



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



Royal College of Paediatrics and Child Health

Editor

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Four new studies are scheduled to start in June and July; details of three of these studies, chylothorax in infants & children, raised blood lead levels in children and bacterial meningitis in babies are presented within this month's bulletin. The bulletin also includes details of the recent RCPCH conference and the upcoming INoPSU conference.

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Chylothorax in Infants & