SCiF
SICKLE CELL IN FOCUS
LONDON • WASHINGTON

THE 10TH SICKLE CELL IN FOCUS CONFERENCE

June 2 - 3, 2016

Natcher Conference Center

National Heart, Lung and Blood Institute (NHLBI)

National Institutes of Health (NIH)

Bethesda, near WASHINGTON DC, USA

NIH National Heart, Lung, and Blood Institute

South Thames Sickle Cell & Thalassaemia Network

KING'S HEALTH PARTNERS


NATIONAL INSTITUTES OF HEALTH

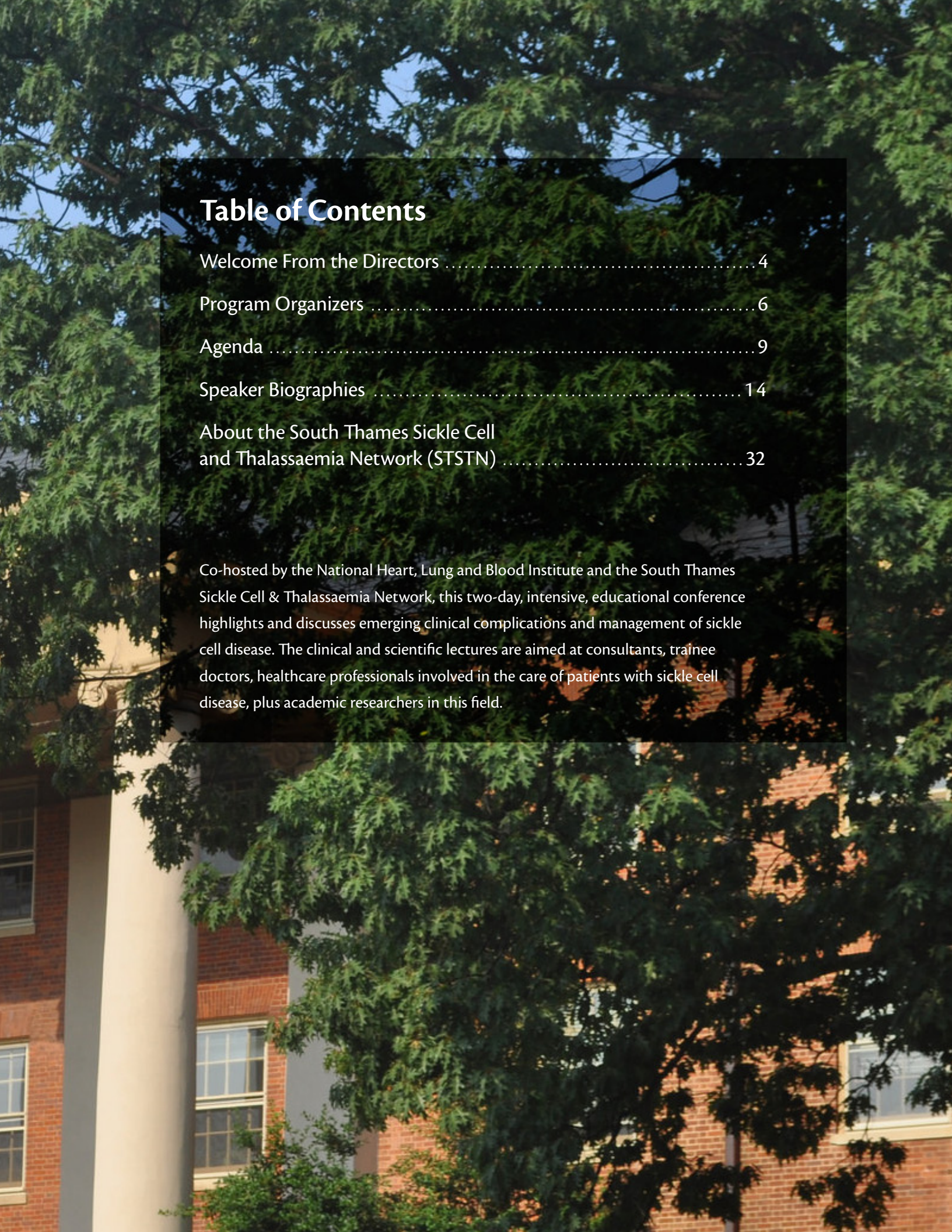


Table of Contents

Co-hosted by the National Heart, Lung and Blood Institute and the South Thames Sickle Cell & Thalassaemia Network, this two-day, intensive, educational conference highlights and discusses emerging clinical complications and management of sickle cell disease. The clinical and scientific lectures are aimed at consultants, trainee doctors, healthcare professionals involved in the care of patients with sickle cell disease, plus academic researchers in this field.

PROGRAM DIRECTORS

Welcome

Hello and a very warm welcome to SCiF 2016, once again hosted by the National Heart, Lung and Blood Institute, NIH in Bethesda.

This year we are going global with speakers (Kathy Hassell, Beatrice Gulbis, Dapa Diallo, Jennifer Knight, Anna Barbara Proietti, and Roshan Colah) giving perspectives of how SCD is a health issue in their respective countries and possibilities of collaboration. Sickle cell disease has much in common with Malaria, and has been referred to as a "Neglected Tropical Disease". This year we have devoted a session with Tom Williams, Hans Ackerman and Ming Dao, who will present on their commonalities in pathology and diagnostic platforms. SCD is often considered a chronic inflammatory disease; after an introduction on inflammation in health and disease by Fayyaz Sutterwala, John Belcher and Dachuan Zhang will tell us about the drivers of inflammation in SCD.

We continue on with our comprehensive update on management of newborn screening (Carolyn Hoppe), clinical trials (Deepa Manwani), bone marrow transplants (John Horan), the use of hydroxyurea (Jane Hankins) and blood transfusions (Stella Chou), while Patrick Carroll and Deepika Darbari will update us on the most recent research and management of pain in our patients. With hypoxia remaining a concern for all clinical investigators, Roberto Machado will present on some of the causes and complications in managing hypoxia. Kenneth Ataga will conclude our update on management session with his presentation on "Coagulation activation in sickle cell disease."

Genetics and genomics loom large in SCD. Stephen Chanock, a leading expert on discovery of common inherited genetic variants associated with cancer risk and outcomes will share his expertise on genetics and genomics in clinical studies. Swee Lay Thein will review genetic studies carried out in SCD to date, while Dan Bauer and John Tisdale will speak on how genetics is transforming our approach to hemoglobin disorders. But, environment has a big impact on SCD, and David Rees will report to us on the environmental determinants on SCD severity.

One feature that continues to make SCiF a unique conference is our debates between experts on current controversial topics in SCD. This year, the debates will explore opposing views (Michael Debaun and Elliott Vichinsky) on the use of hematopoietic stem cell transplantation (HSCT) as a therapy for secondary prevention of "silent" stroke, and the effect of the transition to adult care on the mortality of young adults with SCD (Mariane de Montalembert and Sophie Lanzkron).

We are privileged and grateful to have so many speakers who have come to share their research and expertise, making SCiF an educational experience. A special thanks to NIH Director, Francis Collins and NHLBI Director, Gary Gibbons for being a part of this year's conference and for their invaluable support in sickle cell research. Most importantly, we would like to thank our attendees, some of whom have travelled long distances. It is your participation that motivates the mission of Sickle Cell in Focus.

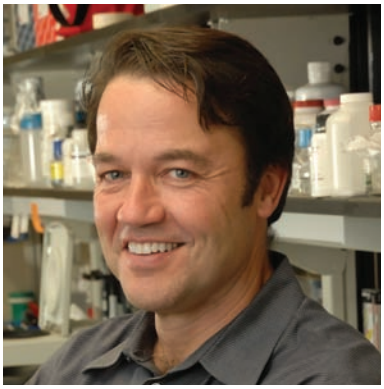
We sincerely hope you will enjoy SCiF 2016. Please take a moment to complete the evaluation form at the end of the conference. Your feedback is vital in making Sickle Cell in Focus an exciting and impactful conference.

