

Sickle Cell Warriors, IASNAPA, and Sickle Cell 101

presents

SICKLE CELL DISEASE
Patient & Family Symposium

THURSDAY to SUNDAY
July 28-31, 2016

LOEWS HOLLYWOOD HOTEL
1755 Highland Ave,
Los Angeles, CA 90028



Theme: "Spirit Indestructible"
Inspired by @SCAF_Nigeria

www.sicklecellconvention.com

Powered by Sickle Cell
Community Consortium

Welcome

Greetings!

It's so great to officially welcome you to the Annual Sickle Cell Patient & Family Educational Symposium and Awards Gala.

We have attendees from across the nation and are thrilled to welcome patients, families, CBO representatives, and health care & research partners to the iconic Hollywood, California.

This symposium will give patients {hereby known as Warriors}, caregivers, and advocates an opportunity to come together. We can share experiences, learn strategies to improve our lives, and make new lifelong friends. It's also a great time to recharge your batteries, take a break, enjoy a vacation, meet your online friends or reconnect.

Throughout the symposium we will be joined by experts in a diverse range of fields to provide insight on managing sickle cell disease. We will host a series presentations, breakout sessions, panel discussions and even afterhour gatherings aimed to equip you with the tools needed to live a vibrant life despite sickle cell disease.

On Saturday night, we will be recognizing the achievements and efforts of those within the sickle cell community at the Sickle Cell Stars Awards Gala, with the Sickle Cell Community Consortium, Sickle Cell Warriors Inc., Supporters of Families with Sickle Cell Disease, Inc., and Sickle Cell 101 presenting awards. It will be a night of Hollywood themed, red carpet glamour.

The theme for this year's symposium is "Spirit Indestructible" which was inspired courtesy of the Sickle Cell Anemia Foundation in Nigeria. Our hope is that you leave here with the tools and guidance to help you live your very best life, regardless of having sickle cell. We are not victims to be pitied, we are Warriors. Even though sometimes sickle cell may knock us down or slow us down, we can still accomplish every goal and dream we have for ourselves.

We have an eventful few days ahead of us. Don't forget to pace yourself, stay hydrated and soak in this event in all its entirety. Thank you for for joining us as we come together, learn and unite for those living with sickle cell disease.

Ready? **Let's do this!**



SICKLE CELL 101

Powered by the Sickle Cell Community Consortium

Contents

Sponsors	1
At-A-Glance	2
About the Hosts	3
Planning Committee	5
Agenda	7
Speaker Profiles	16
About the Sickle Cell Community Consortium	25
Thank You Note	26

Thank You to Our Sponsors

The Hosts would like to thank the following sponsors for their full financial support of the Sickle Cell Patient & Educational Symposium, and for leading the way in clinical research and treatment therapies for those with sickle cell disease.

PLATINUM SPONSOR



GOLD SPONSOR



ADDITIONAL SPONSORS



At-A-Glance

THURSDAY, JULY 28

- ❑ **Registration**
- ❑ **Peer Navigators**
Ify Osunkwo, MD, MPH
- ❑ **Opening Reception**
Sponsored by St. Jude's Children's Hospital
- ❑ **Visual Explorers**
Yvonne Carroll, RN JD
- ❑ **Warriors After Dark**
Hosted by #BoldLipsForSickleCell

FRIDAY, JULY 29

- ❑ **Plenary: Sickle Cell Warrior - Spirit Indestructible**
Tosin Ola, RN/BSN
- ❑ **Breakout Sessions**
- ❑ **Lunch**
- ❑ **Breakout Sessions**
- ❑ **Insomniac's Cafe**
For men: Dr. Trevor Thompson
For women: Dr. Tandua Washington

SATURDAY, JULY 30

- ❑ **Parenting Issues from Birth to Adult**
Adrienne Bell-Cors
- ❑ **Caring for the Caregiver**
Velvet Brown-Watts, MSW, CM
- ❑ **Plenary**
Lakiea Bailey, PHD

- ❑ **CBO & Research Spotlights**
 - ❑ **Physician Education in the Emergency Department**
Kirshma Khemani, MD
 - ❑ **Get Connected**
Cayenne Wellness Center and Children's Foundation
 - ❑ **HBCU Sickle Cell College Tour**
Jew-EL Darbone
 - ❑ **Patient-Powered Sickle Cell Literature Project**
Cassandra Trimnell
 - ❑ **Sickle Cell & Thalassemia Patient Registry**
Lanetta Bronte, MD
 - ❑ **Sickle Options**
Diana Ross, MSN, RN
 - ❑ **Sickle Cell Awareness Across the Curriculum**
Judy Johnson, BS, M.Ed.
- ❑ **Lunch**
- ❑ **Breakout Sessions**
- ❑ **Awards Gala**
Hosted by Sickle Cell 101
Keynote: Gary A. Gibson

SUNDAY, JULY 31

- ❑ **Breakfast with the Warriors**
- ❑ **Closing & Business Meeting**
- ❑ **Advocacy Training and Certification**

About the Hosts

Sickle Cell Warriors, Inc.

