND IDENITY STORY BOARD EXAMPLES WHAT'S IN YOUR BAG? (EQUIPMENT & GEAR) EQUIPMENT CHECKOUT OPENED PROFESSIONAL HEAD SHOT SIGN-UP ONE ON ONE SIGNUP OPENED

REVIEW STORYBOARD SOFTWARE ACTORS VS REAL PEOPLE LOCATION HOW TO FRAME A SHOT FOR VIDEO PROFESSIONAL PHOTOS VIDEO DROPS FOR THE CPNSORITUM PRODUCT SHOOT

PROFESSIONAL PHOTOS PRODUCT SHOOTS PRODUCTS POSTING, WEBSITES, & BUSINESS CARDS VIDEO SHOOTING ONE <u>ON ONE</u> EDITING SOFTWARE - HOW TO

EDITING ONE ON ONE DROPS **PRODUCT SHOOT** INTERVIEWS CHECK IN ALL EQUIPMENT



DORIS BAILEY, MFIN ASSOCIATE DIRECTOR OF FINANCE

Doris Bailey is the Associate Director of Finance for the Sickle Cell Community Consortium. She completed her B.S. in Business with a concentration in Accounting from Indiana University-Bloomington, followed by a M.S. in Accounting and Financial Management. She is the parent of a sickle cell warrior and has been a vocal advocate for over 30 years.



ERIC NTI-FREMPONG, CPA, MTAX, PMP DIRECTOR OF FINANCE

Eric Frempong is the Director of Finance for the Sickle Cell Community Consortium. He is president of a professional firm specializing in individual income tax preparation and planning. He also prepared S-Corporation financial statement and income taxes.









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.

PROGRAMS MANAGER

NIKKI PETERSON SPECIAL EDUCATION SERVICES



KIMBERLY M. DAVIS

ADMINISTRATIVE COORDINATOR FOR GEORGIA

Diagnosed with Sickle Cell Anemia, type SS at the age of 11, Kimberly is a dedicated and hardworking individual who has overcome many of the challenges faced by those fighting the battle against sickle cell disease.

With an earnest desire to increase awareness of SCD and to see marked improvement in the care and treatment of those who suffer from SCD, including her 12 year old niece. She seeks to inspire and provide hope for all of those who battle daily with this egregious disease. Kimberly is committed to the idea of being the change that she wants to see

RAYMONA LAWRENCE, DPH, MPH, MCHES

DIRECTOR OF RESEARCH

ALEXIS WARDLOW-PERRY

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

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

OUR GREAT TEAM!



JANEEN GREENE EVENTS COORDINATOR

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

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

Janeen JV Greene has a Bachelors degree in Social Work from Buffalo State College SUNY. In 1999 she became a Mary Kay representative and is regularly available for consultations, sales and party planning.

Janeen is a member of the Faith Missionary Baptist Church in Buffalo New York where Elder James R Banks, II is Pastor. She is the mother of three successful children and is married. Janeen is so very Thankful for her Village who raised her, loved on her and stood in the gap as needed. This tradition continues with her offspring. To God be the Glory for the marvelous things He has done.







SHARONDA HUDSON MEDIA & MARKETING MANAGER

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

MARIA RIVERA

SPECIAL PROJECTS COORDINATOR

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

DOMINIQUE GOODSON

SPECIAL PROJECTS COORDINATOR

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



YOLANDA LEWIS WEBSITE MAINTENACE

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



SHAYLA WALKER EXECUTIVE ASSISTANT



GBT is committed to partnering with the community to change the future of sickle cell disease (SCD).

We seek to understand the unique needs of people living with SCD.

Our team is passionate about transforming SCD treatment.

Community is our strength and inspiration.



