2018 SICKLE CELL COMMUNITY CONSORTIUM

LEADERSHIP SUMMIT & GENERAL ASSEMBLY

www.sicklecellconsortium.org

UNITY

COMMITMENT

PROGRESS

FRI MARCH 23 - MON MARCH 27

Atlanta Evergreen Marriott Conference Resort
4021 Lakeview Dr., Stone Mountain, GA 30083

Letter from the Director

Welcome to the third annual Sickle Cell Community Consortium Leadership Summit and General Assembly of Patients, Caregivers and Community-Based Organizations (CBOs). We are thrilled to welcome over 100 partners and supporters, representing 32 CBOs from 23 states (and 3 countries!) to scenic Stone Mountain, Georgia. The Summit is the main meeting of the Consortium. During your time here we will review our progress from the 2016 and 2017 General Assembly priorities; provide training on best practices for effective advocacy in the rare disease space and maintaining strong, effective CBOs; participate in the partner infrastructure meeting of the Consortium; and convene the 3rd Session of the General Assembly.

The General Assembly is the primary organ and decision-making body of the Consortium. Comprised of partnered CBOs, sponsored patient organizations, and patient and caregiver advocates, you will be tasked with defining and prioritizing the top needs and gaps within the sickle cell community; developing community-based solutions; and identifying the CBO, community and corporate partnerships best equipped to execute those solutions. Working in partnership with healthcare/research advisers and community partners, you will each lead the teams dedicated to tackling each priority.

This year we are excited to present COMPASS: Community Participation to Advance the Sickle Cell Story, a PCORI-funded initiative, launched as part of our CLINICAL TRIALS and PATIENT-CENTERED OUTCOMES INITIATIVE. As with all Consortium projects, platforms and initiatives, COMPASS was created at the request of the Warrior community and future directions will be defined and powered by you, the patients, caregivers and CBOs of the Consortium. Collectively, we will identify and define the research priorities of the sickle cell community.

We are also delighted to bring back the Digital Visual Content Workshop with Creative Space Lab. Partners will have access to experts, hardware and software to improve the creation of visual content. Partners who wish to access lab space must be present for the digital content best practices session on Friday, March 23rd. As part of this, we are delighted to welcome Jaqai Mickelsen, writer, editor and producer of *SPILLED MILK,* a sickle cell documentary featuring lifelong friends, one of whom is living with sickle cell disease. Join us Monday night at 7pm EST for film screening and a chat with Jaqai.

The Leadership Summit & General Assembly of patients, caregivers and CBOs is our most important meeting. The Summit is our opportunity to further develop and execute the Consortium's founding mission to provide a platform to harness and amplify the power of the patient voice and to provide infrastructure support and training for sickle cell CBOs. We are grateful to our corporate and community sponsors for your continuous support of this mission. The 2018 Summit was made possible with support from Global Blood Therapeutics, bluebird bio, Ironwood Pharmaceuticals, and Rare Life Solutions. Thank you to all CBO partners and patient/caregiver Advocates. We are only as effective as your constant drive, will and commitment to our collective cause.

Thank you,

Lakiea Bailey, PhD

Contents

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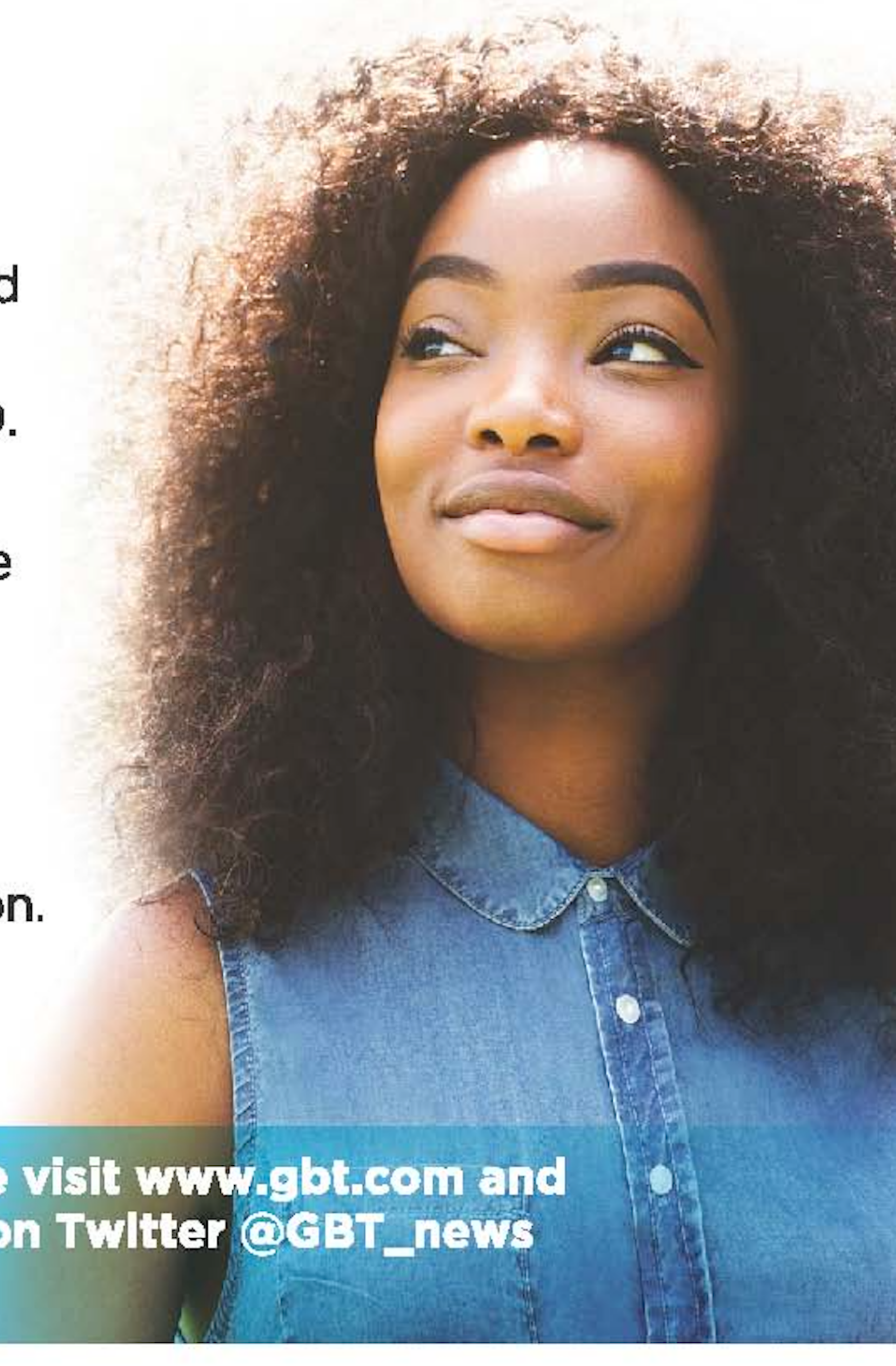


At-A-Glance

Friday, March 23

OPENING OF THE GENERAL ASSEMBLY

2:00 PM	Welcome and Opening
2:15 PM	2017 Review: Mental Health Update
2:30 PM	2017 Review: Transition Workgroup & SCD Toolkit
2:45 PM	2017 Review: SCD Anthology
3:00 PM	2017 Review: Patient Toolkit
3:15 PM	Warrior University
3:30 PM	2018 Update: Parent-to-Parent Initiative
3:45 PM	Fair Treatment for Warriors
4:00 PM	Return of the SCD Soldier Network
4:30 PM	oneSCDvoice
	Reception: The Opioid Epidemic
5:30 PM	Creative Content Workshop
	Creative Content Laboratory

