



THE FIRST GLOBAL CONFERENCE OF SICKLE CELL DISEASE ORGANIZATIONS

MAY 20-22, 2022

Friday, 20 May, 2022		
7:00 AM- 7:30 AM	Allies Morgan - Poet Canada	
7:30 AM - 8:00 AM	OPENING CEREMONY <i>Biba Tinga, Caregiver Remarks - Conference Co-chair (5 min)</i> <i>Pastor Dotty Nicholas (5 min)</i> <i>Issa Ali, GASDCO Chair (5 min)</i> Welcomes <i>Mary Ampomah, GASDCO CEO (5 min)</i> <i>Conference Co-Chair, Adlette Inati</i> Program Overview (5 min) <i>Ted Love, MD, President and CEO, Global Blood Therapeutics (5 min)</i>	
8:00 AM – 9:15AM	EDUCATIONAL SESSION 1 - SICKLE CELL DISEASE CARE <i>Moderators</i> <i>Julie Kanter, MD, USA and Adlette Inati, MD, Lebanon</i> 8:00 AM - 8:20 AM (20 mins) Care in Children <i>Adlette Inati, MD, Lebanon</i>	

	<p>8:20 AM -8:40 AM (20 mins) Care during Transition <i>Baba Inusa, MD, UK</i></p> <p>8:40 AM - 9:00 AM (20 mins) Care in Adults <i>Julie Kanter, MD, USA</i></p> <p>9:00 AM - 9:15 AM (15 mins) Q&A</p>	
<p>9:15 AM- 9:30 AM</p>	<p>COFFEE BREAK</p>	
<p>9:30 AM – 10:30 AM</p>	<p>PRESENTATION & PANEL 1 – PAIN AND SCD</p> <p><i>Moderator</i> <i>Hatoon Ezzat, MD, KSA/Canada</i></p> <p>9:30 AM – 9:55 AM (25 mins) Presentation: Pain and SCD <i>Sophie Lanzkron, MD, USA</i></p> <p>9:55 AM – 10:20 AM (25 mins) Panel Experiences of people living with SCD <i>Belinda NaaOyoe Appiah, Nurse, Ghana</i> <i>Shelly Crosby, Patient, Canada</i> <i>Suman Jain, MD, India</i></p> <p>10:20 AM-10:30 AM (10 mins) Q&A</p>	<p>SIMULTANEOUS ARABIC SESSION</p>
<p>10:30 AM- 11:00 AM</p>	<p>SPECIAL SESSION 1– GLOBAL SCD INITIATIVES</p> <p><i>Moderator</i> <i>Adlette Inati, MD, Lebanon</i></p> <p>10:30 AM-10:45 AM ASH SCD initiatives in Africa (15 mins) <i>Andrew Zapfel, MPH, PMP, USA</i></p>	

	<p>10:45 AM-11:00 AM EHA SCD Program (15 mins) <i>Mariane De Montalembert, MD, France</i></p>	
<p>11:00 AM - 12:00 PM</p>	<p>PRESENTATION & PANEL 2 - HYDROXYUREA</p> <p><i>Moderator</i> <i>Arafa Salim Said, Advocate, Tanzania & Alvin Merchant,</i> <i>Patient/Advocate, Canada</i></p> <p>11:00 AM – 11:20 AM (20 mins) When to start and how to use <i>Clark Brown, MD, USA</i></p> <p>11:20 AM – 12:00 PM (40 mins) Panel Lived experiences with hydroxyurea Side effects and mitigations <i>Renée Esdaille, GASCDO Board/ Patient, Trinidad</i> <i>Alvin Merchant, Patient/Advocate, Canada</i> <i>Priti Nagrare, NASCO and Caregiver, India</i> <i>Lalit Pargir, Patient, India</i></p>	<p>SIMULTANEOUS ARABIC SESSION</p>
<p>12:00 PM – 12:30 PM</p>	<p>CLINICAL TRIALS 1– Global Blood Therapeutics OXBRYTA</p> <p>12:00 PM – 12:15 PM (15 mins) <i>Carolyn Hoppe, MD, GBT</i> Therapeutic potential of Inclacumab for the reduction of VOC episodes (THRIVE) Study</p> <p>12:15 PM – 12:30 PM (15 mins) <i>Eleanor Lisbon, MD, GBT</i></p>	

