

Day One: Wednesday 7 October 2015

08:00-09:00 Registration and Coffee

09:10-09:15 Welcome – **Dr Eugene Oteng-Ntim**; *Guy's and St Thomas NHS Trust*

- **Associate Professor Baba Inusa**; *Evelina, Guy's and St Thomas NHS Trust, London* - Overview of Sickle Cell Disease and treatment options
- **Professor Sebastian Lucas**; *King's College London* - Pathology of Sickle Cell Disease
- **Professor Antonio Piga** *School of Medicine, S. Luigi Gonzaga site University of Torino, Italy*- Assessment and management of iron overload in β -Thalassaemia major patients during the 21st century: a real-life experience from the Italian WEBTHAL project.

10:40-11:00 Coffee Break

11:00-12:50 Parallel session A: Determinants of Sickle Cell Disease Severity

- **Professor David Rees**; *Paediatric Haematology, King's College Hospital, King's College London* - Environmental determinants of severity
- **Dr Stephan Menzel**; *Molecular Genetics, King's College London* - Genetic determinants of severity
- **Dr Valentine Brousse**; *Hôpital universitaire Necker-Enfants malades, France* - Biomarkers of severity
- Oral abstract to be chosen

Parallel session B: Laboratory Diagnosis

- **Dr Vishal Jayakar**; *St George's London* - Morphology cases (Quiz)
- **Dr Yvonne Daniels**; *Viapath Guy's Hospital, London* - Laboratory Diagnosis of haemoglobinopathy with HPLC examples
- **Dr Mary Petrou** *Department of Haematology; University College Hospital, London* - Molecular diagnostics in haemoglobinopathy
- **Dr Noémi Roy**- Haemoglobin switching

12:50-14:00 Lunch

Meet the Expert

- **Professor Antonio Piga** - The management of Thalassaemia in Europe
- **Professor David Rees** - Vitamin D in Sickle Cell Disease – when to treat
- **Mrs Yvonne Harrington** – Meet the bone marrow transplant co-ordinator

14:00-15:40 USA NIH Clinical Excellence Research Centres

- **Associate Professor Charles Quinn**; *Cincinnati Children's Hospital* - The Cardiomyopathy of Sickle Cell Disease
- **Professor Kalpna Gupta**; *University of Minnesota Medical School* - Molecular Mechanisms of Pain in Sickle Cell Disease
- **Associate Professor Solomon Ofori-Acquah**; *School of Medicine; University of Pittsburgh* - Novel Insights into the Pathogenesis of Acute Chest Syndrome
- Oral abstract to be chosen

15:40-16:00 Coffee Break

16:00-17:00 Highlights from other international meetings

Chair: **Dr Andrew Campbell**; *University of Michigan*

- **Associate Professor Lanetta Jordan**; *Foundation for Sickle Cell Disease Research (FSCDR)* - Highlights from the 2014 FSCDR Sickle Cell Meeting and Overview of the 2015 10th Anniversary Meeting
- **Professor Adekunle Adekile**; *Faculty of Medicine, Kuwait University* - Highlights of the 2015 World Sickle Cell Day Conference in Abuja, Nigeria

17:00-18:00 Poster walk and Refreshments

Day Two: Thursday 8 October 2015

08:00-09:00 Meet the Experts –

- **Emeritus Professor Kwaku Ohene-Frempong**; Philadelphia and **Associate Professor Solomon Ofori-Acquah**; University of Pittsburgh – Establishing North-South Collaboration
- **Professor Kathryn Hassell** – Research Opportunities for Adult patients with a haemoglobinopathy
- **Dr Marsha Treadwell** – Assessing and managing mental health in haemoglobinopathies

09:00-10:45 Thalassaemia Plenary Session

- **Dr Banu Kaya**; Department of Paediatric Haematology and Oncology, Barts Health NHS Trust, Royal London Hospital, London – Iron chelation in paediatric patients with haemoglobinopathies
- **Associate Professor Antonis Kattamis**; First Department of Pediatrics; University of Athens, Athens, Greece - Endocrine and bone complications in β -thalassaemia: current understanding and treatment.
- **Professor Ali Taher**; Department of Internal Medicine, American University of Beirut Medical Centre, Beirut, Lebanon (Electronic Address) - Guidelines for diagnosis and management of Beta-Thalassaemia intermedia.
- **Dr Maddalena Casale**; Centro pere la Cura delle Microcitemie, Cardarelli Hospital, Napoli, Italy – Multiparametric Cardiac Magnetic Resonance Survey in Children with Thalassaemia Major; A Multicenter Study

