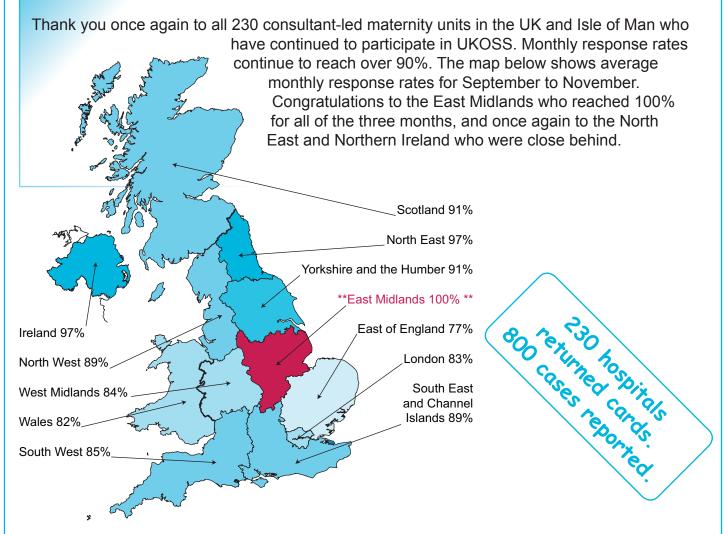




Royal College of Obstetricians and Gynaecologists

Newsletter 4: January 06

The national system to study rare disorders of pregnancy



Disorder	Actual Number of Cases	Expected Number of Cases
Acute Fatty Liver	52	88
Amniotic Fluid Embolism	14	11
Antenatal Pulmonary Embolism	109	55
Eclampsia	242	275
Myocardial Infarction	4	24
Peripartum Hysterectomy	305	275
Tuberculosis	74	187

Thanks to the following hospitals who have returned cards for the last three months:

Aberdeen Maternity Hospital Airedale General Hospital Alexandra Hospital Altnagalvin Area Hospital Antrim Hospital Arrowe Park Hospital Ayrshire Central Hospital Barnet and Chase Farm Hospitals Barnsley District General Hospital Basildon Hospital Bassetlaw District General Hospital **Bedford Hospital** Birmingham City Hospital Birmingham Women's Hospital Borders General Hospital Bradford Royal Infirmary Bronglais Hospital Burnley General Hospital Caithness General Hospital Calderdale Royal Hospital Causeway Hospital Chelsea & Westminster Hospital Cheltenham General Hospital Chesterfield & North Derbyshire Royal Hospital City General Hospital City Hospitals Sunderland NHS Trust Colchester General Hospital **Conquest Hospital** Countess of Chester Hospital Craigavon Area Hospital Cumberland Infirmary Daisy Hill Hospital Darent Valley Hospital Darlington Memorial Hospital Derby City General Hospital Derriford Hospital Dewsbury and District Hospital Diana Princess of Wales Hospital Doncaster Royal Infirmary Dorset County Hospital Dr Gray's Hospital Dumfries & Galloway Royal Infirmary Ealing Hospital East Surrey Hospital Eastbourné District General Hospital **Epsom General Hospital** Erne Hospital Fairfield General Hospital Forth Park Hospital Friarage Hospital Frimley Park Hospital Furness General Hospital George Eliot Hospital Glan Clwyd District General Hospital Gloucestershire Royal Hospital Good Hope Hospital Guy's and St Thomas' Hospital Harold Wood Hospital Harrogate District Hospital Heatherwood Hospital Hereford County Hospital Hexham General Hospital Hillingdon Hospital Hinchingbrooke Hospital Homerton Hospital Hope Hospital Horton Hospital Hospital of St John and St Elizabeth Huddersfield Royal Infirmary Hull Royal Infirmary Ipswich Hospital James Cook University Hospital James Paget Hospital Jersey General Hospital John Radcliffe Hospital

