



15TH ANNUAL SCD EDUCATIONAL SUMMIT 2023

WELCOME



CAYENNE

Wellness Center and Sickle Cell Disease Education & Awareness



Cayenne Wellness Center's Sickle Cell Pledge

It starts with you. It is unacceptable for the medical community to tolerate this racist mistreatment of patients living with SCD in our emergency departments and hospitals. Our hospitals and clinics must be safe spaces for patients with SCD.

It starts with you. All healthcare providers must be open-minded and self-aware as they care for patients with SCD, recognizing their own implicit biases and making a conscious effort to treat patients equitably, regardless of race.

It starts with you. United action against racism's impact on the health of patients with SCD is long overdue.

It starts with you. Change begins with a conversation, but words are not sufficient; we must take action to make enduring improvements in the care of patients with SCD.

It begins NOW. Let's take the pledge.

Persons diagnosed with SCD are born into pain.

Persons diagnosed with SCD are human beings. They are someone's wife, husband, daughter, son, mother, father.

I will stop calling and referring to patients as 'sicklers' and 'frequent flyers', and correct others when they do it. (When I See something, I will Say something).

I now know that the majority of patients diagnosed with SCD are NOT drug addicts nor are they feigning their pain. Only 1% of the population may have issues with addiction.

Persons diagnosed with SCD know what works for them to manage their pain. Knowing this does not make them suspect for addiction.

When a patient states that the pain they are experiencing is different, I will assist in making the physician aware to run more tests and keep them for observation. This action can save their life. (DDX for acute chest syndrome, blood clot).

I will assist in getting persons with SCD assessed and triaged rapidly, assigned high priority for evaluation AND receive their first analgesic within 60 minutes of arrival to the ED.

I pledge to be a nurse, physician, and caregiver advocate for persons diagnosed with SCD.

Sickle Cell Lives Matter and it begins with ME.

NAME: _____

DATE: _____

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**
- 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**
- 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**
- 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
- 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
- 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 SCTrait and SCD Letter. **Speakers: Elle Cole (SCTrait 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	Stephanie Mulkey Keynote Speaker Session - Location: Salon D Are We Where They Want Us To Be? (Management and Treatment of SCD) Moderators: Kim Smith-Whitley, MD, and J. Hoxi Jones <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 Frempong10:15 am - Break10:30 am - Historical Perspectives: A Journey of Triumphs Speaker: Clarice Reid, MD11:00 am - Nurses: The Essential and Ever-changing Role of Nurses in the Sickle Cell Community Speaker: Yvonne Carroll, JD, RN11:30 am - Break11:45 am - Patient Experiences Speaker: Adrienne Shapiro
12:30 pm	Lunch
12:30 pm	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
1:30 pm	Wellness Break - Marjorie DeJoie Brewer, MD - Location: Salon D Hydration, Breathing, and Mental Health
2:00 pm	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 <ul style="list-style-type: none">2:00 pm - Social work in the sickle cell movement Honoring Ruth White, June Vavasour, MPH, and Kermit Nash, PhD, and others that promoted sickle cell disease. Speaker: Trudy Tchume-Johnson, LCSW2:22 pm - A SC Warrior speaks Speakers: Sheila Marchbanks, MBA, and Jody Johnson2:35 pm - A Caregiver speaks Speakers: Vivian Smith and Karen Shea2:45 pm - What can a social worker offer me and my family? Speaker: Artangela Henry, PhD2:52 pm - How can having a relationship with a social worker help your build resilience? Speaker: Rebecca Morgan, LCSW3:00 pm - Summary Speaker: André Harris
3:15 pm	Break
3:30 pm	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 <ul style="list-style-type: none">Baby Boomers Session (60 and older) Moderator: Wanda Williams - Location Pier 1Generation X Session (43 - 59) Moderator: Felicia Hunt, PsyD - Location Pier 2Millennials Session (27 - 42) Moderator: Dorian Archie - Location Pier 4Generation Z (18 - 26) Moderator: Dalia Thomas - Location Pier 7Generation Alpha (11 - 17) Moderator: Ninah Walters - Location: Pier 6Caregiver (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 **Welcome and Cayenne Wellness Center Board Updates - Location: Salon D**
Speaker: Shona Stephens, Cayenne Wellness Center's Board Chair
- 8:30 am **Awards - Location: Salon D**
- 9:45 am **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