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10:0

10:

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Tuesday, March 12 (Piedmont)

TUESDAY, MARCH 12 9:00 AM - SC3 Programs, Platforms & Initiatives: High Level Summary

1:00 PM - LUNCH: COLLECTIVE IMPACT AND THE POWER OF THE PATIENT VOICE

Wednesday, March 13 (Piedmont)

2:00 PM -	Registration Desk Opens
4:00 PM -	OPENING RECEPTION & PARTNER MEET-N-GREET
	Welcome: SC3 Staff
	Networking Activities & Icebreakers: BLFSC
	Memory Book: Jontrece, Jazmine, Diamond Ray: Sharonda Hudso
	Creative Content Sponsorship Remarks: Holly John
6:00 PM -	Creative Content Overview

Thursday, March 14 (Piedmont

- MA 00	OPENING OF THE GENERAL ASSEMBLY
	Welcome: Collective Impact: Dr. Lakiea Bailey
	Partner Services
30 AM -	RESEARCH REVIEW – HOPE ON THE HORIZON
	Patient-Powered Research Agenda: Dr. Raymona Lawrence
	Update on Endari: Mark Diamond
	HRSA - EMBRACE: Shirley Miller
	ASH Clinical Trials Network: Dr. Lakiea Bailey
	ACEP – EDSC3
	STAR/NMDP
	Palliative Care: Dr. Wanda Shurney
) PM -	LUNCH *SPONSORED BY VERTEX/CRISPR - Matthew McLeod

Creating transformstive gene-based medicines for hemoglobinopathies

2:00 PM - CONSORTIUM PARTNER ONBOARDING *Closed Session*

Consortium Organization & Infrastructure: Dr. Lakiea Bailey Credentialing, Partnership & Dissolution: Dominique Goodson Code of Conduct, Ethics: Esterphine Greene Roberts Rules of Order: Janeen Greene SC3 Roles, Positions & Committees: Dr. Lakiea Bailey

6:00 PM - CREATIVE CONTENT WORKSHOP & LAB - Sharonda Hudson

10:00 AM -	GENERAL ASSEM Mental Health Pri Sickle Cell Anthole Sickle Cell Toolkits
	Clinical Trials Initia Diversity Outreac
	Sickle Cell & Aging
1:00 PM -	LUNCH *SPONSO GBT440: Dr. Ken CURE SICKLE CE
2:00 PM -	GENERAL ASSEM
	Sickle Cell Exemp
	ED Initiative: Goir

Transition Workgroup/Toolkit (2017 Priority): Alexis Wardlow-Perry

Sickle M.A.N. (2016 Priority): Clayton Andrews

National Awareness Campaign (2018 Priority)

AGENDA CONT.

Friday, March 15 (Piedmont)

9:00 AM - BREAKFAST *SPONSORED BY: BLUEBIRD BIO Talk Saves Lives: Peer-to-Peer Mental Health Training: Taylor Chambers Grief & Bereavement: Curtesy & Etiquette: Clayton Andrews

IBLY STRATEGY SESSION I

iority (2016 Priority): Clayton Andrews logy (2017 Priority): Kadeem Gayle s (2017 Priority): Dr. Wanda Shurney ative: Dr. Marie Ojiambo ch (2018 Priority) g (2018 Priority)

ORED BY GLOBAL BLOOD THERAPEUTICS

Bridges LL INITIATIVE (CureSCi): Dr. Benz

ABLY STRATEGY SESSION II

otion in Opioid Policies: A Success Story: George Carter

ng Positive: Dominique Friend, Chandra White-Cummings

6:00 PM - CREATIVE CONTENT WORKSHOP & LAB - Sharonda Hudson

AGENDA



Saturday, March 16 (Piedmont)

- 9:00 AM BREAKFAST *SPONSORED BY NOVARTIS PHARMACEUTICALS 10:00 AM - Public Policy & Advocacy: Dr. Chic Smith
- 11:00 AM TRACK A: COMMUNITY-BASED ORGANIZATIONS Best Practices: Infrastructure & Capacity Building
- 11:00 AM Access to Federally Qualified Health Centers: Dr. Wanda Shurney Driving Operational Effectiveness with Digital Technologies: Patricia Smith Grant Writing Overview: OMH
 - TRACK B: INDEPENDENT PATIENT/CAREGIVERS (Peach Tree C) Best Practices: Expert Advocacy Training
- 11:00 AM Dress for Advocacy Success #Advocating Style Expert Advocacy Training - Telling Your Story: Tosin Ola 501c3 for jCBOs: Dan Moore Building Your Advocacy Resume - Dr. Lakiea Bailey