Saturday, March 24

FOCUS ON RESEARCH

10:00 AM	COMPASS: Providing Direction for Community Engaged SCD Research
1:00 PM	Lunch: Blood Transfusion - What Patients Need to Know and Do
2:30 PM	NHLBI "Cure Sickle Cell" Initiative
3:00 PM	HRSA: EMBRACE
3:30 PM	General Assembly I: The Docket
	Creative Content Laboratory

Sunday, March 25

10:00 AM	General Assembly II: The Discussion
1:00 PM	Lunch: Global Blood Therapeutics
2:15 PM	Sponsored Presentation: Ironwood Pharmaceuticals
3:00 PM	Best Practice: Guide to Nonprofit Development
4:00 PM	Business Meeting: Amendments, Addendums and Infrastructure
	Creative Content Laboratory

Monday, March 26

	BEST PRACTICES
10:10 PM	Harnessing the Power of the Collective: Collaborating with Sister CBOs
10:45 PM	Advocacy within a Social Justice Framework
11:20 PM	Grant Writing Seminar
12:30 PM	Responding to Disaster
1:15 PM	Lunch: Infrastructure Committee Meetings
	BEST PRACTICES
2:15 PM	Forming Partnership with Public Health
2:50 PM	Sickle Cell and Social Media By-The-Numbers
3:25 PM	Social Media Tools, Tips and Strategies
4:00 PM	Forming Partnership with Pharma
4:35 PM	Creating a Volunteer Network
7:00 PM	Film Screening and Conversation with Writer/Director of Spilled Milk

Tuesday, March 27

9:30 AM	Breakfast
10:00 AM	Best Practice: Professional Advocacy

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 the last two years we've 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 annual Sickle Cell Patient and Family Education Symposium has been attended by over 200 patients, caregivers, researchers and providers. All workshops, panels and education session topics are chosen by sickle cell patients and caregivers. We launched our Patient-Centered Outcomes & Clinical Trials Initiative, formed the Transition Workgroup, launched the Warrior Mental Health Initiative, the Sickle Cell Men's Action Network (M.A.N.) and the Parent-to-Parent Initiative. We published the first in the Patient-Powered Educational Literature series, "A Guide to Living with Sickle Cell", and have partnered to create a patient-powered guide to blood transfusion as well as a patient-powered guide to bone marrow transplant.

Together, the patients, caregivers and supports 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.

The Sickle Cell Community Consortium Board and Staff

Lakiea Bailey, PhD
Executive Director

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.

Eric 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.

Doris Bailey, BS
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.

Raymona Lawrence, DrPH, MPH, MCHES
Associate Director of Finance

Dr. Raymona H. Lawrence is an Assistant 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 academic section chair for the Georgia Public Health Association.

Kimberly Davis
Administrative Coordinator

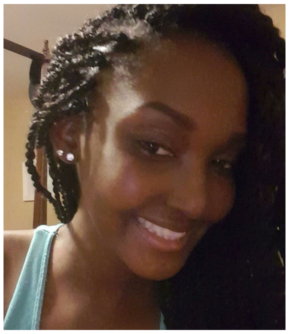
Diagnosed with Sickle Cell Anemia, type SS at the age of 11, Kimberly is a dedicated and hardworking individual who has overcome many of the challenges faced against sickle cell disease. With an earnest desire to increase awareness of SCD and to see marked improvement in the care and treatment of those who suffer from SCD, she seeks to inspire and provide hope for all of those who battle daily with this egregious disease.

Nikki Peterson
Special Projects Coordinator; Director of Special Education Services

Nikki Peterson is a 42 year old sickle cell warrior living in Upper Marlboro, Maryland. With a degree in Special Education from Bennett College, Nikki has taught special education grades K through 12 and is currently the president and CEO of TutorsRUs, an educational service in Maryland. Nikki enjoys working with children and advocates for children with special needs as well as for patients with sickle cell disease. Nikki was among one of the first employees of the Consortium wearing multiple hats. She currently serves as Special Projects Manager and is the Consortium liaison for Special Needs Education services.

Jazmine Rivera
Marketing Director

Jazmine Alexis Rivera obtained her Bachelor's in Business Administration with an emphasis in Marketing. She is huge advocate for Sickle Cell Disease where she is determined to educate people on this illness. She noticed the lack of education, information, and research on Sickle Cell Disease and therefore went on to become a patient advocate, and is currently a intern with the Sickle Cell Community Consortium. She advocates for Sickle Cell Disease, through her YouTube channel, and her social media accounts. Jazmine create videos, content and manage multiple social media accounts in order to provide the education to other patients, caregivers, with hopes of continuing the education process.



Alexis Perry
Special Projects Manager

Alexis J. W. Perry is a 24 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 (Crohn's Disease/Ulcerative Colitis & Primary Sclerosing Cholangitis).

Perry has been in the Culinary/Baking & Patisserie as an online E-Nutritionist for the last five years, helping other individuals manage their chronic disorders through balanced dieting. Also working for the City of Los Angeles in Recreation & Parks as a Recreation Assistant and Chef Instructor, she helps her community become educated about their bodies, and the purpose of healthy eating. In 2016, Alexis was brought on to work with the Sickle Cell Community Consortium as a Patient Coordinator/Intern, having the opportunity to be apart of community projects and workgroups that strive to better the Sickle Cell Community.

In 2017, she started working as a broker for an FMO, and currently helps people throughout the U.S. find health and life insurance coverage. She is inspired to work with anyone she can to give a stronger voice for the individuals within the Sickle Cell community, and positively impact the lives of Sickle Cell Warriors and Caregivers, as well as the best nutritional aspect of health to all warriors to better their quality of life.

Helen Mitchell
Special Projects Administrator

Maria Rivera
Administrative Assistant

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.

e. Smalls
A Year of Septembers (AYOS) Director

an artist, advocate, + abolitionist working to improve the visibility + representation of coloreds + queers and fighting for the improved quality of life + liberation of all oppressed peoples, with a spotlight on Black mental health, OCD, chronic illness, + invisible disability.

L'Bonne Walker
Special Projects Coordinator

Janeen Green
Administrative Assistant

A 28 year career in the flight industry Janeen is grateful to have survived 9/11/2001 and a company merger. Janeen is living with Sickle Cell Thalassemia disorder. Two of her children also carry the sickle trait. 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 Capitol 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.

Teonna Wolford
Intern

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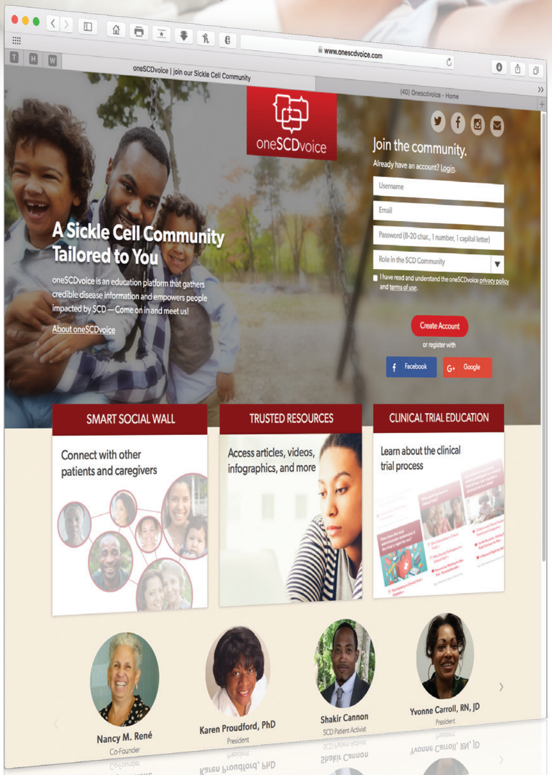

