



2nd Sickle Cell  
& Thalassaemia  
Virtual Conference

2022  
January  
26-28  
Virtual Global  
Conference

Day  
01

26TH JANUARY 2022

Welcome To ASCAT

10.00 – 11.45

**ORAL ABSTRACTS – PARALLEL SESSION TWO:** Catherine Chinda (Chair)

Long-Term Follow-up of Beta-Thalassemia Patients Treated with Hematopoietic Stem Cell Gene Therapy: **Sarah Marktel** (15mins)

Adding Azathioprine/Hydroxyurea Preconditioning to Alemtuzumab/TBI Conditioning Improves Donor Chimerism in Matched Sibling Donor Stem Cell Transplantation in Adult Sickle Cell Disease Patients: **Elisabeth Doavern** (15mins)

Feasibility of haploidentical allogeneic stem cell transplantation with post-transplant cyclophosphamide for patients with severe sickle cell disease with end-stage renal disease (ESRD) on hemodialysis: **Alexandra Gomez Arteaga** (15mins)

Obligate N-terminal but not C-terminal Monoferric Transferrin Ameliorates Anemia in <beta>-Thalassemic Mice: **Stefano Rivella** (15mins)

Preliminary Results of a Phase I Study in Healthy Subjects Administered Inclacumab, a Fully Human IgG4 Anti-P-Selectin Monoclonal Antibody in Development for Treatment of Sickle Cell Disease: **Mark Davis** (15mins)

Randomized controlled trial of the efficacy and safety of deferiprone: subgroup analysis of pediatric patients in iron-overloaded patients with sickle cell disease and other anemias: **BI. Inusa** (15mins)

Combination of a Luspatercept-like Drug (RAP-GRL) and TMPRSS6-ASO is Superior to Either Drug Alone for Correcting <beta>-Thalassemia: **Stefano Rivella** (15mins)

**ORAL ABSTRACTS – PARALLEL SESSION THREE:**

Subarna Chakravorty (Chair)

Activation of pyruvate kinase-R with etavopivat (FT-4202) is well tolerated, improves anemia, and decreases intravascular hemolysis in patients with sickle cell disease treated for up to 12 weeks: **MJ. Telen** (15mins)

A systematic post-marketing (PM) review of rare infusion-related reactions (IRRs) presenting as pain events during or after crizanlizumab infusion in patients with sickle cell disease (SCD): **J. Kanter** (15mins)

Trial in progress: A phase 2, open-label study evaluating the safety and efficacy of the PKR activator etavopivat (FT-4202) in patients with thalassemia or sickle cell disease: **A. Lal** (15mins)

Long-Term Safety and Efficacy of Voxelotor for Patients With Sickle Cell Disease: Results From an Open-Label Extension of the Phase 3 HOPE Trial: **Maureen Achebe** (15mins)

Long-term efficacy and safety of the oral pyruvate kinase activator mitapivat in adults with non-Transfusion-dependent alpha- or beta-thalassemia: **K.H.M Kuo** (15mins)

P-Selectin Inhibitor Inclacumab Reduces Cell Adhesion in an In-Vitro Assays Showing Potential for Prevention of Vaso-Occlusion Events in Sickle Cell Disease: **Michael Tarasev** (15mins)



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# Day 01

26TH JANUARY 2022

Continued

11.45 – 12.00

**BREAK**

12.00 – 13.00

**SPONSOR PROGRAMME:** **GBT**

13.00 – 13.15

**BREAK**

13.15 – 14.00

**SPONSOR PROGRAMME:** **Agios**

14.00 – 16.00

**PARALLEL SCD PATIENTS EDUCATIONAL SESSION:**

**ERN-EuroBloodNet & ASCAT**

**Spotlight on Racism**

An Interactive Webinar with Patient Testimonies and Lead by Expert Physicians.  
Open Discussion with the Audience.

**Moderators:** *Mariane de Montalebert*, SCD expert physician, AP-HP Hôpital Necker &  
*Noémi Roy*, Oxford University Hospitals, NHS Trust & A patient representative

**Speakers:** *Dr Noémi Roy*, SCD expert physician, Oxford University Hospitals, NHS Trust &  
*Dr Zeshan Quershi*, University of Cambridge, paediatrician & a patient representative

15.00 – 16.30

**SPONSOR PROGRAMME:** **Novartis**



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# Day 01

## 26TH JANUARY 2022

Continued

16.30 – 18.00

### ORAL ABSTRACTS – PARALLEL SESSION FOUR:

Andrew Cambell (Chair)

The Role of the Microbiome as a Sickle Cell Disease Modifier: An Expert Review:  
*Chandre Oosterwyk (15mins)*

