



*Sickle Cell Warriors Inc.*

# SICKLE CELL

*Community Gathering and Educational Symposium*

## PROGRAM

July 17-20 in Atlanta, GA  
DoubleTree by Hilton Hotel  
Buckhead, Atlanta, GA

[www.sicklecellwarriors.com](http://www.sicklecellwarriors.com)

Be educated. Be supported. Be inspired. Be Empowered.





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*Community Gathering and Educational Symposium*

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# WELCOME

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Hello everyone!

It's so great to finally, officially welcome you to the Sickle Cell Warriors, Inc. Annual Gathering, Educational Symposium and Awards Banquet. Affectionately known as the Gathering, this is an annual event specifically for those directly impacted by sickle cell disease. My name is Tosin, and I'm the President and Founder of Sickle Cell Warriors, Inc. (SCW), the largest patient-run organization for sickle cell disease in the world. With over 12,500 members, what started as a tiny blog 7 years ago has grown into an empowering nonprofit organization dedicated to ending sickle cell disease, and the struggles that those with sickle cell often face.

The concept for the Gathering started 3 years ago. Lakiea (V.P. of SCW) and I had been talking on the phone, communicating online for years and had become good friends. Together, we were working on the initiatives for SCW and had grown the community astronomically. The weird part was that we had never met in person! Living on opposite sides of the country, both having sickle cell, demanding careers, enrolled in graduate school, while balancing full lives and families, definitely made meeting up somewhat of a challenge. Although we connected often enough that we felt like besties in the battle against sickle cell disease, nothing beats actually getting to meet someone in person. To see their smile, hear their voice, watch the inflections they make when telling a joke, and give them a warm hug—you can't replicate that technologically...at least, not yet!

We finally had a chance to meet in Indianapolis, IN in 2011. Because of the work with Sickle Cell Warriors, we had been invited to speak and visit the Martin Center at their annual banquet. **Finally!** After years of talking online and via the phone, we finally had a chance to give each other a real hug! That weekend was a blast, and as Kiea says, it was the spark that ignited an inferno.

During the weekend, we were chilling in our hotel room and Lakiea said, "Wouldn't it be awesome if we could do this every year? Not just with us, but with the entire Sickle Cell Warriors' group?" And from that statement, the Gathering was born. There has always been a need for a conference focused solely on the experience of patients, families, and those directly fighting on the front lines and dealing with sickle cell disease every day.

Last year, we had several folks state that they would have loved to attend, but the 'cruise' thing threw them off! So we decided that every other year will be a cruise (for the adventurous ones) and the even years will be a land event (for everyone else!). Atlanta was chosen by popular vote on the SCW FB page. So here we are!

The Gathering gives the sickle cell community: parents, patients {hereby known as Warriors}, families, and advocates an opportunity to come together. We can share their 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, see your online buddies, and reconnect. Our goal is that you leave here refreshed and revitalized. The theme for this year's Gathering is "**Daring to Dream, Live, Love & Achieve!**" The 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. And even though sometimes sickle cell may knock us down or slow us down, we can still eventually accomplish every goal and dream we have for ourselves. Ready? **Let's do this!**

Can't wait to FINALLY get a chance to meet you!



Tosin Ola, BSN, RN-BC  
President & Founder, Sickle Cell Warriors, Inc.  
tosin@sicklecellwarriors.com

# CONFERENCE SPONSORS

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## To our Conference Sponsors & Community Partners:

Sickle Cell Warriors, Inc. would like to thank the following sponsors for their contributions and support toward the success of the organization and the 2014 Annual Gathering & Educational Symposium and Awards Ceremony Banquet. Sickle Cell Warriors, Inc. especially like to thank Mr. Dan Moore, Apex Black History Museum and Marrow For Life, Inc., for his constant, unyielding support.

### Community Partners



Marrow for Life [www.marrowforlife.org](http://www.marrowforlife.org)



The African-American Panoramic Experience Museum.

[www.apexmuseum.org](http://www.apexmuseum.org)

To support the APEX Museum, visit <http://www.apexmuseum.org/donate.html>



Children's Sickle Cell Foundation, Inc. [www.cscf.org](http://www.cscf.org)

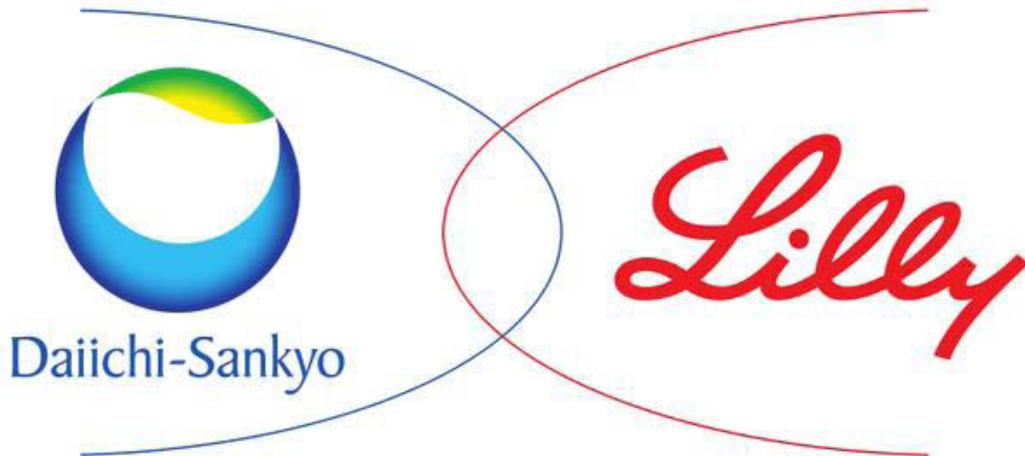


The 1091 Group. [www.the1091group.com](http://www.the1091group.com)

# CONFERENCE SPONSORS

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SCW would like to thank the following pharmaceutical companies for their full financial support of the Gathering & Educational Symposium, and for leading the way in clinical research and treatment therapies for those with sickle cell disease.



# CONFERENCE SPONSORS

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SCW, Inc. thanks the Coca-Cola Company and The World of Coca-Cola for their generous product donation to support the 2014 Sickle Cell Community Gathering & Education Symposium. Drinks on them!



