

Dear all,

On behalf of the national haemoglobinopathy panel and Haemoglobinopathy Coordination centres, England, I would like to invite you to our first webinar to address recent issues raised about the co-existence of '*Paediatric multisystem inflammatory syndrome temporally associated with COVID-19 and sickle cell disease*'.

Below is the text of the clinical alert from the President of the Royal College of Paediatrics and Child health, Professor Russell Viner

'Most children are asymptomatic or exhibit mild symptoms from COVID-19 infection. However, in the last two months a small number of children have been identified who develop a significant systemic inflammatory response. All children have been diagnosed and managed appropriately along standard referral pathways. Affected children may require paediatric intensive care and input from paediatric infectious diseases, cardiology, and rheumatology.

This rare syndrome shares common features with other paediatric inflammatory conditions including: Kawasaki disease, staphylococcal and streptococcal toxic shock syndromes, bacterial sepsis and macrophage activation syndromes. It can also present with unusual abdominal symptoms with excessive inflammatory markers.

Early recognition by paediatricians and specialist referral including to critical care is essential.

Advice currently given to families and carers of children and young people (for example RCPCH parent advice during COVID-19 leaflet) supports appropriate referral to health services.

This document is to raise awareness and gives management advice to clinicians and has been developed after expert review of the cases.

Case definition:

1. A child presenting with persistent fever, inflammation (neutrophilia, elevated CRP and lymphopaenia) and evidence of single or multi-organ dysfunction (shock, cardiac, respiratory, renal, gastrointestinal or neurological disorder) with additional features (see listed in [Appendix 1](#)). This may include children fulfilling full or partial criteria for Kawasaki disease.
2. Exclusion of any other microbial cause, including bacterial sepsis, staphylococcal or streptococcal shock syndromes, infections associated with myocarditis such as enterovirus (waiting for results of these investigations should not delay seeking expert advice).
3. SARS-CoV-2 PCR testing may be positive or negative'

Kindly join us on 15th June, 2020 at 1700 hours (1700-1900 hours) BST

Yours sincerely

Professor Baba Inusa

Chair, National Haemoglobinopathy Panel.

“Paediatric multisystem inflammatory syndrome temporally associated with COVID-19 and Sickle cell disease – what is the link?”

15th June 2020, 17:00 to 19:00 BST

17:00 – **Introduction and welcome address**

Prof Baba Inusa - Department of Paediatric Haematology, Evelina London Children’s Hospital, Guy’s and St Thomas NHS Foundation, UK

Moderators:

Prof. David Rees - Professor of paediatric sickle cell disease at King’s College London and consultant in paediatric haematology at King’s College Hospital, UK

Prof. Jo Howard - Consultant Haematologist at Guy’s and St Thomas' NHS Foundation Trust, Honorary Professor in Haemoglobinopathies at King’s College London UK

17:05 – **The perspective of infectious diseases specialists** (5 minutes for Q&A)

Dr. Julia Kenny - Consultant in paediatric infectious diseases & immunology Lead for paediatric HIV, lead for paediatric immunology at Evelina London Children’s Hospital, London, UK

Dr. Alasdair Bamford - Consultant and Specialty Lead in Paediatric Infectious Diseases, Great Ormond Street Hospital for Children NHS Trust, London, UK

17:25 - **Case presentations** (10 minutes each including Q&A)

Dr. Jonathan Broad, Specialist Registrar, Evelina London Children’s Hospital, GSTT, London, UK

Dr. Debbie Sobande, Paediatric Registrar at Evelina Children's Hospital, London, UK

Dr. Andrea Leigh - Paediatric Consultant at University College London Hospitals NHS Foundation Trust, London, UK

17:45 - **Debate: The diagnosis of PIMS-TS is sustainable, and the treatment is not sustainable in Sickle Cell Disease**

Yes - Dr. Subarna Chakravorty - Consultant Paediatric Haematologist, King’s College Hospital London, UK

