Organised by



In association with





Sickle Cell 2009:

support and management of children with sickle cell

Education Centre, University College Hospital London

30th November & 1st December 2009

12 CPD points applied for



Objectives

Sickle Cell 2009 brings together leading experts in the fields of haematology, paediatrics, nursing and school nursing, to discuss the central issues and practical management of children with sickle cell.

It is anticipated that participants will benefit from:

- Comprehensive reviews of the biology, causes and symptoms of sickle cell and beta thalassaemia
- Insights on the experiences of mothers of young people living with sickle cell
- An understanding of the roles of the sickle cell counsellor and the school nurse working with sickle cell children
- An opportunity to learn about how children with sickle cell can be supported within the education setting
- Expert opinions on the optimal clinical management of sickle cell patients
- Overviews of advances in bone marrow transplantation and in the development of new therapies for sickle cell
- An opportunity to share and exchange ideas with leading practitioners in the field

Who should attend?

Day one of the conference is particularly relevant to health professionals working within the education sector, while day two is aimed at all those in the medical professions. However both days will prove interesting and informative to all who work in the care of sickle cell children.

It will be of particular interest to:

- Haematologists
- Paediatricians
- Specialists in public health medicine
- General practitioners
- School nurses and members of school health teams
- Clinical nurse specialists in haematology and haemoglobinopathies
- Nurse practitioners in haematology and haemoglobinopathies
- Public health nurses
- Community nurses
- Commissioners and managers of children's services
- Genetic counsellors
- All trainees in these disciplines

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Monday 30th November 2009

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08.15 - 09.15	Registration and refreshments
09.15 - 09.20	Welcome and introduction
09.20 - 09.50	An introduction to sickle cell Sherill Gregory, Specialist Nurse in Sickle Cell and Thalassaemia, Mayday Healthcare NHS Trust, Croydon
09.50 - 10.00	Discussion
10.00 - 10.30	Strokes in children with sickle cell Dr David Rees, Consultant Haematologist, Kings College Hospital, London
10.30 - 10.40	Discussion
10.40 - 11.10	An introduction to beta-thalassaemia Elaine Miller, Coordinator, UK Thalassaemia Society, London
11.10 - 11.20	Discussion
11.20 - 11.40	Refreshments
11.40 - 11.55	The experiences of mothers of sickle cell children at school
	Mothers of young people living with sickle cell
11.55 – 12.05	Discussion
12.05 – 12.25	From school nurse to specialist sickle cell counsellor Barbara Bailey-Squire, Haemoglobin Disorders Nurse Counsellor, Coventry Sickle Cell Service
12.25 - 12.35	Discussion
12.35 - 13.30	Lunch
13.30 - 14.15	Sickle cell and education Professor Simon Dyson, Professor of Applied Sociology, De Montfort University, Leicester
14.15 - 14.25	Discussion
14.25 - 14.55	The role of incentive spirometry in school <i>To be confirmed</i>
14.55 - 15.05	Discussion
15.05 - 16.25	Workshops (30 minutes + 10 minutes discussion each) These workshops will run twice each to enable participants to attend both
	1: The role of the school nurse in sickle cell Suzi Crawford, Specialist Nurse in Haemoglobinopathies, Birmingham Sickle Cell Service
	2: What should be in a school policy for sickle cell? Simon Dyson, Professor of Applied Sociology, De Montfort University, Leicester

3 EASY WAYS TO BOOK

Refreshments and close of day one





16.25

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Tuesday 1st December 2009

	iy 131 December 2007
08.15 - 09.00	Registration and refreshments
09.00 - 09.30	Update on the NHS screening programme for haemoglobinopathies Cynthia Gill, Implementation Manager, NHS Sickle Cell and Thalassaemia Screening Programme
09.30 - 10.00	Perspectives on effective genetic counselling Margaretha van Mourik, Lead Genetic Counsellor, West of Scotland Regional Genetic Service
10.00 - 10.30	Are patients receiving optimal treatment? Dr Moira Dick, Consultant Community Paediatrician, King's College Hospital and Lambeth PCT, London
10.30 - 10.40	Discussion
10.40 - 11.00	Refreshments
	Management of complications
11.00 - 11.20	
11.20 - 11.40	Pulmonary hypertension Dr Simon Gibbs, Consultant Cardiologist, National Pulmonary Hypertension Service, Hammersmith Hospital & Imperial College London
11.40 – 12.00	Renal complications Dr Claire Sharpe, Clinical Senior Lecturer and Honorary Senior Consultant in Renal Medicine, King's College London
12.00 – 12.20	Chelation therapy and its alternatives Professor John Porter, Professor of Haematology and Consultant Haematologist, University College London Hospitals
12.20 – 12.40	Chronic leg ulceration Sharon Robinson, Clinical Nurse Specialist in Haemoglobinopathies, University College London Hospitals
12.40 - 12.50	Discussion
12.50 - 13.40	Lunch
13.40 - 14.10	Managing the transition from paediatric to adult care Dr Jo Howard, Consultant Haematologist & Dr Baba Inusa, Consultant Paediatrician, Guy's and St Thomas' Hospitals NHS Trust, London
14.10 - 14.40	Psychological support for patients in transition to adult care Dr Nicky Thomas, Consultant Health Psychologist, Guy's and St Thomas' NHS Foundation Trust, London
14.40 - 14.50	Discussion
14.50 - 15.10	Refreshments
15.10 - 15.40	Developments in specialist local service provision for sickle cell Dr Lorna Bennett, Clinical Service Manager, NHS Islington, London & Trustee, Sickle Cell Society
15.40 – 16.10	Advances in bone marrow transplantation Dr Phil Darbyshire, Consultant Paediatric Haematologist, Birmingham Children's Hospital NHS Trust
16.10 - 16.40	Current and emerging therapies Professor Swee Lay Thein, Professor of Molecular Haematology & Head of Division of Gene and Cell Based Therapy, King's College Hospitals NHS Foundation Trust, London
16.40 - 17.00	Discussion and evaluations
17.00	Close of conference