GLACÉAU  
**vitaminwater.**



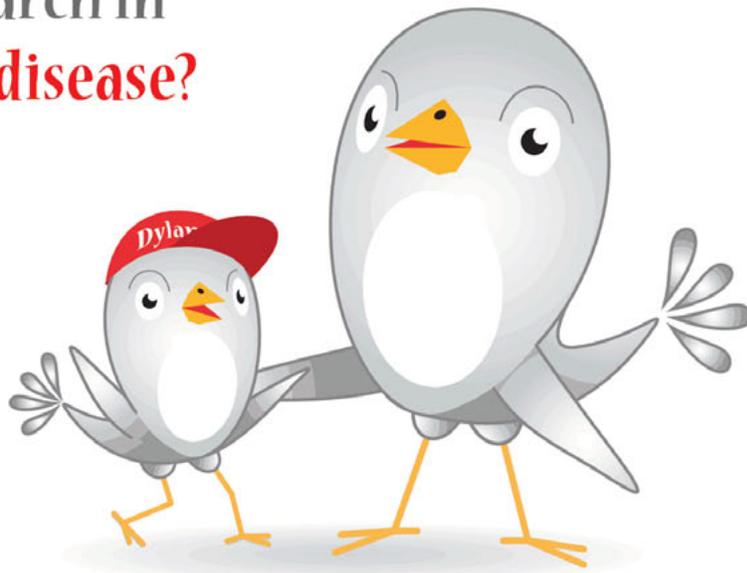
**JOT HERE!** 

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# D O V E

Determining effects of platelet inhibition on vaso-occlusive events

Could your child benefit  
from research in  
**sickle cell disease?**



For more information contact 1-877-CTLilly

Parent Brochure [V02 USA(EN)01]

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bluebird bio is proud to support the Sickle Cell Warriors community



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## TRANSFORMING THE LIVES OF PATIENTS WITH SEVERE GENETIC AND ORPHAN DISEASES

bluebird bio (NASDAQ:BLUE) has two clinical-stage products in development, one for childhood cerebral adrenoleukodystrophy (CCALD) and another for both beta-thalassemia and sickle cell disease.

Our LentiGlobin® product candidate aims to treat sickle cell disease by inserting a functional human beta-globin gene into the patient's own hematopoietic stem cells. We have sponsored a Phase 1/2 clinical trial in France (HGB-205), which is enrolling sickle cell disease patients as well as beta-thalassemia patients. We also plan to initiate a Phase 1 clinical study (HGB-206) in the US for the treatment of patients with sickle cell disease in the second half of 2014.

Please visit us at [www.bluebirdbio.com](http://www.bluebirdbio.com) for more information or to learn about participation in our clinical studies.



## **Sickle cell pain crises: a life on hold**

**Do you or someone you care for have Sickle Cell Disease?**

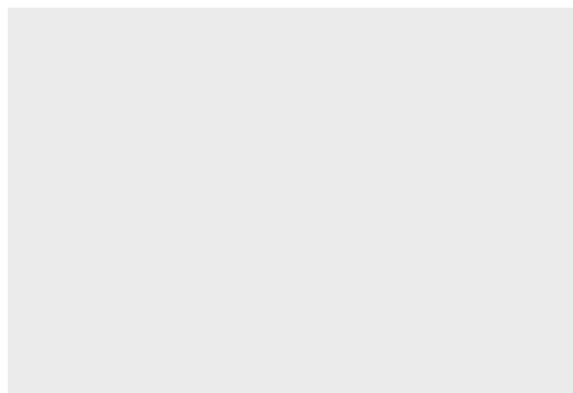
### **Have you or someone you care for had pain crises in the past year?**

If yes, you may be eligible to participate in an important study evaluating an investigational medication for the treatment of sickle cell pain crises.

If you are between 18 and 65 years of age and have had two or more sickle cell-related pain crises that needed treatment by a healthcare professional in the past year, we want to hear from you. The SUSTAIN Study is taking place at a treatment center near you.

You will be looked after by an experienced study team of doctors and nurses and all study-related medications and the medical care that you will receive during the SUSTAIN Study will be provided at no cost to you.

  
**sustain**  
A SICKLE CELL PAIN CRISIS STUDY



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# Education...Plain & Simple!



**Do you live with Sickle Cell?**  
**Do you love someone who does?**  
Confused, Curious, or just plain DESPARATE for some  
USEFUL info that is accurate and actually interesting?

## LOOK NO MORE!

We've got you covered...on the WEB, in PRINT and in  
PERSON, we educate anyone, anywhere!

←-----→

 **www.HOPEforSCD.org**  
Includes tools, resources and our BLOG!

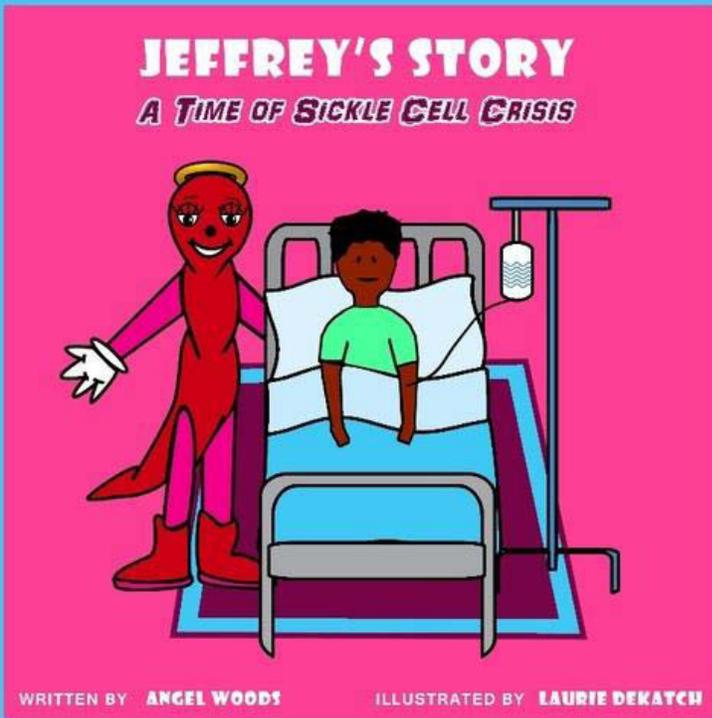
 **Twitter.com/hopeforscd**  
Daily updates on our newest  
education endeavors!

 **YouTube.com/channel/  
UCCnXjr87ZXIMkeRnFcOoKAA**  
Awesome videos about  
EVERYTHING Sickle Cell!

 **Facebook.com/hopeforscd**  
Join our group to stay connected  
with others!

 **Instagram.com/hopeforscd**  
A picture's worth a thousand words!  
Inspiration + Motivation

←-----→



Angel Woods is an Atlanta, Ga. native the creator of Cilly Cell, The founder of The Cilly Cell Project & Author of "Jeffrey's Story: A Time Of Sickle Cell Crisis.

