

Reproductive Health in Women and Girls with SCD: From Gaps to Solutions

Day 1, May 11, 2023, and Day 2, May 12, 2023, Hybrid Meeting

William H. Natcher Conference Center, Building 45

National Institutes of Health

Day 1 - Thursday May 11, 2023

9:00 –9:15 AM	Welcoming Remarks and Meeting Overview
9:00– 9:05 AM	Introduction: Nahed El Kassar, MD, PhD- DBDR-NHLBI, <i>Meeting Chair</i>
9:05 –9:15 AM	Welcome: “Why now” Julie Panepinto MD, MSPH- DBDR Director-NHLBI
9:15 - 9:45 AM	Plenary Speaker: <i>Is Women’s Health the Key to Solving Sickle Cell Disease?</i> Eugene Oteng-Ntim, MD- London, UK
9:45 - 12:30 PM	Day 1 - SESSION 1: <i>Reproductive Lifespan & Fertility Preservation in SCD</i> Leaders: Julia Kopeika, MD and Nana-Bilkisu Habib, MPH
9:45 – 10:00 AM	<i>Patient Perspective</i> Nana-Bilkisu Habib, MPH- Maryland
10:00 – 10:15 AM	<i>Health Equity and Reproductive Health</i> Erica Marsh, MD, M.S.C.I- University of Michigan
10:15 – 10:45 AM	<i>Decrease of Ovarian Reserve in SCD Women: Overview</i> Lydia Pecker, MD- JHU, Maryland
10:45 – 11:00 AM	<i>Studying the Mechanisms of Ovarian Aging and Chemotherapy Induced-Damage in SCD</i> Kutluk Oktay MD, PhD- Yale, CT
11:00 – 11:15 AM	<i>BMT and Gene Therapy/Editing Effects on Fertility</i> Lillian Meacham, MD- Emory, Atlanta, GA
11:15 – 11:30 AM	<i>Break</i>
11:30 – 11:45 AM	<i>Cryo-Preservation: at What Age, Before What Procedure, in Which Patient; PGT?</i> Mindy Christianson, MD- Cleveland, OH
11:45 – 12:00 PM	<i>Cryo-Preservation: The UK Experience</i> Julia Kopeika, MD- London, UK
12:00 - 12:30 PM	Panel Discussion: Includes All Speakers and Leaders
12:30 - 1:15 PM	Lunch Break
1:15 - 4:30 PM	Day 1 - SESSION 2: <i>Menstruation and Contraception in People with SCD: From Physiopathology to Treatment</i> Leaders: Titilope Fasipe, MD, Ph.D and Andrea Roe, MD
1:15 – 1:30 PM	<i>Patient’s Perspective</i> Ms. Mia Robinson- Sickle 365, Atlanta, GA
1:30 –1:45 PM	<i>Pathophysiology of Pain in Menses in SCD Insights from Kingston</i> Zachary Ramsay, MD- (Kingston)-West Indies, Jamaica
1:45 – 2:00 PM	<i>Pain, Menstruation and Contraception</i> Andrea Roe, MD- UPENN, PA
2:00 – 2:15 PM	<i>Epidemiology: What Do We Know About Contraception and the Risk of Thrombosis</i> Antoinette Nguyen, MD, MPH, FACOG- CDC
2:15 – 2:30 PM	<i>Pathophysiology of Contraception and VTE Risk in Girls and Women with SCD</i> Erica Sparkenbaugh, PhD- UNC Blood Research Center
2:30 – 2:45 PM	Break
2:45 – 4:00 PM	<i>Grantees of RFA HL18-003</i> 1 - Matthew Rondina MD, MS- University of Utah, 2 - Charles Lowenstein, MD- JHU, 3 - Nanette Boyle-Colorado School of Mines, CO, 4 - Maria Cristina Bravo- UVermont

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4:00 – 4:30 PM	Panel Discussion: “Putting it All Together: Managing Menstruation and Contraception in Support of Management for Girls and Women with SCD” Led by Titilope Fasipe, MD, Ph.D and Andrea Roe, MD
4:30 – 4:45 PM	Closing Remarks
4:45 PM	Adjourn Day 1

