

12th Annual Sickle Cell Disease Educational Summit

Event Schedule

Thu, Sep 17, 2020

8:00am

Movement: Exercise & Stretching

🕒 8:00am - 8:45am, Sep 17

Description: Mild to moderate exercise can lead to improvements in a person's muscle function and overall physical ability, and for some patients there are improvements in sleep, concentration and social interactions. When it comes to exercise, the best time of day to get in a workout session is one that you can do consistently. We invite the community to join us daily for a daily dose of exercise. Here are some benefits for those who chose to workout in the morning: fewer distractions, beat the heat, healthier food choices, increased alertness, more overall energy, better focus, better mood, support weight loss, helps regulate your appetite, increased overall activity, improve sleep, to name a few.

Join Eryn for a mild stretching exercise. Benefits of stretching include increased flexibility, range of motion, blood flow to your muscles, improves your posture, can calm your mind, and is great for stress relief.

🗣️ Speaker



Eryn Young, MPH CEO, Lead Trainer, Just Muv Consulting

9:05am

Welcome

🕒 9:05am - 9:10am, Sep 17

Cayenne Wellness Center's mission is "To increase the quality of life for individuals diagnosed with sickle cell disease in California by ensuring expert, unbiased, and comprehensive care." This mission is part of a broader vision of (1) a medical system which effectively addresses the unique needs of individuals with sickle cell disease and (2) patients who are empowered and equipped to advocate for themselves.

Dr. Rowley will give welcome everyone to Cayenne Wellness Center and Axis Advocacy's 12th Annual Sickle Cell Disease Educational Seminar: A Global Approach to Sickle Cell Disease.

🗣️ Speaker



Dr. Carolyn Rowley Founder and Executive Director, Cayenne Wellness Center

9:10am

Legislative Action Workshop

🕒 9:10am - 12:15pm, Sep 17

For over fifty years, grass root organizations have rallied together to bring forward legislation to improve Sickle Cell Disease treatment, research, monitoring, and prevention. Recognition of September as Sickle Cell Awareness Month, Newborn Screening, World Sickle Cell Day are just a few of the bills that have passed nationally and globally. Unique to California, our very own Dr. Keith Quirolo put together AB 1488. AB 1488 was the first piece of legislation in California to mandate the development of a Sickle Cell Disease Center which would not only provide care for patients, but also train medical providers across the state. Under the guidance and tireless work of Dr. Keith Quirolo, we were able to mobilize sickle cell patients from every corner of California and provided them with the tools necessary to notify legislators of their needs. AB 1488 was passed – thanks to the phenomenal effort of patients, but ultimately lacked the funding necessary to see the program come to fruition. AB 1488 would have meant long-term, meaningful change for patients across California, and we believe that it was simply one step along the way getting us closer to the changes and action patients deserve.

Panel:

9:25 am - update on AB1105 (Drs. Diane Nugent and Keith Quirolo)

The Networking California for Sickle Cell Care Initiative (NCSCC) was developed through advocacy and stakeholder engagement. On February 21, 2019, California Assembly member Mike Gipson (D – 64th District, South Los Angeles) introduced a bill AB-1105 into the California legislature. On June 27, 2019, Governor Newsom signed the Budget Act of 2019 (AB 74, Chapter 23) which approved Sickle Cell Disease funding. And on January 1, 2020, were granted \$14.4 million to expand access to SCD services over the next three years. Dr. Diane Nugent will update the community on progress made these past eight months.

9:45 am - update on ICER (Maggie Jalowsky and Ashley Valentine)

Last year Sick Cells, founded by Ashley Valentine and her brother Marqus Valentine, introduced the ICER Review to our community. ICER wanted to assess the comparative clinical effectiveness and value of treatments for sickle cell disease: Crizanlizumab (Novartis), Voxelotor (Global Blood Therapeutics), and Endari (Emmusa). Sick Cells will update the community on ICERs most recent findings.