<p>12:30 PM – 1:30 PM</p>	<p align="center">PRESENTATION & PANEL 3 – SICKLE CELL AND MENTAL HEALTH</p> <p align="center"><i>Moderator</i> <i>Rae Blaylark, Caregiver</i></p> <p align="center">12:30 PM – 12:50 PM (20 mins) Best practices to positive mental health <i>Lori Crosby, PSYD, USA</i></p> <p align="center">12:50 PM – 1:30 PM (40 min) Panel <i>Marjorie Dejoie-Brewer, MD & Patient, U.S.A</i> <i>Heather Rawle, Clinical Psychologist, UK</i> <i>Enam Sefakor Bankas, Patient/MD, Ghana</i> <i>Kofi Anie, Psychologist/Therapist, UK</i> <i>Mary Ampomach, Psychologist/Therapist, Ghana</i></p>	
<p>1:30 PM - 2:15 PM</p>	<p align="center">LUNCH and GASCDO VIDEOS (45 mins)</p>	
<p>2:15 PM – 3:15 PM</p>	<p align="center">PRESENTATION & PANEL 4 - THE NEED FOR A GLOBAL SICKLE CELL REGISTRY</p> <p align="center"><i>Moderator</i> <i>Hatoon Ezzat, MD, KSA/Canada</i></p> <p align="center">2:15 PM – 2:35 PM (20 mins) What is a registry and why is it important? <i>David Page, National Director of Health Policy at Canadian Hemophilia Society, Canada</i></p> <p align="center">2:35 PM – 3:15 PM (40 min) Panel The need for a global registry and patient concerns <i>Kawaldip Sehmi, CEO, IAPO</i> <i>Hatoon Ezzat, MD, KSA and Canada</i></p>	
<p>3:15 PM- 3:30 PM</p>	<p align="center">SPECIAL SESSION 2- GLOBAL SCD INITIATIVES</p> <p align="center"><i>Moderator</i></p>	

	<p><i>Dr. Simone Eastman Uwan, Advocate, USA</i></p> <p>WHO/UN ADDRESS- The Burden of SCD in Africa, Challenges and WHO recommendations at mitigation</p> <p><i>Joana Ansong, MD, Health promotion officer, WHO, Ghana</i></p>	
3:30PM – 3:45 PM	<p>PATIENT TESTIMONIAL (10 mins)</p> <p><i>Simone Eastman Uwan, Patient/MD, USA</i></p> <p>CLOSING REMARKS (5 mins)</p> <p><i>Biba Tinga, Conference Co-Chair</i></p>	

Saturday, 21 May, 2022		
7:00 AM – 7:10 AM	<p>GASCDO: Hope -Gloria</p>	
7:10 AM - 7:15 AM	<p>GASCDO GREETINGS (5 min)</p> <p><i>Patient TBC</i></p>	
7:15 AM – 8:15 AM	<p>EDUCATIONAL SESSION 2 – ER CARE</p> <p><i>Moderator</i></p> <p><i>Rachel Kesse-Adu, MD, UK</i></p> <p>7:15 AM – 7:35 AM (20 mins)</p> <p>ER Care in Adults</p> <p><i>Rachel Kesse-Adu, MD, UK</i></p> <p>7:35 AM-7:55 AM (20 mins)</p> <p>ER Care in Children</p> <p><i>Mariane de Montalembert, MD, France</i></p> <p>7:55 AM – 8:15 AM (20 mins)</p> <p>Q&A</p>	<p>SIMULTANEOUS ARABIC SESSION</p>