1:00 PM - LUNCH: INFRASTRUCTURE COMMITTEES

- 2:00 PM BUSINESS MEETING
- 2:00 PM SC3 KIDS LEADERSHIP TEAM: STRATEGY SESSION
- 4:00 PM CREATIVE CONTENT SHARONDA HUDSON

CLOSING OF THE 4TH GENERAL ASSEMBLY OF PATIENTS, CAREGIVERS, CBOS



12:00 PM - LUNCH

1:00 PM - Intro to Government Grants **Proposal Narrative**



VISION, DESIGN, CAPACITY GRANT WORKSHOP: OFFICE OF MINORITY **HEALTH RESOURCE CENTER - DAY 2**

10:00 AM - Recap and Review of VDC Elements Logic Models - Writing Lab

12:00 PM - LUNCH

SMART Objectives and Skills Building Practicum/Learning Lab

1:00 PM - Evaluation Methodology Federal Grant Application Process Summary and Evaluations

AGENDA CONT.

10:00 AM - Introduction to Private Foundation/Philanthropic Grant Funding: Locating Private/Philanthropic Grant Resources Identifying Partnerships & Private Funding Grant Cycles: Dr. Chic Smith

Navigating Online Grant Portals - Dr. Lakiea Bailey

VISION, DESIGN, CAPACITY GRANT WRITING WORKSHOP: **OFFICE OF MINORITY HEALTH RESOURCE CENTER - DAY 1**

Facilitated Vision, Design, & Capacity Proposal Design - Parts of the Grant: "Share the Dream" Proposal Design: Parts of the Grant: Technical Review in the

Monday, March 18 (Piedmont)

A CLOSER LOOK

Pat Smith - Driving Operational Effectiveness with Digital Technologies

This session focuses on the evolving role of digital technologies in the day-to-day operations of non-profits large and small. Emphasis will be placed on understanding the importance of key performance indicators and how technology can drive the collection, analysis and reporting of the information in a way that informs constituents, and improves both new fundraising and donor retention.

George Carter - Sickle Cell Exemption to Opioid Policies and Ov

This session will outline what was doen in Virginia to get an exception to the opioid guidelines and what can be done in other states.

Funmi Makinde, MPH, CHES; Elton Naswood - Overview of Government Grants Broad Overview

What you need to know when applying for government grants

The VDC (Vision, Design and Capacity) Workshops have been conducted in a variety of communities across the United States since 2002. The workshops have improved the writing skills of participants and increased their understanding of the components and usual requirements of completing successful grant applications. The trainings were initially offered to community-based organizations and have since expanded to address research funding at institutions of higher education in the United States. Participants are sequentially engaged through lectures and interactive exercises, over 1-2 days. We review principles of technical writing, practice strategies to relay information in grant applications, and share the tips and standards Grant Reviewers use as they screen applications going to the Funder.

Taylor Chambers, MPH - Talk Saves Lives: Peer-to-Peer Mental Health Training

Talk Saves Lives is a community-based presentation that covers the general scope of suicide, the research on prevention, and what people can do to fight suicide. Attendees will learn the risk and warning signs of suicide, and how together, we can help prevent it. Following the presentation, attendees will have the opportunity to ask questions and learn how they can present the training in the community.

Matthew Mcleod - Creating Transformative Gene-Based Medicines For Hemoglobinopathies

Overview of CRISPR Therapeutics approach to treating hemoglobinopathies

a Lawrence - COMPASS: Guiding The Direction Of Community-Engaged Sickle Cell Disease Research

Clayton Andrews - Grief, Loss And Bereavment

The process of bereavement: what it means to grieve, how to grieve and what "moving on" means.

The EMBRACE Project seeks to expand access to quality care, improve care delivery, and provide knowledge and support via ECHO clinics (virtual grand rounds) presenting patient case presentations for didactic learning and mentoring.

A CLOSER LOOK CONT.

This is for advocates taking their activism to the next level. Learn how to tell your personal story in a short, impactful, and motivating, to create awareness and change in the audience.