Sickle Cell Warriors, Inc. (SCW) 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 and educate the public on sickle cell disease.

Over the last 7 years, SCW has grown into a dynamic community with over 18,000 members. We are the largest patient-run sickle cell community-based organization on Earth and have members from almost every single country in the world. We are predominantly web-based. This gives us the ability to interact regularly with our community, gather valuable intel, receive almost-instant feedback, and engage our users across multiple platforms, countries, and demographics.

We have several projects, classes, and events throughout the year that focus on our core mission pillars. Most notably the Advocacy Training Program, Mentorship Program, Warriors Annual Gathering (in July of every year), and our collection of classes and challenges geared toward educating our community. We also have several strategic partners, sponsors, and events throughout the year in various cities across the world. Our message is that sickle cell doesn't define and you can live a vibrant and fulfilling life despite having sickle cell disease. Join us and become a warrior today.

International Association of Sickle Cell Nurses and Physician Assistants

IASCNAPA is committed to strengthening the relationship between nurses and physician assistants who care for patients with sickle cell disease. Nurse and physician assistants make significant contributions that further the depth of knowledge about sickle cell disease. Our cooperative efforts allow us to play vital roles in clinical research as demonstrated by our participation in NIH studies that have defined the natural history of sickle cell disease and proven the efficacy of prophylactic penicillin for children with the disease.

The Association strives to unite and organize sickle cell nurses and physician assistants throughout the world in order to benefit professionals and patients, while establishing guidelines for standards of nursing care for individuals with sickle cell disease. IASCNAPA also supports the development of research protocols that surface during sickle cell studies funded by governmental or private agencies.

Powered by the Sickle Cell Community Consortium

About the Hosts

Sickle Cell 101

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 any given one of their posts can reach up to 50,000 users. Their information is accessed by followers from over 72 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.

Hosts' Contact Information



Website

www.sicklecellwarriors.com

Email: tosin@sicklecellwarriors.com

Facebook: /SickleCellWarriors

Twitter: @SCWarriorTweets



Website: www.iascnapa.org

Email: please visit website

Facebook: /groups/iascnapa

SICKLE CELL 101

Website: <http://sc101.org>

Email: hello@sc101.org

Facebook: /SickleCell101

Instagram: @SickleCell101

Twitter: @SickleCell101

Powered by the Sickle Cell Community Consortium

Planning Committee

Cassandra Trimnell

President & Founder
Sickle Cell 101
ctrimnell@sc101.org

Pat Corley, RN

Director
IASCNAPA
patcorle@usc.edu

Jew-EL Darbone

Chief Financial Officer & Co-Founder
#BoldLipsForSickleCell
jeweldarbone.blfsc@gmail.com

Shamonica Wiggins

Chief Executive Officer & Co-Founder
#BoldLipsForSickleCell
shamonicawiggins.blfsc@gmail.com

Kimberly Davis

Administrative Coordinator
Sickle Cell Community Consortium
kdavis@sicklecellconsortium.org

Tosin Ola, RN/BSN

Founder & President
Sickle Cell Warriors, Inc.
tosin@sicklecellwarriors.com

Lakiea Bailey, PhD

Executive Director
Sickle Cell Community Consortium
director@sicklecellconsortium.org

Yvonne Carroll, RN, JD

President
IASCNAPA
yvonne.carroll@stjude.org



Global Blood Therapeutics (GBT) is dedicated to developing therapies to transform the treatment of patients with severe blood disorders, including sickle cell disease.

GBT440, is a novel, oral, once daily therapy for sickle cell disease (SCD) in clinical trials. Designed to inhibit red blood cell sickling, GBT440 has the potential to treat the underlying cause of SCD.

We hope you will join us for lunch on Friday July 29th for a discussion of GBT440 and the clinical trial process.

Please visit us at www.globalbloodtx.com for more information

Agenda

THURSDAY, JULY 28

Time	Event	Location
10:00 am – 2:00 pm	Registration	Echo Park Foyer
2:00 pm – 4:00 pm	Peer Navigators Ify Osunkwo MD, MPH The power of peer-to-peer navigation in successfully coping with transition into adulthood as an individual affected by sickle cell disease.	Echo Park
4:00 pm – 5:00 pm	Opening Reception Sponsored by St. Jude Children's Hospital	Echo Park Foyer
5:00 pm – 7:00 pm	Visual Explorers Yvonne Carroll, RN, JD Using Visual Explorer™, a tool for creative conversations and deep dialogue, to explore situations encountered in the Emergency Department and on the hospital floor.	Echo Park
10:00 pm	Insomniac's Cafe Hosted by #BoldLipsForSickleCell Come talk about anything on your mind -- a slumber party for those who are still awake and looking for something to do. Games on deck, come join us!	TBA

