VOL 26 NO 2 JULY 2012

# BPSU

# BPSU Bulletin

**The British Paediatric Surveillance Unit** (BPSU) is part of the Research & Policy Division of the Royal College of Paediatrics and Child Health

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## Inside this issue





## Surveillance of Surgical Ligation of the Patent Ductus Arteriosus in Premature Babies

## Beginning September 2012

Patent ductus arteriosus (PDA) will be added to the Orange Card for 13 months from September 2012. This will be the 9th Sir Peter Tizard funded projected and will be run by the recipient of the award Dr Lleona Lee and Dr Wilf Kelsall (inset)

In this article Lleona describes her project.

The ductus arteriosus is a normal connection between the pulmonary artery and the aorta in the foetus but usually closes after birth. In premature babies the ductus arteriosus can remain open and is then called a patent ductus arteriosus (PDA). The abnormal flow of blood through the PDA has been associated with chronic lung disease, necrotising enterocolitis and retinopathy of prematurity. It can also cause symptoms of cardiac failure and poor growth. It is not always clear when a PDA becomes haemodynamically or clinically significant and therefore requires treatment. Medical treatment to close a patent ductus arteriosus is with non-steroidal anti-inflammatory drugs. If medical treatment is contraindicated or not successful, a small minority of premature babies are referred for surgical ligation of their PDA.

This UK study aims to determine the incidence of PDA ligation in premature babies under 37 weeks gestation. Case ascertainment will be maximised by involving paediatric cardiologists. We will report the distribution by gestational age, birth weight, sex and ethnicity. In these babies we aim to describe:

1. The investigations including echocardiography and clinical management, including use of NSAIDs, prior to surgical ligation
2. The respiratory and cardiovascular support of these babies at the time of PDA ligation
3. The ages at ligation
4. The post-ligation complications
5. The presence of chronic lung disease, necrotising enterocolitis, retinopathy of prematurity and intraventricular haemorrhage

**Case definition:** Any baby born before 37 completed weeks of gestation, without any other structural cardiac abnormality, who has undergone surgical ligation of a patent ductus arteriosus before first discharge home.

Please note that a patent foramen ovale is not considered a structural cardiac abnormality.

**Ethics approval:** This study has been approved by NRES Committee East Midlands – Derby (Ref: 12/EM/0149) and has been granted Section 251 NIGB permission under reference: ECC 3-02(FT6)/2012.

**Public information leaflet:** Available at www.rcpch.ac.uk/bpsu/pda

**Further information:** If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact:

Lleona Lee: lleona.lee@nuh.nhs.uk Tel: 0115 9691169

*Supported by the Department of Health*

DH Department of Health

## Study News

**Approved studies**
Twenty years after the completion of the first BPSU study into **Kawasaki disease** we are preparing for the start of our second. Led by Professor Robert Tulloh, the study aims to examine disease epidemiology, to review treatment and assess cardiac and non-cardiac complications.

As with the PDA study we will be involving the paediatric cardiologists in order to ascertain cases. We are currently awaiting the final approvals but we expect the study to start in the Autumn so please look out for the study on the card. For further details contact Robert Tulloh robert.tulloh@UHBristol.nhs.uk

A study on **Exchange blood transfusion** has been approved, the principal investigator is Dr Ruth Gottstein (Ruth.Gottstein@cmft.nhs.uk). The aim is to ascertain the incidence of neonatal exchange blood transfusions being performed, and to examine morbidity and mortality. The start date will be dependent on protocol finalisation and ethics approval.

**Recently completed studies:** Richard Reading reports:


Richard Reading

"Our 25 months of surveillance of **Gonorrhoea**, **Syphilis**, **Chlamydia** and **Trichomonas surveillance in children under 13 years** ended in January this year. Thank you to all who reported possible cases – thanks also of course to all the many thousands of "Nothing to report" responses. These really are as important to investigators as cases because it gives us greater confidence that we are ascertaining as many of the new cases that occur as possible. This was particularly important for this study as we have only had 16 confirmed reports over the two years. Of the 16 cases, 15 were female, one male. Seven cases were of Gonorrhoea, one of Syphilis, six of Chlamydia and two of Trichomonas. What we can say then, is that these infections present extremely rarely. This is at odds with the literature from elsewhere which suggest that, while uncommon, these infections are present in a small proportion of sexually abused children.