No - Dr. Banu Kaya – Consultant Haematologist, The Royal London and St Bart’s NHS Trust, London, UK

18:05 – **The diagnostic conundrum, Rheumatology perspectives** (5 minutes for Q&A)

Dr. Vinay Shivamurthy - Consultant paediatric rheumatologist at Evelina London Children’s Hospital, London, UK

18.15 – **The Cardiologist role in diagnosis and treatment** (5 minutes for Q&A)

Dr Owen Miller, Paediatric Cardiologist, Evelina London Children's Hospital, Guy's and St Thomas NHS Foundation, UK

18.25 – **The role of pharmacy** (5 minutes for Q&A)

Dr Carol Ann Jones - Pharmacist at Guy's and St Thomas NHS Foundation, UK

18.35 – **Neurologist role** (5 minutes for Q&A)

Prof. Fenella Kirkham - Consultant Paediatric Neurologist, King's College Hospital and University Hospital, Southampton; Professor of Paediatric Neurology, Developmental Neurosciences Unit, UCL Great Ormond Street Institute of Child Health and Clinical and Experimental Sciences, University of Southampton, UK

18.45- Discussion Forum and wrap

Team of summarisers

- Dr. Elizabeth Chalmers – Consultant Paediatric haematologist, Royal Hospital for Children, Glasgow, UK
- Dr. Mark Velangi - Consultant Paediatric Haematologist and Lead for Haemoglobinopathy at Birmingham Women's and Children's NHS Foundation Trust, UK
- Dr. John Grainger - Consultant Paediatric Haematologist at Manchester University NHS, UK
- Dr Perla ELEFTHERIOU, Consultant Haematologist, University College London Hospitals NHS Foundation Trust, UK

To attend the event, register here: <https://attendee.gotowebinar.com/register/5425419588439574795>.

After registering, you will receive a confirmation email containing information about joining the webinar.

Faculty:

Prof. David Rees



David Rees is professor of paediatric sickle cell disease at King's College London and consultant in paediatric haematology at King's College Hospital. He has research and clinical interests in sickle cell disease, and other red cell abnormalities, including porphyrias, thalassaemia and enzymopathies. He has previously worked in Jersey, Bath, Milton Keynes, Oxford and Sheffield. He is involved in the care of more than 1000 children with sickle cell disease and thalassaemia in southern England. He is a medical adviser to the Sickle Cell Society in the UK.

Prof. Jo Howard



Jo Howard is a Consultant Haematologist at Guy's and St Thomas' NHS Foundation Trust, London and is Honorary Professor in Haemoglobinopathies at King's College London where she is lead for the adult Haemoglobinopathy service. Her research interests include the natural history and management of SCD in adults. She has authored over 50 peer reviewed papers, book chapters and a textbook.

She is lead for the South Thames Sickle Cell and Thalassaemia Network, chair of the Clinical Reference Group for Haemoglobinopathies and chaired the national peer review (2012-2017) and the UK Forum on Haemoglobin Disorders (2017-2019). She is chair of the British Society of Haematology Guidelines group, has contributed to national and international guidelines on sickle cell disease (SCD) and was editor of the UK Standards for care for Adults with SCD (available at www.sicklecellsociety.org).

Dr. Jonathan Broad



Jonathan Broad is a paediatric academic clinical fellow in London with an interest in infectious disease. He is currently in a training job at the Evelina Children's Hospital.

Dr. Debbie Sobande



Debbie Sobande is a paediatric registrar at Evelina Children's Hospital.