A severe mouse model of alpha-thalassemia shows abnormal iron metabolism, erythropoiesis and coagulation, and can be rescued by a novel gene therapy approach: *Stefano Rivella (15mins)*

Long-term efficacy and safety of deferiprone for patients with sickle cell disease or other anemias: *Bl. Inusa (15mins)*

Safety and efficacy of crizanlizumab in adolescents with sickle cell disease (SCD): initial data from the Phase II, multicenter, open-label SOLACE-kids trial: *M.M. Henney (15mins)*

Safety and efficacy of early-start deferiprone in infants and young children with beta-thalassemia (START study): *M.H. Hamdy (15mins)*

Comparative Score of Howell-Jolly Bodies in Sickle Cell Disease Patients According to Genotype, Age, Splenectomy or Stem Cell Transplantation History: *Francoise Bernaudin (15mins)*

16.30 – 18.30

### PARALLEL SCD PATIENTS EDUCATIONAL SESSION:

ERN-EuroBloodNet & ASCAT

#### Spotlight on Mental Health

An interactive webinar with patients testimonies and lead by two specialised psychologists. Open discussion with the audience.

**Moderator:** *Raffaella Colombatti*, SCD expert physician, AUO Padova, Italy

**Speakers:** *Gabriela Medin*, Psychologist and Psychoanalyst, Hospital General Universitario Gregorio Marañón. Madrid & *Adrienne Lerner*, Clinical Psychologist, Psychologue clinicienne, hôpital Louis-Mourier, Colombes



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# Day 01

## 26TH JANUARY 2022

Continued

18.20 – 19.30

**TOPIC: NEW THERAPIES:**

*Biree Andemariam and Miguel Abboud (Chairs)*

Introduction to New Therapies – Chair:

*Biree Andemariam and Miguel Abboud (20mins)*

Real life experience of Novel therapies use: *Dr Julie Kanter (20mins), Dr Biree Andemariam (20mins)*

Pipeline (Emerging Therapies) Where Will They Fit In: *Dr Bart Biemond (30mins)*

19.30 – 19.45

**BREAK**

19:45 – 21.00

**DISCUSSION PANEL:** *Roanna Maharja (Chair)*

Real World Perspectives *Dr Salam Akindi, Dr Jo Howard, Dr Julie Makani*



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# Day 02

## 27TH JANUARY 2022

10.00 – 11.30

### ORAL ABSTRACTS – PARALLEL SESSION FIVE:

**Sama Babiker (Chair)**

Implementation of Hydroxyurea Therapy for Sickle Cell Disease on a Large Scale in Ghana:  
**Kwaku Ohene-Frempong (13mins)**

Consortium on Newborn Screening in Africa for Sickle Cell Disease: **Obiageli Nnodu (13mins)**

Long-term follow up of Dutch patients with SCD diagnosed by neonatal screening - Effect on the morbidity and mortality in the Netherlands: **Caroline Vuong (13mins)**

Acute and chronic pain management in sickle cell disease: outcomes of an English national audit:  
**Sanne Lugthart (13mins)**

Brain perfusion changes in beta-thalassemia: **Renzo Manara (13mins)**

Processing Speed Declines Over Time in 4--25-Year-Olds with Sickle Cell Disease:  
**Elise Walker (13mins)**

10.00 – 11.30

### ORAL ABSTRACTS – PARALLEL SESSION ONE:

**Wale Atoyebi (Chair)**

An EU - ARISE initiative gap analysis approach to improving the quality of laboratory systems in sub-Saharan Africa: **Wale Atoyebi (13mins)**

Regional assessment of the experiences of healthcare professionals (HCPs) treating patients with sickle cell disease (SCD): the international Sickle Cell World Assessment Survey (SWAY):  
**L. Osunkwo (13mins)**

Reduced rate of vaso-occlusive crises (VOCs) in patients (pts) with sickle cell disease (SCD) treated with crizanlizumab for 12 months: results from a real-world, managed access program (MAP): **A.C. Silva-Pinto (13mins)**

Continuous Quality Improvement in Paediatric Sickle Cell Disease: **Emtan Ahemad (13mins)**

Adverse Events Following COVID-19 Vaccination in Transfusion-Dependent -Thalassemia Patients:  
**Polyxeni Delaporta (13mins)**

Cost of illness, Epidemiology and Healthcare resource utilization for Sickle Cell Disease in Gulf Countries (CESCGU): **Ahmed Ibrahim (13mins)**



