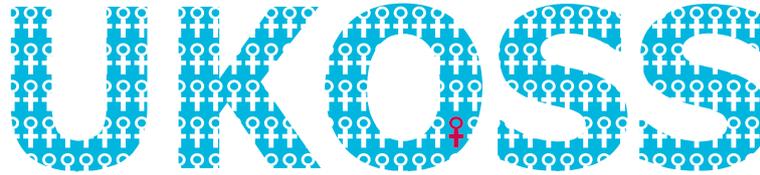
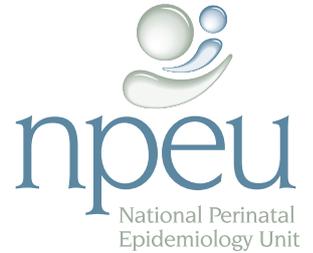




Royal College of  
Obstetricians and  
Gynaecologists



UK Obstetric Surveillance System



## Newsletter 6: July 06

### 100% hospitals!

Thank you once again to all of you who have reported cases and completed case reports for UKOSS. The list below shows all those hospitals who have returned all their monthly report cards and completed all their data collection forms for the first year – an amazing 77 hospitals. We really appreciate what a fantastic effort this has been. Sometimes cards do go astray in the post, so if there is anyone who thinks they should be on this list as well, please get in touch and we will identify for you which months we are missing. The regional response honours this quarter go to the North East who have returned 100% of cards for the past three months.

Aberdeen Maternity Hospital  
Airedale General Hospital  
Alexandra Hospital  
Altnagalvin Area Hospital  
Ayrshire Central Hospital  
Barnsley District General Hospital  
Bassetlaw District General Hospital  
Borders General Hospital  
Bronglais Hospital  
Chelsea & Westminster Hospital  
City Hospitals Sunderland NHS Trust  
Colchester General Hospital  
Countess of Chester Hospital  
Craigavon Area Hospital  
Cumberland Infirmary  
Daisy Hill Hospital  
Dr Gray's Hospital  
Dumfries & Galloway Royal Infirmary  
Eastbourne District General Hospital  
Gloucestershire Royal Hospital  
Good Hope Hospital  
Hereford County Hospital  
Horton Hospital  
Hospital of St John and St Elizabeth  
Ipswich Hospital  
John Radcliffe Hospital  
King's Mill Hospital  
Lagan Valley Hospital  
Leeds General Infirmary  
Lincoln County Hospital  
Macclesfield District General Hospital  
Maidstone General Hospital  
Manor Hospital  
New Cross Hospital  
Nobles Hospital  
Norfolk & Norwich University Hospital  
North Hampshire Hospital  
Nottingham City Hospital  
Pilgrim Hospital

Pontefract General Infirmary  
Poole Hospital  
Princess Elizabeth Hospital  
Princess of Wales Hospital  
Queen Elizabeth Hospital  
Gateshead  
Queen Elizabeth the Queen Mother Hospital  
Queen Mary's Hospital  
Queen's Park Hospital  
Rotherham District General Hospital  
Royal Alexandra Hospital  
Royal Cornwall Hospital  
Royal Hampshire County Hospital  
Royal Lancaster Infirmary  
Royal Oldham Hospital  
Salisbury District Hospital  
South Tyneside District Hospital  
Southend Hospital  
Southmead Hospital  
Southport & Ormskirk Hospital NHS Trust  
St James's University Hospital  
St John's Unit at Howden  
St Mary's Hospital, Portsmouth  
St Richard's Hospital  
Taunton and Somerset Hospital  
The Portland Hospital  
Torbay Hospital  
Trafford General Hospital  
University Hospital Lewisham  
University Hospital of North Tees  
Victoria Hospital  
West Cumberland Hospital  
West Wales General Hospital  
Whiston Hospital  
Wishaw General Hospital  
Worthing Hospital  
Wrexham Maelor Hospital  
Wythenshawe Hospital  
Ysbyty Gwynedd District General Hospital

## UKOSS funding

We are aware that the fee for conducting a study through UKOSS (£12,000) may appear high. We thought it would be helpful, therefore, to let you know about the funding of UKOSS and what the £12,000 fee buys.

### Why do I have to pay a study fee to undertake a study through UKOSS?

UKOSS has no external funding. It is funded entirely by these study fees. Since all the initial studies are being run by Marian Knight at the NPEU, the current funding is mainly provided through the NPEU. However, in the long run a greater proportion of the running costs of UKOSS will be provided by other sources. Both the two new studies starting in the autumn are funded by other sources.

### What does it cost to run UKOSS?

The total running costs of UKOSS are approximately £90,000 per annum. This includes the staffing costs, the monthly cards, the data collection form printing, data entry and the cost of the Steering Committee meetings. We therefore charge £12,000 per study on the assumption that there will be 6 to 8 studies on the card at any one time (the fee applies per study, regardless of the length of data collection, i.e. studies which run for three years in order to collect sufficient cases cost the same as studies which run for only one year).

### What does each investigator get for £12,000?

The fee covers all the services provided by UKOSS:

- Peer review of study proposal by UKOSS Steering Committee and assistance with developing data collection instrument
- Assistance with information for submission to ethics committee
- Data collection form formatted by NPEU webmaster/designer
- Study publicity through UKOSS newsletter and mailings to individual reporters
- Case notifications collected
- Case/control data collection forms mailed
- Missing forms chased
- All data checked back and double-entered into a customised database
- Missing information queried
- Data coding undertaken if required
- Interim dataset given to investigators four months after mid-point of the study to enable the testing of analysis procedures and abstract preparation
- Complete, clean dataset given to investigators four months after completion of the study
- Mentorship from Steering Committee members if required
- Study results publicised through UKOSS newsletters and annual report

In exchange the investigator undertakes to analyse the data and submit for publication within two years of study completion. We feel this undertaking is extremely important in order to ensure that study results are communicated to reporting clinicians as quickly as possible.