Edward J. Benz, Jr., MD - CURE SICKLE CELL INITIATIVE

The Cure Sickle Cell Initiative (CSCI) is a collaborative effort to utilize an innovative mechanism called the Other Transactional Authority (OTA) to provide resources, funding, and convening power for projects and engagements that will accelerate the application of emerging gene therapy and gene-editing technologies to curing sickle cell syndromes. The root cause of Sickle Cell anemia, a change in one code letter out of the entire human genome has been known for decades, but methods to correct or replace the error are just now emerging. CSCI will utilize a more flexible approach made possible by the OTA to support innovative projects to deploy resources that cannot otherwise be funded and efforts to engage more patients and families in the clinical research that must be done in order to develop a cure.

Best practice how to dress for success when advocating. I'll include warriors to model example outfits & have a gift card raffle.

Lakiea Bailey - ASH Clinical Trials Network

Lakiea Bailey - Emergency Department Sickle Cell Care Coalition (EDSC3

Dispelling The Myth That Palliative Care Is Only For The Dying

Wanda Shurney - Access to Federally Qualified Health Centers Engaging Federally qualify Health Center to provide primary care for adults living with sickle cell disease

Ken Bridges - Global Blood Therapeutics: An update on GBT440

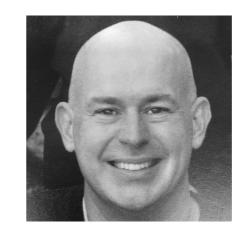
Dan Moore - 501c3's for iCBOs

Sharonda Hudson - Creative Content

Update on newly created Clinical Trials Network of the American Society of Hematology

Update on the projects and plans of EDSC3, created by the American College of Emergency Physicians

An overview of IRS requirements and the process to formally developing and filing you 501c3



sickle cell

communityconsortium

SPEAKER

Matt McLeod works as the Executive Director of Program Management at CRISPR Therapeutics. Over the last 15 years he's focused drug development program management across 3 oncology companies. He's excited to have returned to his roots in gene therapy, which he studied and worked on at the University of Pennsylvania (MS) and MIT's (SB) Whitehead Institute. Outside of work, he and his wife Kate have 3 boys, ages 8, 6, and 3, and he enjoys coaching their hockey, drinking craft beer, and curling.

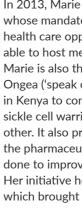
SPEAKER

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

SPEAKER

Trained at St John's University, College of Pharmacy and Health Sciences in New York, Marie Ojiambo is a Formulation Scientist by profession specializing in drug research and development. She is also a Sickle Cell warrior and a global advocate. Diagnosed at the age of 1, Marie her knowledge and to raise awareness about sickle cell disease (SCD).

Currently consulting with Pfizer Inc. and SCDAA, Ojiambo uses her experiences to inform researchers, advocates and various stakeholders within the SCD space on strategies to advance the healthcare and treatment options available to sickle cell warriors.



sickle cell communityconsortium

SHIRLEY MILLER

SPEAKER

Shirley Miller has more than 20 years of experience in sickle cell disease in program development clinical trials and patient advocacy. She has served on the Comprehensive Centers Clinical Trials Consortium, the NHLBI Sickle Cell Advisory Committee as well as other educational committees. Prior to her work in Charlotte, Shirley worked at the Southwestern Comprehensive Sickle Cell Center in Dallas, Texas with Dr. George Buchanan, one of the many pioneers in sickle cell disease. She has established herself as a knowledgeable and confident speaker and advocate as it relates to living and managing a chronic illness such as sickle cell disease. She currently works in Charlotte, NC at Atrium Health (formerly Carolinas HealthCare System) in an Adult Sickle Cell Program directed by Dr. Ify Osunkwo. Shirley holds a Bachelor of Business Administration from Northwood University and a Masters in Psychology from the Chicago School of Professional Psychology. She has served on the board of directors for the Sickle Cell Disease Association of America and currently serves on the NHLBI Sickle Cell Advisory Committee and the FDA Advisory Committee for the approval of new Oncologic Drugs. She is the author of the book entitled "The Stranger Within Me", the story of her journey living with sickle cell disease.