Dr. Andrea Leigh



Qualified from Barts and The London Medical School in 2001 with degrees in medicine (MBBS) and neuroscience (BSc). General and subspecialty paediatric training in North Central and East London including tertiary Oncology and Haemoglobinopathy posts. General paediatric and neonatal consultant at Whipps Cross Hospital from 2013-2019, being Clinical Lead for the Paediatric Oncology Shared Care Unit (POSCU) and Haemoglobinopathy service, was the Barts Health Lead for Adolescent Care, and Barts Health Network Lead for POSCU redevelopment. Since 2019, general paediatric consultant at UCLH with an interest in paediatric oncology, haematology and haemoglobinopathies. Interest in paediatric supportive care oncology and member of the team develop supportive care pathways for Proton Beam Therapy at UCLH. Red cell clinics at UCLH with Dr Sara Trompeter and contribute to the red cell MDT and inpatient service. We look after children with haemoglobin disorders and other non-malignant conditions. Paediatric Lead for the Red Cell Network (North London and east Anglia) for Sickle Cell Disease. Particular areas of interest are adolescent care and transition. During the covid19 pandemic, she has been providing inpatient care for the general paediatric and red cell patients from across North Central London at Great Ormond Street Hospital.

Dr. Subarna CHAKRAVORTY



Subarna Chakravorty MBBS, FRCP, MRCPCH, FRCPath, PhD
Consultant Paediatric Haematologist, King’s College Hospital and Honorary Senior Lecturer, King’s College London
Subarna is a Paediatric Haematologist at King’s College Hospital London and has a special interest in non- malignant haematology including haemoglobin disorders. Subarna is part of a team that looks after one of the largest cohorts of paediatric sickle cell disease in the UK. She has several national roles in haemoglobinopathy in the UK and leads several research projects in pediatric sickle cell disease. She has authored several scientific papers and book chapters in non- malignant haematology.

Dr. Vinay Shivamurthy



Dr. Vinay Shivamurthy is a Paediatric Rheumatologist at Evelina London Children’s Hospital. He received training in Paediatrics in the East Midlands in the UK and got training in Paediatric Rheumatology in Vancouver, Canada. He is Paediatric Rheumatologist at Evelina London since 2016, where he is Lead of Paediatric Rheumatology Training.
His Interest is in Chronic pain in children, auto inflammatory diseases
He is actively involved in the management of PIMS –TS cases at Evelina London Children’ hospital.

Dr. Julia Kenny



Consultant in paediatric infectious diseases & immunology Lead for paediatric HIV, lead for paediatric immunology, deputy lead for PIID Research Julia graduated from the University of Oxford and completed her postgraduate paediatric training in Oxford, Newcastle and London. Julia completed the Diploma in Tropical Medicine and Hygiene at the Liverpool School of Tropical Medicine and then worked in Blantyre, Malawi as a Lecturer in Paediatrics with her clinical work based at Queen Elizabeth Central Hospital, Blantyre. She was awarded a Wellcome Trust Clinical Training Fellowship to study “Cardiovascular Effects of HIV in African Children” and was awarded her PhD in 2016. Julia worked for the MRC Clinical Trials Unit at UCL focusing on International Paediatric HIV trials. Julia holds postgraduate qualifications in teaching and enjoys teaching. She has been a consultant at Evelina London Children’s Hospital since 2017 and has been leading the Evelina PIMS-TS research.

Dr. Alasdair Bamford



Dr Alasdair Bamford is paediatric infectious disease consultant and specialty lead at Great Ormond Street Hospital, London, UK. He is a clinical advisor to RCPCH/NHSE projects to produce guidance relating to COVID and PIMS-TS in children in the UK and also the RECOVERY trial paediatric subgroup.

Dr. Elizabeth Chalmers

Consultant Paediatric Haematologist at the Royal Hospital for Children, Glasgow. Responsible for the care of children with SCD in the West of Scotland and a member of the Scottish Haemoglobinopathy Managed Clinical Network.