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Day 2: Friday May 12, 2023 – Pregnancy in SCD

9:00 – 9:30 AM	Summary of Day-1 by <i>Lydia Pecker, MD-JHU and Eugene Oteng-Ntim, MD</i>
9:30 – 10:00 AM	Plenary Speaker: Under-Acknowledged End-Organs: Lessons Learned from Developing a Risk Prediction Tool and Studying the SCD Placenta Dr. Kinga Malinowski- Toronto, CA
10:00 – 10:15 AM	Patient’s Perspective <i>Ms. Wemi Foluke- Toronto, CA</i>
10:15 – 10:30 AM	Patient’s Perspective <i>Ms. Heather Avent- Chair of the “NIH Cure Initiative’s” Community Input Panel- Dallas, TX</i>
10:30 – 10:45 AM	<i>Break</i>
10:45 – 12:00 PM	Day 2 - SESSION 1: Pathophysiology of Sickle Cell Disease Pregnancy (Interactive Hem/Ob/Gyn) Leaders: Rachel G. Sinkey, MD, UAB and Kinga Malinowski, MD Toronto, CA
10:45 – 11:00 AM	Pregnancy with ART for SCD Kamaria Cherise Cayton Vaught, MD- JHU
11:00 – 11:30 AM	Anemia, Hemolysis and Hypoxia in SCD, Hypoxia in Pregnancy Jane Little, MD- UNC
11:30 – 11:45 AM	Thrombosis in SCD, Thrombosis in Pregnancy Ted Wun, MD, FACP- UC Davis, CA
11:45 AM – 12:00 PM	Panel Discussion: OB/GYN Perspective Guidelines and Gaps - Rachel G. Sinkey, MD, UAB and Kinga Malinowski, MD - Toronto, CA
12:00 - 12:45 PM	Lunch Break
12:45 – 2:15 PM	Day 2 - SESSION 2: Treating SCD During Pregnancy Leaders: Dr. Pecker and Dr. Oteng -Ntim
12:45 – 1:00 PM	Transfusion in Pregnancy: Published Data and Remaining Questions on the Only Acceptable Treatment in Pregnant Women with in SCD Deva Sharma, MD- Vanderbilt
1:00 – 1:15 PM	Drug Trials in Pregnant People with SCD Lessons from TAPS2 & PIPSICKLE Bosede Afolabi- Nigeria and Eugene Oteng-Ntim, MD- London, UK
1:15 – 1:30 PM	Genome Editing in Hemoglobinopathies Kyle Cromer, PhD- UCSF, CA
1:30 – 1:45 PM	Ethical Questions (Including HU) in Pregnancy Ruth Farrell- Cleveland, OH
1:45 – 2:15 PM	Panel Discussion with Session Leaders
2:15 – 2:30 PM	<i>Break</i>
2:30 – 4:15 PM	Day 2 - SESSION 3: Defining High-Quality, Multi-Disciplinary Care for Sickle cell disease pregnancy Implementation Leader: Dr. Alecia Nero
2:30 – 2:45 PM	The Power of Multi-disciplinary Expertise, Lessons from Korle-Bu Teaching Hospital-(Including Pregnancy Complications and Fetal Outcomes)- Eugenia Vicky Asare, MD- Accra, Ghana
2:45 – 3:00 PM	How Much is Enough? End-Organ Evaluations Before, During and After Pregnancy Santosh Saraf, MD- UIC, IL
3:00 – 3:15 PM	Genetic Counseling and Screening; and Long Term Effects on Babies Deepa Manwani, MD- Bronx, NY

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3:15 – 3:30 PM	<i>Implementation Science for Pregnancy in SCD</i> Alecia Nero, MD- Dallas, TX
3:30 – 4:15 PM	Panel Discussion: The Fierce Urgency of Now Alecia Nero, MD- Dallas, TX
4:15 – 4:45 PM	Summary of Day 2 Lydia Pecker, MD-JHU, Maryland and Eugene Oteng-Ntim, MD- London, UK
4:45 – 5:00 PM	Guidelines or Gaps and Future Steps Nahed El Kassar, MD, PhD-DBDR-NHLBI
5:00 PM	Adjourn Day 2