Best Wishes,

Swee Lay Thein & John Tisdale

Swee Lay Thein, M.B,B.S., FRCP, FRCPath, D.Sc.
Senior Investigator and Chief
Sickle Cell Branch
NHLBI, National Institutes of Health

Email: sl.thein@nih.gov



John F. Tisdale, M.D.
Senior Investigator
Molecular and Clinical Hematology Branch
NHLBI, National Institutes of Health

Email: johntis@nhlbi.nih.gov

MEETING ORGANIZERS

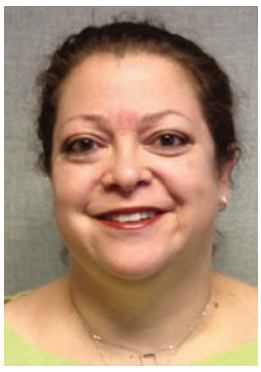
Annabelle Kelly
Manager
South Thames Sickle Cell Network (STSTN), King's College Hospital, London
Email: belle.kelly@kcl.ac.uk / info@ststn.co.uk

After graduating with a BA (Hons) in Print and Broadcast Journalism, Annabelle has worked in a variety of administration roles and now has over 12 years experience as a creative, senior business administrator.

She began working with Professor Swee Lay Thein in 2007, first as Division Manager for the Division of Gene and Cell Based Therapy at King's College London, before taking up her current role in 2011 as the Manager for the South Thames Sickle Cell Network (STSTN), based at King's College Hospital, London.

Annabelle is also a Counsellor and Psychotherapist and works in the NHS and private practice providing short and long term counselling and psychotherapy to adult clients.

This is Annabelle's 10th year of organising Sickle Cell in Focus and she is grateful to the NHLBI and NIH for supporting this global event. Unfortunately, Annabelle won't be joining you in Bethesda this year, but she hopes you all have an exciting and inspirational time. SCiF wouldn't have grown to become such a respected international conference without the commitment of the speakers and enthusiastic delegates who attend each year. For this she extends her thanks and a special thank you to Karen Kendrick and Emily Moldiz for all their hard work and excellent organisation for this year's event.



Karen Kendrick
Program Technician
NHLBI, National Institutes of Health
Email: karen.kendrick@nih.gov

Karen Kendrick is very excited to take part in planning this year's conference. Karen is responsible for the administration for Drs. Griffin Rodgers' lab and John Tisdale's labs: Molecular, Clinical Hematology Branch, National Heart Lung and Blood at the National Institutes of Health. This is her third time planning the SCiF conference, however, it is the first one without the presence of Annabelle Kelly.

Emily Moldiz
Administrative Assistant
Sickle Cell Branch, NHLBI, National Institutes of Health
Email: emily.moldiz@nih.gov

Emily Moldiz serves as the Administrative Assistant for Dr. Swee Lay Thein and the Sickle Cell Branch at the National Institutes of Health. After graduating with a degree in history and journalism, Emily moved from the Midwest to Maryland in 2013 where she started at NIH as a Program Technician and Sickle Cell Patient Care Coordinator. In her spare time, Emily enjoys watching nerdy Marvel movies with her husband and spending time with her two daughters. She is excited to join Annabelle and Karen in organizing Sickle Cell in Focus 2016.

8:00am **Registration**

9:00am **Welcome and Introduction**
Gary Gibbons, Director
National Heart, Lung and Blood Institute, National Institutes of Health

SESSION ONE – CHAIR: Kwaku Ohene-Frempong, *The Children's Hospital of Philadelphia, USA*

SICKLE CELL DISEASE: A GLOBAL HEALTH ISSUE

9:05am **United States of America**
Kathy Hassell
Colorado Sickle Cell Treatment and Research Center, University of Colorado, USA

9:20am **Europe**
Beatrice Gulbis
Department of Clinical Chemistry and Molecular genetic - Hôpital Erasme - U.L.B, Belgium

9:35am **Africa**
Dapa A. Diallo
Department of Hematology, Faculty of Medicine & Dentistry University of Bamako, Mali

CHAIR: **Norma Lerner,** *Division of Blood Diseases and Resources/National Institutes of Health, USA*

9:50am **The Caribbean**
Jennifer Knight
Sickle Cell Unit, Tropical Medicine Research Unit, University Hospital of the West Indies, Jamaica

10:05am **Brazil**
Anna Barbara Proietti
Fundação Hemominas, Belo Horizonte, Brazil

10:20am **India**
Roshan B. Colah
National Institute of Immunohaematology, Mumbai, India

10.35am **BREAK**

Agenda – THURSDAY JUNE 2, 2016

SESSION TWO – CHAIR: Bill Eaton, *National Institute of Diabetes and Digestive Kidney Diseases / NIH, USA*

SICKLE CELL DISEASE AND MALARIA – MORE THAN JUST A BALANCING ACT?

11:05am **Protective role of HbS and other red blood cell defects on malaria**
Tom Williams
Department of Medicine at Imperial College London, UK / KEMRI-Wellcome Trust Collaborative Programme, Kilifi, Kenya

11:35am **The impact of iron availability on malaria and sickle cell disease severity**
Hans Ackerman
National Heart, Lung and Blood Institute / National Institutes of Health, USA

12:05pm **A microfluidic platform to assess biorheology in malaria and sickle cell disease**
Subra Suresh[1] & Ming Dao[2]
[1]*Carnegie Mellon University, Pittsburgh, USA*
[2]*Massachusetts Institute of Technology, USA*

12:35pm **LUNCH**

SESSION THREE – CHAIR: Alan Schechter, , *National Institute of Diabetes and Digestive Kidney Diseases / NIH, USA*

VASCULAR INJURY AND INFLAMMATION IN SICKLE CELL DISEASE

1:35pm **Inflammasomes in health and disease**
Fayyaz Sutterwala
University of Iowa, USA

2:05pm **TLRs, inflammation and sickle cell disease - the innate connection**
John Belcher
Division of Hematology, Oncology and Transplantation, University of Minnesota, USA

2.35pm **Drivers of inflammation in sickle cell disease - Role of neutrophils**
Dachuan Zhang
Albert Einstein College of Medicine, New York, USA

3:05pm **BREAK**

SESSION FOUR – CHAIR: Laura De Castro, *University of Pittsburgh Medical Center, USA*

UPDATES

3:30pm **Newborn screening and point-of-care testing in developing countries**
Carolyn Hoppe
Children's Hospital & Research Center, Oakland, USA

3:55pm **Clinical trials**
Deepa Manwani
The Children's Hospital at Montefiore, New York, USA

4:20pm **Bone marrow transplant**
John Horan
Children's Healthcare of Atlanta, USA

4:45pm **SHORT BREAK**

SESSION FIVE – CHAIR: Oswaldo Castro, *Howard University College of Medicine, USA*

DEBATE: **HSCT IS RECOMMENDED FOR SECONDARY PREVENTION OF CEREBROVASCULAR INFARCTS IN SCD?**

5:00pm ***Pro:*** Michael DeBaun
Vanderbilt University School of Medicine, USA

5:20pm ***Con:*** Elliott Vichinsky
Children's Hospital & Research Center, Oakland, USA

5:40pm **Debate**

6:00pm **DAY ONE CLOSE**

Please note: all details are subject to change at short notice

Agenda – FRIDAY JUNE 3, 2016

8:00am **Registration**

9:00am **Welcome and Introduction**
Francis Collins, Director
National Institutes of Health, USA

SESSION ONE – CHAIR: David Bodine, *National Human Genome Research Institute / NIH, USA*

GENETICS AND GENOMICS: PRIME TIME IN HEMOGLOBIN DISORDERS?