<p>8:15 AM- 9:30 AM</p>	<p align="center">EDUCATIONAL SESSION 3- TRANSFUSIONS AND IRON OVERLOAD</p> <p align="center"><i>Moderator</i> <i>Adlette Inati, MD, Lebanon</i></p> <p align="center">8:15 AM – 8:40 AM (20 mins) Transfusion indications <i>Adlette Inati, MD, Lebanon</i></p> <p align="center">8:40 AM – 9:05 AM (20 mins) Transfusion modalities and complications other than iron overload <i>Erin Goodhue, Director of Clinical Research and Development</i> <i>Terumo Blood and Cell Technologies, U.S.A.</i></p> <p align="center">9:05 AM – 9:30 AM (20 mins) Iron overload – pre-recorded <i>Ali Taher, MD, Lebanon</i></p> <p align="center">9:15 AM – 9:30 AM (15 mins) Q&A</p>	<p>SIMULTANEOUS ARABIC SESSION 8:15 AM-9:05 AM</p>
<p>9:30 AM- 9:45 AM</p>	<p align="center">COFFEE BREAK</p>	<p>ARABIC SESSION Novel therapies 9:05 AM- 9:30 AM</p>

<p>9:45 AM – 11:00 AM</p>	<p align="center">PANEL 5 -SOCIAL STIGMA AND PSYCHOSOCIAL SUPPORT</p> <p align="center"><i>Moderator: Elle Cole, Caregiver, USA</i></p> <p align="center">9:45AM – 10:30AM (45 mins) Patients and Caregivers experience: role of psychosocial support, social stigma, relationships, social life, employment and financial issues <i>Alvin Merchant, Patient/Advocate, Canada</i> <i>Rae Blaylark, Caregiver, USA</i> <i>Khaled Warwar, Patient, Lebanon</i> <i>Adlette Inati, MD, Lebanon</i></p> <p align="center">10:30AM – 10:50AM (20 mins) What needs to change? <i>Khaled Warwar, Patient, Lebanon</i> <i>Flaminia Macchia, RDI Executive Director, Italy</i></p>
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	<p>10:50 AM – 11:00 AM (10 mins) Q&A</p>
11:00 AM - 11:40 AM	<p>MENTAL HEALTH BREAK</p> <p><i>Moderator: Storma McDonald, Patient/Advocate</i></p> <p>11:00 AM – 11:20 AM (20 mins) Meditation and Yoga (active session) <i>Marjorie Dejoie-Brewer, MD/Patient, U.S.A</i></p> <p>11:20 AM – 11:40 AM Benefits of mental health alternative therapies (20 mins) <i>Henry Claflin, Caregiver/Therapist, Canada</i></p>
11:40 AM - 12:10 PM	<p>CLINICAL TRIALS 2– NOVARTIS Novartis Commitment to the Global SCD Community</p> <p><i>Kwaku Marfo, Pharm D, MBA, MPH, Global Brand Medical Director-SCD program</i></p>
12:10 PM - 1:00 PM	<p>LUNCH</p>
1:00 PM – 1:30 PM	<p>EDUCATIONAL SESSION 4– SICKLE CELL TRAIT</p> <p><i>Moderator: Gautam Dongre, Caregiver, India</i></p> <p>Sickle Cell Trait <i>MB Agarwal, MD, India</i></p>
1:30 PM – 2:00 PM	<p>HYDRATION & PHYSICALACTIVITY</p> <p><i>Moderator</i> <i>Dr. Mary Akua Ampomah, Ghana</i></p> <p>Announcing World Sickle Cell Awareness Day 2022 Hydration Challenge</p> <p>1:30 PM – 1:45 PM (15 mins) Hydration Overview <i>Prantar Chakraborty, MD, India</i></p> <p>1:45 PM – 2:00 PM (15 mins) Benefits of physical activities in SCD</p>