MATTHEW MCLEOD

CLAYTON ANDREWS

MARIE OJIAMBO

In 2013, Marie founded the Sickle Strong Initiative, a Kenyan based NGO whose mandate is to raise awareness around SCD and to advocate for better health care opportunities for patients in Kenya. Through SSI, she has been able to host medical training and awareness campaigns for patients in Kenya. Marie is also the proprietor of the annual sickle cell public awareness forum, Ongea ('speak out!' in Swahili). This annual summit that takes place every June in Kenya to commemorate World Sickle Cell Day, and provides a platform for sickle cell warriors to speak out about their condition, and interact with each other. It also provides an opportunity for patients to challenge the government, the pharmaceutical industry, insurance companies, the public on what is being done to improve the health care and environment that they are exposed to. Her initiative hosted the third edition of Ongea on the 18th of June 2016, which brought together an estimated 300 warriors and their families.



KEN BRIDGES

Dr. Kenneth R. Bridges received the MD degree from Harvard Medical School, and subsequently trained in internal medicine and hematology in Boston, at Massachusetts General and Brigham and Women's Hospitals, respectively. Following medical subspecialty training, Dr. Bridges worked on the biology of cellular iron metabolism for three years at the National Institutes of Health in Bethesda, Maryland. Dr. Bridges returned to Harvard as a member of the Hematology Division at Brigham and Women's Hospital where he achieved the faculty rank of Associate Professor of Medicine. In parallel with his laboratory investigation of iron metabolism, Dr. Bridges maintained active clinical work and established the Joint Center for Sickle Cell and Thalassemic Disorders at Brigham and Women's Hospital and Massachusetts General Hospital, emphasizing bench-topatient 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 the new treatment for sickle cell disease. GBT440.



EDWARD J. BENZ, JR., M.D., F.A.C.P

SPEAKER Dr. Benz is President and Chief Executive Officer Emeritus of the Dana-Farber Cancer Institute, Director Emeritus of the Dana-Farber/Harvard Cancer Center, Richard and Susan Smith Distinguished Professor of Medicine, Professor of Pediatrics and Genetics at HMS and Executive Director of the NIH's Cure Sickle Cell Initiative.

A graduate of Princeton University (cum laude), and HMS (1973, magna cum laude), where he received the Soma Weiss and Leon Resnick Research Awards, he trained in internal medicine and hematology at Brigham and Women's Hospital, Boston Children's Hospital, NIH, and Yale. Board certified in Internal Medicine and Hematology, he is an active hematologist with special expertise in inherited anemias.

Benz served previously as Professor of Medicine and Genetics, Chief of Hematology, and Vice Chair of the Department of Internal Medicine at Yale (1978 – 1993); Jack D. Meyers Professor, and Chairman of the Department of Medicine at the University of Pittsburgh (1993 – 1995); Physician in Chief, Director of the Department of Medicine, and Sir William Osler Professor at Johns Hopkins (1995-2000).

His research, started in medical school, identified molecular defects underlying hemoglobinopathies, and subsequently contributed to our understanding of the molecular pathology of the red cell membrane cytoskeleton. He was instrumental in founding one of the nation's first Family Medicine Residencies in Lancaster, Pa., while an HMS student.

Benz and Dr. Ronald Hoffman are the founding co-editors of Hematology: Principles and Practice. It won the First Prize Award for Textbooks from the British Medical Society. He was co-editor of the Oxford Textbook of Medicine, Ed.4, which received the Royal Society of Authors Textbook First Prize Award. He was previously an associate editor of the New England Journal of Medicine.

He is a member of the National Academy of Medicine, the American Society of Clinical Investigation (past President), Association of American Physicians, Phi Beta Kappa, Alpha Omega Alpha, the American Academy of Arts and Sciences, the American Clinical and Climatological Association (past President), and an elected Fellow of the American Association for the Advancement of Science. He has also served as president of the American Society of Hematology, the Friends of the National Institute of Nursing Research, and the Association of American Cancer Institutes, and Chairperson of the National Cancer Policy Forum. He is on the Boards of Directors of the American Cancer Society and the Mount Desert Island Hospital.