9:05am **Genetics and genomics in clinical studies –potentials and pitfalls**
Steve Chanock
National Cancer Institute, Division of Cancer Epidemiology & Genetics, NIH, USA

9:35am **Impact of genetics and genomics in sickle cell disease**
Swee Lay Thein
National Heart, Lung and Blood Institute, NIH, USA

10:05am **Gene therapy**
John Tisdale
National Heart, Lung and Blood Institute, NIH, USA

10:35am **BREAK**

SESSION ONE (CONT...) – CHAIR: Courtney Fitzhugh, *National Heart, Lung, and Blood Institute / NIH, USA*

11:00am **Application of genome editing in hemoglobin disorders**
Dan Bauer
Children's Hospital Boston, USA

11:30pm **Environmental determinants of disease severity**
David Rees
King's College Hospital NHS Foundation Trust / King's College London, UK

12:00pm **SHORT BREAK**

SESSION TWO – CHAIR: Samir Ballas, *Thomas Jefferson University, USA*

UPDATES ON MANAGEMENT (PART ONE)

12:15pm **Management of pain and opioid use in patients with sickle cell disease**
Patrick Carroll
Johns Hopkins University School of Medicine, Baltimore, USA

12:40pm **Inflammation and pain in sickle cell disease**
Deepika Darbari
Children's National Medical Center, Washington DC, USA

1:05 pm **Causes, complications and management of hypoxia in sickle cell disease**
Roberto Machado
University of Illinois College of Medicine at Chicago, USA

1:30pm **LUNCH**

SESSION THREE – CHAIR: Paul Swerdlow, *Wayne State University / Karmanos Cancer Center, USA*

UPDATES ON MANAGEMENT (PART TWO)

2:30pm **Expanding use of hydroxyurea in sickle cell disease**
Jane Hankins
St Jude Children's Research Hospital, Memphis, USA

2:55pm **Blood transfusion, alloimmunization, and role of genotyping for variant antigens**
Stella Chou
The Children's Hospital of Philadelphia, USA

3:20pm **Coagulation activation in sickle cell disease**
Kenneth Ataga
University of North Carolina at Chapel Hill, USA

3:55pm **BREAK**

SESSION FOUR – CHAIR: Kathy Hassell, *Colorado Sickle Cell Treatment and Research Center, University of Colorado, USA*

DEBATE: **HIGH MORTALITY IN YOUNG ADULTS IS DUE TO BREAKDOWN IN TRANSITION TO ADULT CARE?**

4:25pm ***Yes*:** Mariane de Montalembert
Necker-Enfants Malades Hospital, Paris France

4:45pm ***No*:** Sophie Lanzkron
Johns Hopkins University School of Medicine, Baltimore, USA

5:05pm **Debate**

5:30pm **CLOSE OF CONFERENCE**

SPEAKER BIOGRAPHIES

Kenneth Ataga, M.D.
Professor of Medicine
Director, UNC Comprehensive Sickle Cell Program
Division of Hematology/Oncology
University of North Carolina at Chapel Hill
Email: Kenneth_Ataga@med.unc.edu

Dr. Kenneth I. Ataga obtained his medical degree from the University of Benin, Benin City, Nigeria. Following the completion of a rotating internship at the University of Benin Teaching Hospital, he relocated to the United States, where he completed an internship and residency in Internal Medicine at the State University of New York Health Sciences Center (Upstate Medical University) at Syracuse. Upon completion of his residency, he underwent a clinical and research fellowship in Hematology/Oncology at the University of North Carolina at Chapel Hill under the mentorship of Dr. Eugene Orringer. He is presently Professor of Medicine and Director of the Comprehensive Sickle Cell Program at the University of North Carolina at Chapel Hill.

Dr. Ataga is recognized as an expert in sickle cell disease. His research is focused on the vasculopathy of sickle cell disease, with an emphasis on pulmonary hypertension, renal complications and coagulation activation. In addition, he has a strong research interest in the development of new therapies for sickle cell disease. His research is funded by the National Institutes of Health and the Pharmaceutical Industry.

Daniel E. Bauer, M.D. Ph.D.
Principal Investigator, Boston Children's Hospital
Assistant Professor, Harvard Medical School
Email: daniel.bauer@childrens.harvard.edu

Daniel Bauer is a physician-scientist whose research integrates genetic, epigenetic, and functional genomic methodologies to understand the determinants of blood cell development and develop innovative therapeutic strategies for blood disorders. By comparing common trait-associated genetic variation with epigenetic modification of primary human erythroid precursors, and applying genome editing technology, he identified an erythroid enhancer element of the *BCL11A* gene that is a critical determinant of fetal hemoglobin level and a potential therapeutic target for the β-hemoglobin disorders. His laboratory has developed techniques to perform genome editing using CRISPR-Cas9 RNA-guided endonucleases in hematopoietic cells. He has developed a method termed Cas9-mediated *in situ* saturating mutagenesis to determine at high-throughput and high-resolution the function of non-coding elements in their native chromosomal setting. His clinical work in pediatric hematology focuses on the care of patients with hemoglobin disorders. He received his BS in Biology from Brown University and MD-PhD from the University of Pennsylvania. He completed clinical training in Pediatrics and Pediatric Hematology/Oncology at Boston Children's Hospital and Dana-Farber Cancer Institute. He is a Principal Investigator and Staff Physician at Dana-Farber/Boston Children's Cancer and Blood Disorders Center, where he is Associate Director of the Thalassemia Program. In addition, he is Assistant Professor of Pediatrics at Harvard Medical School, Principal Faculty at the Harvard Stem Cell Institute, and Associate Member of the Broad Institute. He has received awards including the Young Physician-Scientist Award of the ASCI Council, Junior Faculty Scholar Award of the American Society of Hematology, and Career Award for Medical Scientists from the Burroughs Wellcome Fund.

John Belcher, Ph.D.
Associate Professor of Medicine, Division of Hematology, Oncology and Transplantation
University of Minnesota
Email: belcher@umn.edu

Dr. Belcher was born in Roanoke, Virginia and earned his B.A. in Chemistry from the University of Virginia and his Ph.D. in Biochemistry from Bowman Gray Medical Center at Wake Forest University. He completed a post-doctoral fellowship at the Cardiovascular Research Institute at the University of California, San Francisco, before joining the University of Minnesota, Division of Hematology, Oncology and Transplantation in 1996. In collaboration with Dr. Greg Vercellotti, Dr. Belcher's research is focused on the pathobiology of sickle cell disease (SCD)—principally hemoglobin, heme, and iron toxicity to endothelium and the endothelium's adaptive cytoprotective responses. His work has demonstrated that heme is central to the pathobiology of SCD. Currently, he is investigating toll like receptor-4 signaling and complement activation in SCD pathogenesis. His preclinical research is exploring cytoprotective therapies for SCD including carbon monoxide, dimethyl fumarate, haptoglobin, hemopexin, and phosphodiesterase inhibitors. Dr. Belcher's laboratory work is committed to the successful translation of laboratory discoveries into clinical care.

C. Patrick Carroll, M.D.
Director of Psychiatric Services to the Sickle Cell Center for Adults
Service Line Director, *Intensive Treatment Unit*
Assistant Professor, *Psychiatry and Behavioral Sciences, The Johns Hopkins School of Medicine*
Email: ccarrol1@jhmi.edu

Dr. Carroll is an internationally recognized expert in the multidisciplinary management of complex and high utilizing patients with sickle cell disease (SCD). After completing his graduate medical training at Washington University in St. Louis, he completed residency in the Department of Psychiatry and Behavioral Sciences. Thereafter he was a fellow in the Behavioral Pharmacology Research Unit, studying the behavioral pharmacology of opioids. Upon leaving the fellowship, he joined faculty as an associate medical director of Addiction Treatment Services, a leading addiction treatment center at Johns Hopkins Bayview Medical Center. In 2007, he assumed his current role in the Sickle Cell Center for Adults, combining his interests in chronic pain, opioid pharmacology, and the care of complex patients. He attends in the Department of Psychiatry's Pain Treatment Program, an intensive multidisciplinary treatment program for patients with refractory chronic pain or abnormal illness behavior. Recently he assumed the role of service line director for the Intensive Treatment Unit, an inpatient addiction treatment unit with which he has a long association. He has published a number of peer-reviewed papers on SCD pain and treatment utilization, in addition to his earlier work in behavioral pharmacology and addiction treatment. Along with the multidisciplinary team of the Johns Hopkins Sickle Cell Center for Adults, he has been consulted regionally and internationally regarding management of chronic pain, psychiatric illness, and treatment utilization in SCD.

SPEAKER BIOGRAPHIES

Stephen Chanock, M.D.
Director
Division of Cancer Epidemiology and Genetics, National Cancer Institute, NIH
Email: chanocks@mail.nih.gov

Dr. Stephen Chanock is a leading expert in the discovery and characterization of cancer susceptibility regions in the human genome. He has received numerous awards for his scientific contributions to our understanding of common inherited genetic variants associated with cancer risk and outcomes.

Dr. Chanock received his M.D. from Harvard Medical School in 1983 and completed clinical training in pediatrics, pediatric infectious diseases, and pediatric hematology/oncology and research training in molecular genetics at Boston Children's Hospital and the Dana-Farber Cancer Institute, Boston. Since 1995, Dr. Chanock has served as the Medical Director for Camp Fantastic , a week-long recreational camp for pediatric cancer patients, which is a joint venture of the NCI and Special Love, Inc.