Organised by





How to get to the venue

Education Centre, University College London Hospital, 250 Euston Road, NW1 2PG

Tel +44(0)845 155 5000 Web: www.uclh.nhs.uk

BY BUS: Tottenham Court Road - North bound (Warren Street station) - Bus No's 10, 73, 24, 29, 134 Gower Street - South bound (University Street) - Bus No's 10, 24, 29, 73, 134, Euston Road - Bus No's 18, 27, 30, 88

BY TUBE: Warren Street (Northern / Victoria Lines) Euston Square (Circle / Hammersmith & City / Metropolitan Lines)

Accommodation details

Grange Hotels are offering a special rate for delegates attending Sickle Cell 2009. To make a reservation please contact Grange Hotels central reservations quoting: 'MA Healthcare'.

GRANGE HOTELS Telephone number: 0207 233 7888

Fax number: 0207 630 9897

Email: reservations@grangehotels.com

Expotel can provide a complimentary hotel booking service for delegates attending Sickle Cell 2009.

To enquire about making a reservation or to get details of other hotels contact Expotel on the number below, choose the 'hotel' option and quote MA Healthcare/Sickle Cell 2009

EXPOTEL Telephone number: 0141 331 1771

> Fax number: 0141 331 1117 Email: glres@expotel.com

Booking conditions

MA Healthcare Ltd (The Company) accepts bookings under the following conditions

- All correspondence will be sent to the participants at the address specified on the booking form or over the telephone. (This address will also appear on the official participant's list given out at the event).
- The completed booking form together with full payment must be sent to MA Healthcare Ltd. A confirmation will then be issued. Cheques should be made payable to MA Healthcare Limited. Returning the signed registration form constitutes a firm booking.
- Bookings may be made by 3 telephone but payment must be made in full by credit card.
- All payments, including credit card, must be in sterling.
- The Company reserves the right to cancel a booking if payment is not made six weeks prior to the conference taking place. Any outstanding payment becomes the responsibility of the signatory made on the reservation form.
- Payment for any booking made within six weeks of the conference will still be due to the company irrespective of whether the delegate attends.

- Should you be unable to attend, a substitute delegate may take his/her place. Notification must be received in writing one week prior to the conference.
- The Company reserves the right to change the conference speakers in cases of illness or other conditions beyond its control.
- The Company does not accept responsibility for loss or damage to delegates' own property and/or personal effects caused by events beyond its control, including (but without limitation) fire, flood, strikes, civil disturbances or for consequential loss or damage of any kind whatsoever.
- 10 Speakers approached at time of print.

Cancellation of booking

Written cancellations received six weeks prior to the conference will be accepted and a refund of 90% of the booking charge will be made. After this date, no refunds can be given. Verbal cancellations will not be accepted.

If written cancellation is not received six weeks prior to the conference full payment will still be due irrespective of whether the delegate attends the conference.





Registration form I would like to secure my place at Sickle Cell 2009 PHOTOCOPIES OF THIS FORM ACCEPTED Title (Dr, Mr, Mrs etc): Forenames Surname..... Job title Home address

...... Post code Telephone..... Emgil..... I understand that this registration booking is subject to the booking conditions. Signature **DELEGATE RATES** Please tick the box as applicable Consultants and GPs

...... Post code

Work address

£450 incl VAT

Specialist Registrars, Junior doctors, nurses and other non-medics 250 incl VAT

The conference fee includes:

- Entrance to the conference
- · Lunch and refreshments
- Full conference documentation
 Certificate of accreditation

I WISH TO PAY BY:

· Credit card

Please debit my ☐ Visa ☐ Mastercard ☐ Maestro ☐ American Express Card no Expiry date ☐ 3 digit security code ☐ ISSUE NO (Maestro cards only)

Call the Credit Card Booking Hotline 0207 501 6762

- Book online at www.mahealthcareevents.co.uk
- · Make your cheque payable to MA Healthcare Ltd

Requesting an invoice and signing this form will secure your place at the conference. All invoices must be paid in full before the event. See booking condition 5. To receive an invoice you must complete this section in full giving either your work or Trust address. We are unable to send out invoices to home addresses PLEASE COMPLETE IN FULL WITH CONTACT NAME IF DIFFERENT FROM ABOVE

PO Number Contact Full invoice address....

Post code

Telephone...... Fax..... Signed

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