

— SICKLE CELL

GIANTS PIONEERS & VISIONARIES

PAST, PRESENT & FUTURE.

ARE WE WHERE THEY WANTED US TO BE?

15TH ANNUAL SICKLE CELL DISEASE EDUCATIONAL SUMMIT **SEPT 13 - 16, 2023**

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WELCOME

I would like to give honor to God who is the source of my strength and the reason for my being. I thank you all for being here - in person and virtually.

What happens to any of us Sickle Cell Warriors anywhere in the world had better be the business of us all for anything that has been or will be done is in essence futile, and a loud clanging bell (just a lot of noise). For the 17th year, I would like to welcome you to our 15th Annual Sickle Cell Disease Educational Summit where our theme this year focuses on the Giants, Pioneers, and Visionaries - Past, Present, and Future. Are We Where They Wanted Us To Be? Well, are we? Some will say, in the matter of science and technology, a resounding Yes. Gene Therapy falls in this category as well as the FDA approved and emerging modifying therapies. However, when it comes to care, managing pain, and being granted dignity, a resounding No echoes throughout. We are still dying prematurely at home or after being turned away from emergency rooms. We are still not believed for the reports of our pain and are seen as drug addicts. We are not treated with dignity and compassion. In fact, these same persons with medical degrees would treat an animal with far more humanness than our human Warriors. And that is a fact.

Today, we are here to honor those that have made great strides in their own right within the sickle cell landscape. You will hear from iconic physicians, such as Drs. Marilyn Gaston and Clarice Reid, a compassionate social worker, Trudy Tchume Johnson, and hear about the giants that have played a part in sickle cell history (Charles F Whitten, Roland Scott, Doris Wethers, Jeanne Smith, and the list goes on).

On Friday evening, we invite you to our Celebration Fundraising Gala where we honor our CA Giants and give tribute to Hertz Nazaire to support Cayenne Wellness Center's Client Assistance Program (CAP). CAP allows Sickle Cell Warriors to apply for aid up to \$500 for support of rental assistance, utility assistance, medical devices, and transportation, to name a few.

You have now entered a healing zone; your words and behavior matter. From this point on everyone deserves to be treated and spoken to with courtesy, respect, and kindness. We invite you to take Cayenne Wellness Center's Sickle Cell Pledge. So, take a deep breath in, hold it, and exhale. Be mindful and present.

No matter the greatness of the achievements, we still face many challenges in the struggle to bring healthcare equity and justice to people living with sickle cell disease. You Matter. What We All Do Matters. If you see something - say something. 50 to 100 years from now, will they be where we want them to be?

Thank you.



Carolyn Rowley, PhD
Executive Director and Founder
Cayenne Wellness Center

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AGENDA

DAY 1 - WEDNESDAY, SEPTEMBER 13, 2023	
1:30 pm	Past, Present, and Future: The Therapies - Location: The Lighthouse Moderators: Keith Quirolo, MD, and Monique Sanchez, MD
2:00 pm	Four (4) FDA-Approved Therapies - Location: The Lighthouse <ul style="list-style-type: none"> 2:00 pm - Siklos - (Medunik) 2:10 pm - Endari - (Emmaus Life Sciences) 2:25 pm - Oxbryta - (Pfizer) 2:40 pm - RBC - (Terumo) 2:55 pm - Questions and Answers
3:10 pm	Emerging Therapies - Location: The Lighthouse <ul style="list-style-type: none"> 3:10 pm - Agios Pharmaceuticals 3:25 pm - Novo Nordisk formerly Forma Therapeutics 3:35 pm - Fulcrum Therapeutics 3:45 pm - Questions and Answers
4:00 pm	Break
4:15 pm	Gene Therapies - Location: The Lighthouse <ul style="list-style-type: none"> 4:15 pm - bluebird bio 4:30 pm - Vertex 4:45 pm - Beam Therapeutics 5:00 pm - editas Medicine 5:15 pm - Questions and Answers
5:45 pm	Meet the Vendors - Location: The Lighthouse
6:30 pm	Dinner - Sponsored by Emmaus Life Sciences, featuring Keynote Speaker Yutaka Niihara, MD - Location: The Lighthouse
8:00 pm	Adjourned

DAY 2 - THURSDAY, SEPTEMBER 14, 2023	
7:30 am	Stretching (In-Person Only) - Eryn Young - Location: Village Green (Outside Area)
8:30 am	Welcome - Location: Salon D
9:00 am	Highlight the Giants - Location: Salon D Moderators: Keith Quirolo, MD and Wanda Whitten-Shurney, MD <ul style="list-style-type: none"> 9:30 am - 1. Science - Honoring Betty Pace, MD, Robert Adams, MD, Michael DeBaun, MD, Donald Kohn MD - Speaker: Ward Hagar, MD 9:50 am - 2. Policy - Honoring Charles F. Whitten, MD, Roland Scott, MD, Clarice Reid, MD, Kevin McCormack (CIRM) - Speaker: Ahmar Zaidi, MD 10:15 am - Break 10:30 am - 3. Sociological/Behavioral Health - Honoring Ruth White, Wally Smith, MD, Marsha Treadwell, PhD, Kermit B. Nash, PhD - Speaker: Cage Johnson, MD 11:00 am - 4. Newborn Screening and Clinical Care - Honoring Marilyn Gaston, MD, Doris L. Wethers, MD, Jeanne A Smith, MD, Elliott Vichinsky, MD, Darleen Powars MD - Speaker: Susan Paulukonis
11:30 am	Break
11:45 am	Sickle Cell Jeopardy
12:15 pm	Lunch with the Giants, Pioneers, and Visionaries
1:30 pm	Wellness Break - Marjorie DeJoie Brewer, MD - Location: Salon D Hydration, Breathing, and Movement
2:00 pm	Sickle Cell Trait Education - Location: Salon D Moderator: Pat Corley, RN <ul style="list-style-type: none"> 2:00 pm - Before The Flood: Benefits of the Sickle Cell Movement Speaker: Marilyn Gaston, MD 2:45 pm - STAC - California (Sickle Cell Trait Awareness Campaign - CA) Speakers: Carolyn Rowley, PhD, Chase Jamele, and Elle Cole 3:15 pm - Changing the Lens of Your Life: Receiving the SC Trait and SCD Letter. Speakers: Elle Cole (SC Trait Letter), Adrienne Shapiro (SCD Letter), Aicha Abdoulaye (No Letter) 3:45 pm - What We Do Know About Sickle Cell Trait Speaker: Tomia Austin, DrPH
4:15 pm	Break
4:30 pm	Are We Where They Wanted Us To Be? Gene Therapy, Cost - Location: Salon D Speakers: Betty Pace, MD, and Akshay Sharma, MD
5:30 pm	Celebration of Life - Location: Salon D Moderators: Sheila Marchbanks, MBA, and Felicia Hunt, PsyD
6:00 pm	Adjourned
7:30 pm	Game & Puzzle Night - hosted by Axis Advocacy (In-Person Only) - Location: Salon A & B

AGENDA CONT.