From 2001-2007, he was a tenured investigator in the Genomic Variation Section of the Pediatric Oncology Branch in the NCI Center for Cancer Research. He also served as co-chair of NCI's Genetics, Genomics and Proteomics Faculty for five years. In 2001, he was appointed as Chief of the Cancer Genomics Research Laboratory (formerly Core Genotyping Facility), and in 2007 as Chief of the Laboratory of Translational Genomics, both within the NCI Division of Cancer Epidemiology and Genetics (DCEG). Dr. Chanock co-led the Cancer Genetic Markers of Susceptibility project. From 2012 to 2013, he also served as Acting Co-Director of the NCI Center for Cancer Genomics. Dr. Chanock was appointed Director of DCEG in August 2013.

Stella T. Chou, M.D.
Assistant Professor of Pediatrics
The Children's Hospital of Philadelphia
University of Pennsylvania School of Medicine
Email: CHOUS@email.chop.edu

Dr. Stella Chou is an Assistant Professor of Pediatrics at the Perelman School of Medicine at the University of Pennsylvania. She practices Pediatric Hematology and Transfusion Medicine at The Children's Hospital of Philadelphia (USA) with a particular interest in patients with Sickle Cell Disease. Her work has demonstrated that inheritance of variant or altered blood group antigens in patients with Sickle Cell Disease contributes to their high rate of red cell antibody formation. Her research interests include improving antibody identification and blood antigen matching for patients with Sickle Cell Disease using molecular tools. Since transfusion therapy remains a critical treatment for Sickle Cell Disease, approaches to minimize RBC alloimmunization are crucial to reduce complications and improve therapy.

Roshan Colah, Ph.D.
National Institute of Immunohaematology
Mumbai, India
Email: colahrb@gmail.com

Dr. Roshan Colah retired as Scientist G and Director-in-Charge of the National Institute of Immunohaematology (Indian Council of Medical Research), Mumbai in June 2015. She received her PhD in Biochemistry from Bombay University in 1984 and then trained in biochemical and molecular genetics of Haemoglobinopathies on a WHO Fellowship with Dr Dimitris Loukopoulos in Athens and on a French Govt. Fellowship with Dr Dominique Labie, Dr R. Krishnamoorthy and Dr Jacques Elion in Paris.

She was Head of the Dept. of Haematogenetics at her Institute from 1988 to 2015. Her group worked on Red Cell Disorders in particular the Haemoglobinopathies, Red Cell Enzymopathies and Membranopathies . Her main area of research has been on the epidemiology of the thalassaemias and sickle cell disease, studying the genetic factors contributing to their variable phenotypic presentation, developing prevention programmes in India and establishing newborn screening for sickle cell disorders.

Dr Colah has been involved in many teaching and CME programmes in India and is a Technical Expert for the Maharashtra State Govt. Sickle Cell Programme and an Hon. Consultant of the Indian Medical and Scientific Research Foundation, Rajkot, Gujarat for their Thalassaemia programmes. She has also been a Faculty Member for the "Master of Science in Haemoglobinopathies" e-learning course conducted by University College, London. She was a Member of the Expert Core Group in Haemoglobinopathies of the Global Burden of Diseases Study(2008-2010) and Co-Chair of the Natural History and Newborn Screening Working Group of the Global Sickle Cell Disease Network and is a Member of the Asian Thalassaemia Network.

She has received several awards, has been invited to present her work at many National and International meetings and has published 230 papers in peer reviewed National and International journals.

Ming Dao, Ph.D.
Principal Investigator and Director, *Nanomechanics Laboratory, MIT*
Principal Research Scientist, *Department of Materials Science and Engineering, MIT*
Email: mingdao@mit.edu

Ming Dao is the Principal Investigator and Director of MIT's Nanomechanics Laboratory, a Principal Research Scientist in the Department of Materials Science and Engineering at MIT, and a Principal Investigator in the Infectious Diseases Interdisciplinary Research Group of the Singapore-MIT Alliance for Research and Technology (SMART) Center. He obtained his bachelor's degree in engineering mechanics from Shanghai Jiaotong University in 1989, and his PhD degree in materials science from the University of California at San Diego in 1994. His broad interdisciplinary research interests include cell biomechanics and biophysics, malaria, sickle cell disease, cancer, nanomechanics of advanced materials, and mechanics of micro/nanoindentation. He has published more than 100 peer-reviewed SCI journal papers (averaging more than 45 citations per paper), and delivered more than 90 invited presentations in research conferences, workshops and leading research institutions around the world.

Deepika Darbari, M.B.B.S., M.S.
Attending Physician
Division of Hematology, Center for Cancer and Blood Disorders, Children's National Medical Center, Assistant Professor of Pediatrics, *The George Washington University School of Medicine and Health Sciences, Washington, DC*
Email: DDarbari@childrensnational.org

Deepika Darbari, MBBS, MS is an attending physician in the Division of Hematology at the Children's National Medical Center and Associate Professor of Pediatrics at the George Washington University School of Medicine and Health Sciences in Washington DC. She completed her fellowship training in Pediatric Hematology-Oncology at the Johns Hopkins University, Baltimore, MD and the National Institutes of Health, Bethesda MD. She is a board certified Pediatric Hematologist-Oncologist. At the Children's National Medical Center, her team provides comprehensive care to one of the largest populations of children and adolescents with sickle cell disease in the United States. Dr. Darbari studies complications of sickle cell disease and pain associated with sickle cell disease has been one of her focus areas. She conducts clinical and translational studies directed towards better understanding of pain and its management in sickle cell disease. She has published many research articles and reviews on the subject.

Mariane De Montalembert, M.D.
Associate Professor of Pediatrics & Head of the Hemoglobin Diseases Unit
Necker University Hospital, Paris, France
Email: mariane.demontal@aphp.fr

Professor de Montalembert received her MD from the Paris Descartes Medical School in 1982 and her PhD in Ethics in 1994. She specialized in pediatrics, statistics (option clinical research), and transfusion. She is Associate Professor of Pediatrics and serves as the head of the Hemoglobin Diseases Unit at the Necker University Hospital, and the « ROFSED » healthcare network for SCD children in the Parisian area . Prof de Montalembert is a member of the French Society of Pediatrics, in which she chairs the Ethic Committee, of the French Society of Hematology, the European Network for rare and Congenital Anaemias (ENERCA) the European Association (EHA), and the American Society of Hematology (ASH). She coordinates and participates to several clinical trials, especially on hydroxycarbamide use in SCD.

Dapa Aly Diallo, M.D.
Professor *of Hematology, Faculty of Medicine and Dentistry, USTTB, Mali.* Head *of the Hematology & Medical Oncology Service of Point G hospital, Bamako, Mali.* Director *of the Sickle Cell Disease Research and Control Center (CRLD), Bamako, Mali.*
Email: dadiallo@icermali.org

Training, Good Clinical and Good laboratory Practices (Accra, Ghana, 1999)
Good Clinical Practices for Clinical Investigators (Dallas, USA, 2001)
Bio-Ethics (Harvard School of Public health, USA, 2002)

Publications: More than one hundred publications in international journals with peer reviews (e.g. *Blood, PNAS, Nature, NEJM, Hematology, Current Opinion in Hematology, Lancet hematology, PLOS Med, Bull Cancer...*)

Other administrative and scientific activities:
President of the Malian Society of Hematology and Oncology (SOMAHO).
President of the Francophone African Society of Hematology (SAFHEMA).
Member of the French Society of Hematology (SFH)
Member of the American Society of Hematology (ASH)

Honors: Award of Excellency of the Academic Agency of the Francophonie, 2008.
Foreign corresponding member of the National Academy of Medicine of France, 2009.
Chevalier of the Legion of Honor of France, 2010.
Chevalier of the merit of Health, Mali, 2014

Beatrice Gulbis
Physician & Head of the *Department of Clinical Chemistry* & Head of the department of Clinical Chemistry, she has recently accepted to become the Medical Director of the Laboratories of Clinical Biology and Molecular Genetics.
Email: Beatrice.Gulbis@erasme.ulb.ac.be

Pr. Gulbis is a physician specialized in Clinical Biology who has developed a laboratory reference centre for the diagnosis, prevention and follow-up of patients with hereditary red blood cells disorders and in particular, sickle cell disease. After completing her graduate medical training at Université Libre de Bruxelles, Belgium, she has joined the Academic Hospital Erasme in Brussels, Belgium. With Dr Alina Ferster, a well recognized paediatrician, and her mentor Pr Françoise Vertongen, she has developed a national network of health professionals through the Belgian Hematological Society (**www.bhs.be**) and is working for more than 10 years for a European network on rare anaemias (**www.enerca.org**). Her experience has also been based on grants for research projects in Africa i.e. Burkina Faso and Democratic Republic of Congo. She has published a number of peer-reviewed papers on SCD and supervised thesis work on the subject. She is a professor at the medical school and provides hematology training courses. Being the Head of the department of Clinical Chemistry, she has recently accepted to become the Medical Director of the Laboratories of Clinical Biology and Molecular Genetics.