FRIDAY, JULY 29

10:00 am – 11:00 am	Plenary: Sickle Cell Warrior - Spirit Indestructible Tosin Ola, RN/BSN Note from Supporter Emory University, Diana Ross	Echo Park Foyer
---------------------	---	-----------------

Agenda

FRIDAY, JULY 29 (cont'd)

Time	Event	Location
	BREAKOUT SESSIONS	
11:00 am – 11:30 am	Understanding Gene Therapy Brian Robinson, MD An introduction to human genetics and gene therapy.	Silver Lake
11:30 pm – 12:00 pm	Understanding Bone Marrow Transplant Yvonne Carroll, RN, JD Understanding the different types of bone marrow transplants and their complications.	Silver Lake
12:00 pm – 12:30 pm	Bone Marrow Transplant Roundtable & Video A continuation of the “Understanding BMT” with a conversation with those that have undergone the process.	Silver Lake
	Traditional Herbal Medicine: Lessons from Nigeria A literature review of natural remedies for sickle cell: Lessons from Nigeria and abroad	Trousdale Estates
12:30 pm – 1:00 pm	Navigating the Adult Healthcare System Coretta Jenerette, RN, DNP Strategies to assist the adult living with sickle cell to navigate the healthcare system; Knowing your body and strategies to communicate healthcare needs.	Silver Lake
	Financial Planning with Sickle Cell Disease Trevor Thompson, Ed.D. Managing finances and establishing fiscal stability with sickle cell disease.	Trousdale Estates
1:00 pm – 2:00 pm	LUNCH Sponsored by Global Blood Therapeutics	Elysian Park

Agenda

FRIDAY, JULY 29 (cont'd)

Time	Event	Location
	BREAKOUT SESSIONS	
2:00 pm – 3:00 pm	Professional's Roundtable Discover that it is possible to have a career with SCD.. You can go to school, work, get a job, and follow your passions. Learn from warriors who are living and pursuing their professional dreams.	Silver Lake
3:00 pm – 4:00 pm	Couple's Roundtable Discussing relationships, love, money, emotions, fights, family, and more. Talking to your partner about your health needs. Listen to other couples share their experiences of 5, 10, and 20+ years together.	Silver Lake
	Parent-To-Parent Roundtable Dealing with the emotions associated with having a child with sickle cell. Taking care of yourself and making your other kids feel special too. Learn from other parents support a child living with SCD.	Trousdale Estates
4:00 pm – 5:00 pm	Aging Well with Sickle Cell Warriors are living longer than ever. Join Shirley Miller and other amazing warriors as they discuss how we can age well with sickle cell.	Silver Lake
	Transition with Power What steps can young Warriors take to ensure a successful transition from pediatric to adult care.	Trousdale Estates
5:00 pm – 7:00 pm	Sickle Options Testimonials	Silver Lake
	Sickle Cell Action Network Interviews	Trousdale Estates

Agenda

Friday , JULY 29 (cont'd)

Time	Event	Location
9:00 pm	Warriors After Dark Men: Dr. T. Thompson, Women: Dr. T. Washington Join this gender-specific late night session to have those conversations that you might not wish to have in a mixed crowd. We will cover After Dark topics like priapism, marijuana, alcohol, sex and everything in between. Must be 18 years or older to attend this After Dark Session.	TBA

SATURDAY, JULY 30

9:00 am – 9:30 am	Parenting Issues from Birth to Adult Adrienne Bell-Cors Issues and solutions faced by parents as they support their children living with sickle cell disease.	Trousdale Estates
9:30 am – 10:00 am	Caring for the Caregiver: Dealing with Burnout & Guilt Velvet Brown-Watts, MSW, CM Often Caregivers focus so much on the needs of others that they do not think about resetting and recharging themselves. Soon caregivers can find themselves crippled and overwhelmed under the strain of caregiving. This session seeks to answer the question “how do caregivers recharge and reset themselves?”	Trousdale Estates
10:00 am – 11:00 am	Plenary: Using Our Voice to Influence Research & Policy Lakiea Bailey, PhD The powerful role the sickle cell community can play in influencing research and policy	Silver Lake

Agenda

SATURDAY, JULY 30 (cont'd)

