

SICKLE CELL DISEASE EDUCATIONAL SEMINAR:

A RACE THE FOR CURE

PROGRAM AGENDA

Friday, September 8, 2017

- 8:00 am Press Conference
- 8:30 am Welcome - Carolyn Rowley, PhD
- 8:40 am Introduction - Sonja Banks, President of SCDA

I. Morning Session (Basics)

Sickle Cell 101: Pathophysiology, Complications, Management and Treatment

- 9:00 am In Children - Thomas Coates, MD
- 10:00 am In Adults - Ward Hagar, MD
- 11:00 am Break

II. Keynote Speaker

- 11:15 am Keynote Speaker: Donald Kohn, MD
A Race For The Cure
- 12:15 pm Lunch (Entertainment by Six Foota Slim)

III. Afternoon Session (Curatives)

- 1:15 pm Patient Panel (BMT Adult, BMT Teen/Child, Stem Cell Therapy)
- 2:15 pm Curative Options: (Moderator - Vinod Balasa, MD)
 - 2:25 pm Bone Marrow Transplant (Sandeep Soni, MD- Stanford University)
 - 2:40 pm Stem Cells (Matthew Porteus, MD - Stanford University)
 - 3:00 pm Gene Therapy - BlueBird Bio
- 3:30 pm Break

III. Afternoon Session (Reproductive Health)

- 3:45 pm Sickle Cell Disease and Having Children: Pre-pregnancy Issues for Men and Women; Pregnancy Issues for Women” - Andra James, MD
- 4:30 pm Community Forum: Moderator - Sheila Marchbanks
Roundtable on patients diagnosed with SCD raising children and children with parents diagnosed with Sickle Cell
- 5:15 pm Housekeeping
- 5:30 pm Adjourned
- 5:30 - 7:00 Welcome Network Reception (Live Music by J2 and the Bizzness, Book Signing and Art Reception)

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Saturday, September 9, 2017

8:30 am Summary

I. Morning Session

- 8:45 am Historical Perspective: 107 Years, Where Do We Go From Here? Kim Smith-Whitley, MD
- Emergency Room and Hospitals
- Sickle Cell Community Consortium - Lakiea Bailey, PhD
- 9:45 am Break

II. Keynote Speaker

- 10:00 am Keynote Speakers: Moderator - Lakiea Bailey, PhD
10:15 am: Black Panthers: Where we began - Norma Stoker Mtume
11:00 am: American Society of Hematology: Where we are going - Kim Smith-Whitley, MD
11:45 am: Community Partners - We are in this together.
CA Newborn Screening Program: Newborn Screening for Sickle Cell Disease and other Hemoglobinopathies, Valley Children's Hospital Newborn Screening Area Service Center, Randy Shadle. **Support Group:** Wanda Williams (SCCAC); **Partners:** Axis Advocacy, Sickle Cell 101, No Pain in the Playroom, Voices of Sickle Cell, Whatzdaccount, Hina Patel Sickle Cell Foundation, Sickle Cell Disease Foundation of California
- 12:15 pm Working Lunch - GetConnected - Patient Powered Sickle Cell Registry
Pharmacy Roles In Dispensing Opiates: Do's And Don'ts Every Sickle Cell Patient Must Know - Bhavana Patel)

III. Afternoon Session (Treatments)

- 1:15pm **Patient Panel (Patient on Hydroxyurea, Patient on L-Glutamine)**
- 2:00pm Treatment Options (Moderator: Bill Cummings
2:10 pm: GBT 440 - Kenneth Bridges, MD
2:30 pm ApoPharm
2:45 pm: Prolong Pharmaceuticals - Rosa Real, MD
3:00 pm: L-Glutamine - Yutaka Niihara, MD
3:20 pm: Hydroxyurea
3:45 pm: Iron Overload - Novartis
- 4:00 pm Break

III. Afternoon Session (PsychoSocial)

- 4:15 pm Healing Through Art (Hertz Nazaire)
- 5:15 pm Housekeeping
- 5:30 pm Adjourned