Jane Hankins, M.D., M.S.
Director, *Adolescent Sickle Cell Disease Clinic*, Founder & Director, *Transition to Adult Care Program for sickle cell disease at St. Jude Children's Research Hospital.*
Email: Jane.Hankins@STJUDE.ORG

Dr. Jane Silva Hankins was born in Rio de Janeiro, Brazil. She obtained a Medical Doctor degree from the Federal University of Rio de Janeiro, Rio de Janeiro, Brazil in July 1993. She completed a two-year residency program in Internal Medicine, followed by a two-year fellowship in Hematology and Oncology, both at the Federal University of Parana University Hospital, Curitiba, Brazil. In July 1998, she joined the Pediatrics residency program from the University of Tennessee (TN), Memphis, and in July 2001, Dr. Hankins started the fellowship program in Pediatric Hematology-Oncology at St. Jude Children's Research Hospital, Memphis. In December 2004 she received a Master of Science degree in Epidemiology from the University of TN Health Sciences Center. She completed her fellowship in Pediatric Hematology-Oncology in June 2004, followed by a one-year fellowship in Pediatric Sickle Cell Disease in July 2004 at St. Jude Children's Research Hospital, Memphis, TN. She joined St. Jude Children's Research Hospital Faculty as an Assistant Member on July 1st 2005, with an adjunct appointment as Assistant Professor at the University of TN. She was promoted to Associate Member at St. Jude and Associate professor at the University of TN in July 2011. Dr. Hankins is the director of the Adolescent Sickle Cell Disease Clinic and the founder and director of the Transition to Adult Care Program for sickle cell disease at St. Jude. She has held several federal grants and has numerous publications on the use of hydroxyurea in the pediatric sickle cell population and non-invasive techniques for iron overload management. Dr. Hankins' research interests include integration of health outcomes research with effective models of care throughout the life course of individuals with sickle cell disease. She is the principal investigator of a large multi-center lifetime cohort study for children and adults with sickle cell disease.

Kathy Hassell, M.D.
Director and Professor of Medicine
Colorado Sickle Cell Treatment and Research Center
University of Colorado, USA
Email: Kathryn.Hassell@ucdenver.edu

Dr. Hassell is a Professor of Medicine in the Hematology Division at the University of Colorado Denver, directs the Colorado Sickle Cell Treatment and Research Center and supervises the Hemoglobinopathies Newborn Screening Follow-Up program for the states of Colorado and Wyoming. She has an academic clinical practice at the University of Colorado where150 adults living with sickle cell disease are managed and offers a large thrombosis consultative service, also supervising a pharmacy-directed warfarin monitoring clinic with over 600 patients. For more than 20 years, Dr. Hassell has been actively involved in the design, conduct

and monitoring of clinical research studies in hemoglobinopathies, with an emphasis on adult sickle cell disease, and in venous thrombosis, with an emphasis on new anticoagulants. She has served on and chaired international steering committees for multi-center trials as well as data/safety monitoring boards. Dr. Hassell has participated in multiple national projects sponsored by the NIH, HRSA, and CDC related to clinical research, health services, and disease management guideline development.

Carolyn Hoppe, M.D.
Pediatric Hematologist/Oncologist
UCSF Benioff Children's Hospital Oakland, California
Email: choppe@mail.cho.org

Dr. Carolyn Hoppe is a pediatric hematologist/oncologist at UCSF Benioff Children's Hospital Oakland whose research interests have focused on clinical and translational studies in sickle cell disease (SCD). Dr. Hoppe began her research career investigating genetic modifiers of stroke in children with SCD and has collaborated on several projects using high-density genotyping and genome sequencing to identify genetic determinants of disease severity and Hb F response to hydroxyurea.

Dr. Hoppe recently completed a pilot trial assessing the efficacy of simvastatin to reduce vaso-occlusive pain in patients with sickle cell anemia (SCA). Together with colleagues at UCLA, she developed an electronic pain diary to monitor the frequency and intensity daily pain in this study. Dr. Hoppe served as lead PI on a phase 3 trial evaluating the efficacy of the platelet inhibitor, prasugrel, in preventing vaso-occlusive events in children with SCA. Although the results failed to show efficacy for the primary outcome, the trial successfully accrued over 300 participants, a majority of whom were from low-resource countries with the highest burden of disease. As the director of clinical research at BCHO, Dr. Hoppe is currently overseeing several clinical trials evaluating potential therapeutic agents for SCD. She and colleagues at SCD centers recently received funding from the Doris Duke Charitable Foundation to develop a collaborative SCD data and repository as a resource for multi-centered observational studies and clinical trials.

Lastly, as medical director of the CHRCO Hemoglobinopathy Reference Laboratory, Dr. Hoppe is engaged in public health research. She is co-investigator on an NIH/SBIR-funded project, and collaborating with investigators at Case Western Medical Center to develop a point of care assay for hemoglobinopathy screening. She is involved in HRSA/CDC-sponsored projects to build diagnostic laboratory capacity for universal newborn screening and improved surveillance of hemoglobin disorders nationally.

John Horan, M.D., MPH
Associate Professor of Pediatrics
Emory University, Atlanta, Georgia
Email: John.Horan@choa.org

John Horan, MD, MPH is Associate Professor of Pediatrics at Emory University and a member of the Aflac Cancer and Blood Disorders Center's Blood and Marrow Transplantation Program (Children's Healthcare of Atlanta). He chairs the Scientific Executive Committee of STAR (**curesicklenow.org**), a new organization dedicated to advancing blood and marrow transplantation for Sickle Cell Disease. He is a clinical investigator; his research in transplantation for sickle cell disease focuses on preventing graft versus host disease and infertility. He is also active in the Children's Oncology Group as a member of the Myeloid Diseases and Adolescent and Young Adult Oncology Steering Committees. He vice-chairs a North American multi-center trial of abatacept for graft versus host disease prevention. He received his education at Colgate University (BA), Rutgers University (MD) and the University of Rochester (MPH). He did his post-graduate training in pediatrics, hematology-oncology and transplantation at the Unversity of Rochester and Children's National Medical Center.

Jennifer Knight-Madden, M.B.B.S., Ph.D.
Director
Sickle Cell Unit, University of the West Indies, Jamaica (MRC, UK)
Email: jennifer.knightmadden@uwimona.edu.jm

Prof. Knight-Madden holds the Bachelor of Medicine, Bachelor of Surgery (MBBS) degree from The University of the West Indies, Mona, the Master of Science in Biometry from Duke University Medical College and the Doctor of Philosophy degree from King's College, University of London. She is Board Certified in Pediatrics (1993) and Pediatric Pulmonology (1997) by the American Board in Pediatrics and is a fellow of the Royal College of Physicians and Surgeons of Canada (Pediatrics, 1994).

She joined the staff of the Sickle Cell Unit, Jamaica (MRC, UK) in 1997 and was appointed Director of the Sickle Cell Unit in 2013. Under her watch, in partnership with the Government of Jamaica, universal sickle cell disease (SCD) newborn screening has finally been achieved in Jamaica.

Jennifer Knight-Madden is recognized internationally as SCD expert, particularly regarding the pulmonary complications of SCD. Her articles in peer-reviewed journals have been cited more than 700 times in the medical literature. She has authored two chapters in highly regarded books. Professor Knight-Madden has also presented her research work at several regional and international conferences.