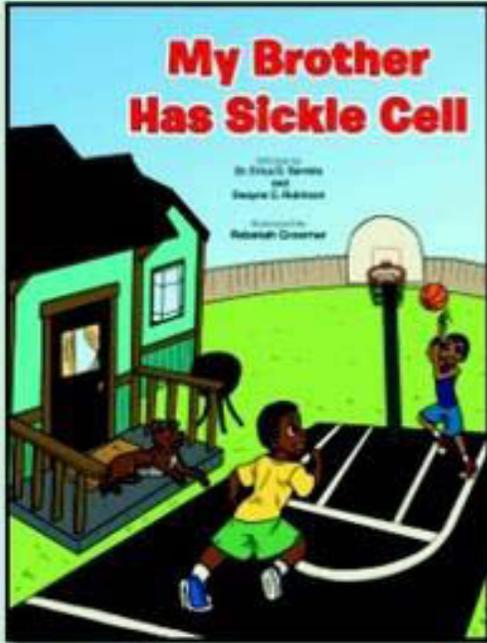
She was born with Hemoglobin SC, a type of Sickle Cell disease. Because of her pain and grief of battling a chronic disease while being a single mom raising 3 children; she wanted to bring hope to others that has this same battle every day. Angel has been an advocate for youth since she was a teenager. She was a summer camp Counselor, a recreational aid and a youth Pastor at different times in her life. Now she's an ambassador fighting for a better life for children with various diseases. Her

current focus is Sickle Cell Anemia. Angel's goal is to use the Cilly Cell Character as a mascot that can visit children in hospitals during their Sickle Cell Crisis to put a smile on their face. She also wants to bring awareness & education in to schools, colleges, and day cares. She'd like to get her book (Jeffrey's Story: A Time of Sickle Cell Crisis), water bottles and the Hope Bear into children's Hospitals around the world to give to the children upon leaving the hospital or clinic. Her main goal is to see the light of hope in every life she helps, see them living healthy, whole lives and totally healed by the blood of Jesus. She is also a Singer/song writer/play writer that has written a play based on the book. She's using the book to help raise funds to get the mascot made and other pertinent things needed to help The Cilly Cell Project move forward into its vision and mission of helping children, adults and families that have been affected by this chronic disease called "Sickle Cell".

To learn more visit: <https://angelcillycellwoods.selz.com/>

# My Brother Has Sickle Cell

Dr. Erica D. Gamble



## About the Book

From mom, professor, author and life coach Dr. Erica Gamble----a heartwarming story about a boy who happens to have sickle cell, based on her son, who has the disease.

"My brother has sickle cell. After learning what sickle cell is I now know more about my brother". Alvin is special and he has a special love for animals, especially Diamond. When Alvin and Diamond are together it helps to ease his pain. Diamond make's Alvin feel better- she licks his face, plays catch with him, lays on his leg when he is in pain and stays close to him when he is sad. Only Alvin can get Diamond to sit,run or roll over.

Dr. Erica Gamble collaborates with her son on this book based on her now 22- year old son, who has sickle cell anemia.

## About the Author

Dr. Erica Gamble, professor, author, life-coach, mother and wife has paired with her son Dwayne to co-author this uplifting book based on their personal perspectives and

experiences with Aaron, Erica's son and Dwayne's brother who has sickle cell anemia. She has been a past board member for the sickle cell anemia association and worked as an advocate and volunteer since 1993 to help families who are raising children with sickle cell. She also serves as an after school volunteer for children with sickle cell in hopes of educating and inspiring children and parents struggling with this disease. Dr. Gamble plans to start an organization in Atlanta and eventually expand globally dedicated to helping children with sickle cell gain access to affordable treatments and therapies.

Dwayne Robinson, age 20, wrote this book with his mother, Dr. Gamble, to help share awareness about sickle cell with other children from his perspective as a young boy. Dwayne has assisted his mother in volunteering with the foundation and has based narrative for this story on real events that happened in his family. Dwayne is a junior at Georgia Southern University in Statesboro Georgia and Dr. Gamble resides in Marietta, Georgia.

Aaron Robinson, age 22 is "Alvin". He is a student at Strayer University in Atlanta Georgia and continues to manage his health and work with his family to help find a cure for sickle cell.



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You can order  
*My Brother Has Sickle Cell*  
directly from the publisher at [www.authorhouse.com](http://www.authorhouse.com).  
Typical Ordering Time: 7-10 Business Days  
This book is also available at your local resellers.  
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# FEATURED SPEAKERS

## Ibrahim Tejan Kargbo, M.P.H.



**Ibrahim Tejan Kargbo** is the Executive Director of **The 1091 Group**. His work spans consulting for hospitals to develop triage and treatment protocols tailored to improving clinical outcomes for sickle crisis to providing Sickle Cell Disease health education. Mr. Kargbo studies Sickle Cell Disease through a public health perspective and focuses on the intricacies patient-provider relationships and their impact on the patient's health care.



The 1091 Group is a team of clinical and public health professionals who strive to improve health outcomes for individuals and communities living with Sickle Cell Disease. Driven by their mission, they provide Sickle Cell Disease-specific health education and work with physicians and hospitals to improve the care provided

to individuals and communities living with Sickle Cell Disease. The basis for their work is a firm belief that people living with Sickle Cell Disease care about their health and want to make everyday life choices that are consistent with having good health. For more info visit [www.the1091group.com](http://www.the1091group.com)

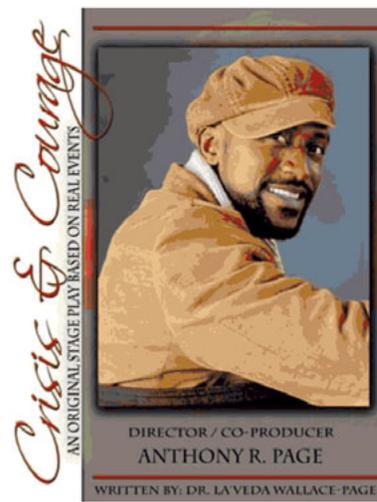
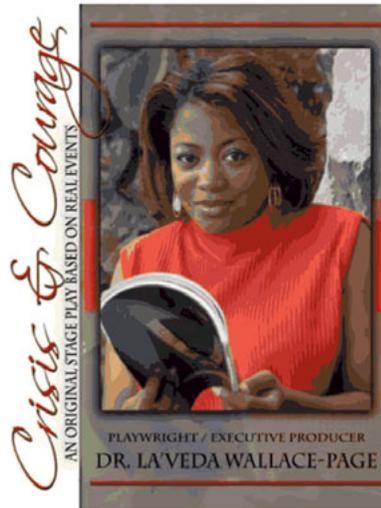
## April Farrell-Hasty

**April Farrell-Hasty** describes herself first and foremost a patient with sickle cell anemia. She chooses to treat her illness more holistically. Ms. Hasty has been a vegetarian for more than 25 years, uses homeopathy, acupuncture, and allopathic medicine. She has volunteered with the sickle cell foundation for decades working as a mentor and working with parents whose child was just diagnosed with sickle cell. April has also worked with transitioning teens and college young adults who were aging out of pediatric sickle cell and not quite ready for the adult group. April has organized sickle cell retreats, trained yoga teachers and teaches yoga. She specializes in restorative yoga, focusing on people with all types of chronic illnesses, and those who have a lot of stress. She feels that people who are chronically ill need yoga to help manage the illness, maintain their health, and prevent further damage. Yoga helps ease the stress of illness, and learning to breathe properly helps manage pain. It has proven to be very

beneficial for people with fibromyalgia, arthritis, sickle cell anemia, and other illnesses. Restorative yoga helps maintain homeostasis. April teaches more physical types of yoga, is a reiki master, and has certifications in personal training, wellness. To learn more visit [www.peacefullotus.com](http://www.peacefullotus.com)



## La'Veda Wallace-Page



La'Veda Wallace-Page was born to parents Bishop Lee Wallace and Apostle Christine Wallace. The youngest of three siblings, she was diagnosed with sickle cell anemia at three weeks old. Her brother Derrick 11 months and three weeks older was diagnosed at 14 months of age. Her sister Lithia, the oldest, was diagnosed with the sickle cell trait.