10:05 am - adopting NHLBI + ASH guidelines for CA Hospitals (Keith Quirolo, MD)

In our second year, we will continue to mobilize our community to bring out a bill that would mandate medical centers to adopt the NHLBI and ASH guidelines for the management and treatment of Sickle Cell Disease.

10:25 am - Birthing Beautiful Communities: An African American Doula Collective (Christin Farmer Kane)

Birthing Beautiful Communities is a Cleveland-based African American doula collective that provides culturally sensitive education, advocacy and emotional support for women during pregnancy and up to a year after birth. BBC was established in 2014 with a mission to address and improve the systemic and community structures that lead to poor birth outcomes through culture, education, advocacy, support and engagement (CEASE). It holistically supports pregnant women to deliver full-term healthy babies, and in achieving equitable birth outcomes. Ms. Farmer's has been honored as a person and organization that have done bold, innovative work to lift up a neighborhood or a community. The women coming to BBC can also access legal assistance, education, art therapy and entrepreneurial opportunities. In the past five years, the organization has trained almost 30 "super doulas" who have worked with more than 600 women. Creating jobs and reducing infant deaths marries Farmer's two passions: community wealth-building and health equalities.

10:50 Question and Answer Period

11:10: Workshop (Breakout Groups)

11:50 am - Wrap-Up

Spokesperson from each group reports on steps to take to implement adopting NHBI and ASH guidelines, etc.

12:10 pm - Fill Out Evaluations

12:15 pm Lunch Break (return at 1:45 pm)

We suggest eating a nutritional meal, getting exercise, and taking a nap

 **Speaker**



Keith Quirolo, MD Retired Pediatrician, Sickle Cell Advocate, UCSF Benioff Children's Hospital Oakland
Department of Hematology

4 Subsessions

- **Workshop Breakout: AB1105**
⌚ 11:10am - 11:50am, Sep 17
- **Workshop Breakout: ICER**
⌚ 11:10am - 11:50am, Sep 17
- **Workshop Breakout: Adopting NHLBI + ASH Guidelines for CA Hospitals**
⌚ 11:10am - 11:50am, Sep 17
- **Workshop Breakout: Birthing Beautiful Communities: An African American Doula Collective**
⌚ 11:10am - 11:50am, Sep 17

12:15pm

Lunch Break (return at 1:45 pm)

⌚ 12:15pm - 1:45pm, Sep 17

We suggest eating a nutritional meal, getting exercise, and taking a nap

1:45pm

Afternoon Session I: Sickle Cell Trait Education and Awareness

⌚ 1:45pm - 3:35pm, Sep 17

The need to outreach and educate the public about Sickle Cell

Disease and Sickle Cell Trait statewide has always been one of our top priorities. This session is dedicated to Sickle cell trait (SCT) education.

Dozier. Farron Dozier has the Sickle Cell Trait and I experienced Trait Exertion. I now Advocate for Sickle Cell Trait, Thalassemia Trait and all red blood cell conditions and disorders

California Department of Public Health (CDPH). The CDPH will discuss the California Newborn Screening Program Hemoglobin Trait Follow-up Services and the expansion services throughout California.

Naik. Sickle Cell Trait (SCT) is unique among the carrier states that are identified during newborn screening. Unlike other heterozygous states for rare recessive diseases, SCT is exceedingly prevalent throughout regions of the world, making sickle cell disease one of the most common monogenetic diseases worldwide. Because of this high frequency, and unlike other carrier states, SCT seems to be a risk factor for several clinical complications, such as extreme exertional injury, chronic kidney disease, and venous thromboembolism. Education in SCT is deemed paramount.