Time	Event	Location
	CBO & RESEARCH SPOTLIGHTS	
11:00 am – 11:15 am	Physician Education in the Emergency Department Kirshma Khemani, MD Providing education and Quality Improvement Strategies for Pediatric Emergency Department Physicians on sickle cell pain crisis based on NIH guidelines.	Silver Lake
11:15 am – 11:30 am	Get Connected Karen Jones, Cayenne Wellness Center and Children's Foundation Linking innovative programs, treatments and research to improve care.	Silver Lake
11:30 am – 11:45 am	HBCU Sickle Cell College Tour Jew-EL Darbone, #BoldLipsForSickleCell A sickle cell awareness tour of Historically Black Colleges and Universities (HBCU) presented by #BoldLipsForSickleCell and Sickle Cell 101.	Silver Lake
11:45 am – 12:00 pm	Patient-Powered Sickle Cell Literature Cassandra Trimnell, Sickle Cell 101 Development of educational literature designed for individuals living with sickle cell, by individuals living with sickle cell. Patient-powered, MD-approved.	Silver Lake

Agenda

SATURDAY, JULY 30 (cont'd)

Time	Event	Location
12:00 pm – 12:15 pm	Sickle Cell & Thalassemia Patient Registry Lanetta Bronte, MD, Foundation for Sickle Cell Disease Research A sickle cell disease and thalassemia patient registry and health portal to allow researchers access to information for data mining, qualitative and quantitative research; and to allow individuals with sickle cell keep track of share vital health information.	Silver Lake
12:15 pm – 12:30 pm	Sickle Options Diana Ross, MSN, RN, Emory University Decision-making regarding treatment of sickle cell disease.	Silver Lake
12:30 pm – 12:45 pm	Sickle Cell Awareness Across the Curriculum Judy Johnson, M.Ed. Guidelines for educators and support for students as they navigate the challenges of their studies and interact with their peers.	Silver Lake
12:45 pm – 1:00 pm	The Sickle Cell Community Consortium: Harnessing the Power of the Patient Voice Lakiea Bailey, PHD An introduction to the mission, structure, and platforms of the Sickle Cell Community Consortium.	Silver Lake
1:00 pm – 2:00 pm	Lunch	Elysian Park

Agenda

SATURDAY, JULY 30 (cont'd)

Time	Event	Location
	BREAKOUT SESSIONS	
2:00 pm – 2:30 pm	The Science of Sickle Cell Julie Kanter, MD Discussing the current understanding of the science of sickle cell disease.	Silver Lake
2:30 pm – 3:00 pm	Workers Rights & Navigating the Workplace Yvonne Carroll RN, JD Understanding the Americans with Disabilities Act (ADA) and how it affects warriors in the workplace; Applying workplace accommodations for individuals living with sickle cell.	Silver Lake
	Traveling with Sickle Cell Tandua Washington, MD Tips and tricks for staying healthy while you travel.	Trousdale Estates
3:00 pm – 3:30 pm	Health and Wellness Candyce Heather The 30 Day Wellness Revolution: Empowering Warriors to live a life they love through coaching and custom wellness plans that will transform the mind and body.	Silver Lake
	Navigating the Primary School System Lisa Tourey and Nikki Peterson Tips and tricks for successfully navigating your young warrior through primary school.	Trousdale Estates

Agenda

SATURDAY, JULY 30 (cont'd)

Time	Event	Location
3:30 pm – 4:00 pm	<p>Depression and Anxiety in SCD: It's More Common than You Think Charles Jonassaint, PHD, MHS</p> <p>The types of mental health conditions affecting individuals living with sickle cell disease; Prevalence estimates of mental health conditions in sickle cell and potential causes; Link between mental health/stress and pain; Symptoms to look out for, recognizing the need for help, what to expect from a consultation.</p>	Silver Lake
4:00 pm – 4:30 pm	<p>Mental Health Roundtable</p> <p>Living with sickle cell affects the body as well as the mind. Let's break down the wall of silence surrounding mental health as we acknowledge that it's ok to feel whatever you are feeling and talk about what we can do to deal with these issues.</p>	Silver Lake
	<p>Navigating the Pediatric Healthcare System</p> <p>Tandua Washington, MD</p> <p>Strategies to assist parents and teens navigate the health care system.</p>	Trousdale Estates
7:00 pm – 10:00 pm	<p>Sickle Cell Stars Awards Gala</p> <p>Hosted by Sickle Cell 101; Keynote: Gary A. Gibson</p>	Elysian Park

SUNDAY, JULY 31

9:00 am – 11:00 am	Breakfast with the Warriors	Elysian Park
11:00 am – 11:30 am	Closing & Business Meeting	Echo Park
12:00 pm – 4:00 pm	Advocacy Training & Certification	Echo Park



bluebirdbio®

TRANSFORMING THE LIVES OF PATIENTS WITH SEVERE GENETIC AND RARE DISEASES

bluebird bio is committed to individuals and families affected by severe genetic diseases and cancer, including severe sickle cell disease, transfusion-dependent β -thalassemia, also known as β -thalassemia major, cerebral adrenoleukodystrophy and multiple myeloma.