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SCD Patient Activist

Yvonne Carroll, RN, JD
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> *“I’m impressed with the quantity of information and the range of topics covered. Without a platform like oneSCDvoice, it would take hours to find this kind of information on sickle cell disease and trait — and then hours more to determine which sources are reliable and trustworthy.”*
>
> *— Karen Proudford, PhD*

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Leadership Summit and General Assembly Agenda

Friday, March 23

Time	Event	Presenter	Location
	OPENING OF THE GENERAL ASSEMBLY		
2:00 PM	Welcome & Opening	Lakiea Bailey, PhD	Salon A, B, C
2:15 PM	2017 Review: Mental Health update	Clayton Andrews, MS	Salon A, B, C
2:30 PM	2017 Review: Transition Toolkit & Workgroup This presentation will cover a brief overview of the three main patient-powered projects and programs geared toward addressing the "Transition problem", as well as the SCD Transition Tool Kit that has focused on Transition needs and how to better address the concerns of this population and their caregivers in the form of a guide/instruction manual.	Alexis Wardlow	Salon A, B, C
2:45 PM	2017 Review: Sickle Cell Anthology Updates on the sickle cell anthology include creating an outline, setting guidelines and preparing a tool to seek submission. An outline was created based on the problems, gaps and needs that are within the community. We are seeking narratives from sickle cell patients and caregivers for a sickle cell anthology. These expressions are intended to promote sickle cell awareness and showcase the challenges that are present in the sickle cell community.	Kadeem Gayle, MFA	Salon A, B, C
3:00 PM	2017 Review: Patient Toolkit	Wanda Shurney, MD	Salon A, B, C
3:15 PM	Warrior University	Lakiea Bailey, PhD	Salon A, B, C
3:30 PM	2018 Update: Parent-to-Parent Initiative	Lisa Rose, MEd	Salon A, B, C
3:45 PM	Fair Treatment for Warriors	Dominique Friend	Salon A, B, C
4:00 PM	Return of the SCD Soldier Network The SCD Soldier Network was founded by Phyllis Thomas in 2010 to provide the sickle cell community with an army of support for its ongoing battle with sickle cell disease. It was their mission to establish a national registry of volunteers, in order to supply the necessary manpower to create a bigger voice that will	Candice Thomas-Cross	Salon A, B, C

	effectively communicate the needs of the sickle cell community.		
4:30 PM	oneSCDvoice	Shamonica Wiggins	Salon A, B, C
4:30 PM	The Opioid Epidemic on Managing Pain for SCD: Challenges and Contradictions In recent years, the CDC has tracked the alarming increase in opioid prescriptions and opioid-related deaths. Consequently, guidelines were developed to address prescribing opioids for non-cancer related pain. This study examines the impact of these guidelines on the experiences of adults with sickle cell disease who are seeking pain management. Not only the challenges encountered in the emergency room environment, but the contradictions experienced in home management, primary care physician, and the emergency room staff as well.	Cynthia Sinha, PhD	Pre-Function Space
5:30 PM	Creative Content Workshop	E. Smalls	Salon A, B, C
	Creative Content Laboratory		Cherry

Saturday, March 24

Time	Event	Presenter	Location
	FOCUS ON RESEARCH		
2:00 PM	COMPASS: Providing Direction for Community Engaged Sickle Cell Disease Research Participants will learn the basics of comparative effectiveness research (CER). Topics will include: 1) What is CER; 2) Ways to determine if CER is right for a particular project, and 3) How CER relates to the Sickle Cell Community Consortium's current funded Patient Centered Outcomes Research Institute (PCORI) project. Participants will also be engaged to develop CER questions that the consortium will potentially use to guide its research focus in the future. This session will further engage participants in the SCCC's philosophy of "Nothing for us, without us".	Raymona Lawrence, DrPh, MPH, MCHES & Coretta Jenerette, PhD, RN, CNE, AOCN, FAAN	Salon A, B, C
2:15 PM	Blood Transfusions: What Patients Need to Know and Do	Ashley Singleton, MPH	Salon A, B, C

	This presentation has 4 parts. The first part is to share information that is important for those with sickle cell disease to know about transfusions. Transfusions are appropriate, life-saving treatments in the right situations; but they can also carry serious risks. We will discuss steps that patients and doctors can take to minimize those risks. One step, increasing blood donations by people with similar genetics as those who need transfusions, is the subject of the next two segments: an overview of what one blood collection agency does to help; and introduction of a program for those in the sickle cell community to "Be the Motivation" for minority blood donations. While each part of the presentation will offer time for questions, the final segment is for obtaining advice from Summit participants on how best to communicate these messages and thereby increase transfusion safety.	James Eckman, MD	
2:30 PM	NHLBI "Cure Sickle Cell" Initiative	Lenora Johnson	Salon A, B, C
2:45 PM	HRSA: EMBRACE	Ify Osunkwo, MD	Salon A, B, C
3:30 PM	General Assembly I: The Docket		Salon A, B, C
	Creative Content Laboratory		Cherry

Sunday, March 25

Time	Event	Presenter	Location
10:00 AM	General Assembly II: The Discussion		Salon A, B, C
1:00 PM	Lunch: GBT		Salon A, B, C
2:15 PM	Sponsored Presentation: Ironwood Pharmaceuticals	Dr. Machelle Manuel	Salon A, B, C
3:00 PM	Best Practice: Filing 501c3 & Building a strong board for Junior CBOs	Dan Moore	Salon A, B, C
4:00 PM	Business Meeting		Salon A, B, C
	Creative Content Laboratory		Cherry

Monday, March 26

Time	Event	Presenter	Location
	BEST PRACTICES		
10:00 AM	Harnessing the Power of the Collective: Collaborating with Sister CBOs USA is one of THE wealthiest countries. Though amidst all this wealth, persons diagnosed with sickle cell disease are homeless (are on the verge to being homeless), are in need of mental health and other resources, and are subject to cruelty (refusal to adequately manage their pain), and stripped of their dignity the minute they step foot in an urgent care facility or ER. Today, it is time to stop accepting the mismanagement and the dehumanization of sickle cell disease and begin putting an end to the stigmatization, ill-equipped providers, and premature, preventable deaths. We must ALL come together to do our part by harnessing the power of the collective. I will go over five key elements of the collective impact. Collective impact allows us to take full advantage of opportunities as they arise.	Carolyn Rowley, PhD	Salon A, B, C
10:45 AM	The Future is Intersectional: Advocacy Within a Social Justice Framework A multi-session social justice 101 workshop designed to make the connection between social justice, intersectional activism, and healthcare advocacy, particularly for Sickle Cell Disease in order to improve efforts and further the agenda of the advocate.	e. Smalls	Salon A, B, C
11:20 AM	Grant Writing Workshop In this beginner's seminar we will identify different types of grants, best practices for beginning and executing the grant writing process, and learn about the best ways to avoid some of the most common mistakes in grant writing.	Brandon Webster	Salon A, B, C
12:30 PM	Responding to Disaster	Tonya Prince	Salon A, B, C
1:15 PM	Lunch: Infrastructure Committee Meetings		Salon D

	BEST PRACTICES		
2:15 PM	Forming Partnership with Public Health	Velvet Brown-Watts, MSW, CM	Salon A, B, C
2:50 PM	Social Media in the Sickle Cell Community Qualitative and Quantitative Content Analysis of Sickle Cell Disease on Social Media	Charles Jonassaint, PhD	Salon A, B, C
3:25 PM	Social Media Tools, Tips and Trends	Patricia Wilson-Smith	Salon A, B, C
4:00 PM	Forming Partnership with Pharma		
4:35 PM	Creating a Volunteer Network	Kemba Gosier	Salon A, B, C
7:00 PM	Spilled Milk: Screening and Conversation with Writer/Director	Jacquai Mickelsen Omar Beach	Laurel Amphitheatre

Tuesday, March 27

Time	Event	Presenter	Location
	BEST PRACTICES		
9:00 AM	Professional Advocacy	Lakiea Bailey, PhD	Salon A, B, C

COMPASS

COMMUNITY PARTICIPATION TO ADVANCE THE SICKLE CELL STORY

COMPASS was created to guide the direction of sickle cell research as well as to capture the sickle cell community's patient voice to determine patient priorities for research. This would bridge the gap between research, practice, and true outcomes (change) for patients with sickle cell disease.

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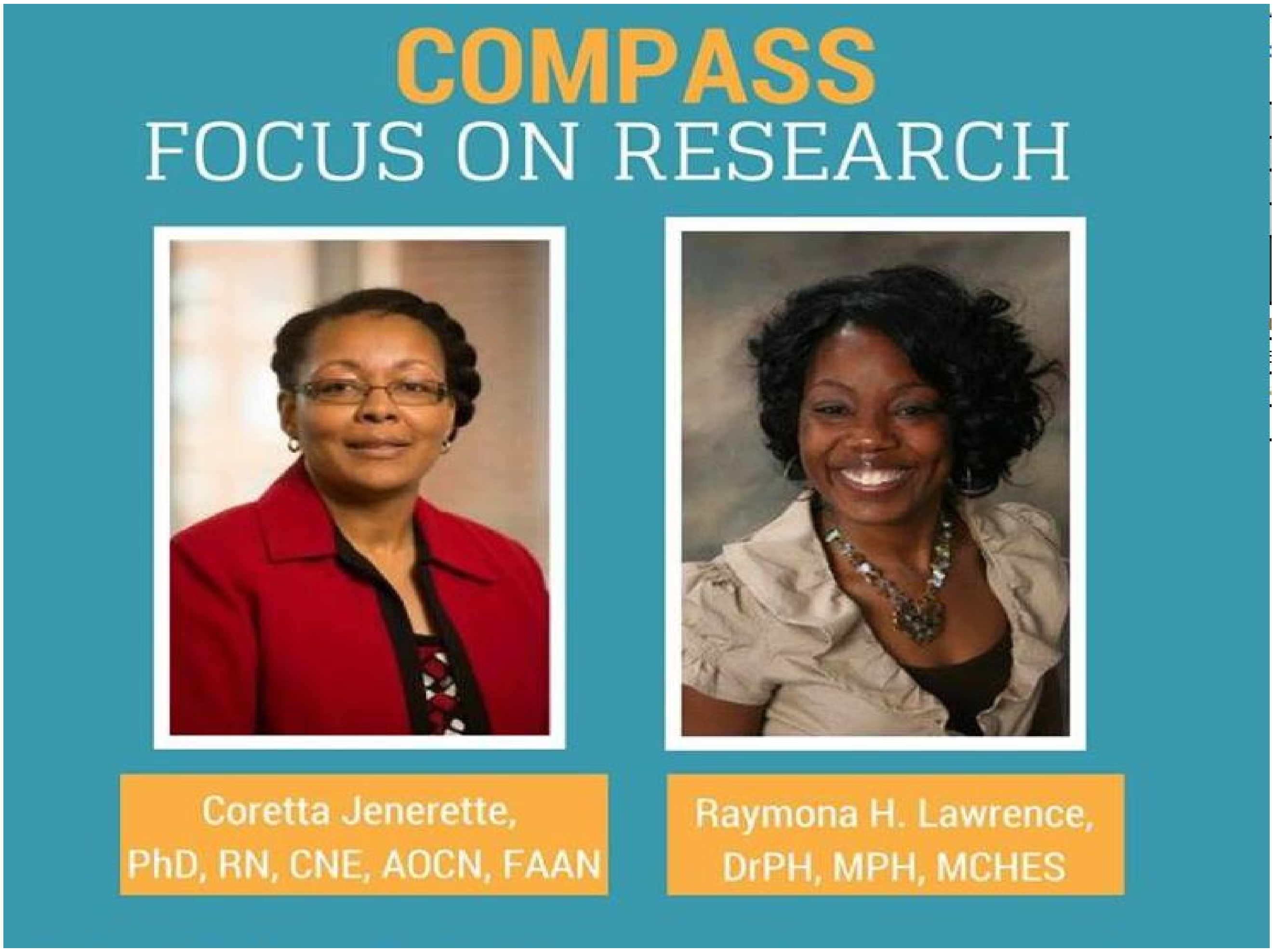


The VOICE of patients is often underrepresented, misrepresented, or completely absent in research. This is even more prominent in research involving minorities such as the case with sickle cell disease (SCD). SCD research has largely been physician or scientist driven with much of the focus on basic science. Although this work is important, it has created a significant gap between outcomes and true needs/priorities of the SCD community. It has also been noted that researchers often use individuals with SCD within the implementation stages of their studies, but fail to recognize their value within the planning or dissemination stages. This forgoes important steps in authentic community-based participatory research engagement.

COMPASS: Community Participation to Advance the Sickle Cell Story was designed to provide a platform to directly involve the sickle cell patient and caregiver community in patient-driven research. All projects, initiatives and platforms of the Sickle Cell Community Consortium are created and powered by the sickle cell "warrior" community. Birthed out of community desire to have a seat at the table (and not just a voice in the crowd), this initiative will engage our existing network of 31 community-based organization (CBO) partners and extensive database of registered patient/caregiver advocates, to generate a list of patient-identified research priorities and CER questions through engagement, education and empowerment. The findings will be used to inform researchers, physicians, policy makers, funding agencies, community based organizations and other entities about the research needs of sickle cell patients using the patient's VOICE and prepare sickle cell CBOs for participating in CER research projects.

Speaker Profiles

Ashley Singleton, MPH
Research Associate II, Georgia Health Policy Center, Georgia State University

Ashley Singleton is a research associate at the Georgia Health Policy Center with expertise in health communications, strategic planning, and program evaluation. Her current activities include leading community-focused efforts to improve outcomes for individuals with sickle cell and thalassemia as part of the Hemoglobin Disorders Data Coordinating Center, and providing fidelity monitoring and workforce development for high-fidelity wraparound initiatives in Georgia as part of the Center of Excellence for Children's Behavioral Health. Ashley holds a masters in public health from the University of South Florida and a bachelor of science from the University of South Carolina.

Brandon Webster

Brandon Webster is a Composer & Dramaturg Based in Brooklyn NYC. As an HBCU Graduate his work thrives on equal parts creative and administrative energy. He bridges experiences in Technology, Arts Administration, Training/Team Development and Publishing to The Visibility Project as the newly appointed Director of Operations.

Candice Thomas-Cross

Candis Thomas-Cross is the daughter of Phyllis Zachery-Thomas, the founder of SCD Soldier Network. Candis was born and raised in Dallas Texas and witnessed the fight of sickle cell early on because of her mother's disease. She was an only child who had to learn to care and advocate on her mother's behalf.

With her knowledge of sickle cell she was able to help council other peers whose parents suffered from the same disease. Candis was able to attend Clark Atlanta University in 2002. While there she was a frequent donor of blood and joined the Be the Match Registry. She truly cares for others and wants to be an instrument of love and light.

For the last 13 years she has been a flight attendant which allows her to travel and interact with others. She is a wife and mother of two residing in McDonough Georgia. Candis truly believes in giving back and sharing her gifts.

Carolyn Rowley, PhD

Dr. Carolyn Rowley is the Founder and Executive Director of Cayenne Wellness Center and Children's Foundation (a non-profit organization dedicated to health and wellness). In her role as Executive Director, she specializes in nutrition (well known for her 3-4-4 nutritional program), health psychology and treating patients and their families with sickle cell disease. She also began another non-profit organization in 2005, as a result of her missionary experience to Kenya, East Africa (The Machao Orphanage Foundation - http://www.machaoorphanage.org).