La'Veda graduated from T W Josey High School in Augusta Georgia and went on to attend Aiken Technical College in Graniteville, South Carolina studying Humanities. She later attended Beulah Heights Bible College working towards a dual major in Biblical Studies and Leadership. She was conferred an Honorary Doctorate at the age of 28 for fifteen years of fine arts instruction in the rural community of Jefferson County, Georgia from The Central Christian University in Columbia South Carolina, formerly The C.E. Graham Bible Institute and Seminary by President Dr. Charles E. Graham. She never required nor received payment for her instruction.

Dr. La'Veda married writer/director/producer and filmmaker Anthony R Page in 2010. Soon after, they welcomed their firstborn over many sickle cell pregnancy obstacles. Together through their theater, film, and film company Blue Bistro Creative they are creating sickle cell centric content e.g. music, plays, and documentaries as a part of their sickle cell advocacy and are members of The Huisman Sickle Cell Foundation in Augusta, Georgia. She adopted the pseudonym Sickle Siren to call attention to the issue of sickle cell and to sound the alarm with her advocacy.

La'Veda Wallace-Page, is a former television host for international evangelical talk show franchise. She is the minister of music for Praise Deliverance International Campus, a motivational speaker, playwright and a sickle cell blogger. Visit her blog page at [www.crisisandcourage.blogspot.com](http://www.crisisandcourage.blogspot.com).

## Andrea Williams, B.A.



**Andrea M. Williams, B.A.**, is the Founder and Executive Director of **The Children's Sickle Cell Foundation, Inc.**, a non-profit, community based organization whose mission is to provide quality program for children with sickle cell disease and their families to help them face the educational, social and economic challenges caused by the disease. The commitment to advocacy on every level, community education, awareness and support for research are natural extensions of the mission. CSCF, Inc. is a leader in the community and corporate education for sickle cell disease (SCD) and sickle cell trait (SCT) and is making an impact in the community through their collaboration with Children's Hospital of Pittsburgh of UPMC and other partners in the region. For more info visit [www.cscf.org](http://www.cscf.org).

Ms. Williams is the mother of four children, Shari, Alaura, Timothy, and Jonathan, who has sickle cell disease. She is determined to increase awareness of SCD in order to make a positive impact for those affected by SCD and the community at large. As Executive Director, Andrea brings her personal and professional experience and expertise to CSCF, Inc. She is a sought-after speaker with a passionate message that motivates parents, individuals with SCD, medical professionals and the community to do more. She is transforming the world of sickle cell disease care and advocacy with her collaborative approach, personal passion and global perspective. She enjoys developing novel approaches to addressing the needs of children living with sickle cell disease. Andrea has been active in advocacy for sickle cell disease, newborn screening testing and follow-up for Hemoglobinopathies and other genetic disorders. At the local, regional and national level she regularly interacts with opinion leaders at the governmental, legislative and executive levels.

She is a current member of the Secretary's Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHCNC) and on the Long-Term Follow-Up and Treatment Subcommittee and a former member of the Education and Training Subcommittee of DACHDNC. She has been involved in a variety of issues including engaging the health care providers in the process of newborn screening, educational messages for the general public, carrier identification and follow-up. She has made public comments to the full committee on behalf of sickle cell disease and newborn screening through her work the Genetic Alliance Newborn Screening Consumer Taskforce.

Andrea is a devout Christian who enjoys music, reading, cooking, and spending time with her children.

She LOVES traveling and experiencing different cultures through their art, music and cuisine.



## Farron Dozier

**Farron Dozier**, Volunteer Patient Advocate for Sickle Cell Trait (SCT) and Sickle Cell Disease, champions prevention about the Sickle Cell Trait and for a community of individuals and families affected by the condition and disorder. Farron is the creator and Host of Trench Talk. Trench Talk is platform for our Veteran Soldiers of all branches of services (men and women) to come and share their most memorable Military stories, experiences and history. Also be a location where veterans services, programs and resources are shared and

available for our Service Members from "Then and Now"

A 24 year Retired Disabled Veteran the United States Army, SFC Dozier advocates to raise awareness of the SCT around genetics talks, military personnel, athletes, and especially youth engaged in sports. He works with national services, faith and community-based organizations to create a lasting positive impact and dispel myths around the condition effecting millions of men, woman and children around the globe.

Dozier is the visionary of the I AM WDC Achievement Award; recognition of youth and adults who overcome obstacles, adversities and challenges as a result of the sickle cell trait and sickle cell disease. He is a collaborator on Public Service Announcements raising awareness about the issue of sickle cell disease and the sickle cell trait empowering listeners in health awareness and healthy life choices.

SFC Farron Dozier is an affiliate member of the SCD Soldier Network and Moretta Solution Team Network, and actively gives back to military families, communities and at-risk youth in America. His most memorable award of his career is the Military Outstanding Volunteerism Service Medal for his Sickle Cell Trait Advocacy work recognized by his peers and his Battalion Commander.

The Preventer

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Email: [wdconscd@gmail.com](mailto:wdconscd@gmail.com)

<http://www.wdconsctawareness.org>

### **Busayo Ola Ajayi, MSHRD, SPHR**



**Busayo Ola Ajayi** is an HR professional with over 10 years of experience in Human Resource Management. She received her undergraduate degree from Western Connecticut State University and a graduate degree from Villanova University in Human Resources. She has worked in union and non-unionized work environments, supporting senior and line leadership in manufacturing, healthcare and higher education environment. She has strong working knowledge of FLSA, FMLA, ADA, ADEA, PDA and other laws that affect employment. She is a member of the march of Dimes and Share Union for families with babies who have been through the NICU or have passed away. She is a preemie baby advocate and a sickle cell warrior caregiver. She is the younger sister of Tosin Ola Weismann, president of Sickle Cell Warriors, and proud to be one of the event coordinators of the annual gathering. She happily married for the last seven years and a proud mother of a preemie angel baby.

