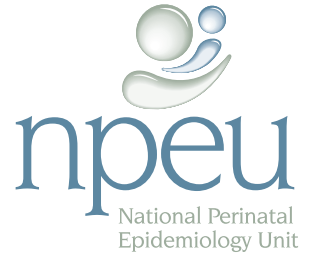


UK Obstetric Surveillance System



Royal College of Obstetricians and Gynaecologists

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. 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
- Daisy Hill Hospital
- Dr Gray's Hospital
- Eastbourne District General Hospital
- Gloucestershire Royal Hospital
- Good Hope Hospital
- Hereford County Hospital
- Horton Hospital
- Ipswich Hospital
- John Radcliffe Hospital
- King's Mill Hospital
- Lagan Valley Hospital
- Lincoln County Hospital
- Maidstone General Hospital
- Manor Hospital
- New Cross Hospital
- Nobles Hospital
- Norfolk & Norwich University Hospital
- North Hampshire Hospital
- Nottingham City Hospital
- Pilgrim Hospital

- Poole Hospital
- Princess of Wales Hospital
- Gateshead
- Queen Mary's Hospital
- Queen's Park Hospital
- Rotherham District General Hospital
- Royal Alexandra Hospital
- Royal Cornwall Hospital
- Royal Hampshire County Hospital
- 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 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 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/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 T¹. Additionally a North-South gradient in birth prevalence has been noted in the UK, although incomplete geographical coverage by regional congenital anomaly registers². This UK-wide descriptive study will measure the birth prevalence of gastroschisis in 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.

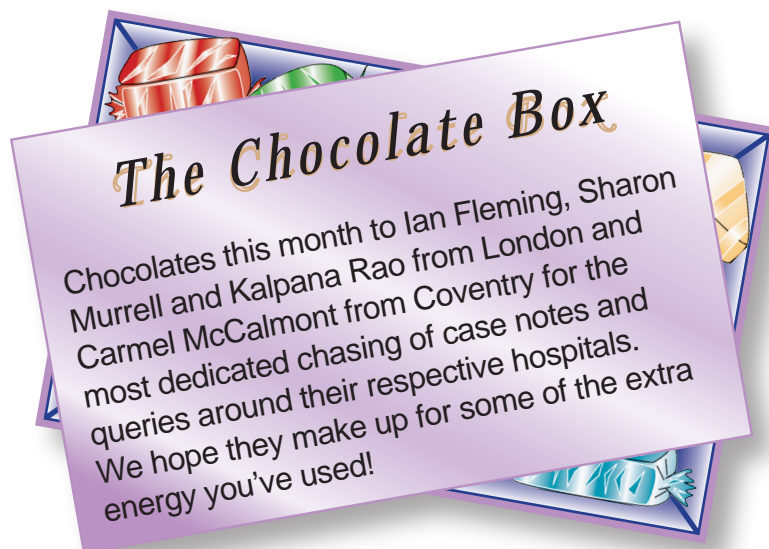
1. Murphy MF, Williamson LM, Urbaniak SJ. Antenatal screening for fetomaternal alloimmune thrombocytopenia: should we be screening? *Arch Dis Child* 2005; 90: 1033-1036.
2. Raymont R, Brunskill SJ, Stanworth S, Soothill PW, Roberts DJ, Murphy MF. Antenatal interventions for fetomaternal alloimmune thrombocytopenia: a systematic review. *Arch Dis Child* 2005; 90: 1037-1041.

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 on the basis of a low platelet count in the fetus or infant. This descriptive, population-based study will address the need for a systematic approach to the diagnosis and management of FMAIT-affected pregnancies^{1,2}. This descriptive, population-based study will allow the outcomes following different antenatal management strategies to be assessed.

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 reported to 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 screening? *Arch Dis Child* 2005; 90: 1033-1036.
2. Raymont R, Brunskill SJ, Stanworth S, Soothill PW, Roberts DJ, Murphy MF. Antenatal interventions for fetomaternal alloimmune thrombocytopenia: a systematic review. *Arch Dis Child* 2005; 90: 1037-1041.



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.