Twelve years ago, Dr. Rowley responded to an immediate need - to house the original 13 children and many that were on the waiting list. Her first strategic plan: Strategic Plan I: Foundation, afforded her the vision to build the dorms, latrines and other buildings (2009); to provide clean water (2010); to put in solar panels (2011); to provide food by building a greenhouse and chicken coop (2012); and to put in solar irrigation (2014-2016). Her second strategic plan: Strategic Plan 2: Impact, has led her to strategically take care of more orphans (80 children) and have the orphanage be sustainable and economically self-reliant by the year 2020.

Charles Jonassaint, PhD

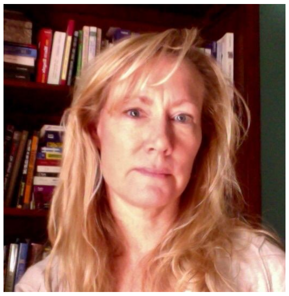
Dr. Jonassaint's overarching career goal is to eliminate health disparities by designing, developing and disseminating, trial tested, evidence-based behavioral interventions to underserved populations. More specifically, his research will lead to a better understanding of the psychological and biobehavioral 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.

Clayton Andrews, MS
Co-Founder Sickle Cell Champions Assn.

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.

Coretta Jenerette, PhD, RN, CNE, AOCN, FAAN

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.



Cynthia Sinha, PhD

Cynthia B. Sinha, PhD is a sociologist with a focus on family, medical sociology, and more specifically, sickle cell disease. Her research examines the challenges in medical decision-making for adults with sickle cell as well as parents of pediatric patients. Additionally, she is heading a study to understand the impact of sickle cell disease across the life course. Most recently, she joined the STELLaR project which focuses on the long-term implications of bone marrow transplant on the patient transplanted for sickle cell disease. She currently is a researcher at Emory University School of Medicine, Aflac Cancer and Blood Disorders Center, Sickle Cell Disease Program, Atlanta, Georgia.

Dan Moore

Dominique Friend

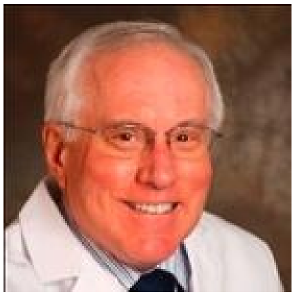
Dominique Friend is an activist for Sickle Cell Disease awareness and research who currently resides in Georgia, but who grew up in Baltimore, Maryland and attended Baltimore City Public Schools. She is a mother of three wonderful children and has one beautiful granddaughter. Although her illness prevented 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.

Ify Osunkwo, MD, MPH

Dr Ify Osunkwo is a lifespan hematologist with over 25 years experience caring for individuals living with sickle cell disease. She graduated from the University of Nigeria with her MD degree, received a Masters in Public Health from Johns Hopkins University and completed her residency training at the University of Medicine and Dentistry of New Jersey. Dr Ify did a combined fellowship in pediatric hematology and bone marrow transplantation at Columbia University and has since dedicated her career to clinical care and research to improve sickle cell outcomes. Her current research interests are in pediatric to adult transition, chronic pain, bone disease, disease management and health literacy.

Jacquai Mickelsen

Jaqai Mickelsen is the writer-director- producer of Spilled Milk, an award-winning documentary that intimately profiles his best friend's experience of living with Sickle Cell Disease. A longtime creative director and cartoon illustrator, Jaqai now works as Head of Story for The Marcus Buckingham Company, a Beverly Hills-based consulting firm, where he works with senior content experts to create media that inspires change. He currently resides in Atlanta, Georgia with his wife and young son, and a crazy cat-sized dog named Bella.



James Eckman, MD
Professor Emeritus in Hematology & Medical Oncology, Emory University School of Medicine

James Eckman, MD is Emeritus Professor of the Department of Hematology and Medical Oncology at Emory University School of Medicine. He was committed to establishing a sickle cell program at Grady Memorial Hospital and, after intensive lobbying for state funding in 1984 became Medical Director of the world's first 24-hour, comprehensive acute care sickle cell center. Dr. Eckman has also championed newborn screening for sickle cell disease on a local and national level; and it was through his efforts that Georgia instituted universal mandatory sickle cell screening for newborns in October of 1998. Dr. Eckman received his medical training and was appointed to the faculty of University of Minnesota Medical School before being recruited to Emory in 1978.

Jane Branscomb, MPH
Senior Research Associate, Georgia Health Policy Center, Georgia State University

Jane Branscomb's career focuses on public and private policy levers to drive population wellbeing and equity. As a senior research associate at the Georgia Health Policy Center, she provides project leadership, research, training and facilitation for local and national clients. Jane directs the multi-year, collaborative efforts of the Center's Hemoglobin Disorders Data Coordinating Center to improve outcomes for individuals with sickle cell disease and thalassemia. She also leads the Center's systems thinking work, using the principles and tools of that discipline to help diverse stakeholders deepen shared understanding and build effective strategies for addressing complex challenges. Jane holds a masters in public health from Emory University and a bachelor of engineering from Vanderbilt University.

Kadeem Gayle, MFA

Kadeem Gayle is a graduate candidate at Drew University, he holds a BA from American International College and an MFA from Adelphi University. Gayle has written for the Republican Newspaper, Springfield MA and has blogged for Masslive.com. In 2014 Gayle received the Donald Everett Axinn Award in Poetry. Gayle was born in Boston, MA and at an early age was diagnosed with sickle cell disease. Gayle has found it rewarding to advocate for sickle cell disease using poetry and has found writing to be a positive outlet especially when coping with sickle cell disease.

Kemba Gosier

Kemba O. Gosier is a native of Miami, FL, and the proud mother of two phenomenal daughters Courtney & Erica. Courtney, at the age of six months, was diagnosed with Sickle Cell Disease (SCD).

Kemba serves as President of the Advancing Sickle Cell Advocacy Project, Inc. (ASAP), a nonprofit 501 c 3 community based organization. Its purpose is to provide support services for people living with Sickle Cell Disease in Dade and Broward Counties FL, including advocating on behalf of Sickle Cell Anemia patients and educating the community on SCD & Sickle Cell trait. Over the past three years ASAP has developed a wide range of networking, awareness and educational services and has had tremendous success by inspiring and improving the quality of life for individuals living with SCD. Forums, community picnics, support groups and Sickle Mother's Day Brunches are just a few of the avenues ASAP uses to spread awareness.

Ken Bridges, MD

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 the new treatment for sickle cell disease, GBT440.

Lisa Rose, MEd

Lisa Rose is the Executive Director of HOPE for SCD, an organization focused solely on providing research based medical education around Sickle Cell Disease, and areas of complimentary interest. She has a Master's Degree in Education and has been developing curricula and trainings for a myriad of companies for over 11 years. Her collaborating efforts include research studies spanning both medical and educational settings. Her current focus is on Adult Education, and the gaps related, within the medical field for patients and families.

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

Patricia Wilson-Smith

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.

Shamonica Wiggins

Co-Founder, CEO, #BoldLipsForSickleCell

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

Tonya Prince

Sickle Cell Association of Houston was birthed to restore our city's rich and rooted legacy in sickle cell education, awareness, and service. A full service coordination and care management resource center for individuals and families affected by sickle cell disease in the Greater Houston Metropolitan area. Our mission has been guided in providing various services aimed at achieving healthier outcomes specific to those suffering from the inherited genetic and rare disorder. Recognizing the state of sickle cell disease in the city, our work has broaden its scope of services through its Community Based integration model; the first free-standing insand only one of its kind in the city.

Sickle Cell Association of Houston has gained the support of the Honorable Mayor Sylvester Turner, Congresswoman Sheila Jackson Lee, Texas State Representative Jarvis Johnson, Texas State Representative Ronald Reynolds, Judge Claresse Rankin Yates, and many more civic and community pillars who wholeheartedly support the efforts and works of Sickle Cell Association of Houston.