DAY 3 - FRIDAY, SEPTEMBER 15, 2023

7:30 am	Yoga (In-Person Only) - Marjorie DeJoie Brewer, MD - Location: Village Green (Outside Area)
9:00 am	<p>Stephanie Mulkey Keynote Speaker Session - Location: Salon D Are We Where They Want Us To Be? (Management and Treatment of SCD)</p> <p>Moderators: Kim Smith-Whitley, MD, and J. Hoxi Jones</p> <ul style="list-style-type: none"> 9:15 am - Elevated and Anchored By Our Ancestors - Honoring Samir Ballas, MD, and Kwaku Ohene-Frempong, MD, Speaker: Janet Frempong 10:15 am - Break 10:30 am - Historical Perspectives: A Journey of Triumphs Speaker: Clarice Reid, MD 11:00 am - Nurses: The Essential and Ever-changing Role of Nurses in the Sickle Cell Community Speaker: Yvonne Carroll, JD, RN 11:30 am - Break 11:45 am - Patient Experiences Speaker: Adrienne Shapiro
12:30 pm	Lunch
12:30 pm	<p>Industry Sponsored Lunch - Agios Pharmaceuticals (In-Person Only) Description: Join the Agios team for a focus group Title: Agios' Focus Group Target Audience: Patients only Meeting: Invite Only / Private Room Location: Salon C</p>
1:30 pm	Wellness Break - Marjorie DeJoie Brewer, MD - Location: Salon D Hydration, Breathing, and Mental Health
2:00 pm	<p>PsychoSocial Part I: Developing Brilliance, Resilience and Strength: We're Smart and We're Strong - Location: Salon D Moderators: Trudy Tchume-Johnson, LCSW, and André Harris</p> <ul style="list-style-type: none"> 2:00 pm - Social work in the sickle cell movement Honoring Ruth White, June Vasseur, MPH, and Kermit Nash, PhD, and others that promoted sickle cell disease. Speaker: Trudy Tchume-Johnson, LCSW 2:22 pm - A SC Warrior speaks Speakers: Sheila Marchbanks, MBA, and Jody Johnson 2:35 pm - A Caregiver speaks Speakers: Vivian Smith and Karen Shea 2:45 pm - What can a social worker offer me and my family? Speaker: Artangela Henry, PhD 2:52 pm - How can having a relationship with a social worker help your build resilience? Speaker: Rebecca Morgan, LCSW 3:00 pm - Summary Speaker: André Harris
3:15 pm	Break
3:30 pm	<p>PsychoSocial Part II: Group Sessions Moderators for each breakout session: Question: Are We Where They Wanted Us To Be? The State of Sickle Cell Care and Services Breakout Groups</p> <ul style="list-style-type: none"> Baby Boomers Session (60 and older) Moderator: Wanda Williams - Location Pier 1 Generation X Session (43 - 59) Moderator: Felicia Hunt, PsyD - Location Pier 2 Millennials Session (27 - 42) Moderator: Dorian Archie - Location Pier 4 Generation Z (18 - 26) Moderator: Dalia Thomas - Location Pier 7 Generation Alpha (11 - 17) Moderator: Ninah Walters - Location: Pier 6 Caregiver (includes Parent/Children/Spouses/Partner/Siblings Session Moderator: Eugene Williams - Location: Pier 8
5:15 pm	Break
6:45 pm	Celebration, Tribute Gala - Location: The Lighthouse
9:30 pm	Adjourned

AGENDA CONT.

DAY 4 - SATURDAY, SEPTEMBER 16, 2023

7:30 am	Exercise (In-Person Only) - Rainey Allen - Location: Village Green (Outside Area)
8:20 am	<p>Welcome and Cayenne Wellness Center Board Updates - Location: Salon D</p> <p>Speaker: Shona Stephens, Cayenne Wellness Center's Board Chair</p>
8:30 am	Awards - Location: Salon D
9:45 am	<p>Pat Corley Keynote Speaker Session - Location: Salon D Shout out to; Call out to; What is your value? What do you bring? Speaker: Stephanie Ibemere, PhD, RN</p>
Patient Track - Location - Salon D	
Moderator: Elle Cole	
11:00 am	<p>Global Patient Panel Moderators: Cassandra Trimmell and Biba Tinga</p> <ul style="list-style-type: none"> Panelist - Eunice Owino (Kenya) Panelist - Nilda Navedo (USA) Panelist - Veronica Hornos (Argentina) Panelist - Kiwanuka Derrick (Uganda) Panelist - KW Young (Trinidad and Tobago)
12:15 pm	Lunch
1:30 pm	Wellness Break - Marjorie DeJoie Brewer, MD - Location: Salon D Hydration, Breathing, and Nutrition
2:00 pm	Self Care (Main Room) - Location Salon D
2:15 pm	<p>Self Care Activities</p> <ul style="list-style-type: none"> Gardening In-Person: Carol Barnes Reid - Location - Outside Area Virtual: Lori Vick, PhD, MAT, RN Art In-Person: Gina Thompkins - Location - Outside Area Virtual: Mia Robinson Vision Board In-Person: Adrienne Shapiro and Casey Gibson Virtual: Vernita Bradford and Betty Wheeler Sound Healing In-Person: Somer Waters - Location: Salon B Virtual: Dr. Carolyn Rowley's Video Cooking In-Person: Melissa Corral - Location (Offsite) Virtual: Misty Williams
3:30 pm	<p>My Journey, My Legacy - Location: Salon D</p> <p>Moderators: Theopia Jackson, PhD</p>
3:45 pm	<p>Breakout Rooms</p> <p>Moderators: Shyra Arrington, Felicia Hunt, PsyD, Farron Dozier, and Jody Johnson</p>
4:45 pm	Living Legacies (SC Warriors / I AM moments) - Location: Salon D
5:30 pm	Adjourned
Physician Track - Location: Salon C	
Moderated by Kim Smith-Whitley, MD	
11:00 am	Patient Experiences (focus on management and treatment)
11:15 am	<p>SC101 Speaker: Ifeyinwa Osunkwo, MD, MPH</p>
12:30 pm	Lunch
1:00 pm	<p>Implicit Bias Training Speaker: Amikaeyla Gaston and Shakti Butler, PhD of World-Trust</p>
3:30 pm	Break
3:45 pm	Patient Experiences (specific to ED)
4:00 pm	<p>Emergency Room</p> <p>Speaker: Jeffrey Glassberg, MD</p>
5:00 pm	<p>Stroke and Intracranial Bleeds Speaker: Christine Fox, MD</p>
6:30 pm	Adjourned

PLANNING COMMITTEE



ADRIENNE SHAPIRO



CAROLYN ROWLEY, PHD



ELLE COLE



KEITH QUIROLO, MD



MARIA RIVERA



MARY ALCOCER



MISTY WILLIAMS



MONIQUE SANCHEZ, MD



SHEILA MARCHBANKS, MBA



PAT CORLEY, RN



WANDA WILLIAMS



ZAHRA PAKBAZ, MD

KEYNOTE SPEAKERS

**STEPHANIE MULKEY KEYNOTE:
ARE WE WHERE THEY WANT US TO BE? (MANAGEMENT AND TREATMENT OF SCD)**



KIM SMITH-WHITLEY, MD

Kim Smith-Whitley, MD, is an Attending Physician in the Division of Hematology and the Former Director of the Comprehensive Sickle Cell Center at Children's Hospital of Philadelphia. **Areas of Expertise:** Bone marrow failure, General hematology, Sickle cell disease.

**STEPHANIE MULKEY KEYNOTE:
ARE WE WHERE THEY WANT US TO BE? (MANAGEMENT AND TREATMENT OF SCD)**

J. HOXI JONES



J Hoxi Jones is a 69 year old sickle cell elder and advocate. She represents the consumer perspective on national, regional, and local committees and has presented at national and state meetings for more than 40 years. She is a graduate of Howard University and resides in Houston, TX.