Panel:

2:00 pm Farron Dozier (Whatz Da Count)

2:15 pm Tracey Bishop (CA Department of Public Health)
2:40 pm Rakhi Naik, MD MPH (Johns Hopkins Medicine - Associate Director for Hematology, Hematology/Oncology Fellowship Program Assistant Professor of Medicine)
3:10 pm Question and Answer Period
3:30 pm Fill out Evaluation

🔊 Speaker



Rakhi Naik, MD, MPH Johns Hopkins Medicine

3:35pm

Break

🕒 3:35pm - 3:45pm, Sep 17

3:45pm

Afternoon Session II: Clinical Trials for Sickle Cell Disease - Part I

🕒 3:45pm - 5:50pm, Sep 17

The potential for new ways to treat the disease have become a major focus of the medical revolution brought on by precision medicine and gene therapy. Recently, The New York Times and "60 Minutes" highlighted the burgeoning number of clinical trials of potential gene therapies for sickle cell disease. In this session, several companies will speak on progress made in the race to cure sickle cell disease.

Crispr Therapeutics. Their gene-editing approach aims to treat β -thalassemia and sickle cell disease by increasing fetal hemoglobin.

bluebird bio. bluebird bio is conducting clinical studies of investigational gene therapies in sickle cell disease and transfusion-dependent β -thalassemia. bluebird bio has three techniques being studied for gene therapy: Gene editing; Gene addition; and Gene-based immunotherapy.

CSL Behring. CSL Behring is investigating the use of gene therapy to create new treatments for people with sickle cell disease. CSL200 for the Treatment of Sickle Cell Disease (SCD) CSL200 aims to provide sufficient functional globin gene to prevent sickling. Pipeline therapies include: CSL200 (lentiviral stem cell gene therapy) and CSL889 (Hemopexin).

4:00 pm CRISPR/Vertex - Sandeep Soni, MD

4:20 pm bluebird bio - Anjulika Chawla, MD

4:40 pm CSL Behring - TBD

5:00 pm Sanofi - TBD

5:20 pm Question and Answer Period

5:45 pm Fill out Evaluation

5:50pm

Dinner Break (return at 6:15 pm)

🕒 5:50pm - 6:15pm, Sep 17

6:15pm

Candlelight Ceremony

🕒 6:15pm - 7:00pm, Sep 17

Our Celebration of Life Candlelight Ceremony honors our brothers and sisters diagnosed with Sickle Cell Disease that have transitioned to a place where they no longer live with pain.

6:20 pm Slide Presentation of Sickle Cell Warriors that fought the good fight - Dr.

Carolyn Rowley
6:40 pm Light your candle, moment of silence, shout out the names of Warriors you knew
6:50 pm Fill out Evaluation
6:55 pm Break (Video presentation)

 Speaker



Sheila Marchbanks

7:00pm


Evening Session: Young Adults (21-40)

🕒 7:00pm - 8:30pm, Sep 17

With Calvaney Nunley, Latrice Atkins, Cassandra Trimnell, Corey Lewis, Obinna Ekwinne

8:30 pm Fill Out Evaluation

8:35 pm Adjourned Day 1 of the 12th Annual SCD Educational Seminar

 Speakers



Caleb Boaz



Jasmyn Tarrant

Fri, Sep 18, 2020

8:00am

Movement: Exercise & Stretching

🕒 8:00am - 8:45am, Sep 18

Mild to moderate exercise can lead to improvements in a person's muscle function and overall physical ability, and for some patients there are improvements in sleep, concentration and social interactions. When it comes to exercise, the best time of day to get in a workout session is one that you can do consistently. We invite the community to join us daily for a daily dose of exercise. Here are some benefits for those who chose to workout in the morning: fewer distractions, beat the heat, healthier food choices, increased alertness, more overall energy, better focus, better mood, support weight loss, helps regulate your appetite, increased overall activity, improve sleep, to name a few.

The session leader will lead a gentle yoga session. Chronic Pain is associated with morbidity and poor quality of life in patients with Sickle Cell Disease (SCD). Complementary therapies, such as yoga are beneficial in patients with non-SCD chronic pain conditions. Yoga was shown to be acceptable, feasible and helpful in one study in acute SCD pain.