Thank you Sickle Cell Community for all you that you do for those living with sickle cell disease.

Please visit us at www.bluebirdbio.com to learn more.



@bluebirdbio



@bluebird_bio



/bluebirdbio

Speaker Profiles

Adrienne Shapiro

Co-founder, Axis Advocacy
adrienne@axisadvocacy.org

Adrienne Shapiro is co-founder and Science Administrator of Axis Advocacy, supporting work to cure Sickle Cell Disease. Adrienne is a fourth generation of mothers in her family to have a child born with Sickle Cell Disease, and was an early supporter of work with bone marrow transplants and later stem cell research. She speaks nationally and internationally at educational conferences. For more information visit: www.axisadvocacy.org

Alesia Evans Wardlow

Alesia is a parent and caregiver of a sickle cell warrior. Her hope is that through sharing my caregiver experiences, other caregivers and warriors will be more prepared to meet the challenges of transitioning into the world of adult health care and managing sickle cell disease.

Alexis J Wardlow

Chef & E-Nutritionist, Le Cordon Bleu
ajwardlow@yahoo.com | [facebook.com/DansIsMyLyfee](https://www.facebook.com/DansIsMyLyfee)

Alexis Wardlow is a Warrior living with Sickle Cell Anemia SS. Although she has struggled with sickle cell, as well as two other chronic conditions (Crohn's Disease and Primary Sclerosing Cholangitis), she manages her diet, nutrition, and exercise in moderation, and it has made her life much easier. She's been afforded the opportunities of graduating with her culinary degree, working with different celebrities all over southern California, and is also going back to work on attaining her Nutritional Science and Psychology Degree to do work in the medical field working with people like herself. With these experiences from personal goals, as well as with her medical situation, she hopes to encourage people to keep going with anything they feel they can do because it is possible. She is convinced that everyone can make a difference!

Brian R. Robinson, MD

Vice President, Medical Affairs, bluebird bio

Brian Robinson joined bluebird bio in June 2015 to lead the Medical Affairs function. He is responsible for driving medical strategies and tactics that support successful product development and guide education, research and communication about bluebird bio's innovative therapies. His team works with numerous stakeholders, including physicians, scientists, advocates, patients, and caregivers. Dr. Robinson has over 12 years of experience in biotechnology Medical Affairs. Most recently, he was the Global Medical Lead for the hemophilia program at Biogen.

Speaker Profiles

Cassandra Trimnell

President & Founder, Sickle Cell 101
ctrinnell@sc101.org

As Founder and President of Sickle Cell 101, Cassandra is an active educator and advocate within the sickle cell community. Her passion for sickle cell stems directly from her living with the disease, hgb SS. Cassandra received a B.A. in Global Studies: Social, Political, and Economic Development from Sonoma State University. In 2014, Cassandra received her sickle cell education certificate, issued by the Department of Public Health. Cassandra is responsible for developing and creating the educational material and curriculum presented by Sickle Cell 101. As a sickle cell educator, Cassandra provides education and awareness through social media platforms such as Instagram, Facebook and Twitter. Other education platforms include community settings such as: Continuing Education Unit trainings for healthcare professionals, health fairs, sickle cell camp kids and teens, and events. Cassandra also volunteers for various sickle cell organizations.

Charles Jonassaint, PhD, MHS

University of Pittsburg, Dept. of Medicine
@c_jonassaint

Dr. Charles Jonassaint is a practicing clinical health psychologist with an MHS in cardiovascular epidemiology focusing on behavioral medicine and health services research. He has clinical expertise in chronic disease self-management and cognitive behavioral therapy intervention and has had extensive experience working with patients who have sickle cell disease. He completed his graduate training at Duke University and medical psychology residency at the Duke University Medical Center. He went on to do a clinical research fellowship at Johns Hopkins University School of Medicine, as well as, a Masters in Epidemiology at the Johns Hopkins Bloomberg School of Public Health. He is currently funded through an AHRQ PCOR K12 grant to lead a program of research in sickle cell disease focused on designing, cost-effective, scalable, mobile technology-delivered, stress and pain management interventions that patients can easily access on their own mobile phones or tablets.

Coretta Jenerette, PhD, RN, CNE

Associate Professor, School of Nursing; University of North Carolina
@DrCJen

Dr. Jenerette 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

Speaker Profiles

Coretta Jenerette, PhD, RN, CNE (cont'd)

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 with a focus on individuals with sickle cell disease. 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.

Diana Ross, MSN, RN

Research Coordinator, Emory University
diana.ross@emory.edu

Over 30 years experience as a registered nurse with 10 years experience in research and 5 years experience working with the sickle cell population.