10:45-11:00 Coffee break

11:15-13:00 Break out session

Parallel session C - Psychosocial theme led by Marsha Treadwell HRQOL-

- **Dr Jerlym Porter, PhD** St. Jude Children's Research Hospital- Quality of life in children with sickle cell disease
- **Dr Marsha Treadwell, PhD UCSF Benioff Children's Hospital Oakland**: Quality of life and quality of care in adults with sickle cell disease
- **Dr Kofi Anie PhD**; Haematology and Sickle Cell Centre, London North West Healthcare NHS Trust, Central Middlesex Hospital, Acton Lane, London- Pain and quality of life in hospital for adults with sickle cell disease
- Oral Abstract to be chosen

Parallel session D - Complications in sickle cell disease in the adult patient - Chair: **Dr Biree Andemariam**, Department of Hematology, University of Connecticut SOM

- **Dr Moji Awogbade**; Department of Haematology, King's College London- Cerebrovascular disease
- **Professor Kathryn Hassell**; Professor of Medicine, Division of Hematology, Department of Medicine, University of Colorado Anschutz Medical Campus, Aurora: Venous thromboembolism
- **Associate Professor Elizabeth Klings**; The Pulmonary Center, Boston University School of Medicine, Boston, MA. -Pulmonary Hypertension in Sickle cell disease.
- Abstract to be chosen

13:00-14:00 Lunch and Meet the Expert sessions

- **Professor Winfred Wang**; St. Jude's Children's hospital, Memphis - Hydroxyurea therapy in Sickle Cell Disease
- **Professor Ali Taher** – The management of Thalassaemia including Thalassaemia intermedia

- **Associate Professor Antonis Kattamis**; Athens - The Role Prevention in Thalassaemia

Educational session 14:00-16:00

Parallel session E

- **Dr Claire Sharpe**; Department of Nephrology, King's College London - Renal complications of Sickle Cell Disease
- **Professor Sophie Lanzkron**; Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland - Impact of a dedicated infusion clinic for acute management of adults with sickle cell pain crisis.
- **Mr Marcus Bankes**; Department of Orthopaedics, Guy's and St Thomas NHS Trust, London - Avascular Necrosis in Sickle Cell Disease
- **Dr Eugene Oteng-Ntim**; Department of Obstetrics, Guy's and St Thomas NHS Trust - Pregnancy in Haemoglobinopathies

Parallel session F

- **Dr Malcolm Walker**; Department of Cardiology, University College Hospital, London - Managing Cardiac Complications in Thalassaemia
- **Dr Alessia Pepe**; aCMR Unit, Fondazione 'G. Monasterio' CNR-Regione Toscana, Pisa bEmatologia-Emoglobinopatie, Civico ARNAS Hospital, Palermo - Cardiac MRI in Thalassaemia
- **Dr Sara Trompeter**; Department of Haematology, University College Hospital, London - Transfusion therapy for Thalassaemia – The ultimate goal
- Abstract to be chosen

15:30-16:00 Tea Break

16:00-17:30 Cure for Sickle Cell and Thalassaemia

- **Professor Alexis Thompson**; 1Lurie Children's Hospital Chicago, IL- Overview of transplantation in hemoglobinopathies-historical perspective focused on hla matched sibling with myeloablative or reduced intensity
- **Dr Josu De La Fuente**; Department of Haematology, Imperial College London and Imperial Healthcare NHS Trust, London - Novel approaches to transplantation in sickle cell and thalassemia- newer data on unrelated donor and haploidentical transplants
- **Professor Marina Cavazzana**; Institut National de la Santé et de la Recherche Médicale, Unité 768, Paris, France - Gene therapy in sickle cell disease and Thalassaemia - preclinical and clinical studies to date

19:00 Faculty Dinner

Day Three: Friday 9 October 2015

08:00-09:00 Meet the Expert:

A – Laboratory practice

Associate Professor Jo Howard; *Department of Haematology, GSTT - Management of Acute Chest syndrome in sickle cell disease*

B – Nursing management

1. **Mr Luhanga Musumadi**; *Guy's and St Thomas NHS Foundation Trust – Transition from Paediatric to Adult care*
2. **Mr Neil Westergate**; *Guy's and St Thomas NHS Foundation Trust – Extended nursing role in patient care for haemoglobinopathies*
3. Abstract to be chosen

09:00-11:00 Parallel session G - Global Burden of SCD

- **Dr Fred Piel**, *Oxford University, Oxford - Global burden of Sickle Cell Anaemia*
- **Professor Cherif Rahimy**; *Faculty of Health Sciences Cotonou, Benin Republic - Lessons from 22 years in improving health of children and pregnant women with SCD in a Sub-Saharan Africa setting*
- **Emeritus Professor Kwaku Ohene-Frempong**; *Children's Hospital Philadelphia - Addressing the challenge of Sickle Cell Disease*

09:00-11:00 Parallel session H - CNS complications in SCD

- **Dr Najibah Galadanci**; *Department of Haematology and Blood Transfusion, Bayero University/Aminu Kano Teaching Hospital, Kano, Nigeria - Prevention and Management of Stroke in Sickle Cell Disease in Nigeria; Progress of the SPIN Trial*
- **Professor Fenella Kirkham**; *From the Development of Clinical Neurosciences Section, UCL Institute of Child Health, London - Neurocognition in Sickle Cell Disease*
- **Professor Winfred Wang**; *Department of Hematology, St. Jude Children's Research Hospital, Memphis, TN, USA - The Significance of Silent Cerebral Infarcts in Children with Sickle Cell Anaemia*

11:00-11:30 Coffee

11:30-13:00 Developing Clinical and Research Capacity for Haemoglobinopathies

Parallel session K - Sub-Saharan Africa

- **Dr Eugenia Vicky Asare**; *Ghana Institute of Clinical Genetics, Korle-Bu Teaching Hospital, Accra, Ghana – Burden of Adult Sickle Cell Disease: Management and challenges*
- **Professor Ambroise Wonkam**; *Division of Human Genetics, Faculty of Health Sciences, University of Cape Town, Cape Town, Republic of South Africa - Perspectives in Genetics and Secondary Prevention in Sickle Cell Disease*
- **Professor Leon Tshilolo**; *Monkole/Centre de Formation et d'Appui Sanitaire (CEFA), Kinshasa, DR Congo - Sickle Cell Anaemia in Central Africa: Environment, Genetics and Clinical features.*
- **Dr Rosemary Ekong**; *University College London – Gene-Disease Databases: Opportunities for research and development in sub-Saharan Africa*

Parallel session L - Europe

- **Dr Stephan Lobitz**; *Charité - Universitätsmedizin Berlin, Klinik für Pädiatrie mit Schwerpunkt Onkologie/Hämatologie/KMT, Germany - Neglect of sickle cell disease in Germany: The example of newborn screening*
- **Professor Mariane De Montalembert**, *Hôpital universitaire Necker-Enfants malades, France - Challenges for the management of sickle cell disease in France*
- **Dr Raffaella Colombatti**; *Azienda Ospedaliera-Università di Padova, Italy - The care of sickle cell patients in Italy: psychosocial issues and Hydroxyurea treatment availability*

13:00-14:00 Lunch

14:00-16:00 Drug therapies in Sickle Cell and Thalassaemia

- **Professor Clarisse Lobo**; *Clinical Hematology Division, Instituto de Hematologia Arthur de Siqueira Cavalcanti - HEMORIO, Rio de Janeiro, Brazil* - Impact of Hydroxyurea therapy on SCD in children: Brazilian experience
- **Professor John Porter**; *Department of Hematology, UCL Cancer Institute, University College London, London, United Kingdom* - New Drug Therapies in Thalassaemia
- **Professor Miguel Abboud**; *Department of Pediatrics and Adolescent Medicine, American University of Beirut, Beirut, Lebanon* - New Drug therapies in Sickle Cell Disease

16:00-16:05 Close