**PAT CORLEY KEYNOTE:
SHOUT OUT TO; CALL OUT TO; WHAT IS YOUR VALUE? WHAT DO YOU BRING?**



STEPHANIE IBEMERE, PHD

Stephanie Ibemere, PhD, Associate Professor at Duke University School of Nursing, is a Registered Nurse with diverse global experience. Her research focuses on Sickle Cell Disease management in Sierra Leone, pain management, and capacity-building for healthcare providers. She's committed to equity through community collaboration, telehealth, and policy influence.

**INDUSTRY DINNER KEYNOTE:
SPONSORED BY EMMAUS LIFE SCIENCES**

YUTAKA NIIHARA, MD



Dr. Niihara has been involved in patient care and research for sickle cell disease for most of his career, and is the principal inventor of the patented L-glutamine therapy for treatment of sickle cell disease. He is a cofounder of Emmaus, principal investigator for LABioMed at Harbor-UCLA Medical Center and Professor of Medicine at the David Geffen School of Medicine at UCLA For more information,

PAST, PRESENT, AND FUTURE: THE THERAPIES

WEDNESDAY, FROM 1:30 PM

SESSION HIGHLIGHTS

– Moderators: Keith Quirolo, MD, and Monique Sanchez, MD

Four (4) FDA-Approved Therapies – Siklos (Medunik) | Endari (Emmaus Life Sciences) | Oxbryta - (Pfizer) | RBC (Terumo)

Emerging Therapies – Agios Pharmaceuticals | Novo Nordisk formerly Forma Therapeutics | Fulcrum Therapeutics

Gene Therapies – bluebird bio | Vertex | Beam Therapeutics | Editas

MODERATOR SPOTLIGHT

KEITH QUIROLO, MD

SC Advocate | SC101 & Cayenne Wellness Center

Dr. Quirolo, with degrees from San Francisco State University, UCSF School of Nursing, and Case Western Reserve School of Medicine, practiced as an RN in pediatric oncology for 10 years. He led UCSF Benioff Children’s Hospital’s Pediatric Sickle Cell Program for 20 years and its Clinical Apheresis Program for 17. Now, he consults for community organizations and advocacy projects.



HIGHLIGHTING THE GIANTS OF SICKLE CELL DISEASE

THURSDAY, FROM 9:00 AM

SESSION HIGHLIGHTS

– Moderators: Keith Quirolo, MD, and Wanda Whitten-Shurney, MD

Science – Honoring B. Pace, R. Adams, M. DeBaun, and D. Kohn

Policy – Honoring C. F. Whitten, R. Scott, C. Reid, K. McCormack (CIRM)

Sociological/Behavioral Health – Honoring R. White, W. Smith, M. Treadwell, K. B. Nash

Newborn Screening and Clinical Care – Honoring M. Gaston, D. L. Wethers, J. A Smith, E. Vichinsky, D. Powars

MODERATOR SPOTLIGHT

WANDA WHITTEN-SHURNEY, MD

Pediatrician, Advocate, CEO and Medical Director | SCDA (Michigan Chapter)

Dr. Wanda Whitten-Shurney, inspired by her father’s sickle cell advocacy, has 30+ years at Children’s Hospital of Michigan. She’s CEO of Sickle Cell Disease Association’s Michigan Chapter and an SC RED advisor. An alumna of Detroit Public Schools, University of Michigan, and Howard University, she’s specialized in Hematology Oncology.



MODERATOR SPOTLIGHT

MONIQUE SANCHEZ, MD

FP with OB/GYN, NCMP | Golden Valley Health Centers

Monique Sanchez, MD, is a physician for Golden Valley Health Centers (GVHC) at the Women’s Clinic in Merced, California. Providing female patients with OB/Gyn and Menopause care. She’s a veteran of the US Army, and affiliated with Dignity Health Mercy Medical Hospital.



SPEAKER SPOTLIGHT

WARD HAGAR, MD

Director | Adult Sickle Cell Center at UCSF Benioff Children’s Hospital

Dr. Hagar leads the Adult Sickle Cell Center at UCSF Benioff Children’s Hospital Oakland, focusing on holistic, lifelong care for over 500 patients regionally and globally. He pioneers clinical studies and research to enhance Sickle Cell Disease care and develops training for healthcare professionals in the field.



MEET THE VENDORS OF LEADING SCD THERAPIES

WEDNESDAY, FROM 5:45 PM

SESSION HIGHLIGHTS

Meet the Vendors – FDA-Approved Therapies, Emerging Therapies, and Gene Therapies

Dinner – Sponsored by Emmaus Life Sciences

SPEAKER SPOTLIGHT

AHMAR ZAIDI, MD

Hematologist | Agios

Ahmar Zaidi, MD, a classical hematologist, specializes in hemolytic anemias and sickle cell disease (SCD). He merges technology with disease research, explores healthcare outcomes, and develops novel biomarkers. A staunch SCD advocate, he harnesses social media for patient education and physician interaction.





SPEAKER SPOTLIGHT

CAGE JOHNSON, MD

Prof. Emeritus of Medicine, Physiology & Biophysics | Keck School of Medicine, USC

Cage S. Johnson, M.D., Professor Emeritus at Keck School of Medicine, USC, and Director of the Adult Sickle Cell Center at LAC+USC Medical Center, specializes in sickle erythrocytes' behavior. A Creighton University alumnus with 100+ publications, he's received honors from both Creighton and the American Society of Hematology for outstanding contributions.



SPEAKER SPOTLIGHT

MARILYN GASTON, MD

SC Advocate | Retired Pediatrician and Director, Primary Health Care

Marilyn Hughes Gaston, M.D. revolutionized SCD care and healthcare equality. Her career includes directing the Bureau of Primary Health Care, promoting sickle cell screening, and co-directing the Gaston and Porter Health Improvement Center. A pediatrician and advocate, her journey reflects dedication to underserved communities and healthcare advancement.

SPEAKER SPOTLIGHT

SUSAN PAULUKONIS

Principal Consultant | Paulukonis Health Data Consulting, LLC

Susan Paulukonis heads California's Sickle Cell Data Collection Program, funded by the CDC, gathering data to inform policy makers, researchers, and care providers on SCD care access and outcomes. Serving since 2010, she's been dedicated to understanding challenges faced by those with SCD since 2006.



SPEAKER SPOTLIGHT

CAROLYN ROWLEY, PHD

Executive Director & Founder | Cayenne Wellness Center & Children's Foundation

Dr. Carolyn Rowley, founder of Cayenne Wellness Center, champions sickle cell care and nutrition. With a Ph.D. in Psychology, she's also dedicated to Kenyan orphanages and was honored by NIH in 2007. A music lover, environmentalist, and faith-driven leader, Rowley continues to inspire and advocate for health and wellness.



SICKLE CELL TRAIT EDUCATION

THURSDAY, FROM 2:00 PM

SESSION HIGHLIGHTS

– Moderator: Pat Corley, RN

Before The Flood – Benefits of the Sickle Cell Movement

STAC: California – (Sickle Cell Trait Awareness Campaign - CA)

Changing the Lens of Your Life – Receiving the SC Trait and SCD Letter

What We Do Know About Sickle Cell Trait



SPEAKER SPOTLIGHT

CHASE JAMELE

Assistant Program Manager | Cayenne Wellness Center & Children's Foundation

Born in Redondo Beach, Chase pursued International Business Management in Antwerp, Belgium, after attending community colleges in California. Graduating in 2020, he returned to Los Angeles and now applies his skills to support Dr. Carolyn Rowley's efforts in aiding those with Sickle Cell Disease.