Patient Track - Location - Salon D Moderator: Elle Cole

- 11:00 am **Global Patient Panel**
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)
- 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 **Self Care Activities**
 - **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 **My Journey, My Legacy - Location: Salon D**
Moderators: Theopia Jackson, PhD
- 3:45 pm **Breakout Rooms**
Moderators: Shyra Arrington, Felicia Hunt, PsyD, Farron Dozier, and Jody Johnson
- 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 **SC101**
Speaker: Ifeyinwa Osunkwo, MD, MPH
- 12:30 pm **Lunch**
- 1:00 pm **Implicit Bias Training**
Speaker: Amikaeyla Gaston and Shakti Butler, PhD of World-Trust
- 3:30 pm **Break**
- 3:45 pm **Patient Experiences (specific to ED)**
- 4:00 pm **Emergency Room**
Speaker: Jeffrey Glassberg, MD
- 5:00 pm **Stroke and Intracranial Bleeds**
Speaker: Christine Fox, MD
- 6:30 pm **Adjourned**

Welcome to the 15th Annual SCD Educational Summit September 13 - 16, 2023

“GIANTS, PIONEERS, AND VISIONARIES: PAST, PRESENT & FUTURE. ARE WE WHERE THEY WANTED US TO BE?”

If you have this packet in hand, it means you've arrived at our event location and hotel. And whether it's at the check-in desk at the Torrance Marriott Redondo Beach or the check-in table at the Summit - we want to make sure you have the materials and information necessary for an amazing weekend.

The Summit @ The Torrance Marriott Redondo Beach

We're proud to be at the Torrance Marriott Redondo Beach. All of our events will take place here (with the exception of the Day 4 activity Nutrition/Cooking session which will be held offsite). If you signed up for this activity, the organizers will share the address on the day of the activity.

Torrance Marriott Redondo Beach
3635 Fashion Way | Torrance CA 90503 | +1-310-316-3636

Our Hotel @ The Torrance Marriott Redondo Beach

Enjoy easy access to Redondo Beach Pier (2 miles away). This scenic South Bay landmark offers spectacular oceanfront dining, seasonal whale watching and kayaking, unique shops, and picturesque views. Please make sure you check into your hotel room as soon as you arrive and get your belongings safely situated.

DAY 1 – Wednesday Night, September 13, 2023

6:30 PM – Industry Sponsored Dinner by Emmaus Life Sciences

Emmaus Life Sciences welcomes attendees to the Summit with a presentation from Dr. Yutaka Niihara.

DAY 2 – Thursday, September 13, 2023

7:30 AM – Stretching

Join Eryn Young who will be providing a 40-minute stretching session to get you up and your morning started. Our volunteers will show you the room. No sign-ups are necessary. Bring your mat or a towel and get your stretch on.

5:30 PM – Candlelight Ceremony

Our Candlelight Ceremony is where we honor our loved ones diagnosed with Sickle Cell Disease that have passed. The Ceremony begins at 5:30 pm with a slide presentation followed by the lighting of the candles.

7:30 PM – Game Night in honor of Aaron Phoenix begins

Whether you are looking to connect with the community or simply have fun, we invite you to participate in games and puzzle-solving activities while enjoying delicious appetizers. The event promises an evening filled with laughter and camaraderie. Don't miss out on this fantastic opportunity to come together and enjoy some friendly competition!

DAY 3 – Friday, September 15, 2023

7:30 AM – Yoga

Ready to let go of some stress and get yourself grounded? Join us Friday morning with Dr. Marjorie Dejoie Brewer who will be leading a class of gentle yoga.

6:45 PM – Celebration Gala featuring Matt Jamele and the Jammin' Jellies

In honor of our Sickle Cell Warriors residing in California, Cayenne Wellness Center is presenting a Benefit Concert to raise funds for their Client Assistance Program or CAP. The 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. The festivities begin at 6:45 PM with our Emcee Dexter Darden. Dinner begins at 7:00 PM and the concert begins at 8:00 PM. Join us and rock out to the funky sounds of Matt Jamele and the Jammin' Jellies.

DAY 4 – Saturday, September 16, 2023

7:30 AM – Exercise

Regular exercise and movement can improve blood circulation, decrease pain crises, enhance lung function, boost overall energy levels, and promote a healthier lifestyle.