Professor Knight-Madden has contributed to teaching and the clinical supervision of DM candidates and leads the pulmonology section of the paediatric curriculum. She has participated actively in the teaching of medical, nursing and physiotherapy students as part of their exposure to SCD.

Her professional and scholarly activity includes leadership roles in the Caribbean Association for Researchers in Sickle Cell Disease and Thalassemia and the Sick Kids Caribbean Initiative. Other professional activities have included membership in the Sickle Cell Technical Working Group (Jamaica) and the Pan African Bioinformatics Network for H3African Sickle Cell Ontology Working Group. She has served on the UWI/ UHWI Ethics Committee since 2010.

She has served as the principal investigator on several grants from local and international agencies.

Sophie Lanzkron, M.D., MHS
Founding Director
Sickle Cell Center for Adults at Johns Hopkins, Baltimore, Maryland
Email: slanzkr@jhmi.edu

Dr. Lanzkron is internationally recognized for her pioneering research on the optimal care and management of patients with sickle cell anemia and other hemoglobinopathies. Dr. Lanzkron is the founding Director of the Sickle Cell Center for Adults at Johns Hopkins which delivers state-of-the art, multidisciplinary care to over 500 patients. She established this comprehensive center exclusively for sickle cell patients who have been historically an underserved population. The Sickle Cell Infusion Center, which opened in 2008, provides urgent care to patients in crisis so that they can bypass the emergency department, where they are often subjected to prolonged, excruciating waiting periods before receiving care. This remarkable innovation has led to countless improvements in the lives of the patients' it serves, the most important of which is rapid relief of pain. Moreover, Dr. Lanzkron's innovative model of care is currently being emulated throughout the country and she received a $4 million grant from PCORI to systematically compare outcomes from infusion models in four states to usual emergency department care for the treatment of vaso-occlusive crisis.

Based on her groundbreaking research, Dr. Lanzkron is considered a leading expert in health services research in sickle cell disease. She has been the recipient of numerous awards and prestigious honors. In recognition for her expertise and research, she served on the National Institutes of Health, Expert Panel in the Management of Sickle Cell Disease and is an NIH funded researcher. She is currently an Associate Professor of Medicine and Oncology in the Division of Hematology at the Johns Hopkins University School of Medicine.

Deepa Manwani, M.D.
Director, *Sickle Cell disease Program, Children's Hospital at Montefiore (CHAM)*
Associate Professor, *Clinical Pediatrics, Albert Einstein College of Medicine, Bronx, NY.*
Email: DMANWANI@montefiore.org

Dr Manwani completed her residency (1993-96) at North Shore University Hospital – Cornell University Medical College, NY. She received her sub specialty training in pediatric hematology – oncology (1996 - 99) at Mount Sinai Hospital, Mount Sinai School of Medicine. In 1997 she initiated basic science research in the field of globin gene regulation, under the supervision of Dr James Bieker, PhD at Mount Sinai School of Medicine. Her primary areas of research focused on exploring mechanisms of fetal hemoglobin reactivation with the ultimate goal of designing novel therapies for sickle cell disease and thalassemia. She has also studied erythropoiesis and red cell-macrophage adhesive interactions in the erythroblast island.

Her research interests focus on fetal hemoglobin activating agents, adhesive cellular interactions in vaso-occlusion in SCD and contribution of neutrophils to SCD pathophysiology. She completed the Phase I Study of IVIG in treatment of SCD vaso-occlusive crises, is leading the follow up Phase II study and has participated in NIH funded studies examining the modifiers of fetal hemoglobin expression. She has led quality improvement efforts that have led to significant reductions in readmission rates and length of stay for patients with SCD. She is currently participating in studies aimed at increased adherence to hydroxyurea, improved pain management approaches and transition to adult care. Her contributions have been recognized by the Sickle Cell Thalassemia Patient Network of New York in the form of the "Distinguished Service Award" in March, 2015.

Anna Barbara Carneiro Proietti, M.D., Ph.D.
Researcher
Fundação Hemominas, Belo Horizonte - MG, Brazil.
Email: annaproietti@gmail.com

Anna Barbara Carneiro Proietti, MD, PhD is a researcher at Fundação Hemominas (Minas Gerais State Center of Hematology and Blood Transfusion). Her training was at the Federal University of Minas Gerais (Brazil) and Johns Hopkins University in Baltimore (USA) She was for 12 years president of Hemominas Foundation (1999-2010). She is an Eisenhower Fellow (EF, year 2000, Multi-nation program) and directed its Brazilian chapter for four years. She is currently the chair of the selection committee of EF. Participated in work groups of the Ministry of Health and ANVISA (Government health agencies) as advisor. She is the founder and coordinator of the Interdisciplinary Research Group on HTLV (GIPH) since 1997, advising students in undergraduate programs, master's and doctoral degrees. Participates in the international multicenter study REDS in transfusion safety and SCD, and in research in the areas of blood transfusion, blood-borne infections (HTLV, HIV, hepatitis, Chagas), blood donation and Sickle Cell Disease. She is currently interested in psychoanalysis and is connected to the Psychoanalytic Circle of Minas Gerais, Brazil.

David Rees
Paediatric Haematologist
King's College Hospital, London
Email: david.rees2@nhs.net

David Rees is a paediatric haematologist at King's College Hospital, London. He has research and clinical interests in paediatric sickle cell disease and other inherited red cell abnormalities. He has previously worked in London, Oxford and Sheffield and spent six years at the Weatherall Institute of Molecular Medicine in Oxford. He is involved in the care of more than 500 children with sickle cell disease.

Swee Lay Thein, M.B.B.S., FRCP, FRCPath, D.Sc.
Senior Investigator and Chief
Sickle Cell Branch, National Heart, Lung and Blood Institute, NIH
Email: sweelay.thein@nih.gov

Swee Lay Thein joined NHLBI in spring 2015 as senior investigator and chief of the institute's newly formed Sickle Cell Branch.

Prior to this, she was professor of molecular hematology and consultant hematologist at King's College London, where she served as clinical director of the Red Cell Centre in King's College Hospital. At the hospital, she was involved in the care of 800 adult patients with sickle cell disease and other red blood cell disorders.

Swee Lay Thein was educated in both Malaysia and the United Kingdom. She completed her specialist training in hematology at the U.K. Royal Postgraduate Medical School, Hammersmith, and the Royal Free Hospital, London. She has also worked in Oxford at the Weatherall Institute of Molecular Medicine (Medical Research Council Molecular Hematology Unit) where she held various positions, including clinical training fellow, Wellcome Senior Fellow in Clinical Science, senior MRC clinical scientist, and the John Radcliffe Hospital as honorary consultant hematologist.

Her lab focuses on the genetic factors underlying the phenotypic variability and pathophysiology of sickle cell disease. Developing evidence base for management of sickle-related complications and education is another focus of her work. Since 2006, she has directed and planned the programme of a 2-day international conference in sickle cell disease, previously held in KCL, London; now the 10th Sickle Cell in Focus at the NHLBI/NIH. She has also been previously involved in planning and organising various educational meetings (national and international), and working with the European School of Haematology and European Haematology Association. She is the feature editor of Blood Hub on sickle cell anemia in *BLOOD*, and Associate Editor of *Haematologica*.

John F. Tisdale, M.D.
Senior Investigator
Molecular and Clinical Hematology Branch, National Heart, Lung and Blood Institute, NIH
Email: johntis@nhlbi.nih.gov

John Tisdale received his M.D. degree from the Medical University of South Carolina in Charleston in 1990. He completed an internal medicine and chief residency at Vanderbilt University Medical Center in Nashville and then trained in hematology in the Hematology Branch, National Heart, Lung and Blood Institute (NHLBI), where he served as a postdoctoral fellow. He joined the Molecular and Clinical Hematology Branch of NHLBI in 1998 and is currently a senior investigator in that lab. His group focuses on bone marrow stem cell-based approaches to treat sickle cell disease. The work focuses on the development of methods for transplantation of either normal donor-derived or genetically modified patient-derived bone marrow stem cells.