MODERATOR SPOTLIGHT

PAT CORLEY, RN

Nurse Advocate/Educator | Cayenne Wellness Center & Axis Advocacy

With 40 years in patient care, Ms. Corley is a trailblazer in sickle cell nursing. Recognized by Dr. Cage Johnson, she influenced national sickle cell care. Honored with the Elliott Vichinsky Award, she collaborates with major nonprofits and continues a legacy of service through her family.



SPEAKER SPOTLIGHT

ELLE COLE

Sr Digital Marketing Manager | Cayenne Wellness Center & Children's Foundation

Elle Cole, an author and Senior Digital Marketing Manager at Cayenne Wellness Center, boasts 13+ years of writing, and marketing prowess. As Editor In Chief of Cleverly Changing Press, she empowers parent educators, advocates for health needs, and hosts podcasts. Elle is a certified sickle cell advocate, and caregiver leader.





SPEAKER SPOTLIGHT

AICHA ABDOULAYE

Director | Tahirih Justice Center

After surviving child marriage and escaping to America, Achia Abdoulaye found herself trapped. With help from the Tahirih Justice Center, she gained documentation and rebuilt her life. She is now the Director of the center, an entrepreneur, and a mother to a young sickle cell warrior. She shares her story to empower women in similar situations to find their way to freedom.



SPEAKER SPOTLIGHT

BETTY PACE, MD

Distinguished Chair of Pediatric Hematology/Oncology | Augusta University

Dr. Betty Pace, Augusta University's Francis J. Tedesco Distinguished Chair of Pediatric Hematology/Oncology, is a physician and researcher. Her NIH-funded lab focuses on globin gene regulation and SCD treatments, with a clinical trial underway. She directs diversity-focused programs, training over 100 young scientists to expand the biomedical science workforce.

SPEAKER SPOTLIGHT

ADRIENNE SHAPIRO

Executive Director & Founder | Axis Advocacy | SCD Community & Support

Adrienne Shapiro, continuing her family's generational battle with SCD, became an advocate after her daughter Marissa's diagnosis. Co-founder of Axis Advocacy SCD Support, she passionately supports stem cell research, having faith in its potential cure. Awarded at the 2018 World Stem Cell Summit, she champions evidence-based care and patient dignity.



SPEAKER SPOTLIGHT

AKSHAY SHARMA, MD

Clinician-Scientist, Bone Marrow Tx and Cellular Therapy | St. Jude Children's RH

Akshay Sharma is a clinician-scientist in the Department of Bone Marrow Transplantation and Cellular Therapy at St. Jude Children's Research Hospital, Memphis TN. During his clinical fellowship, he worked on understanding the genetic regulation of fetal hemoglobin and continues to translate that work developing novel transplant and gene therapy clinical trials for patients with sickle cell disease.



SPEAKER SPOTLIGHT

TOMIA AUSTIN, MD, DRPH

Executive Director | As One Foundation

Tomia Austin, DrPH, leads the As One Foundation, promoting youth empowerment through athletics and education. Founded in memory of her brother, a sickle cell trait exertion victim, she initiated "Operation Hydration" for awareness and prevention. Her leadership emphasizes global sickle cell education and comprehensive resources.

CELEBRATION OF LIFE: CANDLELIGHT CEREMONY THURSDAY, FROM 5:30 PM

SESSION HIGHLIGHTS

– Moderators: Sheila Marchbanks, MA, and Felicia Hunt

Honoring our loved ones diagnosed with Sickle Cell Disease that have passed

ARE WE WHERE THEY WANTED US TO BE? GENE THERAPY, COST THURSDAY, FROM 4:30 PM

SESSION HIGHLIGHTS

– Speakers: Betty Pace, MD, and Akshay Sharma, MD

Snapshot on the Current State and Cost of Gene Therapy

SPEAKER SPOTLIGHT

SHEILA MARCHBANKS, MBA

Sickle Cell Warrior | Former Aerospace Executive

Sheila Marchbanks, a dedicated Sickle Cell Disease Warrior, serves her family and community with unwavering commitment. A former aerospace executive for 20+ years, she now channels her expertise into advocating for the SCD community. As a wife, mother, and grandmother, she cherishes family support and champions comprehensive care for SCD adults.





SPEAKER SPOTLIGHT

FELICIA HUNT, PSYD

MA in Marriage & Family Therapy (MFT), Sex Coach, and Sex Educator | 6EXCoach, LLC

Felicia Hunt specializes in treating African American families through trauma, sexual assault, breaking barriers, and tearing down social constructs that oppress and marginalize people of color, especially Black people. Currently, she is promoting her sex coaching business called “6ExCoach”, that teaches people “Mental-Fitness” and, “Live in Desire 100%!”



SPEAKER SPOTLIGHT

YVONNE CARROLL, JD, RN

Director, Patient Services | St. Jude Children’s Research Hospital - Dept. of Hematology

Yvonne Carroll, JD, RN, St. Jude Department of Hematology, Patient Services director, is a principal investigator and program manager for the sickle cell disease program. She has facilitated the continuity of care for young adults with sickle cell disease by improving the transition from pediatric to adult medical care through developing a skills lab, a transition readiness assessment and transition educational material.

STEPHANIE MULKEY KEYNOTE: ARE WE WHERE THEY WANT US TO BE?

FRIDAY, FROM 9:00 AM

SESSION HIGHLIGHTS

– Moderators: Kim Smith-Whitley, MD, and J. Hoxi Jones

Elevated and Anchored By Our Ancestors – Honoring Drs. Samir Ballas and Kwaku Ohene-Frempong

Historical Perspectives – A Journey of Triumphs

Nurses – The Essential and Ever-changing Role of Nurses in the Sickle Cell Community

Patient Experiences

PSYCHOSOCIAL PART I:

DEVELOPING BRILLIANCE, RESILIENCE AND STRENGTH: WE’RE SMART & WE’RE STRONG

FRIDAY, FROM 2:00 PM

SESSION HIGHLIGHTS

– Moderators: Trudy Tchume-Johnson, LCSW, and André Harris

Social work in the sickle cell movement – Honoring R. White, J. Vavasour, K. Nash and others that promoted sickle cell disease

A SC Warrior speaks

A Caregiver speaks Speaker

What can a social worker offer me and my family?

How can having a relationship with a social worker help your build resilience?



SPEAKER SPOTLIGHT

JANET FREMPONG

SC Advocate | Strategic Partner - Health Literacy

Janet Ohene-Frempong’s decades of experience with sickle cell disease has been a personal one, as the wife of Dr. Kwaku Ohene-Frempong and as Kwame’s mother. Both are now deceased. Bereaved, but not defeated, Mrs. Ohene-Frempong is passionate about supporting the efforts of all sickle cell warriors globally.



MODERATOR SPOTLIGHT

TRUDY TCHUME-JOHNSON, LCSW

Program Manager/Newborn Screening Coordinator | The Children’s Hospital of Philadelphia

Trudy Tchume-Johnson, MSW, LSW, is the social work Manager in the Division of Hematology and a social worker in the Comprehensive Sickle Cell Center at Children’s Hospital of Philadelphia. Her areas of Expertise include providing psychosocial support for chronically ill children with sickle cell disease, Newborn screening for abnormal hemoglobinopathies.