8:50am

Lifetime Achievement Award

🕒 8:50am - 9:00am, Sep 18

9:00am

Welcome

🕒 9:00am - 9:05am, Sep 18

🗣️ Speaker



Shona Stephens M., MPH, CEPH Board Chair, Cayenne Wellness Center

9:05am

Presentation of Awards

🕒 9:05am - 9:15am, Sep 18

- Stephanie Mulkey Sickle Cell Warrior Award presented by Sheila Marchbanks last year's winner
 - Pat Corley Sickle Cell Ambassador Award presented by Pat Corley, RN
-

🗣️ Speakers



Pat Corley, RN



Sheila Marchbanks

9:15am

Introduction to the 12th Annual SCD Educational Seminar: Global Approach to Sickle Cell Disease

🕒 9:15am - 9:30am, Sep 18

Dr. Hebert will give the introduction of our 12th Annual Sickle Cell Disease Educational Seminar and discuss the theme A Global Approach to Sickle Cell Disease.

🗣️ Speaker



Corey Hebert, MD

9:30am

Morning Session I: Reflections on the Experience of Becoming the First Ever UK Sickle Cell Nurse Specialist in 1979

🕒 9:30am - 10:50am, Sep 18

Our Keynote Speaker, Professor Dame Elizabeth Nneka Anionwu in 1979 became the United Kingdom's first sickle cell and thalassaemia nurse specialist, helping establish the Brent Sickle Cell and Thalassaemia

Counselling centre with Consultant Haematologist Dr. Milica Brozovic. Her keynote talk will focus on her experiences.

10:45 am Fill out Evaluation

10:50 am Break

Speaker



Professor Dame Elizabeth Nneka Anionwu Emeritus Professor of Nursing, University of West London

11:05am

Morning Session II: Living Well With Sickle Cell Disease

🕒 11:05am - 12:40pm, Sep 18

In this session, Dr. Thompson will moderate a panel of adult persons diagnosed with Sickle Cell Disease. Each person will reflect on the trials and growth in become a person Living Well With Sickle Cell.

Patient Panel:

11:15 am Global Patient Panel

Bahrain - Mr Zakareya Al Kadhem

Brazil -

France - Dianaba Ba Kenya - Eunice Owino

Kenya - Eunice Owino

Australia -

North America

USA - Lanett Morgan

Canada - Ismaël Kando/Sherman Moore

12:35 pm Fill out Evaluation

Speaker



Alexis Thompson, MD American Society of Hematology

12:40pm

Lunch Break (return at 1:00 pm)

🕒 12:40pm - 1:00pm, Sep 18

1:00pm

Afternoon Session I: Living With Sickle Cell Disease, Part II

🕒 1:00pm - 1:55pm, Sep 18

3 Subsessions

- Breakout Session 1: Men Living With Sickle Cell Disease

🕒 1:00pm - 1:55pm, Sep 18

- **Breakout Session 2: Adolescents Living With Sickle Cell Disease**

🕒 1:00pm - 1:55pm, Sep 18

- **Breakout Session 3: Mature Adults Living With Sickle Cell Disease**

🕒 1:00pm - 1:55pm, Sep 18

2:00pm

Afternoon Session I: Summary of Lunch Presentations

🕒 2:00pm - 2:35pm, Sep 18

2:30 pm Fill out Evaluation

2:35 pm Break

🗣️ Speakers



Wally R. Smith, MD Florence Neal Cooper Smith Professor of Sickle Cell Disease, Virginia Commonwealth University



Cierra Jackson



Eunice Lisberg

2:50pm

Afternoon Session II: Sickle Cell Disease and the Battle for Equality, Justice, and Respect

🕒 2:50pm - 4:05pm, Sep 18

Dr. Ahmar Zaidi is a pediatric hematologist who focuses on the care of people with sickle cell disease. He works at the Children's Hospital of Michigan and is involved in research looking at pain in sickle cell disease patients. Dr. Zaidi will poignantly discuss the inhumanity and health inequities persons diagnosed with Sickle Cell Disease face.