However, the great strength of BPSU studies is that they are epidemiologically robust surveillance studies of a whole population rather than from selected cases being seen in specialist centres. We have only just completed our data collection so do not have any further results to report, but we hope these data will help in determining policy of what to do when a sexually transmitted infection is found in a child. The study was funded by WellChild and supported by the Survivors Trust."

For further information contact Richard Reading richard.reading@nnuh.nhs.uk or visit www.rcpch.ac.uk/bpsu


Rachel Knowles

**Congenital hypothyroidism:** Rachel Knowles reports:

"The UKCS-CHT study completes its year on the Orange Card in June 2012. We would like to thank everyone who has contributed to the 400 notifications that we have received through the BPSU. Currently our questionnaire response rate is 79% but we will be sending out additional reminders for the remaining questionnaires in the near future – so please keep on sending them back! Questionnaires have been completed using the new online system and this has proven very successful with very few complaints or problems. We have learned a lot from this trial of an online system and would be happy to share our experience with any new BPSU applicants who are considering using secure online questionnaires.

An important part of the study was to find out how many babies with a positive newborn screening test eventually turned out to have congenital hypothyroidism after diagnostic investigations. **We do therefore need to know about all the babies who were found not to have hypothyroidism even though their screening test was positive.** As newborn screening laboratories notified to us around 600 babies who had a positive screening test for congenital hypothyroidism and needed further investigations, over the next few months we will be chasing up any cases that have not already been notified to us on the Orange Card.

Please do contact us if you want any further information about the study or to report a case – we are very grateful to you for helping with this study as it would not have been possible without you!"

For further details contact Rachel Knowles/Juliet Oerton: r.knowles@ucl.ac.uk or j.oerton@ucl.ac.uk

Two further studies have now ended **End Stage Renal Failure**, principal investigator Dr Karl McKeever (karl.mckeever@belfasttrust.hscni.net) and **Autoimmune Addison's disease**, principal investigator Dr Hima Avatapalle (bindu.avatapalle@cmft.nhs.uk). On behalf of the investigators can I thank you for your reports. If you have any unreported cases please can you let the BPSU office know and please do return any outstanding questionnaires.

**BPSU Annual report: This years report will come out in September and will be produced as a pdf to be placed on the BPSU website. We will have limited numbers of copies printed so do let us know NOW if you wish to receive a hardcopy.**

## Child Adolescent Psychiatry Surveillance System (CAPSS) celebrates its 3rd birthday

CAPSS was officially launched in 2009 and recently celebrated its 3rd birthday. We are pleased to report that the system is going from strength to strength. The system is housed within the Royal College of Psychiatrists College Centre for Quality Improvement where it is managed by Dr Alan Quirk and administered by Alison Hunter. Five studies have been run or are running on the system (Table 1), and several other studies are under development.

**New CAPSS Chair**
Dr Tamsin Ford

The system is based on the well-established methodology of the British Paediatric Surveillance Unit (BPSU). The executive committee includes clinical and academic child psychiatrists, the CAPSS manager of operations, and two paediatricians, Dr Richard Reading and Dr Hani Ayyash, with expertise from the BPSU Scientific coordinator Richard Lynn.

Much of the ground work for the establishment of the system was down to Dasha Nicholls and Richard Lynn through their work on early onset eating disorders. Such was the success and impact of the study the opportunity to continue and extend the system could not be passed up. Funding is always an issue but we have managed to obtain several grants to keep the system afloat, including a substantial amount of financial support in the early days from the Child and Adolescent Faculty.