	<i>Yves Pastore, MD, Canada</i>
2:00 PM – 3:00 PM	<p>PANEL 6 -SOCIAL LIFE & RELATIONSHIPS</p> <p><i>Moderator</i> <i>Biba Tinga, GASCDO Board, Canada</i></p> <p><i>Shelley Crosby, Patient, Canada</i> <i>Seshie Eyram Kudjoe, MPH, Ghana</i> <i>Henry Clafin, Caregiver/Therapist, Canada</i></p>
3:00 PM – 3:15 PM	<p>CLINICAL TRIALS 3- FORMA</p> <p><i>Katharine Batt, MD, Forma Therapeutics</i></p>
3:15 PM – 3:30 PM	<p>PATIENT TESTIMONIAL (5-10 mins)</p> <p><i>Augustina Bempong, Patient, Canada (5 mins)</i></p> <p>CLOSING REMARKS (5 mins)</p> <p><i>Issa Ali, Chair GASCDO, Trinidad</i></p>

Sunday, 22 May, 2022	
7:00 AM - 7:10 AM	ARTISTIC PERFORMANCE
7:10 AM - 7:15 AM	<p><i>GASCDO WELCOME</i></p> <p><i>Gautam Dongre, GASCDO Board Member, Warrior Dad, India (5 min)</i></p>

<p>7:15 AM - 8:15 AM</p>	<p align="center">EDUCATIONAL SESSION 5 - SCD COMPLICATIONS – Part 1 (Pre-recorded sessions)</p> <p align="center"><i>Moderators</i> <i>Salam Alkindi, MD, Oman and Santosh Sarraf, MD, USA</i></p> <p align="center">7:15 AM - 7:35 AM (20 mins) Cerebrovascular disease <i>Fenella Kirkham, MD, UK</i></p> <p align="center">7:35AM - 7:55AM (20 mins) Renal disease <i>Santosh Sarraf, MD, U.S.A.</i></p> <p align="center">7:55AM - 8:15AM (20 mins) Pulmonary Complications <i>Ammar Saadoon, MD, USA</i></p>
<p>8:15 AM - 8:30 AM</p>	<p align="center">CLINICAL TRIALS 4– ROCHE</p> <p align="center">Research and Development Activities in SCD <i>Himaka Patel, Senior Clinical Scientist</i></p>
<p>8:30 AM - 9:30 AM</p>	<p align="center">EDUCATIONAL SESSION 6 - SCD COMPLICATIONS – Part 2 (Pre-recorded sessions)</p> <p align="center"><i>Moderator</i> <i>Hatoon Ezzat, MD, KSA/Canada</i></p> <p align="center">8:30AM - 8:50AM (20 mins) Priapism <i>Arthur L. Burnett, MD, USA</i></p> <p align="center">8:50AM –9:10 AM (20 mins) Leg ulcers <i>Caterina Minniti, MD, USA</i></p> <p align="center">9:10 AM- 9:30 AM (20 mins) Osteonecrosis <i>Oyebimpe Adesina, MD, USA/Nigeria</i></p>

<p>9:30 AM – 10:45 AM</p>	<p style="text-align: center;">EDUCATIONAL SESSION 7 - REPRODUCTIVE HEALTH</p> <p style="text-align: center;"><i>Moderator: Ufuoma Muwheh, Advocate, Canada</i></p> <p style="text-align: center;">9:30AM – 10:00 AM (30 mins) Reproductive health issues and planning <i>Teonna Woolford, Patient, USA</i> <i>Kim Smith-Whitley, MD, USA</i></p> <p style="text-align: center;">10:00 AM – 10:15 AM (15 mins) Q&A</p> <p style="text-align: center;">10:15 AM – 10:35 AM (20 mins) Pregnancy Management <i>Eugene Oteng-Ntim, MD, UK</i></p> <p style="text-align: center;">10:35 AM – 10:45 AM (10 mins) Q&A</p>
<p>10:45 AM– 11:45 AM</p>	<p style="text-align: center;">EDUCATIONAL SESSION 8-TRANSPLANTATION APPROACHES IN SCD</p> <p style="text-align: center;"><i>Moderator</i> <i>Salam Al Kindi, MD, Oman</i></p> <p style="text-align: center;">10:45AM - 11:05AM (20 mins) Hematopoietic stem cell transplantation <i>Miguel Abboud, BMT Expert, Lebanon</i></p> <p style="text-align: center;">11:05AM - 11:35AM (30 mins) Cell and genetic cell approaches in SCD <i>(Educational session sponsored by Vertex Pharmaceuticals)</i> <i>Bill Hobbs, VP, Clinical Development, Vertex</i></p> <p style="text-align: center;">11:35 AM-11:45 AM (10 mins) Q&A</p>
<p>11:45AM - 12:00 PM</p>	<p style="text-align: center;">COFFEE BREAK</p>