SPEAKER SPOTLIGHT

CLARICE REID, MD

SC Advocate | Former NIH Director and Renowned Neurologist

Clarice Reid, MD, former Director of the Division of Blood Diseases and Resources at the National Institutes of Health, overcame segregation and lack of resources to become a renowned physician specializing in neurology. Her remarkable work included research in blood diseases, sickle cell disease, AIDS, and bone marrow transplantation. Honored with the Presidential Meritorious Executive Rank Award and a place in the Book of Black Heroes.



MODERATOR SPOTLIGHT

ANDRÉ HARRIS

SC Advocate | Certified Community Health Worker

André Marcel Harris, is a certified Community Health Worker and advocate who collaborates with the Sickle Cell Disease Association of America, Inc. (SCDAA). André works to enhance health equity for SCD patients, aspiring to lead a nonprofit supporting the cause. His research delves into healthcare barriers and combating stigma.





SPEAKER SPOTLIGHT

JODY JOHNSON

SC Advocate | Award-Winning Musician

Christian rapper Jody Johnson, aka DBC, diagnosed with Sickle Cell Anemia at age one, has released nine albums and written 200+ songs. Winner of the 2005 Gospel Rap Album of the Year, he aims to inspire and show that faith and determination can overcome challenges.



SPEAKER SPOTLIGHT

REBECCA MORGAN, LCSW

MSW Intern Supervisor | Cayenne Wellness Center

Rebecca Morgan, LCSW, brings 6+ years of therapy experience, specializing in LGBTQIA+ and trans/non-binary support, anxiety, depression, trauma, and life transitions. Trained in DBT, EMDR, IFS, and somatic therapies, she empowers clients to overcome challenges and achieve a more fulfilled life through empathetic guidance, validation, and humor.

SPEAKER SPOTLIGHT

VIVIAN SMITH

SC Advocate | Early Childhood Care & Education Professional

Vivian Smith is a mother, wife, and owner of her own family daycare for the last 36 years. Before the pandemic she was active in her church, as part of the Women's department, hosting the annual Mother/Daughter tea, and giving out backpacks after Vacation Bible School.



PSYCHOSOCIAL PART II (GROUP SESSIONS):

ARE WE WHERE THEY WANTED US TO BE? THE STATE OF SICKLE CELL CARE

FRIDAY, FROM 3:30 PM

SESSION HIGHLIGHTS

– Moderators: Wanda Williams, Felicia Hunt, Dorian Archie, Dalia Thomas, Ninah Walters, Eugene Williams

Baby Boomers Session (60 and older)

Generation X Session (43 - 59)

Millennials Session (27 - 42)

Generation Z (18 - 26)

Generation Alpha (11 - 17)

Caregiver (includes Parent/Children/Spouses/ Partner/Siblings Session)

SPEAKER SPOTLIGHT

KAREN SHEA

SC Advocate | Board Member, Cayenne Wellness Center & Children's Foundation

Karen Shea is an energy industry veteran skilled in regulatory, legislative, and business facets. She managed projects for top energy utilities, leading cross-functional teams, interconnection agreements, and regulatory strategies. Former CPUC Advisor, now with CPUC's Safety and Enforcement Division, she brings a wealth of experience to her role.



MODERATOR SPOTLIGHT

WANDA WILLIAMS

Sickle Cell Warrior | Retired Educator

I have been successfully living with sickle cell (SC) for the past 73 years. My advocacy started as I became one of the founders of the Sickle Cell Community Advisory Council. A career in education gave me the opportunity to teach at an Alternative High School, and work as a Supervisor of Child Welfare & Attendance. I've been married for 35 years, the mother of 5 children, grandmother of 17 and a great grandmother of 3.



SPEAKER SPOTLIGHT

ARTANGELA HENRY, PHD

SC Advocate | Nurse Practitioner and Healthcare Consultant

Artangela Henry, PhD, is a nurse practitioner, disease state advocate and healthcare consultant strategist. She has clinical experience in internal medicine, acute care services and underserved outpatient population centers. Her focus is preventative care, management, and research of sickle cell disease in the adult population.



MODERATOR SPOTLIGHT

DORIAN ARCHIE

Community & Political Organizer | Cayenne Wellness Center & Children's Foundation

Dorian Archie is a community and political organizer, advocate and motivational speaker, who currently serves as Associate Program Manager for the Cayenne Wellness "March on Hospital" Campaign. He is a graduate of Howard University's John H Johnson School of Communication and has worked in a variety of capacities since graduating.





MODERATOR SPOTLIGHT

DALIA THOMAS

Sickle Cell Warrior | Art Enthusiast

Hello. My name is Dalia Kenlow-Thomas, I'm the second of four children, aka the fly over state child, and I was born with Sickle Cell Anemia SS. I have many dreams and ambitions and I hope to accomplish every single one. Although the arts, particularly dance, are my first love and true passion I plan on returning to school and completing a degree in psychology.

MODERATOR SPOTLIGHT

NINAH WALTERS

Sickle Cell Warrior | Fashion Enthusiast and Junior Pianist

Ninah Walters is a 13-year-old sickle cell warrior and the daughter of Dr. Rayna Walters. As a California native, Ninah enjoys designing clothes, playing the piano, crocheting and traveling. After playing the piano for over seven years, she is the junior pianist at her church and has written and performed her own original compositions.



SPEAKER SPOTLIGHT

SHONA STEPHENS, MPH

Board Chair | Cayenne Wellness Center & Children's Foundation

With 27 years in bankruptcy and mortgage litigation, Ms. Stephens has represented both small businesses and major corporations. Holding a B.A. in Psychology from USC, she pursued her legal passion, earning a B.S. in Paralegal Studies with a focus on Litigation and Criminal Law from UWLA Law School.



PAT CORLEY KEYNOTE: SHOUT OUT TO; CALL OUT TO; WHAT IS YOUR VALUE? WHAT DO YOU BRING?

SATURDAY, FROM 9:45 AM

SESSION HIGHLIGHTS

– Speaker: Stephanie Ibemere, PhD, RN
An engaging discussion about the value that each of us brings to the table (education, advocacy, and awareness) in the SCD movement.

PATIENT TRACK

MODERATOR: ELLE COLE

GLOBAL PATIENT PANEL

SATURDAY, FROM 11:00 AM

SESSION HIGHLIGHTS

- Moderators: Cassandra Trimmell and Biba Tinga
- Panelist - Eunice Owino (Kenya)
- Panelist - Nilda Navedo (USA)
- Panelist - Veronica Hornos (Argentina)
- Panelist - Kiwanuka Derrick (Uganda)
- Panelist - KW Young (Trinidad and Tobago)

MODERATOR SPOTLIGHT

CASSANDRA TRIMNELL

Patient Advocate & Executive Director | Sickle Cell 101

Cassandra Trimmell is an advocate for individuals living with SCD, renowned for her role as the executive director of Sickle Cell 101. As the first child diagnosed with SCD through the Iowa Newborn Screening Program, Trimmell has dedicated her life to addressing the needs of the global SCD community.



MODERATOR SPOTLIGHT

BIBA TINGA

President/Executive Director | Sickle Cell Disease Association of Canada

Biba Tinga serves as the President & CEO of the Sickle Cell Association of Ontario, established in 1981. Holding a key C-Level executive position, she plays an instrumental role in the organization's direction and impact. Biba is currently based in Toronto, Canada.



SELF CARE ACTIVITIES: RELEASING STRESS TO GET YOURSELF GROUNDED

SATURDAY, FROM 2:15 PM

SESSION HIGHLIGHTS

Gardening – In-Person: Carol Barnes Reid, and Virtual: Lori Vick, PhD, MAT, RN

Art – In-Person: Gina Thompkins, and Virtual: Mia Robinson

Vision Board – In-Person: Adrienne Shapiro and Casey Gibson, and Virtual: Vernita Bradford and Betty Wheeler

Sound Healing – In-Person: Somer Waters, and Virtual: Dr. Carolyn Rowley's Video

Cooking – In-Person: Melissa Corral, and Virtual: Misty Williams



SPEAKER SPOTLIGHT



MIA ROBINSON

SC Advocate & Caregiver

Mia Robinson, an Atlanta native with Sickle Cell SC, transitioned from camper to founder of Sickle Cell Awareness 365. Overcoming challenges, she earned a bachelor's in sociology from Georgia State University in 2021. Mia is also a dedicated caregiver to her mother and college-bound niece.

SPEAKER SPOTLIGHT

CAROL BARNES REID

Manager of Nutritional Services | Loma Linda University Medical Center

Carol has been a dietitian for over 30 years, and has worked in academia, clinical nutrition, and foodservice management. She currently serves as Director of Nutritional Services for Loma Linda University Hospital. Carol's hobbies are gardening and hiking, and her passion is teaching about health.



SPEAKER SPOTLIGHT

CASEY GIBSON

Executive Director | Cayenne Wellness Center & Children's Foundation

Casey Gibson, daughter of fervent Sickle Cell Disease advocate Adrienne Shapiro, carries the Sickle Cell trait. Committed to raising awareness, Casey works alongside her mother to emphasize the importance of education and understanding surrounding the sickle cell trait, championing informed and proactive health management.



SPEAKER SPOTLIGHT



LORI VICK, PHD, MAT, RN

Nursing Professor & Researcher | University of South Carolina

Lori Lynn Vick, PhD, a nursing professor at UofSC, specializes in improving health outcomes for Sickle Cell Disease patients. Her recent research applied motivational interviewing to promote medication adherence. A board member of IASCNAPA, she's also vice president of MSCBNA and chairs UofSC College of Nursing's DEI committee.



SPEAKER SPOTLIGHT



VERNITA BRADFORD, MSW

Social Worker | Kaiser Permanente

Vernita Bradford is a social worker at Kaiser Permanente. She is also the co-founder of Healthy Road Lifestyle wherein she promotes health and wellness on a virtual platform. She enjoys helping people to identify and reach their goals, hosting vision board events and walking. She resides in San Bernardino, California.



SPEAKER SPOTLIGHT

GINA THOMPKINS

Owner & Artist | GinaSmiles Paint & Sip

Gina has been synonymous with smiles for over 20 years. Whether it's helping you navigate a Home Purchase or creatively curating one of her famous "Smile & Sip" events. Gina Thompkins has been a servant to her community for over 20+ years. "I am a native San Diegan who loves Real Estate and Painting. There is something about putting a paint brush in your hand that feels empowering."



SPEAKER SPOTLIGHT



BETTY WHEELER, LCSW, MSW

Licensed Clinical Social Worker | Volunteer Work: Healthy Road Lifestyle

Betty Peoples Wheeler has a Master's Degree in Social Work from the University of Michigan. She is a Licensed Clinical Social Worker (LCSW). She enjoys facilitating yearly vision board gatherings to help others focus on their dreams and goals as this tool has helped her in accomplishing various goals.





SPEAKER SPOTLIGHT

MELISSA CORRAL, DN

Degreed Nutritionist & Dietitian | Nutrition Savvy, LLC

Melissa earned her Bachelor of Science in Nutrition & Dietetics, minoring in Plant- Based Food & Nutrition in December 2022 from California State Polytechnic University, Pomona. She is a prospective master’s student for 2023 and has completed 6 of 8 years of nutrition education.

SPEAKER SPOTLIGHT

SOMER WATERS

Sound Healer | Somer Waters Energy Works

Somer Waters has been practicing as a sound healer for 23 years as a cellist and breathwork facilitator for the last four years. Somer brings his group facilitation training and contracting background to help create the “safe vessel” of the healing space for clients. An active facilitator Somer is also behind the scenes and on the front end in client relations.



SPEAKER SPOTLIGHT

THEOPIA JACKSON, PHD

Chair, Department of Humanistic Clinical Psychology | Saybrook University

Dr. Theopia Jackson, a licensed clinical psychologist, chaired the Clinical Psychology program at Saybrook University and served at UCSF Benioff Children’s Hospital. Past president of The Association of Black Psychologists, she co-founded Oakland’s Therapist-in-Residency Program and champions culturally-affirming healthcare and training.



SPEAKER SPOTLIGHT

SHYRA ARRINGTON

SC Advocate | Entrepreneur and Board Member of the National Congress of Black Women

Shyra Arrington, Graduate of California Baptist University has a Degree in Public Administration and serves as a leader in the Sickle Cell Community and many other arenas. Service is an integral focus of her life. As a Board Member of the National Congress of Black Women (NCBW) and the Chaplain for the NCBW-Los Angeles Chapter, Shyra is instrumental in facilitating scholarships and community resources throughout Southern California.



SPEAKER SPOTLIGHT



MISTY WILLIAMS

Chef-Owner | Inevitable Creations Catering

Misty Williams, chef-owner of Inevitable Creations Catering, is a lifelong advocate for SCD. Starting as a child spokesperson, she progressed to organizing events, and founded her SCD organization in 2011. Despite focusing on her career, Misty responded to the 2020 pandemic by aiding patients and continues her advocacy journey.



SPEAKER SPOTLIGHT

FARRON DOZIER

SFC, Retired | US Army

Farron Dozier served for 24 years as Sergeant First Class (SFC) in the US Army. He is now retired. After his service, he founded WHATZ DA COUNT, a Nonprofit Organization that educates the public on Sickle Cell Trait Prevention. He is the co-host of The Revolution Radio Show on God’s House of HipHop Powered by DASH Radio, which airs on Sunday at 5 pm PT. He also proudly hosts the Farron Dozier Show on KCAA Radio 102.3 FM / 106.5 FM / 1050 AM.



MY JOURNEY, MY LEGACY

SATURDAY, FROM 3:30 PM

SESSION HIGHLIGHTS

– Moderator: Theopia Jackson, PhD

Breakout Rooms

Moderators: Shyra Arrington, Felicia Hunt, Farron Dozier, Jody Johnson

PHYSICIAN TRACK

MODERATOR: KIM SMITH-WHITLEY, MD

PATIENT EXPERIENCES: FOCUS ON MANAGEMENT AND TREATMENT SATURDAY, FROM 11:00 AM

SESSION HIGHLIGHTS

- Patient Experiences (focus on management and treatment)
- SC101
- Implicit Bias Training
- Patient Experiences (specific to ED)
- Emergency Room
- Stroke and Intracranial Bleeds

SPEAKER SPOTLIGHT



SHAKTI BUTLER, PHD

Transformative Educator | World Trust

Shakti Butler is a transformative and collaborative educator. For three decades, she has been developing curricula, keynotes, and learning labs geared towards elevating communication, collaboration building racial equity through structural change. Her focus is creating transformative learning processes that embrace the principles and practices of racial equity through a social justice frame.