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# Day 02

## 27TH JANUARY 2022

Continued

11.30 – 14.05

### PARALLEL TOPIC – MANAGEMENT OF SICKLE CELL DISEASE IN PAEDIATRICS: *Russel Ware (Chair)*

Introduction to Management of Sickle Cell Disease in Paediatrics – Chair: *Russel Ware (5mins)*

Discussion Panel – Newborn sickle cell disease screening and early testing: global approach to address challenges and opportunities: **Europe – *Stephan Lobitz*, Brazil – *Ana Cristina Silva Pinto*, India – *Dr Dipty Jain*, *Dr Jacques Elion*, CONSA – *Dr Obiageli Nnodu* (20mins)**

Break (15mins)

Newborn screening and early testing: challenges and opportunities: *Dr Venee Tubman* (10mins)

Hydroxyurea therapy –Sub-Saharan Africa: *Dr Leon Tshilolo* (10mins)

Changing the Clinical Paradigm Through Precision Medicine: *Dr Patrick McGann* (20mins)

11.30 – 14.05

### PARALLEL TOPIC – CLINICAL MANAGEMENT: *Dr Rachel Kesse-Adu (Chair)*

Introduction of clinical management – Chair: *Dr Rachel Kesse-Adu (Chair)* (10mins)

Asthma diagnosis and treatment in SCD: *Dr Atul Gupta* (25mins)

Acute Chest syndrome –Clinical Management: *Dr Subarna Chakravorty* (25mins)

Cerebrovascular damage and neurocognitive complications : time to screen early: *Dr Raffaella Colombatti* (25mins)

Managing Chronic Pain During Transition from Paediatric to Adult Care: *Dr Ify Osunkwo* (25mins)

The Management of Avascular Necrosis in Sickle Cell Disease: *Marcus Bankes* (25mins)

Discussion (30mins)

14.05 – 14.20

**BREAK**



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Continued

14.20 – 17.00

### PARALLEL GLOBAL AGENDA: *Dr Isaac Odame* (Chair)

Burden of Disease - Chair: *Dr Isaac Odame* (10mins)

Overview of Diagnostic Dilemmas in Sickle cell disease and Thalassaemia:  
*Dr Antonio Piga* (20mins)

Global Perspective on Thalassaemia Prevention: *Dr Michael Angastiniotis* (25mins)

Panel Discussion: 'Compassion fatigue and how they have managed it', moderated by *Maria Caparellini* and *Rachel Kesse-Adu*. Panel: *Dr Russell Ware, Dr Mona Hamdy, Dr Mariane de Montalembert, Dr Miguel Abboud, Dr Mark Layton, Dr Hatoon Ezzatt* (50mins)

14.30 – 16.30

### PARALLEL SCD PATIENTS EDUCATIONAL SESSION:

ERN-EuroBloodNet & ASCAT

#### Spotlight on Pregnancy

An interactive panel lead by one expert physician, one specialised obstetrician and two patients representatives. Open discussion with the audience.

**Moderators:** *Celeste Bento*, SCD expert physician, Centro Hospitalar e Universitário de Coimbra, EPE, G. Eda Ömür

**Speaker:** *Prof Oteng-Ntim Eugene*, Consultant Obstetrician (Guy's and St Thomas' NHS Foundation Trust), Professor of Obstetrics (King's College London) & an expert physician

17.05 – 17.20

BREAK



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17.00 – 19.25

**PANEL SYMPOSIUM:** John James (Chair)

Addressing Inequalities in Sickle cell disease - Introduction: **John James** (10mins)

To address the problem of inequalities in service provision and how to address the gaps in policy, practice and Patient Experience. Highlighted in a number of national reports No one is listening –UK, National Academics of Science, medicine and Science (NASEM), American Society of Hematology (ASH)- US, as well as Africa, Europe, and the Lancet group.

*Hon McFadden MP, Dawn Butler MP (30mins)*

*Dr Lola Oni (15mins)*

*Dr Michael DeBaun (20mins)*

*Dr Kim Whitely-Smith (20mins)*

*Dr Mariane DeMontalambert (15mins)*

*Mrs Bola Ojo (15mins)*

19.25 – 20.30

**Q&A SESSION**





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# Day 03

## 28TH OCTOBER 2022

10.30 – 12.20

**TOPICS:** *Dr Maria Domenica Cappellini (Chair)*

Chair: *Dr Maria Domenica Cappellini (10mins)*

Current and Future Perspectives in Bone Marrow Transplantation for Thalassaemia:  
*Dr Donatella Baronciani (20mins)*

Gene Editing in Haemoglobinopathies: *Dr Annarita Miccio (20mins)*

Setting up a molecular Research Laboratory Research Programme in Sickle cell disease:  
*Dr John Strouboulis (20mins)*

Setting up a genetic Laboratory Research Programme in Africa: *Dr Ambroise Wonkam (20mins)*

The Promise of Novel Pharmacological Agents I in Thalassaemia: *Dr Kevin Kuo (20mins)*

12.20 – 12.35

**BREAK**

12.35 – 13.45

**TOPICS CONTINUED:** *Dr Maria Domenica Cappellini (Chair)*

Curative v Maintenance therapy - Chair: *Dr Maria Domenica Cappellini (10mins)*

Round table Panel on Curative v Maintenance therapy

PANELLISTS: *Ali Taher, J. Porter, V. Viprasit, A. Kattamis, Josu Delafuente, T Coates (70mins)*

14.00 – 16.20

**PARALLEL TOPIC - PSYCHOLOGICAL AND MENTAL HEALTH IN HAEMOGLOBINOPATHIES:** *Marsha Treadwell (Moderator)*

The importance of Neuropsychological assessment for adults: *Judith Cavazos (20mins)*  
STIGMA: *Kofi Anie (20mins)*

Transition practices for Haemoglobinopathies: *Sarah Brennan and Hatel Bhatt (25mins)*

Mental Health and Curative Therapy: *Jerlym Porter (20mins)*

Factors associated with Adherence with Therapies: *Susan Creary (20mins)*

General/Panel Discussion: Moderated by *Marsha Treadwell (30mins)*

16.20 – 16.50

**BREAK**



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14.00 – 16.00

**PARALLEL SCD PATIENTS EDUCATIONAL SESSION:**

ERN-EuroBloodNet & ASCAT

**Spotlight on Bone Marrow Transplant**

An interactive panel lead by one expert physician, one specialised nurse and two patients representatives. Open discussion with the audience.

**Moderator:** *Subarna Chakravorty*, SCD expert physician, King's College Hospital NHS Foundation Trust

**Speakers:** *Marco Zecca*, BMT physician, Fondazione I.R.C.C.S. Policlinico "San Matteo", Pavia

16.20 – 16.50

**BREAK**

16.50 – 18.50

**PARALLEL SESSION A – CLINICAL BURDEN OF THALASSEMIA IN OLDER ADULTS: Dr Paul Telfer (Chair)**

Liver Cancer – Chair: *Dr Paul Telfer* (5mins)

Case Presentation: *Junior physician/fellow* (10mins)

State-of-the-art lecture/expert opinion: *Dr Ali Taher* (25mins)

**Cardiac Arrhythmias**

Case Presentation: *Junior physician/fellow* (10mins)

State-of-the-art lecture/expert opinion: *Dr Dimitrios Farmakis* (25mins)

Case Presentation: *Junior physician/fellow* (10mins)

State-of-the-art lecture/expert opinion: *Dr Nikos Skordis* (25mins)

**Fertility and Pregnancy**

Case Presentation: *Physician/ Fellow* (10mins)

State-of-the-art lecture/expert opinion: *Perla Eleftheriou* (30mins)



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17.00 – 19.00

**PARALLEL SESSION B – CLINICAL BURDEN OF SICKLE CELL DISEASE IN ADULTS:** Thomas Coates (Chair)

Chair of sickle cell session: *Thomas Coates (10mins)*

End stage renal Failure

Case presentation: *Junior Physician/Fellow (5mins)*

State-of-the-Art/How I manage: *Dr Claire Sharpe (25mins)*

Pulmonary hypertension

Case presentation: *Junior Physician/Fellow (10mins)*

State-of-the-Art/How I manage: *Dr Liz Klings (25mins)*

Facilitating shared decision-making between providers and families of youth with sickle cell disease?

State-of-the-Art/How I manage: *Dr Lori Crosby (30mins)*

Pregnancy: When to Offer Blood Transfusion

Case presentation (10mins)

State-of-the-Art/How I manage: *Dr Eugene Oteng-Ntim (30mins)*

19.20 – 19.35

**BREAK**

19.45 – 20.10

**PLENARY PATIENT FEEDBACK:** Mariangela Pellegrini

Participants to the ERN-EuroBloodNet&ASCAT SCD Patients Educational sessions presenting the feedback of the program to the plenary session of ASCAT 2022

20.10 – 20.25

**HISTORY OF RACISM:** Zeshan Qureshi



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20.25 – 20.40

**RACIAL BIAS:** Raselle Miller

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20.40 – 20.50

**FEEDBACK FROM PATIENT WORKSHOPS ON RACE:** Oxford Support Team

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20.50 – 21.20

**WRAP SESSION:** Andrew Campbell, Crawford Strunk, Baba Inusa

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