Elliott Vichinsky, M.D.
Professor, *University of California San Francisco;* Director of Hematology/Oncology, *UCSF Benioff Children's Hospital Oakland;* Director, *Northern California Sickle Cell and Thalassemia Centers*
Email: evichinsky@mail.cho.org

Dr. Vichinsky is Professor of Pediatrics at University of California San Francisco, the Director of Hematology/Oncology at UCSF Benioff Children's Hospital Oakland, as well as the Director of the Northern California Sickle Cell and Thalassemia Centers. He has had many honors, including lifetime achievement awards from the Cooley's Anemia Foundation and the National Sickle Cell Disease Association. He was Editor-in-Chief of Pediatric Hematology and Oncology, Chairman of the Thalassemia Clinical Research Network, and Director of the Cooley's Medical Board. Dr. Vichinsky has published over 300 articles and several books. His major interest is in understanding and improving the care of patients with hemoglobinopathies and has focused his career on translational research in hemoglobinopathies. He has been Principal Investigator or Co-Investigator on many of the key translational studies supported by the National Institutes of Health, including the Cooperative Study of Sickle Cell Disease, Prophylactic Penicillin Studies, Pediatric and Adult Hydroxyurea Trials, the Stroke Prevention Trials (STOP), the National Preopera¬tive Transfusion Study, the National Acute Chest Syndrome Study, the National Avascular Necrosis of the Hip in Sickle Cell Disease Study, Hemochromatosis in Sickle Cell Disease, Pulmonary Hypertension in Thalassemia, the Walk-PHAST trial, and the Neuropsychological Dysfunction in Neurologically Intact Adult Patients with Sickle Cell Disease Study.

Dr. Vichinsky is a key principal investigator on several key translational projects, including understanding the mechanism and treatment of neurologic injury in sickle cell disease, iron trafficking and iron overload in hemoglo¬binopathies, and new therapies to change the pathophysiology of sickle cell biology as well as the principal investigator in trials evaluating novel iron chelators that cross the brain barrier as treatment for neurodegenerative brain disease, such as neurodegenerative brain iron accumulation.

Tom Williams, M.D.
Professor
Hemoglobinopathy Research at Imperial College, London
Email: tom.n.williams@gmail.com

Tom Williams is a pediatrician and clinical investigator with more than 25 years of scientific experience. He has worked full time at the KEMRI/Wellcome Trust Research Programme (KWTRP) in Kilifi, Kenya (**http://www.kemri-wellcome.org**) since 2000, while holding parallel appointments at UK Universities. A Professor of Tropical Medicine at the University of Oxford from 2009-13, Dr Williams took up the post of Professor of Hemoglobinopathy Research at Imperial College, London in April 2013. The main focus of Dr Williams' research is on genetic conditions that affect red cell structure and function. His early focus was on the epidemiology and biology of the malaria resistance phenotype that is associated with many of these conditions (including the thalassemias and the sickle cell trait), but with time he has also turned to the negative consequences of these conditions, with a particular focus on sickle cell disease (SCD). Dr. Williams runs a program of research on the epidemiology and basic science of hemoglobin disorders in Kenya, and a specialist research clinic serving >700 children with SCD. In addition, he is Head of the Department of Epidemiology and Demography at the KWTRP and is responsible for the management and scientific oversight of the largest demographic surveillance system in Africa (280,000 under surveillance). Dr. Williams has published extensively on the burden and natural history of SCD on local and global scales, and is active in the national dialogue for the development of treatment guidelines in Kenya. He has collaborated successfully in a range of previous network studies, most recently with the REACH multicenter trial of hydroxyurea in the management of children with SCD in 4 sites in Africa.

Dachuan Zhang, Ph.D.
Postdoctoral Fellow
Albert Einstein College of Medicine, New York, New York
Email: dachuan.zhang@phd.einstein.yu.edu

Dachuan Zhang received his PhD at Albert Einstein College of Medicine, under the supervision of Dr. Paul S. Frenette. Dachuan's studies focused on the interactions between the microbiota and circulating neutrophils. He found that microbiota-driven neutrophil aging contributes to inflammation-induced tissue damage in sickle cell disease and septic shock. His studies were published in high-impact journals including Nature, Blood, and etc. Dachuan was a recipient of AHA predoctoral fellowship. He also received Julius Marmur Award and Chinese Government Award for Outstanding Student Abroad for his graduate studies. Dachuan is now a postdoctoral fellow in Dr. Paul S. Frenette's lab.

Venue Information

The NIH campus is located in Bethesda, Maryland, ten miles from the center of Washington, DC. The event is taking place in the William H. Natcher Building (building 45), which is situated on Center Drive, a short walk from the Medical Center Metro station. The Natcher building, is also home to the NIH Visitor Center and the Nobel Laureate Exhibit Hall.

NOTE: New security measures have been put in place on the NIH campus, affecting both staff and visitors. For more information, please refer to the NIH Visitor Information [**nih.gov**] page. We strongly encourage taking the Metro to the Natcher Conference Center. The Natcher Building contains a cafeteria, with open and private dining facilities, located on the first floor level, A Wing.

Service Hours;

- Breakfast: 6:30 a.m.-9:30 a.m.
- Lite Fare: 9:30 a.m.-11:00 a.m.
- Lunch: 11:00 a.m.-2:30 p.m.

Soda and snack vending machines are located in the galley areas of levels two through six, A Wing on the P2 level of the Natcher Conference Center B Wing, adjacent to the north and south walls of the floor.

This view of the NIH campus looks south beyond the Stokes Labs (*Building 50*) and Natcher Building (*center*) to the reflective façade of the National Library of Medicine (*upper right*).

Shuttle services are provided throughout the day on the NIH Campus for employees, patients, and visitors.

Dining at the NIH campus

For dining on the NIH campus, the NIH Dining Centers offers a variety of meal options to employees and guests. For more information, visit **http://www.ors.od.nih.gov/pes/dats/food/dining/Pages/dining_locations.aspx**

For more information about the NIH campus, visit the NIH Visitor Center located in the Natcher Conference Center, Room 1AS-13. The telephone number is 301-496-1776.

Dining near NIH campus

Many of the local restaurants are clustered around two areas – Bethesda Row and Woodmont Triangle. Bethesda easily has the highest concentration of restaurants in the D.C. metro area. Downtown Bethesda's restaurant community showcases diverse cuisine from around the world. Whether you're looking for a deli, bakery, sushi or fine American cuisine, Bethesda's nearly 200 restaurants are sure to deliver a delectable dining experience. You can find what you need right next to NIH.

Bethesda Row

Located a few blocks southwest from the Bethesda Metro stop, Bethesda Row is home to a number of Maryland branches of DC landmark restaurants, including Jaleo, Lebanese Taverna , and Georgetown Cupcake. The area also boasts the Bethesda chapters of popular cheap eats like Five Guys and SweetGreen. That's not to say that all the restaurants on Bethesda Row are chains – one need only look at Mussel Bar and Redwood to find fine dining options that are unique to Bethesda Row.

Woodmont Triangle

The Woodmont triangle region, directly south from the NIH campus, features many restaurants that are unique to Bethesda. Many of these eateries are perfect for a quick lunch. Whether you're looking for burgers, Chinese, Ethiopian or an Indian buffet, there are plenty of choices to enjoy.

Wherever you do decide to go for a meal, you'll never run out of new places to try in Bethesda. With hundreds of restaurants within the city's 12 square miles, guests to the NIH have ample options without having to leave city limits.

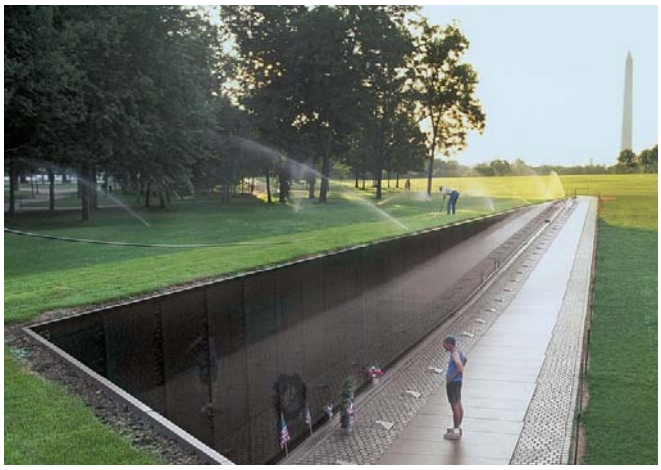
WIFI

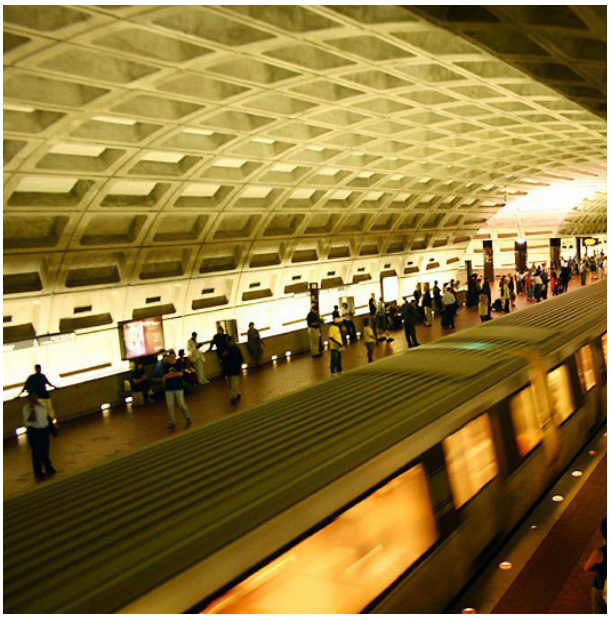
There is free wifi for all visitors to NIH. To use, just choose the NIH Network and agree to the terms and conditions of use.