3:55 pm Fill Out Evaluation

4:00 pm Break

🗣️ Speaker



Ahmar Urooj Zaidi Assistant Professor of Pediatrics, Division of Pediatric Hematology/Oncology, Central Michigan University SOM, Wayne State University SOM, Comprehensive Sickle Cell Center, Children's Hospital of Michigan

4:05pm

Afternoon Session III: ASH Updates on Sickle Cell Disease

🕒 4:05pm - 5:25pm, Sep 18

Dr. Thompson will introduce this session with an update from the American Society of Hematology's Sickle Cell Coalition.

4:15 pm - Sickle Cell Centers (Michael DeBaun, MD)

4:25 pm - Patient Engagement and Clinical Trials (Shauna Whisenton)

4:45 pm - Global Coalition (Kwame Frempong, MD)

5:05 pm Question and Answer period 5:20 pm Fill out Evaluation

5:25 pm Adjourned Day 2 of the 12th Annual SCD Educational Seminar

🔊 Speaker



Alexis Thompson, MD American Society of Hematology

5:25pm

Dinner Break (return at 7:00 pm)

🕒 5:25pm - 7:00pm, Sep 18

We suggest eating a nutritional meal and taking a nap.

7:00pm

Art Reception - Sponsored By Vertex

🕒 7:00pm - 7:55pm, Sep 18

8:00pm

Network Reception - Gen S Rock the Block (sponsored by Novartis)

🕒 8:00pm - 9:30pm, Sep 18

Sat, Sep 19, 2020

8:00am

Movement: Exercise & Stretching (QiGong)

🕒 8:00am - 8:40am, Sep 19

Mild to moderate exercise can lead to improvements in a person's muscle function and overall physical ability, and for some patients there are improvements in sleep, concentration and social interactions.

When it comes to exercise, the best time of day to get in a workout session is one that you can do consistently. We invite the community to join us daily for a daily dose of exercise. Here are some benefits for those who chose to workout in the morning: fewer distractions, beat the heat, healthier food choices, increased alertness, more overall energy, better focus, better mood, support weight loss, helps regulate your appetite, increased overall activity, improve sleep, to name a few.

The session leader will lead us into an instructed QiGong session. QiGong also known as a meditative movement, result in physiological and psychological health benefits such as improved balance and quality of life, to name a few.

8:40am

Terumo BCT (Patient Experience)

🕒 8:40am - 9:00am, Sep 19

Ms. Wiggins will share with us her experience of receiving red blood cell exchange for transfusion

management of her sickle cell disease.

 Speaker



Rona S. Wiggins, MSW

9:00am

Summary of the 12th Annual SCD Educational Seminar

🕒 9:00am - 9:15am, Sep 19

Ms Francis-Gibson will summarize the first two days of the Seminar along with giving us an update on all the happenings with SCDA.

 Speaker



Beverley Francis-Gibson President, Sickle Cell Disease Association of America

9:15am

Morning Session I: The Brain and Executive Function Part II and Pat Corley Keynote Speaker

🕒 9:15am - 10:05am, Sep 19

Dr. Lance will continue her talk from last year's Seminar on neurodevelopmental issues and Sickle Cell Disease. By popular demand, Dr. Lance was invited back to continue her talk so patients, caretakers, and providers could gain full understanding of the impact Sickle Cell Disease has on attention and memory, to name a few.

10:00 am Fill Out Evaluation
10:05 am Break

 Speaker



Eboni Lance

10:20am

Morning Session II: Psycho-Social Topic: Understanding Mental Health in Sickle Cell Disease

🕒 10:20am - 12:55pm, Sep 19

10:30 am Signs of depression + anxiety, grief, and hopelessness - Charles Jonassaint, PhD
11:05 am Suicide Prevention - Sickle Cell Disease, COVID-19 and beyond Didi Hirsch Suicide Prevention Center
11:30 am Solution Focused CRM Model - Beverly Buckles Dean of Behavioral Health at Loma Linda University
12:05 pm Building blocks to feeling well - Dr. Charles Jonassaint 12:35 pm Question and Answer
12:50 pm Fill Out Evaluation