Dr. Fenella Kirkham



Fenella Kirkham is a paediatric neurologist with an interest in acute paediatric neurological problems. She has developed an interest in the role of sleep in cognition in sickle cell disease and is currently analysing data from the East London and Sleep Asthma cohorts with her Post-docs, PhD and MSc students. She collaborates with haematologists in England, Europe, the USA and Africa. She ran a Phase II randomised controlled trial (RCT) of auto-adjusting continuous positive airways pressure with cognitive and MRI endpoints in children and adults. She has been a member of the American Society of Hematology working groups on Guidelines for Sickle Cell Disease: Evidence-based Strategies to Prevent, Screen, and Treat CNS Disease and End points for sickle cell disease clinical trials: patient-reported outcomes, pain, and the brain. In 2020, she will commence across London an RCT of Montelukast in children aged 3-8 years (primary endpoint NIH toolbox processing speed).

Dr. Mark Velangi



Consultant Haematologist in Birmingham Children's Hospital and regional lead for the paediatric haemoglobinopathy service.

I graduated from the University of Edinburgh Medical School in 1991. I am a Consultant Paediatric Haematologist and, in 2006, joined the team at Birmingham Children's Hospital which has a large sickle cell and thalassaemia unit. He has been the lead for the Haemoglobinopathy service since 2014 and has helped to develop the West Midlands HCC. He has also served as one of the paediatric clinical leads on the National Peer Review steering group in the recent round of reviews 2019/20. He has developed a particular interest in acute complications of sickle cell disease.

Dr. John Grainger

Consultant Paediatric Haematologist/ Oncologist, Central Manchester University Hospitals NHS Foundation Trust

Dr. Banu Kaya



Dr Banu Kaya joined Barts Health NHS Trust as a consultant haematologist based within the departments of Paediatric Haematology/Oncology and Clinical Haematology in 2007. Banu jointly leads the paediatric haematology and haemoglobinopathy services at Barts Health and the Haemoglobinopathy Coordinating Centre for the region.

Banu led the paediatric component of the National Haemoglobinopathy Peer Review Programme and co-chaired the steering group, 2014-2016. She was appointed to the haemoglobinopathies Clinical Reference Group (CRG) in 2019, is a Trustee of the British Society of Haematology and member of the BSH paediatric haematology special interest group (SIGG).

Banu has been the UK Chief Investigator for a number of international clinical trials and contributed to a number of national guidelines.

Dr. Carol Ann Jones



Paediatric Intensive Care Pharmacist at Evelina Children's Hospital, London. Active in research and committed to education and training.

Dr. Owen Miller



Dr Miller is a Consultant in Paediatric and Fetal Cardiology and Clinical Director of the Congenital Heart Disease Network.

Dr. Perla Elefteriou



Consultant Haematologist at University College Hospital London. Area of expertise is Red Cell Disorders: haemoglobinopathies and rare anaemias. Yearlong interest in clinical research in this field, Co - investigator, Principal and Chief Investigator in numerous clinical trials in thalassaemia, sickle cell disease and rare anaemias. Lecturer of Haematology at the London School of Hygiene and Tropical medicine, UCL and University of Westminster. Honorary Clinical Senior Lecturer at UCL. Clinical/scientific adviser to Thalassaemia International Federation (TIF) and co-author and editor of clinical national and international guidelines as well as coordinator of web seminars and workshops in this field. Coordinator of the International Fellowship (Renzo Galanello) for overseas haematologists, hosted at UCLH. Clinical governance Lead of Red Cell Haematology Department at UCLH and active member of the national data collection and analysis working group for COVID red cell patient

Prof. Baba Inusa



Baba Inusa is a Professor of Paediatric Haematology, King's College London. Chair, National Haemoglobinopathy Panel, England and consultant paediatrician, Evelina London Children's Hospital, Guy's and St Thomas NHS Foundation Trust.

He is Principal investigator African Research innovative initiative for Sickle Cell Education (ARISE) Horizon 2020 Marie Skłodowska –Curie \$2.1million research exchange grant between institutions in Europe, Africa, US and Lebanon institutions 2019-2023. He is the founder/Director, Academy for sickle cell and thalassaemia (ASCAT) www.scorecharity.com.