PROGRAMME

1:15–2:00 Registration and lunch

2:00 Welcome (Dr Roiyah Saltus, WEDHS Chair)

2:00 – 2:40 Panel One: Setting the Scene

- Introduction by the Chair (Dr Alison May, Senior Research Fellow, Cardiff University)
- *Prenatal diagnosis for high risk couples* (Dr Bryan Beattie, Consultant Obstetrician, UHW)

2:40 – 3:45 Panel Two: Living with Sickle Cell or Thalassaemia

- Panel discussion led by Tessa Liburd & Paulette Palmer (Cardiff Sickle Cell and Thalassaemia Centre)

3:40 – 4:00 Comfort break

3:50 – 5:00 Panel Three: Working with people with Sickle Cell or Thalassaemia

- *A Sickle Crisis? Findings from a recent report published by the National Confidential Enquiry into patient outcome and death* (Dr George Findlay, NCEPOD)
- *Sickle Cell in Children* (Dr Phil Connor, Consultant Paediatric Haematologist, Children's Hospital for Wales)

5:00 Closing Remarks (Dr Alison May)

The Cardiff Sickle Cell and Thalassaemia Centre

- Provides information screening and counselling to those at risk from haemoglobinopathies
- Targets and educates the communities at risk
- Provides support, advice and co-ordination of care to affected families
- Acts as a specialist resource for Health Care Professionals
- Holds the patient register for Wales

You can find us at the
Butetown Health Centre, Loudoun Square,
Cardiff, CF10 5UZ

We are open weekdays, 9am–5pm

Tel: **029 20471055**
sickle.cell@cardiffandvale.wales.nhs.uk

For further information about this workshop, please contact:

The Sickle Cell and Thalassaemia Centre (details can be found above)
or
Dr Roiyah Saltus
WEDHS Chair, University of Glamorgan
Tel: **01443 483194** • Email: **rsaltus@glam.ac.uk**

All proceeds from this event will be used by the Centre to host future events

Living or Working with People who have Sickle Cell or Thalassaemia

Half Day Workshop

Tuesday, 23rd September 2008

The Japan Room
Wales Millennium Centre
Cardiff Bay

1:00pm–5:00pm

WEDHS
Wales Equality and Diversity in Health and Social Care Research and Support Service
Gwasanaeth Cydraddoldeb ac Amrywioldeb Cymru mewn Ymchwil Gofal Cymdeithasol

NHS WALES GIG CYMRU

UNIVERSITY OF GLAMORGAN PRIFYSGOL MORGANNWG

BOOKING FORM

To reserve a place, please send this completed section, together with £20.00 registration fee* (cash, or cheque payable to 'University of Glamorgan') to:
Andrew Hale, Research Office,
Faculty of Health,
Sport and Science,
University of Glamorgan,
Pontypridd, CF371DL.
The dead-line to register is **19 September 2008**

Name: _____

Address: _____

_____

Post code: _____

Contact telephone: _____

Contact email: _____

Post held: _____

Name of your organisation: _____

_____

Special requirements: _____

_____

**Please contact us if you wish to raise a purchase order to receive an invoice to cover payment. The registration fee will be reduced to £5.00 for Friends of the Cardiff Sickle Cell and Thalassaemia Centre and for medical and health care students.*

Living or Working with People who have Sickle Cell or Thalassaemia

The haemoglobinopathies are a group of genetic blood disorders in which either the structure (sickle cell disorders) or the quantity (thalassaemias) of haemoglobin produced is affected. Sickle cell disorder (SCD) and beta thalassaemia major are two of the most common haemoglobinopathies. These disorders are inherited and vary greatly according to the type of disorder and the severity of the symptoms. Sickle cell disorders affect, to a disproportionate extent, people of African and African Caribbean origin, although they may also affect people from the Eastern Mediterranean, the Middle East and India. Thalassaemia mainly affects people from the Eastern Mediterranean, Asia, the Middle East and the Far East.

Wales has a long history of minority ethnic settlement, concentrated mainly in the south Wales coal ports, but with pockets of settlement throughout Wales. The histories, settlement patterns, residential status and occupational profiles of BME groups in Wales are different from that found elsewhere in the UK. There is a need, therefore, to consider the particularities of the Welsh context when examining the health and social care of BME groups, not least in regards to genetic conditions like sickle cell and thalassaemia.

This half-day workshop will be of interest to service users and their families, health care/clinical scientists, health visitors, midwives, nurses, academics and community health workers.

OBJECTIVES OF THE WORKSHOP

To provide:

1. An opportunity to listen to the views, and learn from the experiences, of people affected by these disorders;

2. A forum in which to provide information, research findings and best practice guidance to those working or living with sickle cell or thalassaemia in Wales;

3. A network opportunity for people to meet and discuss how to improve the quality of genetic services in Wales and beyond.

LEARNING OUTCOMES

To gain:

- Knowledge of best practice in caring for those with sickle cell or thalassaemia;

- An awareness of the impact of factors such as 'race', ethnicity and culture in relation to specific genetic disorders.

WEDHS offers a way to improve the health and wellbeing for black and minority ethnic (BME) people in Wales through an innovative programme of research and development. **www.wedhs.org.uk**