

British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS)



Newsletter 9: March 2009

The national system to study the surgical management of a range of neonatal conditions

Congenital Diaphragmatic Hernia study starts April 2009

The charity Action Medical Research have funded the next BAPS-CASS study to commence in April 2009. Congenital Diaphragmatic Hernia (CDH) is a musculoskeletal defect of the diaphragm which occurs during fetal development. The available information about infant management and outcomes largely comes from case series collected over long periods of time reported from referral centres rather than population-based data. These indicate that, despite advances in treatment, mortality in the newborn period remains high, with estimates of up to 50% mortality. Controversially, the best results (>80% survival) are reported from specialist centres. Population-based information on the impact of different management strategies is therefore essential to provide a true picture of the prognosis for infants with CDH in the UK. However, existing congenital anomaly registers cover only 50% of UK births and cannot be used to study the condition on a national basis.

This combined study with the UK Obstetric Surveillance System (UKOSS) and the British Isles Network of Congenital Anomalies Registers (BINOCAR) will estimate the diagnosed and birth incidence of CDH, describe the surgical management and the short and medium term outcomes after corrective surgery.

Paul Losty from Liverpool is the Clinical Lead for the study and Jennifer Kurinczuk from Oxford the study Principal Investigator. Further information for BAPS-CASS centre coordinators is enclosed with this newsletter and also available on the website at www.npeu.ox.ac.uk/baps-cass.



Case Report Summary to 17/03/2009

Condition	Cases Reported	Forms returned	Confirmed Cases	Unconfirmed Cases	Duplicate Cases
Gastroschisis	435	414 (95%)	394 (95%)	8 (2%)	12 (3%)
Oesophageal Atresia	141	99 (70%)	97 (98%)	0	2 (2%)

Card Return Rates Oesophageal Atresia Study April 08-January 09



All card returns, even those reporting zero cases, are extremely important, as they allow us to calculate the denominator number of births to estimate the incidence of a condition. They also help us to be sure we have not missed any cases. Thank you very much to everyone who has sent back cards to date. Please send us back, via snail or email, any monthly cards you still have. Up to the end of February, 14 units have returned all their monthly cards, 6 units have returned 90% of their cards, 1 unit has returned 80%, 3 units 70% and 2 units 60%. There are only two units in the UK which have returned fewer than 50% of monthly cards – you know who you are! There are also only three units in the UK who have not yet returned any forms. It is really important to get a truly representative study that we get forms from everyone – and has the added advantage that we will stop nagging you!

Star hospitals

Thanks to the following units who have returned 100% of cards and 100% of forms for the first six months of the TOF/OA study:

Addenbrooke's Hospital Chelsea and Westminster Hospital Glasgow Royal Hospital for Sick Children Great Ormond Street Hospital for Sick Children Hull Royal Infirmary John Radcliffe Hospital Nottingham University Hospitals NHS Trust Queen Charlotte's & Chelsea Hospital Royal Aberdeen Children's Hospital Royal Liverpool Children's Hospital Royal London Hospital Southampton General Hospital University Hospital Lewisham University Hospital of Wales

 The chocolate Box

 Chocolates this month for Vivien McNamara

 Chocolates this month for Vivien McNamara

<t

Marian Knight/Sean Marven (Clinical Coordinators): **01865 289727** Carole Harris (Administrator): **01865 289714**

email: BAPS-CASS@npeu.ox.ac.uk

web: www.npeu.ox.ac.uk/BAPS-CASS