## New Studies commencing August/September 2006

### Gastroschisis

Gastroschisis is a congenital anomaly of the anterior abdominal wall. The condition has been noted to be increasing worldwide. A number of reports have provided evidence that this increase is also occurring in the UK, leading to a call for further research on the condition by the Chief Medical Officer for England<sup>1</sup>. Additionally a North-South gradient in birth prevalence has been noted in the UK, although incomplete geographical coverage by regional congenital anomaly registers makes this difficult to study<sup>2</sup>. This UK-wide descriptive study will measure the birth prevalence of gastroschisis and variations in birth prevalence nationally. This will be the first study to attempt to provide accurate birth prevalence rates for gastroschisis for the 50% of UK births not covered by regional congenital anomaly registers, and hence provide a complete picture of regional variations across the UK. The study will in addition provide a detailed description of antenatal management of infants with the condition.

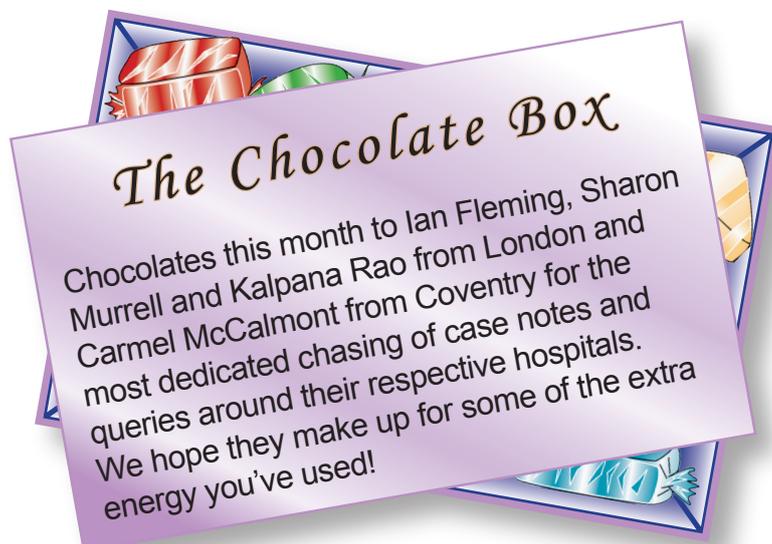
1. Donaldson L. Annual report of the Chief Medical Officer 2004. London: Department of Health, 2005.
2. Stone DH, Rimaz S, Gilmour WH. Prevalence of congenital anterior abdominal wall defects in the United Kingdom: comparison of regional registers. *BMJ* 1998; 317(7166):1118-9.

### Fetomaternal Alloimmune Thrombocytopenia (FMAIT)

FMAIT is the most common cause of severe neonatal thrombocytopenia in otherwise well term infants, and can lead to serious bleeding, intracranial haemorrhage and sometimes death of the fetus or infant. First pregnancies are often severely affected and the diagnosis is usually made with the birth of a first affected infant. There is therefore a current debate about the utility of antenatal screening for the condition. This descriptive, population-based study will address deficiencies in basic epidemiological information about the condition highlighted in a recent evaluation<sup>1</sup>. Additionally, there are considerable controversies in the optimal management of FMAIT-affected pregnancies<sup>1,2</sup>. This descriptive, population-based study will allow the outcomes following different antenatal management strategies to be assessed.

This study will be the first to be conducted jointly with the British Paediatric Surveillance Unit (BPSU). A BPSU study will run simultaneously, collecting information from paediatricians about infants born with FMAIT. This will allow us to collect information about cases which were not diagnosed antenatally, and allow us to check how completely cases are identified through UKOSS. The study is funded by the charity Wellbeing of Women.

1. Murphy MF, Williamson LM, Urbaniak SJ. Antenatal screening for fetomaternal alloimmune thrombocytopenia: should we be doing it? *Vox Sang* 2002; 83 Suppl 1:409-16.
2. Rayment R, Brunskill SJ, Stanworth S, Soothill PW, Roberts DJ, Murphy MF. Antenatal interventions for fetomaternal alloimmune thrombocytopenia. *Cochrane Database Syst Rev* 2005; (1):CD004226.



We are aware these two new studies are more fetal medicine orientated than previous UKOSS studies. If you feel it would help with internal communication in your unit, we would be happy to send additional reporting cards to your nominated fetal medicine specialist. Please let us know if you would like us to do this.

## Who's Who – UKOSS Steering Committee



(Pictured standing L-R) Carole Harris, Cathy Nelson-Piercy, Mervi Jokinen, Peter Brocklehurst, Jenny Kurinczuk, Andrew Dawson, Derek Tuffnell, Ian Greer

(seated) Marian Knight, James Walker, Richard Lilford.

(not present) Jean Chapple, James Dornan, Jenny Furniss, Shona Golightly, Gwyneth Lewis, Mags McGuire, Richard Pebody, Steve Yentis.

Regional card return rates April-June 2006	
E Midlands	95
E of England	78
London	93
NI	94
North East	100
North West	87
Scotland	91
SE & Channel Is	86
South West	88
Wales	76
W Midlands	82
Yorks & Humber	96

### Cases reported - current studies

Disorder	Actual Number of cases	Expected number of cases
Acute Fatty Liver	73	120
Amniotic Fluid Embolism	32	15
Antenatal Pulmonary Embolism	169	75
Myocardial Infarction	7	54
Pulmonary Vascular Disease	9	2
Tuberculosis	104	255

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