Active in the community, he is the 2011 Honoree of the Whittier Street Health Center for his work in Health Disparities, he was named Hero in Medicine by the Massachusetts VNA, and received the Leadership Award from Global Health Catalyst Summit in 2016, the 2016 Clarion Award from the Albert Schweitzer Fellowship Foundation, and the Innovator in Health Care Award from the Network for Excellence in Healthcare Innovation.

He lives in Boston with his wife, Dr. Margaret Vettese, a distinguished nurseresearcher/educator in the field of psychosocial oncology. They have four children and eight grandchildren.

SPEAKERS CONT.



DOMIN SPEAKER

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.



GEORGE CARTER

SPEAKER

George Carter is a 73-year-old male who suffers with Sickle Beta Zero Thalassemia. He has been working with various sickle cell organizations for over 40 years. He serves as a Sickle Cell Disease Patient Consultant for the Food & Drug Administration (FDA) and on the Interagency Pain Research Coordinating Committee of the National Institute of Health. Currently, he primarily serves as the Administrator (unpaid Executive Director) of Statewide Sickle Cell Chapters of Virginia

Statewide Sickle Cell Chapters of Virginia, Inc., also known as Sickle Cell Chapters of Virginia, is a non-profit 501(c)(3) tax-exempt communitybased organization, that has a network of nine (9) community-based organizations (chapters) that provide a variety of services across the Commonwealth of Virginia.

George Carter's main focus is to advocate for those who suffer from Sickle Cell Disease and distribute as much information about sickle cell and uplifting messages to patients. Around 4,000 African American in Virginia suffer with Sickle Cell Disease and approximately 155,000 have Sickle Cell Trait.

Under George Carter's direction and lobbing, Statewide has received over one million dollars in funding from the State of Virginia since 2008. The funds help several chapters provide education and assist individuals and families living with Sickle Cell to develop necessary skills and resources to improve their health status, family functioning, and self-sufficiency.

DOMINIQUE FRIEND

SPEAKER CONT.



SPEAKER

Creative, Leader, Motivator...Jessica Young known as the "Queen of Short Films" has created and produced ground-breaking visual branding products through video production. Her keen eye for creativity and dedication to excellence, propelled her to launch Jessica Young Films, LLC., where she is the CEO and Executive Producer for projects that have graced the platforms of BET, AMC Theatres, Morehouse School of Medicine, the Department of Public Health for the State of Georgia, and countless educational & community-based organizations.

She is also a sought after motivational speaker that is setting trends across various platforms on the value of pursuing your purpose with passion!

Jessica holds an undergraduate degree in Communication Studies and a Master's Degree in Educational Leadership. She is a native of Charlotte, North Carolina, but resides in the ATL, and has a true love and passion for the city of Atlanta!

Despite losing his mother at 12, having his father abandon him the same day and being classified as an orphan, Egypt may have been knocked down...but wasn't knocked out.

to live right...today.



PATRICIA SMITH

SPEAKER

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

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

Technology Leadership : Entrepreneur, Technology Lecturer, and Trainer

* President and CEO of Online Media Interactive-A Digital Marketing and Technology Consulting Firm * Years of hands-on experience in fast-paced, high-pressured team production environments leading developers, project managers, quality assurance resources, and business analysts in building enterprise web and other mission-critical systems that are responsible for netting millions of dollars in new revenue *A proven leader and effective motivator

* Known for consistently helping companies with complex business and technology environments bridge the gap between business goals and technology

* Expert in Internet and Web 2.0 technologies

* Bachelors in Computer Information Systems and a Master's in Information Technology (with an emphasis on Internet technologies) Adjunct Professor for Southern Polytechnic State University from 2003- 2007, delivering custom

curriculum in the areas of Database Systems, Hardware and Software Concepts, Web Development, Technology and Society, Management and Organizational Behavior

*Charter member and Technology Director for the Atlanta Chapter of the National Association of Female Executives

Politics and Activism Radio Host, Political Activist, Commentator

*Regular Guest Host of "The Morning Show" on WAOK 1380 AM, a CBS Radio Station *Host of Press Pause: WAEC-AM, a weekly radio show covering news, politics, and entertainmen *A commentator on "Democracy Now!" with Amy Goodman during the 2008 Obama Campaign representing Obama supporters

