The national system to study rare disorders of pregnancy

Thank you once again to all 230 consultant-led maternity units in the UK and Isle of Man who have continued to participate in UKOSS. Monthly response rates continue to reach over 90%. The map below shows average monthly response rates for September to November. Congratulations to the East Midlands who reached 100% for all of the three months, and once again to the North East and Northern Ireland who were close behind.

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Actual Number of Cases</th>
<th>Expected Number of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Fatty Liver</td>
<td>52</td>
<td>88</td>
</tr>
<tr>
<td>Amniotic Fluid Embolism</td>
<td>14</td>
<td>11</td>
</tr>
<tr>
<td>Antenatal Pulmonary Embolism</td>
<td>109</td>
<td>55</td>
</tr>
<tr>
<td>Eclampsia</td>
<td>242</td>
<td>275</td>
</tr>
<tr>
<td>Myocardial Infarction</td>
<td>4</td>
<td>24</td>
</tr>
<tr>
<td>Peripartum Hysterectomy</td>
<td>305</td>
<td>275</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>74</td>
<td>187</td>
</tr>
</tbody>
</table>

230 hospitals returned cards.
800 cases reported.
Thanks to the following hospitals who have returned cards for the last three months:

- Aberdeen Maternity Hospital
- Airedale General Hospital
- Alexandra Hospital
- Altnagelvin Area Hospital
- Antrim Hospital
- Arrowe Park Hospital
- Ayshire Central Hospital
- Barnet and Chase Farm Hospitals
- Barnsley District General Hospital
- Basildon Hospital
- Bassettlaw District General Hospital
- Bedforvhospital
- 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
- Derbys 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
- Eastbourne District General Hospital
- Epsom General Hospital
- Erne Hospital
- Fairfield General Hospital
- Forth Park Hospital
- Friargate Hospital
- Friary Park Hospital
- Furness General Hospital
- George Eliot Hospital
- Glen Cwyd 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
- Hornetown 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 School Hospital
- Lagan Valley Hospital
- Leeds General Infirmary
- Leicester General Hospital
- Leicester Royal Infirmary
- Leighton Hospital
- Lincoln County Hospital
- Lister Hospital
- Liverpool Women's Hospital
- Macdessofield District General Hospital
- Maidstone General Hospital
- Manor Hospital
- Mater Infirmary
- Medway Maritime Hospital
- Mid-Ulster Hospital
- Milton Keynes General Hospital
- Nevill Hall Hospital
- New Cross Hospital
- Newham General Hospital
- Ninewells Hospital & Medical School
- Noble's 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
- Raglan 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 Hospital
- Royal Lancaster Infirmary
- Royal 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
- Southmead Hospital
- Southend Hospital
- Southern General Hospital
- Staffordshire 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 Midlands University Hospital
- West Suffolk Hospital
- West Wales General Hospital
- Western Isles Hospital
- Wexham Park Hospital
- Whips Cross Hospital
- Whiston Hospital
- Whittington Hospital
- William Harvey Hospital
- Whisht General Hospital
- Withybush Hospital
- Worcestershire Royal Hospital
- Worthing Hospital
- Wrexham Maelor Hospital
- Wycombe General Hospital
- Wythenshawe Hospital
- Yeoill Women's Hospital
- York Hospital
- Ysbyty Gwynedd District General Hospital
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 death. 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 disease; since 1991 there have been 22 maternal deaths in the UK associated with this condition. Eisenmenger’s syndrome is estimated to carry a maternal mortality rate of 40% per pregnancy, with an infant mortality rate of 10-15%. A systematic review of the literature in 1998 suggested that the maternal mortality rate had remained unchanged over the previous 20 years.

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 Anaesthesia; 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.


**The Chocolate Box**

Chocolates this month to Mandish Dhanjal and Sudess Poonye from London and Uday Khopkar from Reading for the most persistence in chasing case notes. Carole still has plentiful supplies left over from Christmas so she didn’t need any this time...

**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.

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.

Star hospitals

For complete data collection form return:
Bradford Royal Infirmary
Frimley Park Hospital, Camberley
Ipswich Hospital
Leeds General Infirmary
Manor Hospital, Walsall
Nobles Hospital, Douglas
Princess Anne Hospital, Southampton
Scunthorpe General Hospital

Thank you!

Total UK monthly response rates

<table>
<thead>
<tr>
<th>Month</th>
<th>Percentage of cards returned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feb-05</td>
<td>80</td>
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<tr>
<td>Mar-05</td>
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<td>Oct-05</td>
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<tr>
<td>Nov-05</td>
<td>80</td>
</tr>
<tr>
<td>Total</td>
<td>80</td>
</tr>
</tbody>
</table>

Marian Knight: 01865 289727  email: UKOSS@npeu.ox.ac.uk
Carole Harris: 01865 289714  web: www.npeu.ox.ac.uk/UKOSS

Star
hospitals

For complete data collection form return: Bradford Royal Infirmary, Frimley Park Hospital, Camberley, Ipswich Hospital, Leeds General Infirmary, Manor Hospital, Walsall, Nobles Hospital, Douglas, Princess Anne Hospital, Southampton, Scunthorpe General Hospital

Thank you!