DAY 5 – Sunday, September 17, 2023

Fun Day in South Bay

For those of you staying an extra day or two, we invite you to relax and lounge. We recommend the following sites that might satisfy your adventurous spirit:

- ▶ Redondo Beach Pier (2 miles away)
- ▶ Palos Verdes Peninsula (4 miles away)
- ▶ King Harbor Marina (3 miles away)
- ▶ Torrance Beach (4 miles away)
- ▶ Alpine Village (4 miles away)
- ▶ Lomita Railroad Museum (4 miles away)
- ▶ South Coast Botanic Garden (5 miles away)
- ▶ Aquarium of the Pacific (16 miles away)
- ▶ The Queen Mary (16 miles away)
- ▶ The J. Paul Getty Museum (20 miles away)
- ▶ Knott's Berry Farm (25 miles away)
- ▶ Disneyland® (29 miles away)
- ▶ Universal Studios Hollywood (29 miles away)

Special Notes & Reminders

- ▶ This is a professional event so dress in business casual to look your finest! Things that are good to wear include slacks, blouses/button-down shirts, jackets, dresses, and medium-long skirts. Please no shorts, flip-flops, slides, t-shirts, no basketball shorts, or sweats.
- ▶ Bring your business cards. This is a chance to network and meet with people who are just as passionate about comprehensive care for individuals with Sickle Cell Disease as you are.
- ▶ **COVID-19 – Cayenne Wellness Center and Axis Advocacy want you to stay safe. The U.S. national emergency to respond to the COVID-19 pandemic ended Monday, May 11, 2023. However, for the safety and enjoyment of others, we will be offering masks and there will be hand sanitizers available on all tables.**

- ▶ **Caution:** Although it is legal to smoke marijuana in California, private businesses such as our hotel still have no-smoking policies in place. This means that you **SHOULD NOT** be smoking in your hotel room or on the premises. We appreciate your understanding and your willingness to do this off-site.

In Case of Emergency

Please keep the following information for your own safety and procedures - but also be sure to tell someone if you are not feeling well.



Sickle Cell Warriors: If you haven't done so already make sure you fill out our Emergency Medical form. You can do it from your phone: scan this QR code or type this address into your browser: <https://goo.gl/forms/tjdAmRPS47N1rLiq2>



Hospitals

Little Company of Mary
514 N Prospect Ave.
Redondo Beach, CA 90277
(310) 832 3311

Torrance Memorial Medical Center
3330 Lomita Blvd.
Torrance, CA 90505
(310) 325-9110

Harbor UCLA Medical Center
1000 W Carson Street
Torrance, CA 90502
(310) 222-6856



Pharmacies

CVS Pharmacy
5020 West 190th St
Torrance, CA 90503
(310) 370-5607

Walgreens
2976 Sepulveda Blvd.
Torrance, CA 90505
(310) 534-0078

Rite Aid
3860 Sepulveda Blvd
Torrance, CA 90505
(310) 373-5884

Contacts in Case of Emergency

Mary Alcocer, Program Manager @ Cayenne Wellness Center: (626) 275-8838
Pat Corley, RN, Nurse Educator @ Cayenne Wellness Center: (310) 480-9857
Adrienne Shapiro, Executive Director @ Axis Advocacy: (323) 506-2224
Sheila Marchbanks, MBA, Planning Committee Member: (909) 851-8194
Dr. Carolyn Rowley, Executive Director @ Cayenne Wellness Center: (818) 731-5408

Parking

While attending the Summit, parking shall be covered at NO COST for REGISTERED ATTENDEES.

At check-in, please inform the front desk personnel that you are staying at the Marriott. Your room key will be activated to allow unlimited access to the parking lot(s).

YOUR ACTIVATED ROOM KEY will function at the entry and exit devices in the parking lot stalls.

Prior to check-in, if given a parking lot ticket when you park your car, you may disregard the paper ticket for your ACTIVATED ROOM KEY shall function as your fully paid (compensated by the organizers) pass.

Compensated Parking shall be covered for registered guests of the Summit for a maximum of 4 nights from Wednesday night, September 13, 2023, through Saturday night, September 16, 2023 (with checkout on Sunday morning).

Please address any parking questions or comments that you have to the Marriott front desk personnel. Thank you.

BREATHE



HYDRATE

ENJOY





Testimonials



Session/Presentation Evaluation



Overall Evaluation



Donations



Landing Page



Program Booklet for the 15th Annual SCD Educational Summit

www.cayennewellness.org