Velvet Brown-Watts, MSW, CM

Velvet Brown-Watts, is the Founder-Chairperson of Supporters of Families with Sickle Cell Disease, Inc. Supporters (as it is affectionately known) is a community-based Oklahoma nonprofit organization that has assisted families living with sickle cell diseases since 2004. Supporters is the only comprehensive grassroots family support and advocacy organization in Oklahoma that serves as a center of contact and referral service for community resources to assist individuals with sickle cell and inherited disorders and traits.

Velvet has spent over 20 years in social services, serving on several non-profit community boards, and volunteering with many different organizations in the Oklahoma community. Velvet holds an AA in Liberal Arts from Tulsa Community College, a Bachelor's Degree in Social Work from Northeastern University and Master of Social Work in Administration from University of Oklahoma. Velvet is a certified case manager for the Advantage Program. She has a medical background as a medical social worker with hospice and home health patients.

Through Velvet's work with Supporters board and advisory committees, a statewide sickle cell taskforce group: Oklahoma Sickle Cell Collective Impact Team, was formed to address the gaps and proving patient center outcomes recommendations. Velvet is passionate about serving the Oklahoma community and empowering others surviving sickle cell diseases and its related conditions and traits. Her motto is "Learn the Facts, Know the Truth, Save a Life- Sickle Cell Disease Awareness".

Wanda Shurney, MD

EXECUTIVE SUMMARY

The Parent to Parent Initiative, powered by the Sickle Cell Community Consortium, is a unified platform of parents and caregivers focused on building connections, increasing access to education and resources, and promoting advocacy through a national parent to parent network of families living with sickle cell.

CONNECTION

Connecting parents regardless of geographical boundaries

CONNECTION:

Goals to increase our support network

Create a safe space for parents to discuss sensitive issues related to sickle cell outside of parent/patient forum

Advocacy

Advocating for sickle cell on both locally and nationally

ADVOCACY:

Goals to increase our presence

Mobilize a parent task force to create political change within the rare disease and sickle cell arena at the local and national level.

Resources

Equipping families with necessary tools

RESOURCES:

Goals to increase access to required tools

Develop a National Sickle Cell and School policy document for use in elementary, secondary, and higher education institutions

Education

Educating families with research-based materials

EDUCATION:

Goals to increase accurate, research-based materials

Design and Implement Warrior Parent University, an online platform utilizing webinars for parents that presents relevant topics identified by the P2P network

Powered by the Sickle Cell Community Consortium- go to www.sicklecellconsortium.org for more information.

Meeting Participants

INDEPENDENT PATIENT/CAREGIVER ADVOCATES

Name	Email	Social Media
Ade Adeyokunnu	dotun2k@gmail.com	TW: sikcell
Charly Richard	charly.blakk86@gmail.com	TW: charlyblakk; IG: charley_blakk; FB: charlyblvkk
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Clarice Peterson	reese.peterson@yahoo.com	
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Sutanna Goode		
Teonna Woolford	smilingjewel24@gmail.com	
Tina Kay Hughes	tkay2006@gmail.com	
Ulysse Gurrier	oursicklelife@gmail.com	

JUNIOR COMMUNITY BASED ORGANIZATIONS (CBOs)

No Pain In the Playroom **Delegates**: Diamond Edmundson, Omeka Edwards **State**: California **Website**: www.nopainintheplayroom.org **Email**: nopainintheplayroom@gmail.com **Social Media**: @nopainintheplayroom	No Pain In The Playroom: A Sickle Cell Awareness organization which focuses on the use of distraction as a form of alternative pain management has been in operation 2011 and is lead by Sickle Cell Anemia Survivors Diamond Ray Edmundson and Omeka Edwards. Together they continue fight for awareness and education for sickle cell using their various social media platforms, their Sickle Cell themed clothing lined and making in person appearances speaking to children ranging from preschool to high school.
Sickle Cell Champions Association **Delegates**: Clayton W. Andrews **State**: Georgia **Email**: sicklecellchampionsassociation@gmail.com **Social Media**: @sicklecellchampionsassociation	S.C.C.A. was formed to bring a male perspective to not only the youth, but also for new parents, and to enlighten the communities of what Sickle Cell Disease is, how it affects the body, and what a child may possibly encounter within their lives. We strive to be an effective voice, for the SCD patient, family member and male community. The program ("Champions Mentoring") was created and implemented to ensure that we place focus on the empowerment, motivation and overall growth of adolescent males living with SCD.
Sickle Cell Mommies Club **Delegates**: Shamir Jubert **State**: California	A place for moms with children with SC or mothers with SC or mothers with SC who are actively trying to conceive. Judgement free zone where we can talk and share about the victories and achievements and sometimes pitfalls of our type of motherhood.
Transition with Power **Delegates**: Tahirah Austin **State**: Pennsylvania **Website**: transitionwithpower.com **Email**: transitionwithpower@gmail.com	
The Red Chair Project **Delegates**: Sharonda Hudson	It is our mission to support, educate and empower warriors and their families through hosting events, visiting warriors and telling their stories.

State: Texas **Website**: www.trcp.info **Email**: theredchairprojectinfo@gmail.com	

COMMUNITY BASED ORGANIZATIONS (CBOs)

Advancing Sickle Cell Advocacy Project, Inc. (ASAP) **Delegates**: Kemba O. Gosier, Alma Brown, Stephanie Bankston, Natalie McGuffie **State**: Florida **Website**: www.asapbeinformed.org **Email**: info@asapbeinformed.org	Advancing Sickle Cell Advocacy Project, Inc. (A.S.A.P.) is a nonprofit organization based in Hollywood FL, comprised of sickle cell warriors, sickle cell trait carriers, caregivers and those who have a passion for the sickle cell community. community. ASAP's mission is to educate and advocate on behalf of sickle cell clients and their families in Miami-Dade, Broward, and Palm Beach counties. Also, we are dedicated educating the general public about sickle cell anemia and sickle cell trait. ASAP wants to see patients live longer and more pain free lives by maintaining good health emotionally, mentally, and physically. We are dedicated to breaking the stigma associated with sickle cell anemia and invoking change in treatment within the healthcare community. We serve as a voice for those who have had no voice.
As One Foundation **Delegates**: Tomia Austin **State:** Texas **Website**: www.asonefoundation.org **Email**: info@asonefoundation.org **Social Media**: @AsOneFoundation	The As One Foundation was established in 2007 by NFL wide-receiver and FBISD Stephen Austin Alum, Devard Darling in honor of his identical twin, Devaughn, who died prematurely and tragically of exertional rhabdomyolysis due to sickle-cell trait & dehydration during Spring football practice at FSU on February 26, 2001. The As One Foundation empowers young people through two main programs: 1. Operation Hydration, a sickle cell trait awareness program that promotes awareness of sickle cell trait through education about the importance of proper hydration and recovery time as prevention of athletic/fitness related death (ARD/FRD) throughout all schools of Fort Bend Independent School District (FBISD); 2. The Devard & Devaughn Darling Scholarship Awards, thatannually awards ten $1000 scholarships to eligible FBISD high-school seniors based not solely on academic merits, but also on demonstrated resiliancy to Devard's turning tragedy into triumph through the work of the As One Foundation.