Gary A. Gibson

President/CEO, Martin Center Sickle Cell Initiative
ggibson@themartincenter.org | 317-927-5158

Gary A. Gibson has enjoyed a distinguished career that features significant positions of authority in the private, public and nonprofit sectors. Currently serving as the President and Chief Executive Officer of Martin Center, Inc., Gary is responsible for leading Indiana's only not-for-profit agency dedicated to Sickle Cell Disease. Under his leadership, Martin Center provides support services to individuals with Sickle Cell Disease and Sickle Cell Trait, provides Sickle Cell education to the community and advocates on behalf of those who must live with the disease. Gary's passion for helping those with Sickle Cell has its roots in his previous life and marriage to a Sickle Cell patient who passed away at the age of 36 due to complications from the disease. Gary is the host of the Sickle Cell Action Network Internet Radio Show, a weekly show that educates, empowers and informs the public about the continuing effort to eradicate Sickle Cell and to support those living with it. He has published two white papers on Sickle Cell, "Sickle Cell Disease: Still Here and Still Causing Pain" and "Sickle Cell Disease: The Ultimate Health Disparity."

Helen Sarpong

sarponghelen@gmail.com

Helen Sarpong is currently a patient advocate and healthcare educational public speaker for Sickle Cell

Speaker Profiles

Helen Sarpong (cont'd)

Disease. She was born with Hemoglobin SS and she has spent her life struggling to navigate the healthcare system, as well as to take back control of her life away from the painful cycles of the disease. She is a mother of twin girls and she has been promoting Sickle Cell Awareness to patients and their families, resident medical students, biotech and pharmaceutical companies for the past six years. Recently, she has partnered with the Greater Boston Sickle Cell Disease Association (GBSCDA) to help reach out to the local community.

Ify Osunkwo, MD, MPH

Medical Director, Adult Sickle Cell Program
Carolinas Healthcare System
Levine Cancer Institute and Associate Professor
University of North Carolina at Chapel Hill

Dr. Ify Osunkwo, a specialist in hematology and Sickle Cell Disease at Levine Cancer Institute in Carolinas HealthCare System (Charlotte NC), had made it her mission to improve the quality of life for Sickle Cell patients. After obtaining her medical degree from the University of Nigeria, she obtained a Masters in Public Health from Johns Hopkins University in Baltimore, MD and completed a fellowship in Pediatric Hematology/Oncology at Columbia University in New York, NY. With over two decades of clinical experience in sickle cell disease, Dr. Ify leads the Transition/Care Coordination working for the South Eastern Regional Genetics Collaborative, and serves as the Secretary for the National Sickle Cell Adult Provider Network. She currently leads a team of dedicated and passionate providers and staff striving to establish a comprehensive, multi-disciplinary system of care for all adults living with SCD in the Charlotte Metro area, approximately 1300 individuals served by Carolinas Healthcare System. This care model involves critical components such as the prominent role of the PCP, multi-faceted care navigation, case management and community support networks and is guided by a robust Community Advisory Board and system led Oversight Committee.

Jew-EL Darbone

Co-Founder, CFO; #Boldlipsforsicklecell
Jeweldarbone.blfsc@gmail.com | @Jew_ELstar06

Jew-EL Darbone is one of the founders of #Boldlipsforsicklecell and its CFO. She is a social media maven and sickle cell advocacy and empowerment is her passion. A graduate of Mount Tabor High School in Winston Salem NC she doesn't allow any obstacle to stop her from living life to the fullest.

Speaker Profiles

Judy Gray Johnson, B.S., M.Ed.

Sickle Cell Educational Resources, Inc.

www.scerinc.org

Judy Johnson has been living with Sickle Cell for more than 70 years. She is a retired teacher of almost 40 years. While she grew up in Virginia and South Carolina, she currently reside in Valencia, California and continues to advocate in the cause of finding real quality of life changes for those suffering with Sickle Cell.

Julie Kanter, MD

Medical University of South Carolina

Director of Lifespan Comprehensive Sickle Cell Center

@jkw4444

Kimberly Monique Davis

Administrative Coordinator

Sickle Cell Community Consortium

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. She seeks to inspire and provide hope for all of those who battle daily with this egregious disease. Committed to the idea of being the change that she wants to see.

Kirshma Khemani, MD

Emory University

AFLAC Cancer and Blood disorders center-Pediatric Bone Marrow Transplant Division

Speaker Profiles

Lakiea Bailey, PHD

Executive Director, Sickle Cell Community Consortium
director@sicklecellconsortium.org

Dr. Lakiea Bailey is a sickle cell disease advocate, educator and research scientist. Diagnosed with sickle cell disease at age three, she has become a passionate advocate for those living with rare diseases and is committed to serving as a voice of encouragement and empowerment within the sickle cell community. Despite the devastating symptoms of sickle cell, Dr. Bailey was determined to complete her educational goals, earning a Bachelor degree in Biochemistry and Molecular Biology in 2001 and a Doctorate degree in Molecular Hematology and Regenerative Medicine in 2012. During the course of her education, Dr. Bailey was named a Southern Regional Education Board (SREB) Doctoral Scholar, was the recipient of multiple honors and awards, including the Fisher Scientific Award for Overall Excellence in Biomedical Research, the Medical College of Georgia Alumni Association Award, the Georgia Regents University Leadership Award and was inducted in the Alpha Upsilon Phi honor society. 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 on patient panels or disease expert with Pfizer, Novartis, FDA, NHLBI and sits on the Research Advisory Board for the Foundation for Sickle Cell Disease Research.