She will be discussing how the federal and state employment laws protect caregivers and employees with medical problems that limit daily life functions such as sickle cell anemia.



## Dr. Abdullah Kutlar

Dr. Kutlar has served Georgia Regent's University (GRU) since 1982 where he has made major contributions to clinical care, basic science, clinical research, and educational activities. He is a graduate of Ankara University Medical School in Ankara, Turkey. He completed his residency and one year as chief resident and fellowship in internal medicine/hematology at Istanbul University Medical School in Istanbul, Turkey. Following clinical and research fellowships in Turkey, a Special Fellow in the Department of Laboratory Hematology at the Cleveland Clinic in Cleveland, OH, and as a Research Fellow at the Medical College of Georgia, he joined the faculty at the Medical College of Georgia as an Associate Professor in 1992. Dr. Kutlar practices hematology with a focus on benign hematology and is an active member of the American Society of Hematology. He has served and continues to serve on state and NIH committees and serves as a reviewer for many journals.

Dr. Kutlar is currently the Co-PD/PI of the multi-institutional National Institute of Minority Health and Health Disparities Southeastern Exploratory Sickle Cell Center of Excellence as well as the Co-PD/PI of the National Heart, Lung, and Blood Institute's Excellence in Hemoglobinopathies Research Award. He has completed more than 20 industry sponsored trials and federally funded projects, is working on two investigator initiated projects, and has brought to GRU an excess of nine million dollars in research support. Dr. Kutlar has 200 original articles, two book chapters, and 177 abstract presentations.

Under Dr. Kutlar's direction, the Sickle Cell Center has maintained continuous funding from the State of Georgia for the newborn screening program through the Sickle Cell Center, which allows for the operation of the pediatric and adult clinics in Augusta and outreach clinics in South Georgia. The Sickle Cell Center's Hemoglobinopathy Laboratory serves as the State's confirmation lab for suspected hemoglobinopathies identified through newborn screening, the core lab for several NIH sponsored research trials in sickle cell disease, a reference lab receiving samples for hemoglobin identification from all around the world, and performs specialized tests in hematology.

## Lakiea J. Bailey, Ph.D.



**Dr. Lakiea Bailey** is a sickle cell disease patient, patient advocate 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 within the sickle cell community.

Despite the devastating symptoms of sickle cell, Dr. Bailey was determined to complete her educational goals, earning a Bachelor's 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. 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, in large part, 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 Director of the Sickle Cell Community Consortium, a newly formed alliance of sickle cell community-based organizations (CBOs), created to provide a platform of unity for the dozens of existing CBOs. She serves on the Board of Directors for the Titus Huisman Sickle Cell Foundation of Augusta, sits on the Research Advisory Board for the Foundation of Sickle Cell Disease Research and is the Vice President and Director of Research for Sickle Cell Warriors, Inc. Founded by the dynamic Tosin Ola, RN, Sickle Cell Warriors, Inc. is currently the largest patient-run, CBO for sickle cell disease in the country. With over 12,000 subscribers, consisting of patients and families with sickle cell, Sickle Cell Warriors, Inc. serves as a platform for Warriors (individuals with sickle cell) to encourage, educate and empower each other. Although Dr. Bailey had been involved in advocacy work for many years, she credits her friendship with Tosin Ola, and the decision to join the Sickle Cell Warriors team as the pivotal spark, igniting her passion for patient advocacy.

### **Tosin Ola, BSN, RN-BC**

**Tosin Ola** is one of the most dynamic voices in the sickle cell community. As a sickle cell warrior herself, she understands and resonates with issues in the SCD community. Tosin is a practicing registered nurse, mentor, and sickle cell advocate. Mrs. Ola is the Founder and President of Sickle Cell Warriors, Inc., and a registered nurse with over 13 years of clinical experience. In addition to her professional exploits, Tosin is a reliable source of sickle cell impressions and advice from the medical, community, and patient perspective.

Many of you know her work or have heard of Sickle Cell Warriors, Inc. In 2007, Tosin went online looking for a sickle cell blog during a long hospitalization. She was unable to find a blog that gave readers the personal portal into a life of someone with sickle cell, so she decided to start her own. There was no topic she was afraid to discuss, and her veracity was a refreshing boon to the sickle cell community. Today the



site has grown into a charitable nonprofit organization dedicated to sickle cell advocacy, education, awareness, empowerment, and activism. Sickle Cell Warriors, Inc. has over 12,000 members, is the largest patient-run sickle cell community in the world, and boasts over 20,000 unique visits weekly. Tosin's goal is to maintain a community where people can feel comfortable asking (and getting answers to), their most pertinent and personal questions related to sickle cell in a supportive, educational, and encouraging environment.

Tosin is dedicated to presenting positive and uplifting messages about sickle cell to the world, as well as empowering sickle cell patients to take control of their disease and think differently about life with sickle cell. She believes that sickle cell does not define you, and that one can have a beautiful and fulfilling life regardless of sickle cell. I'm sure you have heard of the term 'warrior'...well, Tosin is where it started. Years ago, she rebelled against the term sickler, and

started using warrior in reference to herself and others with sickle cell disease. Years later, being a sickle cell warrior is not just a term, but a state of mind, and has become a movement and a rallying call sweeping the world.

Tosin graduated from Oakwood University with an Associate's Degree in Nursing in 2001, and in 2009 from the University of Phoenix with a Bachelor's Degree in Nursing. She will be graduating later this year with a dual-Master's degree in Nursing and Business Administration with an emphasis in Healthcare Management. Tosin lives in San Diego, CA with her husband.

In addition to numerous awards for her advocacy work in the sickle cell community, Tosin has been a source for print publications like ESSENCE, Glamour, Minority Nurse, True Shine; online media like the New York Times, U.S. News & World Report, WEGOHealth, Wellsphere, BlogTalkRadio, and BioCentury. She spends her free time focused on growing the Sickle Cell Warriors' community.

Between managing Sickle Cell Warriors, running all its programs, building the website herself, maintaining fresh content on all its platforms, having sickle cell SS, empowering others, serving as an advocate, completing grad school, working a full time demanding job, and working on her sickle cell book; it's amazing what she gets done! Those of you that know her personally know that she is a warm, sincere, kind person, who truly operates from her heart and is passionate about sickle cell disease. You can reach her via email at [tosin@sicklecellwarriors.com](mailto:tosin@sicklecellwarriors.com).

# EDUCATIONAL SYMPOSIUM SCHEDULE

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## 2014 Sickle Cell Community Gathering & Education Symposium

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### PROGRAM AGENDA

Please note that this schedule is a guideline, but times/rooms/and sessions are not set in stone. Announcements will be made if there are any changes.  
Always bring your journal or notebook with you.