AXIS Advocacy for Sickle Cell Disease **Delegates**: Marissa Renee Cors **State**: California **Website**: www.axisadvocacy.org **Email**: adriennebc_1@yahoo.com	Grassroots organization dedicated to improving the lives of people living with Sickle Cell Disease through Advocacy, Education, Research and Legislation.
Bold Lips for Sickle Cell **Delegates**: Shamonica Wiggins, Jewel Darbone, Brandi Rogers, Tarsha Edwards **State**: Texas, Georgia **Website**: www.boldlipsforsicklecell.com **Email**: boldlipsforsicklecell@gmail.com **Social Media:** @boldlipsforsicklecell	#BoldLipsForSickleCell is a 501 C3 non profit organization geared towards spreading Sickle Cell awareness and empowering individuals who has the illness. They have become a fresh and relevant movement, intended to put a bold and flattering spotlight on this disease and its community. We plan to continue to building a network of supporters and allies who will help make this disease as well-known and positively endorsed as the likes of breast cancer and other high profile diseases. The mission of #boldlipsforsicklecell to educate and raise awareness for SCD through its advocates wearing bold lipstick colors. They are making a loud and boisterous statement which in turn gains attention along with conversations being sparked. They want to infiltrate surrounding communities by hosting events that are geared towards educating and building awareness for SCD.
Cayenne Wellness Center & Children's Foundation **Delegates**: Carolyn Rowley, PhD **State**: California **Website**: cayennewellness.org **Email**: info@cayennewellness.org	Dedicated to health promotion and disease prevention in children, adolescents, adults and their families diagnosed with sickle cell disease. Their mission is to improve the nutritional and mental health of the public and those diagnosed with sickle cell disease. We achieve this mission through education (our Annual SCD Educational Seminar; our upcoming Provider Inservice Training program), research, and public awareness initiatives and community outreach programs (i.e., our Canvassing program that educates the public). We practice the science of helping people make changes in their lifestyle to improve their overall health and quality of life emotionally, physically, and spiritually.
The Committee on Better Racial Assurance	We assist those served to achieve a better quality of life. Sickle Cell Disease services are provided to

Website: cobraagency70.com **Email**: cobraagency@bellsouth.net	patients, their families and the public: case management, patient assistance, education, screening, hemoglobinopathy counseling, referrals and follow-up. The Community Relations services improve and create channels of communication between individuals and entities - governmental bodies, agencies and organizations-which govern or serve them.
Heart of Gold Sickle Cell Foundation of Northern Virginia **Delegates**: Melanie Hurley **State**: Virginia **Website**: heartogold.org **Email**: melanie.hurley@heartogold.org	It is our mission to serve as an advocate for adults and children in the Northern Virginia area. Heart of Gold Foundation is structures to educate, mentor, and support those that battle with Sickle Cell Disease.
Hope for SCD **Delegates**: Lisa Rose, MEd **State**: North Carolina **Website**: hopeforscd.org **Email**: lrose@hopeforscd.org **Social Media**: @hopeforSCD	We are a health literacy NPO started by parents of a child with SCD. Although we are based in Raleigh, NC, we provide international access to research based medical education materials. Our mission to bridge the gap between providers and the lay community through research based health literacy tools and programs.
International Association of Sickle Cell Nurses and Professional Associates (IASNAPA) **Delegates**: Coretta Jenerette, PhD, RN, CNE, AOCN, FAAN; Pat Corley, RN; Yvonne Carroll, RN, JD **State**: North Carolina, California **Website**: www.iascnapa.org **Email**: admin@iascnapa.org	The International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA) is the only organization consisting solely of nurses, physician assistants, and other health care professionals who provide care and advocacy for individuals with sickle cell disease. IASCNAPA recognizes its responsibility to maintain high standards in the provision of quality and accessible health care services for individuals with sickle cell disease. IASCNAPA is committed to strengthening the relationship between nurses, healthcare providers, and people with sickle cell disease to ensure a patient-driven multi-disciplinary approach is used to provide comprehensive care for people with sickle cell disease.
Journey's By Grace Global Missions	Our mission is to encourage growth,development and change while promoting hope and faith in

Delegates: Joyce El **State**: Florida **Website**: journeysbygrace.weebly.com **Email**: journeysbygrace@gmail.com	God's word. To be a light in darkness, a voice in the wilderness. Journey's by Grace is a mission of compassion, a non-profit organization in which the organization is committed and focused to address the social and spiritual need of the community. JBG works actively with groups and organizations to gain funding, collaborations, knowledge, resources and support for the people. Our mission is to share experience and knowledge to help others on their journey of life.
Kids Conquering Sickle Cell Foundation **Delegates**: Carla Lewis **State**: Florida **Website**: kidsconqueringscd.org **Email**: info@kidsconqueringscd.org	To dedicate with compassion to provide education, awareness, advocacy and outreach to improve the quality of life for individuals and families living with sickle cell disease and other hemoglobin disorders. Kids Conquering SCD, Inc. provides awareness, educate and support families, educate the community, promote testing for hemoglobin gene, support research of treatments, and collaborate efforts worldwide. Our mission will not be complete until a universal cure is found for sickle cell & other blood diseases.
Lockhart Morgan Foundation **Delegates**: Gwen Morgan, Ed Morgan **State**: Georgia **Website**: lockhartmorganfoundation.org **Email**: lockhartmorganinfo@gmail.com	Lockhart Morgan Foundation is Atlanta Based organization which is focused on bringing awareness to our community, providing assistance to families in need and providing scholarships for Sickle Cell Students continuing their education.
Martin Center Sickle Cell Initiative **Delegates**: Gary Gibson **State**: Indiana **Website**: themartincenter.org **Email**: information@themartincenter.org	Martin Center, Inc. is a human services agency founded in 1969 by the late Rev. Boniface Hardin, O.S.B., and Dr. Raymond Pierce. Martin Center has remained dedicated to providing a "holistic approach" to clients battling the effects of Sickle Cell in our community for over 40 years. Martin Center assumed the name Martin Center Sickle Cell Initiative (MCSCI) in September 2012 in order to have its name more directly reflect its mission. Martin Center Sickle Cell Initiative exists to aid and enhance the lives of those affected by Sickle Cell and associated disorders by providing services, education, and advocacy. We are committed to providing essential programs and services to benefit individuals and families affected by Sickle Cell. We also educate clients as

	well as community members by providing access to quality educational experiences. MCSCI works with educators, medical professionals, schools and caregivers in the provision of our services and we strive to build public awareness about Sickle Cell Disease, Sickle Cell Trait and other abnormal hemoglobin conditions that primarily impact African- Americans, Arabs, Asians and Latinos. Building public awareness of Sickle Cell Disease, Sickle Cell Trait and associated disorders is necessary in the fight against Sickle Cell.
Scales International (fka Cilly Cell) **Delegates**: Angela Woods, Jennifer Williams **State**: Georgia **Website**: thecillycellproject.weebly.com **Email**: tccfoundationintl@gmail.com	
Sickle Cell Disease Association of Illinois **Delegates**: Talana Hughes **State**: Illinois **Website**: sicklecelldisease-illinois.org **Email**: sicklecelldisease-illinois@scdai.org	Sickle Cell Disease Association of Illinois' (SCDAI) primary mission is to enhance the quality of life for individuals with sickle cell disease and their families. To effectively achieve this goal, SCDAI acts as an advocate for improved healthcare and services for sickle cell patients by educating and informing the community through outreach and educational programs.
Sick Cells **Delegates**: Ashley Valentine **State**: Illinois **Website**: www.sickcells.com **Email**: avalentine@sickcells.com	Sick Cells' mission is to elevate the voice of the sickle cell disease (SCD) community and their stories of resilience. In highlighting the grave disparities this community faces, we hope to influence decision-makers and propel change.
Sickle Cell 101 **Delegates**: Cassandra Trimnell, Stephen Agyenim-Boateng PharmD, RPh **State**: California, Idaho **Website**: http://sc101.org **Email**: info@sc101.org	Sickle Cell 101 (SC101) is a 501(c)(3) non-profit organization educating all people affected by sickle cell through the use of social media. The SC101 team consists of certified sickle cell educators and expert physicians within the field of hematology. SC101's main outlets include their social media platforms, website (sc101.org), and online newsletter. SC101's information is liked, commented on, shared, and reposted, and an