SPEAKER SPOTLIGHT



JEFFREY GLASSBERG, MD

Director | Icahn School of Medicine at Mount Sinai

Dr. Jeffrey Glassberg is currently an Assistant Professor of Emergency Medicine, Hematology and Medical Oncology at Mount Sinai School of Medicine. He obtained his MD and a Masters' degree in clinical research at Washington University in St. Louis School of Medicine in 2006. Dr. Glassberg completed his emergency medicine residency at NYU/Bellevue in 2010, followed by a research fellowship at Mount Sinai in July of 2012.

SPEAKER SPOTLIGHT



IFEYINWA (IFY) OSUNKWO, MD, MPH

Professor of Medicine & Pediatrics / Director of SCD Enterprise | Atrium Health

Ifeyinwa (Ify) Osunkwo, MD, MPH, is a Professor of Medicine and Pediatrics at Atrium Health, and the Director of the Sickle Cell Disease Enterprise at Levine Cancer Institute (LCI) /Atrium Health. With over 28 years of experience in sickle cell disease (SCD) and hematology, she has made significant contributions in improving access to care for underrepresented patients.

SPEAKER SPOTLIGHT



CHRISTINE FOX, MD

Associate Professor of Neurology and Pediatrics | UCSF

Christine Fox is Associate Professor of Neurology and Pediatrics. She directs the Pediatric Stroke and Cerebrovascular Disease Center at the University of California San Francisco (UCSF), caring for children with ischemic or hemorrhagic stroke. Her research is supported by the National Institutes of Health and the American Heart Association.

SPEAKER SPOTLIGHT

AMIKAEYLA GASTON

Public Speaker and co-Executive Director | World Trust

Amikaeyla Gaston is a force for change. Proclaimed the "purest contemporary voices" by NPR, Amikaeyla is a public speaker, performer, and educator. She travels the world serving as a US Cultural Arts Ambassador, the Founder of the International Cultural Arts and Healing Sciences Institute, and co-Executive Director for World Trust.



NOTABLE PROFILES



ANDREW CAMPBELL, MD

Dr. Andrew Campbell, MD, an esteemed expert, trained at Morehouse College and Case Western Reserve University. He led the Sickle Cell Center at the University of Michigan, focusing on SCD research. Now at Children's National, he brings vast expertise to his work, focusing on pulmonary complications, fetal hemoglobin, and more.



AYANA LEE JOHNSON

Ayana Lee Johnson, the 2021-2023 SCDA National Teen Ambassador, advocates passionately for fellow SCD warriors, raising awareness about the condition. She appears at public events, fosters education campaigns, and secures support for SCDA. An honors student, accomplished dancer, violinist, and pageant contestant, Ayana defies SCD limitations. She lives in Virginia.



AYOOLA OLUBUKOLA

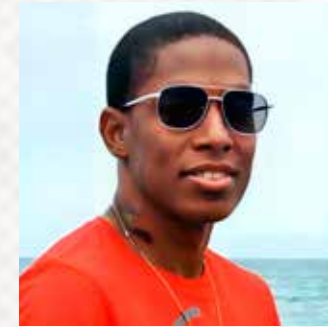
Ayoola Olubukola is a multimedia expressionist, published poet, self-titled griot, Sickle Cell community advocate, and the owner of Healing Through Artistic Mediums LLC. As a prolific creative who centers Vulnerability and catharsis within differing creative mediums, her work dissects elements of intergenerational trauma, cultural identities, and medical experiences through narrative performances.



CALVANAY NUNLEY

Calvanay Nunley from Richmond, California, is a Sickle Cell Warrior and Director of Camp Super Star for children with sickle cell. A Certified Nursing Assistant and founder of "The Pull Up" initiative, she advocates for improved healthcare. Overcoming significant health obstacles, she's now pursuing a career in social work and nursing.

NOTABLE PROFILES



MASTER BURT

From Chicago Heights, artist Master Burt refined his skills at Prairie State College. His detailed portraits, influenced by living with Sickle Cell Type SS, explore Black culture and social justice. Actively engaging the Chicagoland sickle cell community, he paints live on social media, sparking societal art discussions.



MATT JEMELE

The Jammin' Jellies is a multi-stylistic band, playing primarily funk and r&b, but also sprinkling in influences of jazz, fusion, rock, and others. While the size of the band varies from show to show, you can always count on them to bring an energetic show that will have you dancing or tapping your foot by the end.



DR. RAYNA WALTERS

Dr. Rayna Walters is the founder of Ami Enterprises and R.D. Walters, Inc. She is a speaker, coach, and educator who focuses on connection through mind, body, and spiritual wholeness. As a parent of a young Sickle Cell warrior, she understands firsthand the overwhelming nature of caregiving and how it affects every aspect of one's existence.



STEPHANNIE STARR

Stephannie Starr, a 58-year-old Sickle Cell Warrior, was once predicted not to live past 20. Mother and grandmother, she's faced constant health challenges. Employed by Follett Higher Education since 2015, she's now a certified SCD Medical Advocate, promoting transformative treatments and championing holistic pain management.



CORETTA JENERETTE, PHD, RN

Dr. Jenerette holds a Ph.D. and MSN from the University of South Carolina, along with a BSN from Clemson University. A certified nurse educator, she pursued post-doctoral fellowships at Yale University and The University of North Carolina at Chapel Hill. She also earned a DEI certificate from Cornell University.



ERYN YOUNG, MPH

Eryn Young founded "Just Muv" in 2011, a program that contributed to charter programs, publications and earned a business award from the L.A Lakers and California assembly. Eryn advocates for Coalition for Black Health & Wellness, My Hair My Health Conference, and runs the "Walk It Out" local walking group.



JARED SNOW

Jared Snow, an LA comedian and Sickle Cell Warrior from Compton, combines real-life humor with his YouTube channel, JSnowPro. He wrote for the 2022 BET Hip Hop Awards, HBO's Game Theory, produced for MTV, and starred in his short film "Flawd." He's also opened for Ron White and Marlon Wayans.