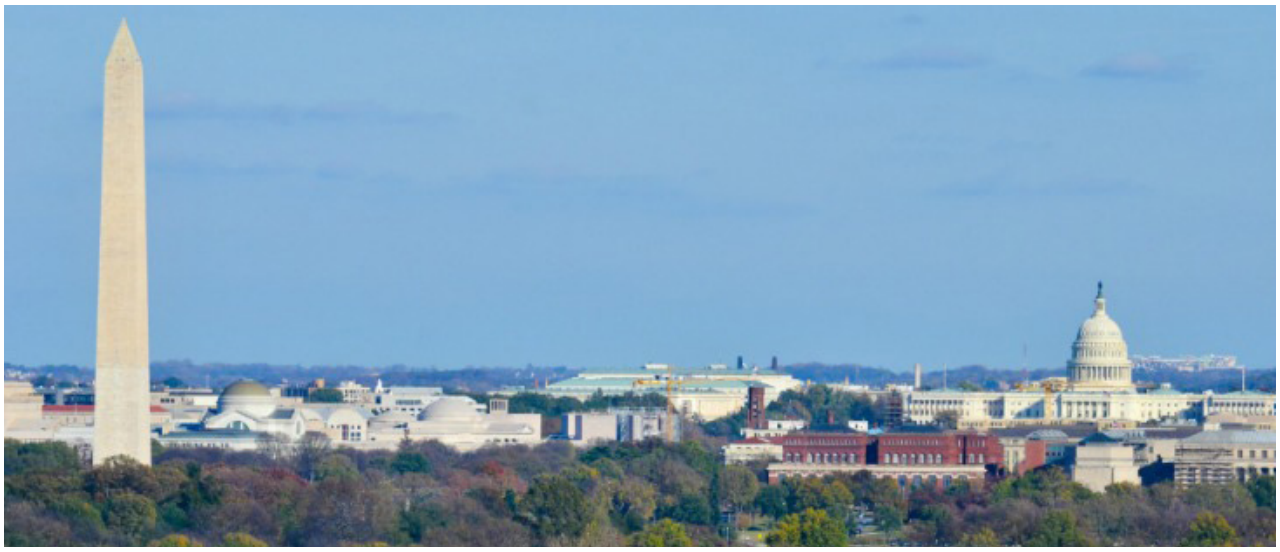
Visitor Information for the Washington, DC area

Make the most of a short trip to Washington — explore restaurants and monuments as well as historic sites. Many of DC's museums, memorials and other attractions are free. Explore 15 Smithsonian museums, plus the National Zoo - all free of charge. No trip to Washington, DC is complete without touring celebrated monuments and memorials, eclectic neighborhoods, true local flavor – Washington, DC is a place unlike any other, it's filled with exciting and memorable places to visit. Getting around town is easy using the Metro system to all the sites. Top attractions include the;

- National Zoological Park
- Washington Monument
- Jefferson Memorial
- Lincoln Memorial
- Smithsonian Museum Castle
- Vietnam Veterans Memorial
- US Capitol
- Air and Space Museum
- National Gallery of Art
- Mount Vernon
- National Harbor Marina
- Martin Luther King Jr. Memorial







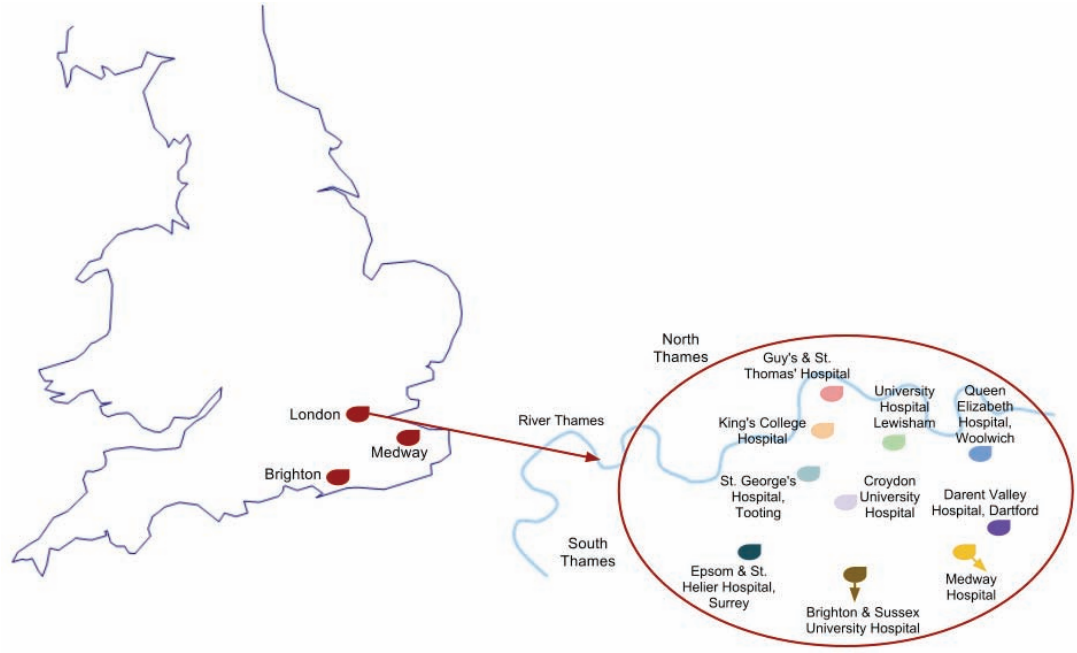
The South Thames Sickle Cell & Thalassaemia Network

STSTN MISSION STATEMENT

To improve the patient experience by offering better treatment outcomes for people with sickle cell disease and thalassaemia.

ABOUT STSTN

STSTN is led by consultants from two large teaching hospitals: King's College Hospital (KCH), Guy's and St. Thomas' Hospital (GSTT) including the Evelina Children's Hospital, all designated specialist centres for haemoglobin disorders. The network also includes the accredited centres at Croydon University Hospital, University Hospital Lewisham, St. George's Hospital and the Queen Elizabeth Hospital, Woolwich. In addition, there are several linked district general hospitals, includings, Darent Valley, Medway, Epsom & St. Helier and Brighton and Sussex.



HOW STSTN AIMS TO ACHIEVE IT's GOALS:

Service

- Establish and maintain joint methods of working throughout the network
- Collaborate in specialist clinics including renal, obstetrics, orthopaedics, pulmonary hypertension, nuerology and urology
- To publish guidelines on the care and treatment of sickle cell disease and thalassaemia
- To produce patient leaflets and separate patient newsletter

Teaching

- To increase the understanding of a patient's experience of SCD and thalassaemia via Patient Forum/ Awareness events
- To provide a peer-support network and educational programme for consultants, GPs, nurses, trainees and other healthcare professional

Research

- To disseminate information and raise awareness of ongoing research in the UK and internationally
- To function as a group and provide critical mass for collaborative research and evidence based audits

Contact information;

Web: www.ststn.co.uk | Tel: +44 (0) 20 7848 5455 | Email: info@ststn.co.uk | Twitter: @STSTNetwork




For more information go to;

http://go.usa.gov/cm4um or **www.ststn.co.uk/scif/scif2016/**