

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



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

Newsletter 18 October 2011

Hirschsprung's disease One year Follow-up

The BAPS-CASS Hirschsprung's Disease project has been collecting data for 12 months and we have identified over 130 cases of infants diagnosed in the first six months of life. We would like to thank all of you who have contributed so far. We will continue collecting birth and early management data for another 6 months and anticipate identifying a final cohort of over 200 infants.

One of the main aims of this project is to establish the outcomes of infants at one year of age, in order to inform future management and parent counselling. As the first infants in the cohort are now approaching 12 months following their initial diagnosis, we will shortly be sending out short forms to collect the one year data, as each infant reaches this milestone. Gregor Walker, the study lead, in consultation with a number of you, has designed the form to facilitate completion in the out-patient setting, and plans to fill the form out for each of his patients in out-patients when they are approximately 12 months post-diagnosis. Hopefully this should make completion fairly straightforward.

Case Report Summary to 20/09/10

| Condition | Cases Reported | Forms returned | Confirmed Cases | Unconfirmed Cases | Duplicate Cases |
|---|-------------------|-------------------|--------------------|----------------------|--------------------|
| Hirschsprung's Disease | 134 | 67 (50) | 61 (90) | 6 (9) | 0 |
| Congenital Diaphragmatic Hernia | 261 | 219 (84) | 207 (95) | 8 (4) | 4 (1) |
| Congenital Diaphragmatic Hernia 1yr forms | 164 | 101 (62) | 101 (100) | 0 (0) | 0 (0) |

CDH Follow-up:

All the surviving infants in the CDH cohort should have reached one year of age now. We would therefore be grateful if you could complete any outstanding follow-up forms as soon as possible so that we can begin to analyse the data.

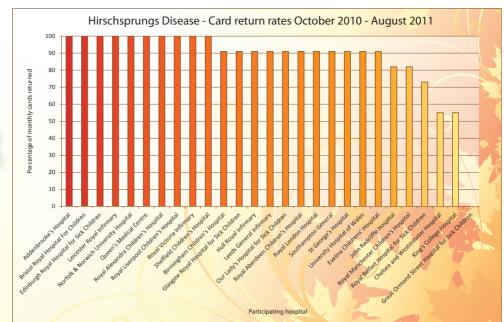
Star hospitals

Many thanks to the following units who have returned all cards and the majority of forms for the Hirschsprung's Disease study to date:

Addenbrooke's Hospital Bristol Royal Hospital For Children Edinburgh Royal Hospital for Sick Children Leicester Royal Infirmary Norfolk & Norwich **University Hospital**

Thank you!

THILL





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