Seven hundred child psychiatrists now report to the system monthly. Our response rate is around 68%, which we aim to increase with the introduction of electronic reporting. Questionnaire completion for those reporting cases is 75%. CAPSS is working with the BPSU, and together we have completed the Eating Disorder and the Conversion Disorder studies. Collaboration on two further studies is ongoing; the Gender Identity Disorder study that commenced in November and, funding permitting, a study on severe self harm. To date there have been 15 presentations/abstracts at national and international conferences and 4 papers, the most recent in this months ADC. We have also held several educational workshops on research development.

We have established a website (www.rcpsych.ac.uk/quality/research/capss1.aspx) where there are suggestions for topics on which we would encourage applications, including early onset OCD, substance dependence in under-16s and dangerous but unusual adverse effects of drugs. If you are interested in these or have your own suggestion please do let us know.

Finally we thank all the paediatricians who have reported cases and returned their questionnaires.

For contact: Alison Hunter/Dr Alan Quirk Email: CAPSS@cru.rcpsych.ac.uk

| Study | Investigator | Surveillance Period | Case reports | Incidence |
|---|---|---|---|---|
| Early onset eating disorder 5-13yrs | D Nicholls, R Lynn, R Viner | 2006-7 | 204 | 3.01/100,000 |
| Conversion disorder 7-15yrs | C Ani, E Garalda, R R Reading, R Lynn | 2008-09 | 204 | 1.30/100,000 |
| Bipolar Disorder 10-16yrs | A Sharma | 2009-10 | 151 | 0.59/100,000 |
| Early onset psychosis | P Tiffin | 2010-11 | 42 (confirmed so far) | 1.8/100,000 |
| Gender Identitiy disorder | S Khadr | 2011-12 | 100 report to date | |

## Public patient involvement (PPI)

**At the recent RCPCH scientific meeting the BPSU held a successful workshop advising researchers on how they can involve patient and public in research. We are now undertaking work to produce a toolkit for researchers which can be used to help address PPI when developing protocols and preparing applications.**

**BPSU has also produced easy to read public information leaflets on our studies and these can be downloaded at: www.rcpch.ac.uk/bpsu/ppi**

## Recent Publications


1. M Absoud et al. Paediatric acquired demyelinating syndromes: incidence, clinical and magnetic resonance imaging features. Mult Scler April 19, 2012. DOI: 10.1177/1352458512445944.
   Full free text on line at http://msj.sagepub.com/content/early/2012/04/19/1352458512445944.1.full
2. M Erlewyn-Lajeunesse, LP Hunt, PT Heath, A Finn. Anaphylaxis as an adverse event following immunisation in the UK and Ireland. Arch Dis Child 2012; **97:**487-490 http://adc.bmj.com/content/97/6/487.full
3. L Hudson, D E Nicholls, R M Lynn, R M Viner. Early onset eating disorders – Medical instability and growth of children and adolescents with early onset eating disorders ADC June 2012.
   Online http://adc.bmj.com/content/early/2012/06/08/archdischild-2011-301055.full.pdf


## Analysis

**Response rate 2011:** Reporting rates for returning the orange cards remain high - the overall card return compliance rate for the year 2011, calculated as a proportion of orange cards returned was 91.4% a fall of 1.6% from 2010. North Scotland has topped the average yearly response rate ranking. Full details of regional response rates are provided in **Table 1**. Overall the response rate is still exceptional and is a testament to the willingness of clinicians to support the BPSU reporting scheme. **However we have already noticed further falls in 2012 so we must not be complacent so please send back the orange cards.** E-card reporting via the web is now being rolled out; the response rates for this are 80%. We expect to see this rise over the next few months. If you are interested in receiving an e-card email us at bpsu@rcpch.ac.uk

**Workload 2011:** 77% of BPSU participants reported no cases in 2011, 14% reported a single case, 7.5% reported between two and four cases and 1.5% reported five or more cases. One HIV specialist reported 91 cases. A big thanks to you all for your continued help and support.

**TABLE 1 - % RESPONSE RATE (Jan-Dec 2011)**

| Region | % rtnd | Rank |
|---|---|---|
| EAngl | 92.0 | 11 |
| Mersey | 93.3 | 5 |
| NET | 85.2 | 20 |
| NScot | 96.1 | 1 |
| NWest | 92.4 | 9 |
| North | 92.9 | 7 |
| NIre | 89.8 | 17 |
| NWT | 90.3 | 16 |
| Oxfrd | 91.6 | 12 |
| RIre | 87.7 | 18 |
| SET | 92.2 | 10 |
| SScot | 95.3 | 3 |
| SWest | 91.5 | 13 |
| SWT | 91.3 | 14 |
| Trent | 90.8 | 15 |
| Wales | 95.4 | 2 |
| Wessx | 92.9 | 6 |
| WMids | 92.7 | 8 |
| WScot | 87.2 | 19 |
| Yorks | 94.1 | 4 |
| **Average** | **91.4%** | |

DATE IS PROVISIONAL AND SUBJECT TO CHANGE

**TABLE 2: Cases followed up to 30.05.2012**

| | | VALID | | | | | INVALID | C&R | D&E | X |
|---|---|---|---|---|---|---|---|---|---|---|
| **Condition** | **Started** | **C/R** | **D** | **E** | **X** | **Total** | | (as % of Total) | | |
| AIDS/HIV | 1986 | 7103 | 772 | 719 | 840 | 9,434 | | 75 | 16 | 9 |
| CR | 1990 | 85 | 35 | 32 | 5 | 157 | | 54 | 43 | 3 |
| PIND | 1997 | 1829 | 401 | 875 | 107 | 3,212 | | 57 | 40 | 3 |
| GSCT | 2010 | 14 | 2 | 32 | 15 | 63 | | 22 | 54 | 24 |
| Lead | 2010 | 15 | 2 | 10 | 10 | 37 | | 41 | 32 | 27 |
| SYP | 2010 | 30 | 5 | 6 | 17 | 58 | | 52 | 19 | 29 |
| Chylo | 2010 | 125 | 15 | 14 | 92 | 246 | | 51 | 12 | 37 |
| GA1 | 2010 | 9 | 6 | 7 | 24 | 46 | | 20 | 28 | 52 |
| ESRD | 2011 | 0 | 0 | 0 | 71 | 71 | | 0 | 0 | 100 |
| CHT | 2011 | 191 | 9 | 23 | 187 | 410 | | 47 | 8 | 46 |
| AAD | 2011 | 6 | 0 | 0 | 23 | 29 | | 21 | 0 | 79 |
| VITD | 2011 | 17 | 3 | 10 | 15 | 45 | | 38 | 29 | 33 |
| HUS | 2011 | 0 | 0 | 1 | 69 | 70 | | 0 | 1 | 99 |
| GID | 2011 | 0 | 0 | 0 | 47 | 47 | | 0 | 0 | 100 |
| **Total** | | **9,424** | **1,250** | **1,729** | **1,522** | **13,925** | | **67** | **21** | **12** |

AIDS/HIV ..Human immunodeficiency virus in childhood
CR.....Congenital rubella
PIND .....Progressive intellectual & neurological deterioration
GSCT.....Gonorrhoea, Syphilis, Chlamydia, Trichomonas infections
Lead.....Raised Blood Lead Levels in Children
SYP.....Congenital syphilis
Chylo.....Chylothorax in Infants and Children
GA1.....Glutaric Aciduria 1
ESRD.....End-Stage Renal Disease
CHT.....Primary Congenital Hypothyroidism
AAD .....Autoimmune Addison's Disease in Children
VITD.....Seizures Vitamin D Deficiency
HUS .....Haemolytic uraemic syndrome
GID .....Gender identity disorder

**C** confirmed/ already known

**D** duplicate

**E** reporting error or revised diagnosis

**X** status not yet reported to BPSU by investigator