*Founder of "Black Women for Obama", formed in 2007 to provide information and coordinate resources around the country - raised \$50,000 as an organization for the 2008 Obama campaign *Member of the "Women for Obama Leadership Council" during the 2008 Presidential Campaign *Recruited by the Obama campaign to serve as Delegate from Georgia's District 7 in 2008; at Invesco Field

in 2008 when President Obama accepted the nomination Recruited by Al Jazeera English to serve as commentator in Denver during acceptance speech

*Author of "Duped By Love"; Screenwriter for television show based on book *Writing/interview/citation credits include opinion pieces for Huffington Post, quotes on BET.com, in the Washington Post, interviews in Rolling Out Magazine, The New York Times, Atlanta Journal Consti and a number of other media outlets

Women Empowerment/Life and Career Transition Author, Speaker, Lecturer

*Developer of the "F.A.C.E. Your Future Power Conference" (2017), a multi-day event designed to help vomen who are in career and life transition adjust to the realities of the new economy, family and personal change, and technology innovation

*Founder of the "Sugar Soldier" Movement - Pat's personal crusade to educate the nation about the ravages of sugar and carbohydrates 2 Author of "Duped By Love", the laugh-out-loud novel about dating and family relationships







JESSICA M. YOUNG

DEVIN T. ROBINSON X, "EGYPT"

Over a span of 10 years, Egypt has led a life many consider a fairytale. His work in Black history storytelling, relationship counseling and HIV education/performing opened doors many seldom see. He's appeared on OWN, MTV, BET, Apollo Theater twice, TEDx twice, FOX with Lee Pitts in addition to countless radio shows, magazine and performance appearances. Egypt has shared stages with A-list celebrities such as John Legend, Alicia Keys and Magic Johnson. He adopted the name "Egypt" because he plans to influence the world just as the great African empire has influenced the earth.

He's touched stages in Johannesburg South Africa, Doha Qatar, Barbados, Haiti, Trinidad and Tobago and a TEDx Talk in Amman, Jordan. Not to neglect he's gained two degrees while being on the Dean's list, graduated Phi Theta Kappa Honors, won the Florida State PAL Boxing Championship, is a devout Christian, created the AIDS Awareness Poets Inc and the AIDS Games. He wrote three top selling relationship books, "How Good Is Sex?", "Change Him... In 100 pages,", "Love Is Not An STD" and 10 Steps To Get Over An Ex...FOR GOOD". He is also the youngest (27) Alumni of the year award recipient at Palm Beach State College for his work in HIV/AIDS. Yet, his highest achievements occurred April 6th, 2014 by marrying his dream woman and May 26th 2018 when his daughter Niya was born.

He is proof, that no matter how your life starts, you can change the middle and alter the ending. His story has inspired many and continues to be a reason why some believe their yesterday won't dictate their tomorrow because they've made a decision



ESTERPHINE GREEN SPEAKER

A New York State licensed clinical social worker with a Masters of Social Work from the City University of New York Hunter College and a BSW degree in Social Welfare from University of Buffalo now SUNY at Buffalo; Esterphine Greene has practiced social work in the State of New York for more than 40 years. She has demonstrated proficiency in working with adult individuals, families and groups within the mental health and substance specific populations. Over the years, Esterphine has provided volunteer hours to community agencies and institutions of higher learning throughout New York State, while serving as Field Instructor to social work and nursing students.

Esterphine is known as a skilled mental health treatment specialist and a professional who really cares. Colleagues and students alike have described her as an excellent teacher who sets the bar high and will help you to achieve. Trainings developed and presented have included Group Process, An Overview; Managing Disordered Personality in Church; Leadership in a Mental Health Residence; Suicide-assessment and intervention; Mental Illness and the Black Community; and Hamlin Park 1950-21st Century to note a few. During the 1990's Esterphine represented the Buffalo Psychiatric Center and Genevieve Collins while coproducing and hosting a weekly radio broadcast, MIND, BODY AND MENTAL HEALTH, which aired live for 5 years in the Western New York area.

