

Conference Learning Objectives:

- Educate patients and family members about Sickle Cell Disease and new treatments available
- Summarize the latest research on the sickle cell trait and Sickle Cell Disease
- Describe the role that patients who have Sickle Cell Anemia and community members play in finding a cure for Sickle Cell Anemia
- Realize the importance of inter-professional collaboration for research into Sickle Cell Disease in Alberta, and the dissemination of this knowledge

Friday, November 16, 2018

8:30 - 9:00am Registration

8:45 - 9:00am Opening Remarks

9:00 - 9:45am **Opening Plenary**

Identifying Severe Sickle Cell Early in Life

Dr. Emily Riehm Meier, Paediatric Hematologist and Director, Sickle Cell Research, Indiana Hemophilia & Thrombosis Center

Session Learning Objectives:

- 1. Review definitions of sickle cell severity
- 2. Examine prediction models for sickle cell anemia severity
- 3. Discuss how prediction models could be used when making treatment decisions

9:45 - 10:15am Break

10:15am - 12:00pm Plenary Panel #2

Matched Sibling Donor Hematopoietic Cell Transplantation for Sickle Cell Disease- Past, Present, and Future

Dr. Greg Guilcher, Paediatric Oncologist, University of Calgary Faculty of Medicine Session Learning Objectives:

- 1. Identify basic principles of HCT, specifically as applied to sickle cell disease using a matched sibling donor
- 2. Describe important measures of safety and success, including engraftment of donor blood cells and graft-versus-host disease
- 3. Outline current and future directions of the practice of sibling donor HCT, including timing/eligibility efficacy, safety, and access (North American and globally)

Stem Cell Transplantation to Cure Adults with Sickle Cell Disease

Dr. Santosh Saraf, Assistant Professor of Medicine, University of Illinois Hospital & Health Sciences System

Session Learning Objectives:

- 1. Comprehend the process of donor selection and stem cell collection.
- 2. Identify the current indications for HLA-matched and haploidentical stem cell transplantation in patients with sickle cell disease.
- 3. Recognize the potential risks and benefits of stem cell transplantation in patients with sickle cell disease



Patient Perspective & Discussion

Patient Panelists to be confirmed

12:00pm - 1:00pm

Lunch

1:00 - 1:45pm

Plenary #3

Bone Biomechanics and Pathology in Sickle Cell Disease

Dr. Gilda Barabino, Dean and Daniel and Frances Berg Professor, Grove School of Engineering

Session Learning Objectives:

- 1. Recognize abnormities in bone biomechanics.
- 2. Identify the role abnormal bone biomechanics play in sickle cell disease pathophysiology.

1:45 - 2:00pm

Break & Room Change

2:00 - 2:45pm

Breakout Sessions

Session A

Blood Soup and Learning through Play: Development of an Educational Curriculum for a Sickle Cell Summer Camp

Dr. Carrie Starnes, Child Life Specialist, Indiana Hemophilia and Thrombosis Center

Session Learning Objectives:

- 1. Identify 4 key components of an education program for children with sickle cell disease in a traditional summer camp environment.
- 2. Describe the value of nonpharmacological coping techniques and impact of age appropriate education in relation to pain and anxiety in children with Sickle Cell disease

Session B

Taking Root, Branching Out: Growth of a Sickle Cell Disease Transition Program

Dr. Sarah Hall, Physician Assistant, Indiana Hemophilia and Thrombosis Center

Session Learning Objectives:

- 1. Recognize the contribution formal transition programs can make in improving adherence and decreasing morbidity in adolescents and young adults with sickle cell disease
- 2. Review the benefits of incorporating knowledge assessments and individual achievements into the structure of a sickle cell disease transition program
- 3. Identify the advantage of early introduction to an adult hematology team in the promotion of healthcare autonomy

2:45 - 3:00pm Break & Room Change

3:00 - 3:45pm Plenary #4

Determinants of Blood and Tissue Donation Among the Non-White Population

Dr. Jean Walrond, Vice President, Sickle Cell Foundation of Alberta

Dr. John Jayachandran, Professor of Sociology, Concordia University of Edmonton

Session Learning Objectives:

- 1. Identify the areas in which current research is being developed by the medical community and stakeholders
- 2. Explain the importance of social community awareness in the development of treatment and cure of sickle cell anemia through blood and tissue donation
- 3. Describe the importance of blood and tissue donation from diverse donors in treating Sickle Cell Anemia and Thalassemia

3:45 -4:30pm Plenary #5

An Update of Hematopoietic Stem Cell Transplantation for Patients with Sickle Cell Disease

Dr. Courtney Fitzhugh, Investigator, Sickle Cell Branch, National Heart, Lung, and Blood Institute, NIH

Session Learning Objectives:

- 1. Review indications for transplant in patients with sickle cell disease
- 2. Discuss HLA-matched sibling transplantation as a curative option for patients with sickle cell disease
- 3. Assess alternative donor transplant approaches for patients with sickle cell disease

4:30 - 4:45pm Award Presentation

4:45 - 6:30pm Reception

Saturday, November 17, 2018

8:30 - 9:15am Registration

9:15 - 9:30am Opening Remarks

9:30 - 10:15am Plenary #6

Race, Wellbeing and the Healthcare of African Canadians

Dr. Carl James, Chair in Education, Community & Diaspora at York University, Toronto Session Learning Objectives:

- 1. Recognize the significance of race and its interlocking relationship with other identity factors in individuals' lives
- 2. Identify that equitable access to healthcare and a healthy life is reliant upon the collection of race data
- 3. Identify the impact of anti-Black racism as a determinant of health

10:15-10:45am Break

10:45am - 12:00pm

Plenary #7

A Patients Perspective on Treatment Options for Sickle Cell Anemia

Panelists to be confirmed

Session Learning Objectives:

- 1. Distinguish different treatment options for patients with Sickle Cell Anemia
- 2. Recognize how the experiences of those being treated for Sickle Cell Anemia may differ
- 3. Identify the benefits and downsides of different treatment options available for patients of Sickle Cell Anemia

12:00 - 1:00pm

Lunch

1:00 - 1:45pm

Plenary #8

Moving Forward: Transitions and Quality of Life in Sickle Cell Disease The MATCH clinic

Dr. Aisha Bruce, Associate Professor, Division of Pediatric Hematology/Oncology & Palliative Care, Faculty of Medicine and Dentistry, Edmonton Health Clinic Academy

Dr. Lauren Bolster, Clinical Lecturer, University of Alberta

Session Learning Objectives:

- 1. Identify potential complications of post-transplant sickle cell anemia patients
- 2. Summarize current research areas in post-transplant sickle cell anemia patients
- 3. Recognize the value of a MATCH clinic program

1:45 - 2:00pm

Break

2:00 - 2:45pm

Plenary #9:

Treatment for SCD: Bridging the Gap between Efficacy and Effectiveness

Dr. Isaac Odame, Professor and Alexandra Yeo Chair in Haematology

Director, Division of Haematology, Departments of Medicine and Paediatrics, University of Toronto, Haematology Section Head, Division of Haematology/Oncology and Centre for Global Child Health, Medical Director, The Global Sickle Cell Disease Network

Session Learning Objectives:

- 1. Summarize the current efficacious treatments for sickle cell disease
- 2. Identify the key barriers to implementing these efficacious treatments
- 3. Recognize the health system changes needed to optimize treatment outcomes for sickle cell disease

2:45 - 3:15pm

Break

3:15 - 4:00pm

Closing Plenary

The Anatomy of a Warrior and the Power of the Patient Voice

Dr. Lakiea Bailey, Executive Director, Sickle Cell Consortium

Session Learning Objectives:

- 1. Identify the role of sickle cell disease in shaping current research trends
- 2. Recognize how sickle cell disease was at the center of multiple major scientific breakthroughs
- 3. Describe the role of the patient in defining research objectives

4:00 - 4:15pm

Closing Remarks