 Speaker



Charles Jonassaint, PhD Assistant Professor, Department of Medicine, School of Social Work, and Clinical and Translational Science University of Pittsburgh School of Medicine

12:55pm

Afternoon Session I: Working Lunch Breakouts

🕒 12:55pm - 1:55pm, Sep 19

2 Subsessions

- **Breakout Session 1: Women Living With Sickle Cell Disease**
🕒 1:00pm - 1:55pm, Sep 19
- **Breakout Session 2: Spouses/Caretakers Someone With Living With Sickle Cell Disease**
🕒 1:00pm - 1:55pm, Sep 19

2:00pm

Afternoon Session I: Summary of Lunch Presentations

🕒 2:00pm - 2:35pm, Sep 19

2:30 pm Fill Out Evaluation
2:35 pm Break

2:50pm

Afternoon Session II: Treatment Therapies and Sickle Cell

🕒 2:50pm - 5:45pm, Sep 19

Ms. Shapiro will moderate this session on both the newest FDA treatments created for Sickle Cell Disease along with promising pipeline therapies on the rise.

Global Blood Therapeutics (GBT) Oxbryta (voxelotor) targets the abnormal hemoglobin that causes the disease. It prevents hemoglobin from sticking together, which destabilizes the large aggregates, or clumps of sickled cells that block blood vessels and prevent blood flow in people with sickle cell disease. It is indicated for the treatment of sickle cell disease (SCD) in adults and pediatric patients 12 years of age and older. The FDA approved Oxbryta in November 2019 for the treatment of sickle cell disease in patients ages 12 and older.

Novartis' Adakveo (crizanlizumab) is also approved as a treatment for sickle cell disease. It contains an antibody that blocks a protein in the blood vessels that binds to sickle cells, causing pain and inflammation when the sickle cells block blood flow. The FDA approved Adakveo in November 2019 as a treatment for

painful vaso-occlusive crisis events caused by sickle cell disease in patients 16 and older.

Endari (L-glutamine), developed by Emmaus Life Sciences, is a therapy that acts to make red blood cells more flexible, reducing their risk of becoming trapped inside blood vessels. This improves blood flow and ultimately increases the amount of oxygen reaching tissues. The FDA approved Endari in July 2017 for the treatment of sickle cell disease in patients ages 5 and older.

Terumo BCT's Red Blood Cell Exchange (RBCX), compared to simple transfusion and manual exchange, provides the following advantages: removes red blood cells containing hemoglobin S and rapidly replaces them with healthy red blood cells; manages iron overload and blood viscosity, and controls hemoglobin S and hematocrit. The FDA approved RBCX in December 2016 for the transfusion management of sickle cell disease in adults and children.

Other pipeline therapies: Imara's IMR-687, a highly selective, potent small molecule inhibitor of PDE9. IMR-687 is an oral, once-a-day, potentially disease-modifying treatment for rare hemoglobinopathies.

Imara will present interim data from the ongoing Phase 2a study of IMR-687 in patients with sickle cell disease.

3:00 pm -Global Blood Therapeutic's Oxbryta (FDA Approved) - Ken Bridges, MD

3:20 pm -Novartis' Adakveo (FDA Approved) - TBD

3:40 pm -Emmaus' Endari (FDA Approved) - Charles Stark, PharmD

4:00 pm -Terumo BCT Exchange Transfusion (FDA Approved) - Zahra Pakbaz, MD

4:20 pm Question and Answer

4:30 pm Other Pipeline Therapies

- Imara - Rahul Ballal, MD

- Cycleron - TBD

5:05 pm Fill out Evaluation

5:15 pm Announcement of the 13th Annual SCD Educational Seminar

5:20 pm Silent Auction Winners

5:30 pm Housekeeping

5:45 pm Adjourned Day 3 of the 12th Annual SCD Educational Seminar

 Speaker



Adrienne Shapiro Axis Advocacy