Social Media: @sicklecell101	outreach of over 85,000 users. Their information is accessed by followers from over 80 countries on six continents. SC101's "social media education" program, is comprised of quick sickle cell facts with supporting graphics, perfect for those looking to learn more about sickle cell in a quick and condensed manner.Additional programs include "Ask Dr. Q, the Sickle Cell & Thalassemia Expert Physician", which is a popular resource to patients who don't have access to a sickle cell doctor; and the Sickle Cell Advocate of the Year Awards, which recognizes sickle cell advocates making a difference in the sickle cell community. In addition to the web-based programs, SC101 also provides sickle cell education in local schools, sickle cell camps, seminars, CEU courses, and within the workplace.
Sickle Cell Alliance Foundation **Delegates**: Lisa Meatchem **State**: Ohio **Website**: www.scafcincy.com **Email**: lisa@scafcincy.com	Launched in May 2014, Sickle Cell Alliance Foundation is a passionate non-profit, community-based organization. It is committed to being a valuable resource to guide and help families and patients- children, teens and adults- living with the life-threatening sickle cell disease. Our goal is to ensure the appropriate programs and needed resources are available and offered to the patient and caregiver(s).
Sickle Cell Association of Texas Marc Thomas Foundation **Delegates**: Linda Thomas, Emily O'Shea **State**: Texas **Website**: www.sicklecelltx.org **Email**: info@sicklecelltx.org	We provide numerous services to children, adults and families in Central Texas, San Antonio, the Texas Gulf Coast, and other affected with sickle cell disease and those carrying sickle cell trait. We provide education, research awareness, outreach, support group meetings, assistance and numerous other services.
Sickle Cell Association of Houston **Delegates**: Tonya Prince **State**: Texas **Website**: www.sicklecellhouston.org **Email**: tonya@sicklecellhouston.org	Serving as Houston's leading sickle cell community based organization and coordination center, we provide various services aimed at achieving healthier outcomes for individuals living with the inherited rare genetic disorder known as sickle cell anemia. Sickle Cell Houston is staffed with certified genetics education counselors in the area of sickle cell disease providing an unmatched level of support and service for the sickle cell population. It

	is our commitment to the Greater Houston Metropolitan area for those living with sickle cell disease, that we hold ourselves accountable by proving programming that assures all persons living with sickle cell disease, can indeed live without limits.
Sickle Cell Foundation of Minnesota **Delegates**: Raenelle Blaylark, Raymond Blaylark **State**: Minnesota **Website**: www.sicklecellmn.org **Email**: sicklecellmn@gmail.com	The Mission of The Sickle Cell Foundation of Minnesota is to improve the quality of life for individuals and communities in Minnesota who are affected by sickle cell disease and sickle cell trait. SCFMN is the only active community-based organization that exists to create education, awareness, and support for the Minnesota sickle cell community. We are passionately dedicated to carrying out this work through education, activities, programs and approaches that provide life skills and patient advocacy for equitable and affordable access to health care that improves life for today's generation and those to come.
Sickle Cell Foundation of Tennessee **Delegates**: Michael Jackson, Shelfina Wilkins **State**: Tennessee **Website**: www.sicklecelltn.org **Email**: mjackson.sicklecelltn@gmail.com	The Sickle Cell Foundation of Tennessee (SCFT) is a 501(c) 3 non-profit organization founded in 2008, by the late Dr. Trevor K. Thompson and Cherry N. Whitehead-Thompson. As an educator (Administrator with Memphis City Schools) and sickle cell disease consumer, Dr. Thompson championed the call for advocacy, educational support and social services for citizens impacted by sickle cell disease in Memphis, across the state of Tennessee, and the region of north Mississippi and eastern Arkansas. His efforts have enabled SCFT to provide educational awareness, through direct contact, via television, radio, print, and social media to more than 1,000,000 citizen across the Mid-South area. Our mission is to provide educational awareness, comprehensive social services and collective supportive impact to all person affected by Sickle Cell Disease within our service areas.
Sickle Cell Foundation Support Group **Delegates**: Parnel Abraham **State**: Georgia **Website**: thesicklecellsupportgroup.yolasite.com	The Support Group addresses the psychosocial/ nutritional issues in coping with Sickle Cell Disease.

Email: parnel@sicklecellsupportgroup.org	
Sickle Cell Support Services **Delegates**: LaKisha Johnson, Whitney Litsney **State**: Arkansas **Website**: arscss.org **Email**: arsicklecell@yahoo.com	Since incorporation, SCSS has provided supportive assistance and services to over hundreds of families affected by Sickle Cell Anemia Disease. In 2008, they launched Sickle Cell Enrichment Camp for children who were born with Sickle Cell Disease ages 7-16. They have been successful to establish community partnerships and collaborations with organizations such as UAMS LIVING Well with Sickle Cell, Little Rock Alumnae Chapter of Delta Sigma Theta, Arkansas Children's Hospital, Arkansas Minority Health and several other organizations. In 2009, their founder and CEO was appointed as Chairperson of the Legislative Taskforce on Sickle Cell Disease. This successful process led to the sickle cell bill passed to support an adult clinic in the state of Arkansas. Their organization continues to advocate, support, provide and help individuals and families impacted by sickle cell anemia disease throughout the state of Arkansas.
Sickle Cell Warriors, Inc. **Delegates**: Tosin Ola, Tiffany Walsh **State**: California **Website**: sicklecellwarriors.com **Email**: sicklecellwarriors@gmail.com	Sickle Cell Warrior's Inc., is a non-profit charitable organization dedicated to education, empowerment, and awareness about sickle cell disease. Our mission is to inspire those affected by sickle cell. As of this minute, you are no longer alone. You have us- and we have you. Welcome to the family.
Sickle International Family Coalition **Delegates**: Dominique Friend, Tynisha Hall **State**: Georgia **Website**: facebook.com/SICKLE1000 **Email**: tynishahall@yahoo.com	The vision of the Sickle International Family Coalition (SIFC) is to work with families affected by Sickle Cell Disease and Sickle Cell Trait worldwide to reduce the burden of living with these chronic conditions that show no outward symptoms.
Sickle Strong Initiative Kenya **Delegates**: Maria Ojiambo, PharmD **State**: New York **Website**: sicklestronginitiative.com	A non-governmental organization registered in Kisumu, Kenya. Its mandate is to raise awareness around the control and management of Sickle cell disease and advocate for better health care options for patients suffering the disease.

E-mail: sicklestronginitiative.kenya@gmail.com	
Supporters of Families with Sickle Cell Disease, Inc. **Delegates**: Velvet Brown-Watts, MSW, CM; Jeremiah Watts, MHR **State**: Oklahoma **Website**: www.sicklecelloklahoma.org **Email**: swithsicklecell@att.net	Supporters of Families with Sickle Cell Disease, Inc.,(AKA "Supporters) is an Oklahoma non-profit organization with IRS 501(c)(3) tax-exempt status. Supporters is the only comprehensive community based organization contracted with the Oklahoma Health Care Authority to provide awareness, education and outreach to families impacted by sickle cell disease and its inherited disorders and traits. Supporters believes self-care management, testing, education, research and development, and economic self-sufficiency are key approaches to empowerment. Supporters' mission is to increase self-efficacy, improve the overall quality of life for individuals living with sickle cell disease and its inherited disorders and traits - children, adults and their families within the State of Oklahoma; through systemic changes in patient care, disability policies, education, family support, nutrition, economic self-sufficiency, awareness, and advocacy.

OTHER PARTICIPANTS

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THE VISIBILITY PROJECT
Battling the Burden. Changing the Spotlight.

As a special offer In honor of The Visibility Project, Brandon will be offering Grant Consulting and Editing services at a discounted rate for Sickle Cell Consortium members.

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