LATHAN SINGLETON

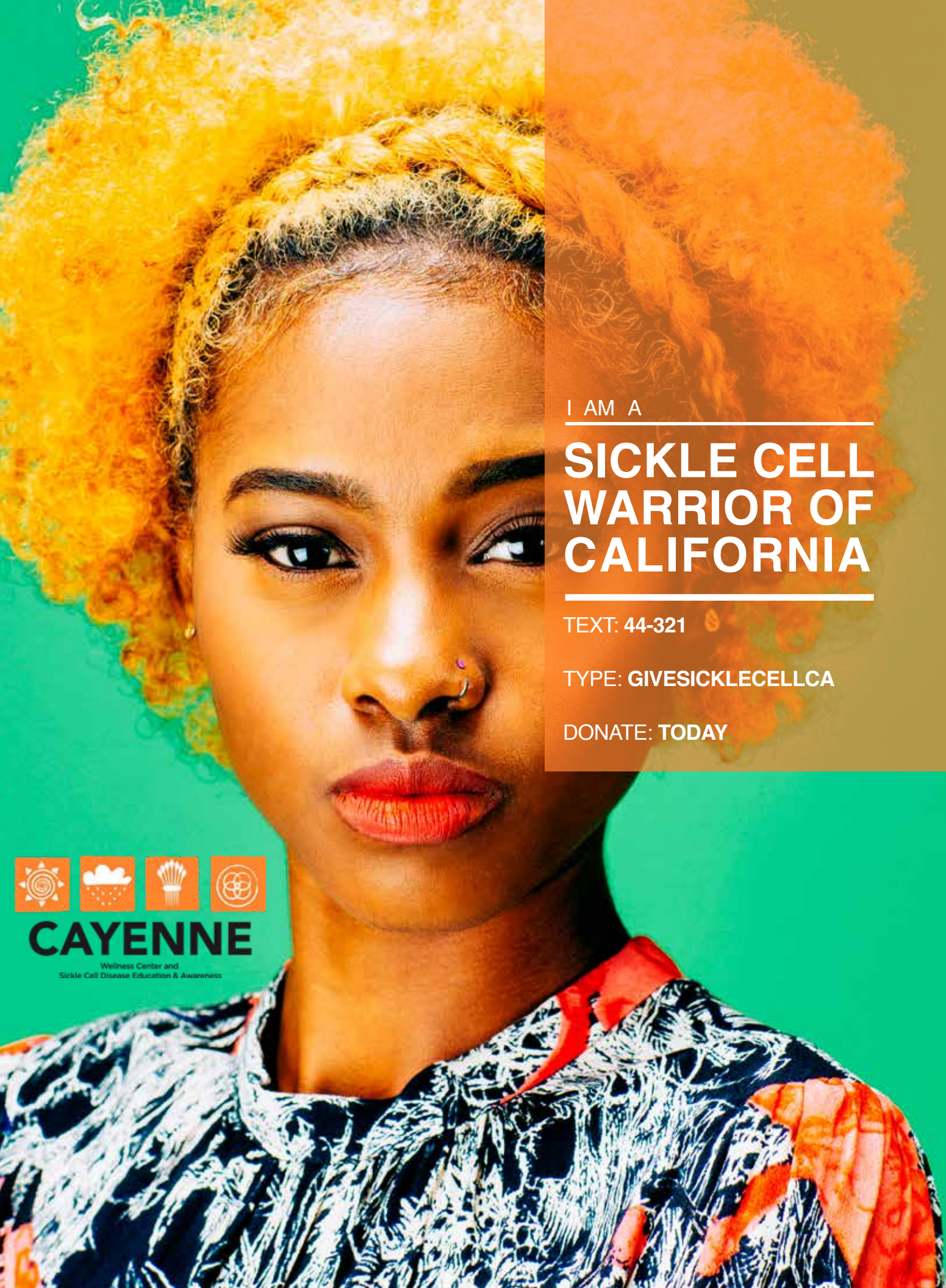
Lathan Singleton is a CHW and Sickle Cell Warrior. For the last 16 years, he has dedicated his life to educating others on Sickle Cell and advocating for those who may be unable to alone. He's a blood drive coordinator, patient advocate and founder of The Unspoken Hero Society.

INDUSTRY PROFILES

COMPANY	SPEAKER	BIO
Medunik - Siklos	Amanda Haikalis	Amanda Haikalis is a pharmacist with previous experience in retail pharmacies. In 2015, she transitioned to the pharmaceutical industry within Medical Information and in team/project management. After completing her MBA, Amanda worked within Medical Affairs as an MSL, and most recently as a Medical Advisor for Medunik USA since 2022.
Emmaus Life Sciences - Endari	Corey Hebert	Dr. Corey Hebert is an Assistant Professor at both LSU Health Sciences Center and Tulane University Medical Center in New Orleans, Louisiana. He has been the Principal Investigator on over 60 phase 1, 2 and 3 FDA-regulated clinical trials on various nutritional and pharmacotherapeutic agents. He is an award-winning medical broadcast journalist, working as on-air Chief Medical Editor for the NBC television affiliate in New Orleans.
Pfizer - Oxbryta	Bridgette Pierre	Bridgette Pierre is a board-certified nurse practitioner who earned her nursing degree and Master of Science in nursing from Southern University and A&M College in Baton Rouge, LA. She has been in healthcare since 2008 and has experience ranging from labor and deliver, home health, emergency room care and her deepest passion, serving individuals living with Sickle Cell Disease.
Terumo - RBC	Elizabeth Valdez	Dr. Melissa Anderson, MD, PharmD, serves as a Senior Medical Science Liaison in the North American Medical Affairs Department for Terumo Blood and Cell Technologies. Dr. Anderson has a diverse professional background including clinical pharmacy, academic anesthesiology, public policy, and biotechnology. She resides currently in Lexington, Kentucky.
Agios Pharmaceuticals	Amber Yates, MD	Dr. Amber Yates graduated from LSU School of Medicine in Shreveport in 2003. She then trained in pediatrics at LeBonheur Children's Hospital followed by pediatric hematology-oncology at St. Jude Children's Research Hospital both in Memphis, TN. She practiced as a pediatric hematologist focused on the care of children with sickle cell disease for a decade. She is now medical director of the SCD clinical program at Agios Pharmaceuticals in Global Medical Affairs.
Agios Pharmaceuticals	Holly John	Holly John, Senior Director of Patient Advocacy at Agios Pharmaceuticals, excels in patient advocacy, education, and engagement. Her expertise includes rare diseases, strategic planning, clinical trial awareness, and fostering cross-functional relationships. With a focus on team leadership and key opinion leader relationships, Holly drives impactful organizational strategies.

INDUSTRY PROFILES

COMPANY	SPEAKER	BIO
Fulcrum Therapeutics	Mel Hayes	Mel joined Fulcrum in September 2021 as Chief Commercial Officer and was subsequently appointed to the role of Chief Operating Officer in June 2022. Mel has responsibility for corporate strategy and operations, in addition to commercial. Mel brings more than 25 years of experience in asset development and management of commercialization strategies in a range of therapeutic areas including many rare, specialty and primary care diseases.
bluebird bio	Jen Leiding	Medical Director at Bluebird Bio within the Severe Genetic Diseases Section. Bluebird Bio is a well-known biotech company which develops gene therapy for hematologic conditions including sickle cell anemia, primary immunodeficiency diseases, and metabolic disorders. I will continue to reside with my family in St. Petersburg.
Vertex	Marjorie DeJoie Brewer, MD	Dr. Marjorie Dejoie-Brewer owns MAD Fit, a wellness consultancy, and was a Medical Consultant for the National SCD Association. With experience at Pfizer and Children's Hospital of Philadelphia, she's a Sickle Cell patient promoting holistic health. She collaborates with organizations like American Red Cross and Global Genes, emphasizing patient-centered healthcare.
Beam Therapeutics	Stephen Huang	Stephen Huang is a Vice President of Clinical Development at Beam Therapeutics. He is the medical lead for Beam's hematology program and its Beacon trial for patients with sickle cell disease. Dr. Huang is a pediatric endocrinologist and worked at Boston Childrens Hospital prior to his work in biotechnology.
editas Medicine	Felice Tsui	Felice Tsui, Associate Director of Patient Advocacy and Medical Affairs at Editas Medicine, is a devoted advocacy professional with a background in healthcare consulting, industry, and academia. Passionate about patient-centered drug development, she blends research with community engagement to shape impactful insights in population health, and in life sciences decision-making.



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