Mattie Robinson, MS, MA

Mattie's professional background includes over 7 years of experience in biomedical research and education. As a scientific researcher, Ms. Robinson worked to develop future treatments for Sickle Cell Disease and related blood disorders. In 2013 she hung up her lab coat and began a rewarding career in nonprofit management, advocating for the rights and needs of people living with the disease. She holds graduate degrees in Microbiology and Cell Science from the University of Florida as well as Human Genetics and Molecular Biology from the Johns Hopkins School of Medicine. Her passion is to teach everyone to understand the elegant intricacies of science and medicine.

Shamonica Wiggins

Co-Founder, CEO, #BoldLipsForSickleCell

Shamonica Wiggins is a 27 years old and I have Sickle Cell SS. She was 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 her family and medical team never told me I could not do something, so she has always striven to be the best. This is not a luxury that every Sickle Cell Warrior is told, so this has

Speaker Profiles

Shamonica Wiggins (cont'd)

always driven her to inspire others like her. That drive is what led to the founding of #BoldLipsForSickleCell in 2014, which is now a 501(c)(3) non-profit. Speaking about this disorder and spreading Sickle Cell awareness is her passion.

Shirley Miller, MA

Carolinas Healthcare System
Shirleyrenee3@gmail.com

Shirley Miller has more than 25 years of experience in sickle cell disease program development and patient advocacy. She has served on the Comprehensive Sickle Cell Centers Clinical Trials Consortium, as a patient representative for the FDA and on an SCD educational committee with the Centers for Disease Control (CDC). Shirley has participated in lectures for 1st year medical students at UT Southwestern Medical Center in Dallas Texas for over 20 years under the medical direction of Dr. George Buchanan. She has established herself as a knowledgeable and confident speaker as it relates to living and managing a chronic illness such as sickle cell disease. She received her Bachelors of Business Administration from Northwood University and her Masters in Psychology from the Chicago School of Professional Psychology and is a current graduate student at Boston University. She is passionate about focusing on the quality of the patient experience in all interactions. Shirley is currently managing the development of a newly formed adult sickle cell disease program at Carolinas Healthcare System in Charlotte North Carolina under the medical direction of Dr. Ify Osunkwo.

Tandua Washington, MD

TSPMG, General Pediatrician
Facebook.com/doctwash

Dr. Tandua Washington is a General Pediatrician in the Atlanta area who has Sickle Cell Disease. A New York native, Dr. Washington graduated Hofstra University with a BS in Biology. She graduated from the Medical College of Virginia with honors and completed her residency at Albert Einstein Medical Center in Philadelphia. She has been practicing Pediatrics for 16 years, with a special interest in caring for children with Sickle Cell. She has received many awards and accolades for her achievements in her field. Dr. Washington is married and has 2 sons who also have Sickle Cell Disease. The family is very committed to advocacy work in the Sickle Cell Community.

Speaker Profiles

Tosin Ola, RN/BSN

President & Founder, Sickle Cell Warriors, Inc.
tosin@sicklecellwarriors.com

Tosin Ola, BSN, RN knows firsthand the challenges of living with sickle cell disease. The practicing registered nurse and mother of twin toddlers, launched the Sickle Cell Blog in 2007 to bond with others and share her experience living with this debilitating and deadly disease. She created an online platform – the Sickle Cell Warriors website – to broaden the discussion and give the community a much-needed voice. The educational site is designed to raise awareness of this complex chronic medical condition, address the serious complications of the disease, provide expert advice and research news, promote local events and much more. To complement those efforts, Tosin's Sickle Cell Warriors Facebook Page supports and encourages members to engage with others going through the same daily struggles. The leading social media channel has connected over 18,000 members, making it the largest online group of people affected by this disease.

Trevor Thompson, Ed.D.

CEO, Sickle Cell Foundation of Tennessee
trevorthompson@sicklecelltn.org

Dr. Trevor Kennebrew Thompson is the Founder/CEO of the Sickle Cell Foundation of Tennessee (SCFT). The mission of the foundation is to provide comprehensive services to individuals living with Sickle Cell in Tennessee and the Mid-South community. The vision of the foundation is to increase the education, health awareness and life skills of individuals living with Sickle Cell Disease to be more self-sufficient and to improve their quality of life. SCFT is responsible for providing comprehensive social services to meet the unmet needs of individuals living with Sickle Cell in the Mid-South (East Arkansas & North Mississippi) and the State of Tennessee. SCFT works diligently to eliminate the stigma that is associated to individuals living Sickle Cell Disease (SCD) and empower them to make a difference through acquired knowledge and skills.