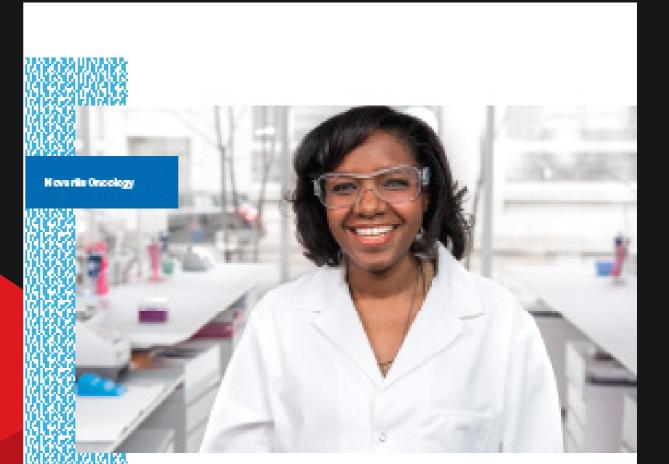
2008 marked Esterphine's 27th year in the employ of NYS Office of Mental Health. 2008 is also the year of her retirement or as Esterphine says the year she "stopped receiving personal, vacation, sick leave and paid holidays". During the 15years immediately preceding retirement Esterphine served the severe and persistent mental health population based in the community, hosted by Buffalo Psychiatric Center and the Buffalo Federation of Neighborhood Centers, a not-for-profit host agency. Since retirement Esterphine has traveled to many places of interest. Oahu city of Honolulu is her favorite location. She says it's one of the most beautiful locations especially at sunrise and sunset on the beach. Esterphine continues to provide volunteer hours in the community as a mental health consultant, staff trainer and board member. She actively participates in her church, attending bible study, is a member of Mission and AWANA ministries; as well as convening the Memorial ministry. Esterphine loves to sing and is a tenor in the senior choir...but no solos!

Since 1989 Esterphine has resided in Hamlin Park a historic residential neighborhood that is the only predominantly African American community in Buffalo New York to be listed on the National and State Historic registries. She has remained active in the resident association, the Hamlin Park Community and Taxpavers Association, Inc. serving the organization as secretary and Development Chair.

Lastly but not least Esterphine Greene is a member of the Faith Missionary Baptist Church where Elder James R. Banks, II is Pastor and only the Word is taught. Proudly, Esterphine says she is a mother and grandmother, sister and friend in the best family God has put together. Esterphine believes, undoubtedly parenthood is her greatest accomplishment for it is the legacy of family that will remain long after her transition. Esterphine says this is the season of her life's newest chapter and... Life is good!

Speakers

Holly John **Taylor Chambers** Chandra White Chic Smith Dan Moore Tosin Ola Mark Diamond



Noverlin proudly joins Sicide Cell Community Conscribut and the 6th Annual Sicide Cell Patient and Family Education Symposium. Reble Call is a

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No Pain in the Playroom **Dreamsickle Kids** Sickle Cell Champions Association Sickle Cell Mommies Club The Red Chair Project

Georgene Glass **Clayton Andrews** Shamir Jubert Sharonda Hudson

Omeka Edwards

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Cayenne Wellness Center & Children Fo	undation	
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Alvsian Thomas

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CBOs (continued)

Sickle Cell Association of Houston
Lockhart Morgan Foundation Advancing Sickle Cell Advocacy Project, Inc. (
TunMicro Sickle Cell Foundation Transition With Power Sickle Cell Alliance Foundation Sickle Cell Anemia Awareness Heart of Gold Sickle Cell Foundation of North
The Martin Center Sickle Cell Initiative Sickle Cell Services

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Raine Love Tonya Prince Gwen Morgan A.S.A.P) **Keemba** Gosier Ola Ogundemi Tahirah Austin Lisa Meatchem NeDina Brocks-Capla crisis@scaasf.org hern Virgina Melanie Hurley Gary Gibson Albertha H. Cook

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Jazmine Rivera



Jontrece Nobles



Diamond Edmundson

We are creating a Warrior Memory-book in honor of each one of these amazing partners. You are welcome to send pictures, notes, poems, or anything from the heart to be added to the book.

We will create a separate book for each of the 3 families containing the pages about their warrior.

inmemory@sicklecellconsortium.com

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