#### THURSDAY, JULY 17TH

**2:00PM – 6:00PM**    **Registration Open**.....**MAIN LOBBY FOYER**

**6:00PM – 7:30PM**    **DINNER** .....**TBD**

**8:00PM – 9:00PM**    **WELCOME**  
**TAMING THE HOSPITAL FRONTIER** .....**PIEDMONT A**  
Role-play with us as we explore the various issues that occur during an ER visit, or hospitalization for sickle cell crisis. How can we improve the care we receive? How can we become better guardians of our health? What strategies should we enforce or avoid? Learn about protecting your rights and your health in the hospital.

**10:00PM - 12:00AM** **INSOMNIACS CAFÉ** .....**PIEDMONT A**  
Come to the hotel lounge and join us as we talk about anything and everything on their minds. Consider it a slumber party for those who are still awake and looking for something to do. Get to know your team better as you prep for the Scavenger Hunt and challenges this weekend. Games on deck: Taboo, Spades, Clue, Cranium, Mafia, etc. This promises to be a fun event!

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#### FRIDAY, JULY 18TH

**7:00AM - 10:00AM**    **HOT BREAKFAST BUFFET (hotel guests only)** .....**THE GREENLEAF**

**8:00AM - 10:00AM**    **REGISTRATION OPEN** .....**BANQUET FOYER**

**8:00AM - 9:00AM**    **YOGA IN THE MORNING**.....**LENOX**  
Wake up and rejuvenate with April Green, certified Yoga instructor. Learn the basics of yoga, using yoga for pain management, and effective poses and techniques for those with sickle cell.

**10:00AM - 11:00AM**    **SYMPOSIUM OPENING CEREMONY**.....**PEACHTREE A**

**10:15AM -11:00 AM THE SCIENCE OF SICKLE CELL.....PEACHTREE A**  
Part of the Sickle Cell Warriors, Inc. Expert Patient Series, this session dives into the science of sickle cell. Learn the details that are often glossed over in biology class, including basic genetics, inheritance, and why sickle cell affects so many people of color.

**11:00 AM – 11:30 AM CONCURRENT SESSIONS**

**TOPIC A: SICKLE CELL MYTHS & CURES .....PEACHTREE A**  
Nutrition, debunking “miracle cures”. Listening to your intuition. How to do basic research. Questions to ask to develop your own BSPP (BS prevention protocol).

**TOPIC B: TRANSITION: GROWING UP & LEARNING TO LET GO .....LENOX**  
Youth: Learn how to successfully transition from being taken care of by your parents to becoming a Guardian of your own health. For Parents: The Art of Letting Go, Learn how to gradually release the reins and allow your children to transition into adults with sickle cell disease. You will always be their parent, but they need to learn to take care of themselves

**11:35AM – 12:00PM CONCURRENT SESSIONS**

**TRACK A: HAVE BAGS WILL TRAVEL (ADULT) .....PEACHTREE A**  
Travel, Sports and Hobbies: How do you travel with sickle cell and prevent a crisis? Get those stamps on your passport, and enjoy your vacation. How can you maintain your health while traveling all over the country? Can you travel with sickle cell? It is possible, with a few strategies to protect yourself—and your vacation.

**TRACK B: NAVIGATION THROUGH GRADE & HIGH SCHOOL .....LENOX**  
How to help your children navigate school and their careers. This session explores everything on the 503B, truancy laws and how to educate the teacher on sickle cell.

**12:05PM – 12:30PM CONCURRENT SESSIONS**

**TRACK A: NAVIGATING EDUCATION AND CAREER.....PEACHTREE A**  
Schooling: Yes, it is possible to go to college and graduate. Learn how to make it through the challenges and finish strong with a degree from professionals who have sickle cell disease too!

**TRACK B: SPORTS & HOBBIES (YOUTH).....LENOX**  
How to run, swim, play, and win over sickle cell. Protecting your children as they mature into well rounded adults with sickle cell

**12:35PM – 1:30PM CONCURRENT SESSIONS**

**TRACK A: COUPLES ROUNDTABLE.....PEACHTREE A**  
How can you date with sickle cell? To tell or not to tell? When do you tell him/her? How do you find the One? Balancing your health and your social life. Find out from warriors just like you. It's time to talk about relationships, love, money matters, emotions, fights, family, and everything in between. Listen to other couples as they

share their experiences and what they've learned through 5, 10, and 20+ years together. Talking to your partner about your health needs.

**TRACK B: PARENT-TO-PARENT ROUNDTABLE .....LENOX**  
 Beating the Guilt Monster: Dealing with the emotional guilt or depression of having a child with sickle cell. Coping emotionally when your child is in pain. Taking care of yourself, so you can take care of your warrior. Family Time: Everyone is important, not just the warrior, making the other kids feel special too. Creating family memories. Learn from other parents how to manage work, school, relationships, insurance, FMLA, and give all you have to your children. Plus get tips on raising great kids, discovering your inner tiger/tigress, taking time out for yourself, and settling into becoming an advocate.

**1:30PM – 2:30PM LUNCH .....PEACHTREE B**  
**HOSTED BY: BE THE MATCH & bluebird bio**

**1:00PM – 7:00PM VENDOR TABLES OPEN .....BANQUET FOYER**

**6:00PM – 8:00PM ATLANTIC STATION SCAVENGER HUNT/FREE TIME .....LOBBY**  
**Join us in the lobby to ride the hotel shuttle to the MARTA station (first run: 5:15pm)**  
 Here is some free time to relax or enjoy Atlanta. Meet us in the hotel lobby and bring your MARTA passes and Warrior discount cards because we're headed to the fabulous Atlantic Station for our Warrior Group Outing. Located in Midtown Atlanta, Atlantic Station offers extraordinary shopping, dining and entertainment! Come prepared to compete against the other teams during the Warrior Scavenger Hunt. Can you figure out all of the clues and find the mystery items?

**10:00PM-12:00PM WARRIORS AFTER DARK .....LENOX**  
 This session covers the fun, crazy, and shared experiences of living with sickle cell. We will also 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. If you want to be on the panel, please contact us.

## SATURDAY, JULY 19TH

**7:00AM - 10:00AM HOT BREAKFAST BUFFET (Hotel Guests Only) .....THE GREENLEAF**

**8:00AM - 10:00AM REGISTRATION OPEN .....BANQUET FOYER**

**8:00AM - 9:00AM YOGA IN THE MORNING .....LENOX**  
*Wake up and rejuvenate with April Green, certified Yoga instructor.*

**10:00AM – 10:45AM PROFESSIONALS ROUNDTABLE .....PEACHTREE A**  
 At this roundtable, discover that it is possible to have a career with sickle cell disease. You can go to school, work, get a job, and follow your passions. Learn from warriors who are living and pursuing their professional dreams.