<p>12:00 PM- 12:50 PM</p>	<p style="text-align: center;">EDUCATIONAL SESSION 9 – BLOOD DONATION</p> <p style="text-align: center;"><i>Moderator</i> <i>Ulysse Guerrier, Advocate, Canada</i></p> <p style="text-align: center;">12:00 PM – 12:30 PM (30 mins) “The need for blood” project <i>Biba Tinga, President SCDAC, Canada</i> <i>Jennie Haw, Researcher, CBS, Canada</i></p> <p style="text-align: center;">12:30 PM – 12:50 PM (20 mins) Hypoxic storage improves oxygen delivery and inhibits adhesion of RBCs to human endothelial cells: implication for transfusion in patients with SCD–HEMANEXT Samuel Coker, PhD, USA</p>
<p>12:50 PM – 1:45 PM</p>	<p style="text-align: center;">PANEL 7 –EMPLOYMENT, EDUCATION AND FINANCIAL ISSUES</p> <p style="text-align: center;"><i>Moderator</i> <i>Ade Sawyer, GASCDO Board, UK</i></p> <p style="text-align: center;">12:50 PM – 1:30 PM (40 mins)</p> <p style="text-align: center;"><i>Richard Langhorne, Parent/Social worker/Psychotherapist ,Canada</i> <i>Marjorie Dejoie-Brewer, MD/Patient, U.S.A</i> <i>Ruchita Patel, Patient, India</i> <i>Judy Grandison, Caregiver, Canada</i></p> <p style="text-align: center;">1:30 PM –1:45 PM (15 mins) Q&A</p>
<p>1:45 PM- 2:30 PM</p>	<p style="text-align: center;">LUNCH and GASCDO VIDEOS</p>
<p>2:30 PM – 3:15 PM</p>	<p style="text-align: center;">PANEL 8 –CURE IN SCD – BONE MARROW TRANSPLANT</p> <p style="text-align: center;"><i>Moderator</i> <i>Biba Tinga, President, SCDAC, Canada</i></p> <p style="text-align: center;">Discussion and Q&A</p> <p style="text-align: center;"><i>Teonna Woolford, Patient Advocate, Sickle Cell Reproductive Health Education Directive, USA</i></p>

	<p><i>Priscille Sanon, Patient, Canada</i> <i>Ufuoama Muwhen, Advocate, Canada</i></p>
<p>3:15 PM - 3:45 PM</p>	<p>EDUCATIONAL SESSION 10 - SCD AND COVID-19</p> <p><i>Moderator: Rae Blaylark, Caregiver, USA</i></p> <p>3:15 PM – 3:35 PM (20 mins) <i>Caterina Minniti, MD, USA</i></p> <p>3:35 PM – 3:45 PM (10 mins) Q&A</p>
<p>3:45 PM – 3:55 PM</p>	<p>Patient Testimonial on Advocacy (10 mins)</p> <p><i>Zakaria Alkadhem, Head, Bahrain Sickle Cell Society, Bahrain</i></p>
<p>3:55 PM - 4:05 PM</p>	<p>CLOSING REMARKS (10 mins)</p> <p><i>Issa Ali, GASCDO Chair and Adlette Inati, MD, Conference Co-Chair</i></p>