Kettering General Hospital King George Hospital Kings College Hospital King's Mill Hospital Kingston Hospital Lagan Valley Hospital Leeds General Infirmary Leicester General Hospital Leicester Royal Infirmary Leighton Hospital Lincoln County Hospital Lister Hospital Liverpool Women's Hospital Macclesfield District General Hospital Maidstone General Hospital Manor Hospital Mater Infirmorum Hospital Medway Maritime Hospital Mid-Ulster Hospital Milton Keynes General Hospital Nevill Hall Hospital New Cross Hospital Newham General Hospital Ninewells Hospital & Medical School Nobles Hospital Norfolk & Norwich University Hospital North Devon District Hospital North Hampshire Hospital North Middlesex Hospital North Tyneside General Hospital Northampton General Hospital Northwick Park Hospital Nottingham City Hospital Pembury Hospital Peterborough Maternity Unit Pilgrim Hospital Pontefract General Infirmary Poole Hospital Prince Charles Hospital Princess Alexandra Hospital Princess Anne Hospital Princess Elizabeth Hospital Princess of Wales Hospital Princess Royal Hospital Princess Royal Maternity Hospital Princess Royal University Hospital Queen Charlotte's and Chelsea Hospital Queen Elizabeth Hospital, Gateshead Queen Elizabeth Hospital, Kings Lynn Queen Elizabeth Hospital, London Queen Elizabeth II Hospital Queen Elizabeth the Queen Mother Hospital Queen Mary's Hospital Queen Mother's Hospital Queen's Hospital Queen's Medical Centre Queen's Park Hospital Raigmore Hospital Rochdale Infirmary Rosie Maternity Hospital Rotherham District General Hospital Royal Albert Edward Infirmary Royal Alexandra Hospital Royal Berkshire Hospital Royal Bolton Hospital Royal Cornwall Hospital Royal Devon & Exeter Hospital Royal Free Hospital Royal Glamorgan Hospital Royal Gwent Hospital Royal Hampshire County Hospital Royal Jubilee Maternity Service Royal Lancaster Infirmary Roval London Hospital Royal Oldham Hospital

Royal Shrewsbury Hospital Royal Surrey County Hospital Royal Sussex County Hospital Royal United Hospital Royal Victoria Infirmary Russells Hall Hospital Salisbury District Hospital Sandwell District General Hospital Scarborough Hospital Scunthorpe General Hospital Sharoe Green Hospital Simpson Centre for Reproductive Health Singleton Hospital South Tyneside District Hospital Southend Hospital Southern General Hospital Southmead Hospital Southport & Ormskirk Hospital NHS Trust St George's Hospital St Helier Hospital St James's University Hospital St John's Hospital St John's Unit at Howden St Mary's Hospital, London St Mary's Hospital, Manchester St Mary's Hospital, Newport St Mary's Hospital, Portsmouth St Michael's Hospital St Peter's Hospital St Richard's Hospital Staffordshire General Hospital Stepping Hill Hospital Stirling Royal Infirmary Stoke Mandeville Hospital Tameside General Hospital Taunton and Somerset Hospital The Great Western Hospital The Jessop Wing The Portland Hospital **Torbay Hospital** Trafford General Hospital Ulster Hospital University College Hospital University Hospital Lewisham University Hospital of Hartlepool University Hospital of North Durham University Hospital of North Tees University Hospital of Wales Victoria Hospital Walsgrave Hospital Wansbeck General Hospital Warrington Hospital Warwick Hospital Watford General Hospital West Cumberland Hospital West Middlesex University Hospital West Suffolk Hospital West Wales General Hospital Western Isles Hospital Wexham Park Hospital Whipps Cross Hospital Whiston Hospital Whittington Hospital William Harvey Hospital Wishaw General Hospital Withybush Hospital Worcestershire Royal Hospital Worthing Hospital Wrexham Maelor Hospital Wycombe General Hospital Wythenshawe Hospital Yeovil Women's Hospital York Hospital Ysbyty Gwynedd District General Hospital

New study – Pulmonary Vascular Disease

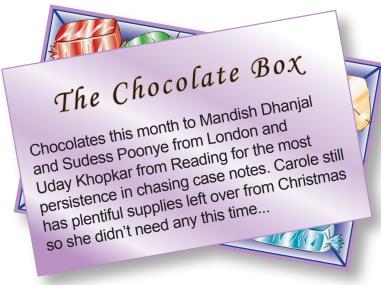
A new study will be added to the card sent out in April 2006 (reporting cases from March 2006). Pulmonary vascular disease, including Eisenmenger's syndrome, primary and secondary pulmonary hypertension, is one of the rare conditions widely considered to pose an extreme risk of maternal death¹. Four of the nine maternal deaths in women with congenital heart disease reported in the UK in the last triennium were associated with pulmonary vascular disease²; since 1991 there have been 22 maternal deaths in the UK associated with this condition². Eisenmenger's syndrome is estimated to carry a maternal mortality rate of 40% per pregnancy², with an infant mortality rate of 10-15%¹. A systematic review of the literature in 1998 suggested that the maternal mortality rate had remained unchanged over the previous 20 years¹. However, the authors of this review recognise that there may be biases in published reports and call for more information from detailed prospective case series in order to differentiate the risks of pregnancy and eventually provide an optimal plan of management. Cases in the UK were collected prospectively on a voluntary basis by the UK Registry of High Risk Obstetric Anaesthesia³; however, the register has now ceased to collect data. This prospective study through UKOSS will provide an appropriate national case series with good ascertainment and allow a comprehensive study of the epidemiology and current management of Eisenmenger's syndrome and pulmonary hypertension. We anticipate about 10 case reports per year.