- 10:50AM – 11:25AM KNOW YOUR EMPLOYEE RIGHTS .....PEACHTREE A**  
 Understand the laws that are available to you in order to take care of yourself and remain employed. Understand how to file for FMLA, ADA, ADAAA, PDA and other laws. Review paperwork and discuss your Healthcare provider's responsibility. Understand the laws that are in place to protect you while in college. Participate in a roundtable to discuss what laws impact you specifically.
- 11:30AM – 12:00PM CONCURRENT SESSIONS**
- TRACK A: THE DO'S AND DON'T'S OF SCD (ADULT) .....PEACHTREE A**  
 Understanding your body and its warning signs. The complexities and complications of sickle cell. Come prepared to hear from Warriors and an adult expert hematologist on how to manage the complications and still pursue your dreams. Get your questions ready. Do you know what your triggers are?
- TRACK B: BECOMING A WARRIOR .....LENOX**  
 Learn how to successfully transition from being taken care of by your parents to becoming a Guardian of your own health. Bring your notebook with you.
- 12:00AM – 1:00PM CONCURRENT SESSIONS**
- TRACK A: ALTERNATIVE MANAGEMENT AND THERAPIES .....PEACHTREE A**  
 New strategies for managing daily pain (including Yoga, Acupuncture, Stress Management). Non-medical ways of managing your sickle cell pain that improve your health, wellness, and mood.
- TRACK B: FOR MEN ONLY .....LENOX**  
 A private, for men only discussion about the topics of concern to Warrior men.
- 12:00PM – 5:00PM VENDOR TABLES OPEN .....FOYER**
- 1:00PM – 2:00PM CLINICAL/PHARMACEUTICAL RESEARCH PANEL LUNCH .....PIEDMONT A**  
 Everything that you need to know about clinical and pharmaceutical research. Why it's important, how you can get involved. Basics of clinical and drug research and Q&A with those directly involved in research directly involving sickle cell patients.
- 6:00PM – 11:00PM WARRIOR BANQUET.....PEACHTREE A & B**  
 Dinner, Dance and Award Ceremony. See pages 25-27 for more details and for a specialized program of events.

*\*Please turn to the next page to see Sunday's schedule\**

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## SUNDAY, JULY 20TH

- 7:00AM – 10:00AM HOT BREAKFAST BUFFET (FOR HOTEL GUESTS).....THE GREANLEAF**
- 8:00AM - 9:00AM YOGA IN THE MORNING.....LENOX**  
Wake up and rejuvenate with April Green, certified Yoga instructor.
- 10:00AM - 10:45AM BECOMING AN EFFECTIVE ADVOCATE.....PIEDMONT A**
- 10:45AM - 11:00AM CLOSING REMARKS.....PIEDMONT A**
- 11:00AM-11:30AM OPEN BUSINESS MEETING .....PIEDMONT A**  
You are invited to join us as we discuss plans for the 2016 Sickle Cell Community Gathering and Education Symposium. Vote for your favorite location and make nominations for planning committee co-chairs. We will also discuss future Sickle Cell Warriors, Inc. community projects and how you can get involved.
- 11:30AM-2:00PM CLOSED BUSINESS MEETINGS .....TBD**

# BANQUET DINNER MENU for JULY 19th



Please join us as we honor the  
**SICKLE CELL COMMUNITY SERVICE**  
nominees and recipients at the

## *2014 Sickle Cell Advocacy Awards Banquet*

**Saturday, July 19, 2014**

6pm - 10pm

Double Tree by Hilton Hotel-Buckhead  
3342 Peachtree Rd NE, Atlanta, GA 30326  
Atlanta, GA

Costs: Gathering attendees complimentary

All Guests: \$50

Full Plated Dinner

Tickets sold in advance

Visit [www.SickleCellWarriors.com/banquet](http://www.SickleCellWarriors.com/banquet) to register

We hope you can join us as we celebrate the honorees!

### **Dinner Service Options**

All menus come with iced tea, coffee service, salad, rolls, and butter.

- ❖ Mixed Field Greens served with Ranch and Creamy Vinaigrette
- ❖ Tomato Mozzarella Salad
- ❖ Grilled Antipasto Display
- ❖ Sliced Beef with Cognac Mushroom Sauce
- ❖ Grilled Salmon with Lemon Pepper Sauce
- ❖ Garlic Mashed Potatoes
- ❖ Seasonal Vegetables
- ❖ Red Velvet or Chocolate Cake

# BANQUET PROGRAM

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**Welcome**

**Invocation**

**Ceremony of Lights**

**Special Presentation**

*“Crisis & Courage” presented by the Blue Bistro Creative Company*

**Dinner Served**

**Introduction of Speaker**

**Key Note Address**

**Sickle Cell Leadership Awards Ceremony**

**Closing Thanks**

**Dance Party!**

# NOTES & SCRIBBLE SCRABBLE

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**Warrior**  
**For Jasmine Bailey (RIP) by Kadeem Gayle**

Already the pain spigots the flow of her content;  
the vibrations twinge  
And crisis is sewed in her veins. Sickle cell  
safely digs her wait-  
Like adverbs inside rotten syntax; the ache  
grows.

*What happens when all you know is pain and  
they*

*Stick.* It jams, the courage is her shield bathed  
within her pain.

She is now at war with her body. A scream that  
busts

through hushed faces. Them cells, these cells,  
floor her.

But a true warrior like her knows how to  
fight when paralyzed.

Her chance is now at time.

Breathe.

Breathe.

Breathe.

Numb to *18, 22, and 24 gauge needles*  
From the day she was born sickle cell has been  
her instinct.

Clots, stuck then plunge- and with her finger she  
holds

A hurt of happy.

And with her smile like sword she stabs the  
pang of conscience.

Warriors don't give up.

Her cells, the sickle cells scent caresses her high  
regimen.

Nonetheless, her cries produce bullets  
calming her treason,  
And though her skin tussles, the guard  
layers an untamed rhythm  
Bobs, bends- swaddled around her war.

The whirlwind of silence catches her gasp.

And the count of her tears will define: unafraid,  
courageous, heroic,  
Fighter, leader  
Warrior.

**A Walk in my Shoes**  
**By Artissa Crump**

Sickle Cell is an inherited disease that attacks the  
blood cells.

But there is not enough numbers to describe our  
pain on a scale.

You can get this disease if both parents have the  
trait.

But only the strong survive because it's a lot to  
deal with on your plate.

It can also affect your organs and make your  
joints feel like they're about to break.

But God already knows how much pain you can  
take.

There is no cure, but there is meds to control the  
pain.

Just please be careful because there are some  
side effects that you can gain,

And not to mention this could damage your  
veins.

Staying in the hospital and getting stuck with  
needles all day and night. Is a reason  
alone to want to give up the fight.

But we must hold on and pray for peace each  
and every night.

Try to think of your loved ones, who can't stand  
to see you cry.

And tell yourself it's not my time yet, I am not  
ready to die.