Velvet Brown-Watts, MSW, CM

Chairperson, Supporters of Families with Sickle Cell Disease, Inc.
P.O. Box 691293 Tulsa, OK 74169

As Founder/Chairperson of Supporters of Families with Sickle Cell Disease, Inc. Supporters Through her leadership, Supporters of Families with Sickle Cell Disease, is working with the State of Oklahoma Medicaid Agency and was award a contract with the Oklahoma Health Care Authority to conduct consultation and

Speaker Profiles

Velvet Brown-Watts, MSW, CM (cont'd)

services for those impacted by SCT/SCD. Supporters has formed the first Oklahoma Sickle Cell Collective Impact Team to address gaps in the sickle cell community. She is the wife of minister, Jeremiah Sr. and mother of four children of whom Jeremiah Jr. is impacted by sickle cell disease.

Yvonne M. Carroll, RN, JD

President, International Assoc. of Sickle Cell Nurses and Physician Assistants
Director, Patient Services, Dept. of Hematology; St. Jude Children's Research Hospital
yvonne.carroll@stjude.org

Yvonne M. Carroll, RN, JD is the Director of Patient Services in the Department of Hematology at St. Jude Children's Research Hospital. Yvonne graduated with a Bachelors of Nursing Degree from the University of Tennessee and a Law degree from the University of Cincinnati. Yvonne served in the United States Navy as a Staff Judge Advocate. She joined SJCRH in 1999 in the Department of Hematology and served in several positions before becoming the Director of Patient Services. Yvonne is active in Hematology and the sickle cell disease community and serves on the Governor's Genetic Advisory Committee for the State of TN and as President of the International Association of Sickle Cell Nurses and Physician Assistants (IASCNAPA). Throughout the years, Yvonne has been a Principal Investigator and Program Manager on numerous sickle cell related grants and has spoken locally, regionally, and nationally on sickle cell disease and trait. Yvonne has developed partnerships with numerous community organizations and rural healthcare workers to improve awareness and treatment for people with sickle cell disease.

Notes

About the Sickle Cell Community Consortium

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



Over the span of the 18 months that followed, Dr. Bailey, Velvet Brown-Watts and Kena Drew would build upon this foundation to develop a cohesive, 501(c)(3) non-profit, created to harness and amplify the sickle cell patient voice.

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

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

Website: www.sicklecellconsortium.org
Email: info@sicklecellconsortium.org

Facebook: /SCCConsortium
Twitter: @SCCConsortium
Instagram: @sc3consortium

Thank You Note

Where would we be without our attendees? We would just have great planned programs, and no one to share them with! Thank you for coming and spending the weekend with us, you made this experience phenomenal. We hope that you found it extremely informative, educational, inspiring, and supportive.

We would also like to thank all of our volunteers for taking the time to help us make this a success. Many hands truly make light work. We couldn't have pulled this off without your support and assistance.

The next set of thanks goes to all our wonderful panelists, advocates, and presenters. Thank you for your patience, flexibility, smarts, and enriching everyone through your experiences and education. Thank you for sharing your knowledge with us, and opening your lives so we could all benefit. Everyone gained something because of you.

Thank you to all our community partners, vendors, and contributing sponsors especially Global Blood Therapeutics, bluebird bio, Pfizer Pharmaceuticals, and Prolong Pharmaceuticals.

A special thank you to Dr. Lakiea Bailey. She was the driving force behind this event.

Last but not most important, thank you to our families. We couldn't do half the things we do if they were not backing and supporting us constantly. Thanks for helping us every step of the way.

We hope that this annual event grows bigger and bigger every year. Don't forget to vote on where next year's events will be! Safe journey home, and once you are settled, please post your pictures online (don't forget to hashtag #SCSymposiumLA) and tag us (Sickle Cell Warriors, IASCNAPA, Sickle Cell 101 and SCCC) in your favorite parts of the weekend, so we can all relive this experience.

As always, please visit us on our individual organization websites:

Sickle Cell 101: <http://sc101.org>,

Sickle Cell Warriors: www.sicklecellwarriors.com

IASCNAPA: www.iasnapa.org

SCCC: www.sicklecellconsortium.org

We will be posting pictures, comments, videos and updates about this and other events that the Sickle Cell Consortium members are planning.

Thanks again, and we hope to see you next year!



**International Association of
Sickle Cell Nurses And
Physician Assistants**

SICKLE CELL 101

Powered by the Sickle Cell Community Consortium