Case definition: *EITHER* Pulmonary hypertension: defined as 1) a mean (not systolic) pulmonary artery pressure equal to or greater than 25mmHg at rest or 30 mmHg on exercise in the absence of a left-to-right shunt or 2) a pulmonary artery systolic pressure greater than 36mmHg. Pulmonary hypertension may be primary (no cause identified) or secondary (known cause identified, for example, vasculitis, connective tissue disease, chronic pulmonary thromboembolism, sickle cell disease, drug use),

OR Eisenmenger's syndrome: defined as pulmonary hypertension secondary to an uncorrected left-to-right shunt from a ventricular septal defect, atrial septal defect or patent ductus arteriosus.

- 1. Weiss BM, et al. J Am Coll Cardiol 1998; 31:1650-7.
- de Swiet M, Nelson-Piercy C. Cardiac Disease. In: Why Mothers Die 2000-2002. London: RCOG, 2004.
- 3. Dob DP, Yentis SM. Int J Obstet Anesth 2001; 10:267-72.

Two studies almost completed



UKOSS has nearly reached its first birthday! This means that two of the

studies, peripartum hysterectomy and eclampsia, are close to completion. We will be collecting cases up until the end of February 2006 (on the card sent out in March). After March, these two conditions will no longer appear on the list on the UKOSS card. Thank you very much to all those of you who have already completed data collection forms. **89%** of case and control forms have been returned to us within four months of the report of the case. Unfortunately, even a small amount of missing information could prevent us from achieving the primary aims of these studies, which are to document the incidence, management and outcomes of each condition, and thus to improve care in the future, so if you have any of the 11% of outstanding forms please could you try to get them back to us.

UKOSS Workshop at the British Maternal and Fetal Medicine Society Meeting Cardiff 6-7th April 2006

We will be holding a workshop at the Annual Conference of the BMFMS, which this year is being held in Cardiff. The workshop is aimed at anyone interested in running a study through UKOSS and will cover possible study types, developing a protocol, the application process and potential sources of funding. We will also be discussing new studies planned for later in the year. If you are attending the meeting and have an idea for a study or are just interested in finding out more about how UKOSS can develop, please come along! The workshop will be held at lunchtime on Thursday 6th April.

Total UK monthly

Extended Reporting

Data collection for the acute fatty liver and antenatal pulmonary embolism studies will be continuing for a further six months due to differences between the actual and estimated case numbers reported.

hospitals

For complete data collection form return:

Frimley Park Hospital, Camberley

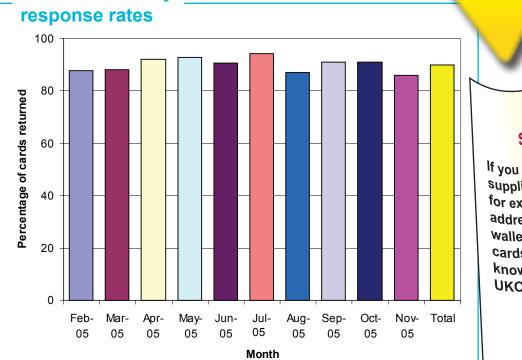
Leeds General Infirmary

Manor Hospital, Walsall

Nobles Hospital, Douglas

Princess Anne Hospital,

Scunthorpe General Hospital



Stationery

If you need any more Supplies for your folder, for example return address labels or plastic Wallets for reporting Cards please let us UKOSS@npeu.ox.ac.uk know.

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email: UKOSS@npeu.ox.ac.uk web: www.npeu.ox.ac.uk/UKOSS