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## **It's a Living by Kadeem Gayle**

Throughout the years my life has been like a lab rat  
See, I was born with sickle cell and my hematologist  
put me up through these dramatic tests  
Just to see if my inside organs still function.

I lost respect for myself because of these crescent shaped cells.  
Although, some say I'm rebellious because I take too much drugs.  
*I say, I can't help it; my body puts me through hell.*  
But, I'm not going lie, those liquid forms of drugs  
Feel good, running through my veins and dancing on my spine.

Like it's too pure to be unclean,  
But it's obvious why they call it morphine, because no doubt about it  
The more you receive the more you glean.  
Pain is my food it gives me the energy to live,  
But popping' these pills just say I need help to live.

I've been forced to drop out of school a few times,  
Not because of the financial recession  
But my body feels like the 1930's, you know, the great depression.  
Living with this disease what's the point of trying to succeed?  
I'm drowning in life and all I want to do is breathe.

I'm tired of these countless nights where I wake up and I can't walk.  
How can a cell, so small, feel like I've been stoned by rocks.  
You thought pain was the only side effect towards this,  
Try: Pancreatitis, pneumonia, and even gall bladder removal-

Blood stained on my ambition, I give up losing.  
I may be born without a dream  
But every day, I'm living to succeed.

## **Artissa Crump – Doing Well**

People always ask me how I deal with all the pain.  
First thing I tell them is that I try not to complain.  
Because in my weakness my strength is gain.  
And every now and then you have to accept some rain.  
But there are times when I don't want to talk.  
Those be the days when I get out of bed and can barely walk.  
When the pain is bad in my eyes, joints, and teeth.  
When I can't sleep at night and it feels like death is calling me.  
When all I can do is cry and pray at night.  
And think of my kid because she is the reason why I fight  
So I will not complain when my life is going through hell.  
Because believe it or not some days I do pretty well.

# THANK YOU

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WOOHOO!!!! *(I hope you are reading this at the end (and not in the midst of the Gathering, you overachiever you!)*

We made it! The 2014 Sickle Cell Warriors Gathering is now officially over! Thank you so much for everyone who has attended and made this experience phenomenal. Lakiea & I hope that you found it extremely informative, educational, inspiring, and supportive. There are so many people to thank, so we are just going to dive right in.

First, we would like to extend much gratitude to Mr. Dan Moore, Sr. at Marrow for Life, Inc., for his invaluable advice, support, and encouragement through the last few years. If you live in Atlanta, please visit the APEX Museum! It's an amazing experience focused on African-American heritage.

Next, we would like to thank the 12 courageous people that came on the cruise with us last year. It was a phenomenal adventure, and we had so much fun! Going to the Bahamas gave us all a vacation, a time to relax, a unique bonding experience, and memories for a lifetime. They were the Alpha class, and part of the reason this year was so great is because Alpha class let us work all the kinks out with them. Plus, they helped us so much with the planning.

We would also like to thank all our volunteers for taking the time to help us make this a success. Jennifer, Mia, Busayo, Doris, L'Bonnee, Angeline, Jacquelyn, Jessica, Adeya, Tamika, Julie, Justin, and James. Many hands truly make light work. There is no way we could have pulled this out 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 with us everything you have, opening your lives, education, and knowledge with us, so we could all benefit. Everyone gained something because of you, even those who said only 1 sentence! (you know who you are!)

Thank you to all our community partners, vendors, and contributing sponsors especially Eli Lilly & Company, bluebird bio, Selexys Pharmaceuticals and the World of CocaCola.

The idea for the Gathering, and the driving force behind everything has been Lakiea Bailey. If you see her, make sure you give her a hug and a pat on the back. Job well done! She turned this from an idea to an actual live annual event, and I'm in awe of her energy, vibrancy and strength. If not for Kiea, the Gathering would have been cancelled a while back due to low initial interest, but she literally pushed, pulled, prodded, and lifted, until it became everything you saw this weekend.

Last but most important, thank you to our families, especially our moms and sisters. They are the wind beneath our wings (yeah, cheesy but true). 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. Lakiea & I both apologize for talking non-stop about the Gathering for the last 6 months, but at least you have a few months break before the cycle starts all over again!

Where would we be without our attendees? We would just have great planned programs, and no one to share them with! So thank you for YOU; for trusting us, for making the financial commitment, for coming and spending the weekend with us. We hope that this continues to be an annual event, and gets 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, start posting pictures online asap, and tag us #sicklecellGathering or #sicklecellwarriors #Iwasthere #ScavengerChampions #sux2bu #LoveaWarrior #I'mAwesome #IDareto...pretty much your favorite parts of the weekend, so we can all relive this experience. Plus, it will make those who didn't come utterly jelly haha;)

As always, please visit us on the website [www.sicklecellwarriors.com](http://www.sicklecellwarriors.com) where we will be posting pictures, comments, videos and updates about this and other events that Sickle Cell Warriors, Inc. are planning.

So long, safe travels, and we hope to see you next year at the next Gathering!

*Tosin & Lakiea*

# DONATIONS

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Imagine life without sickle cell disease—where your mother, children, spouse, sister, or friend doesn't have to worry if he or she will have a child that will be the one diagnosed into a life of pain, tissue damage, organ failure, and suffering with this disease.

While we have made tremendous progress in the fight, people are still dying every day from sickle cell disease—and that's unacceptable. At Sickle Cell Warriors, Inc.®, we are working every minute of every day to save every life, and we need your help.

**BY MAKING A DONATION TODAY, YOU CAN HELP SAVE LIVES.**

Thank you for your commitment to support Sickle Cell Warrior's mission to end sickle cell disease forever. Education is one of the foremost pillars of our organization. Education is a preemptive tool to reduce the population of sickle cell disease in the next generation. Education also drastically reduces the negative stigmas associated with sickle cell, thereby promoting support for those with the disease. Education ensures that those with sickle cell disease live longer, pain-free, healthier lives. We have several programs and initiatives that your donation will support.

There are several ways to donate. You can use credit cards, debit cards or direct transfers. You can send a check or money order to our mailing address. Thank you so much for your assistance.

Checks and money orders can be sent directly to our PO Box:

**Sickle Cell Warriors, Inc.**  
**PO Box 4587**  
**Alpharetta, GA 30023-4587**

To learn more about how your donation will be used, please visit our website at [www.sicklecellwarriors.com/donate](http://www.sicklecellwarriors.com/donate)

You can also donate online (recurring or one-time payment) by going to [www.sicklecellwarriors.com/donate](http://www.sicklecellwarriors.com/donate) or sending a PayPal donation to [donations@sicklecellwarriors.com](mailto:donations@sicklecellwarriors.com)

All donations are tax deductible and will be credited to the calendar year in which they are received. A receipt will be sent for each donation.

*Sickle Cell Warriors Inc.*









*Sickle Cell Warriors Inc.*

[www.sicklecellwarriors.com](http://www.sicklecellwarriors.com)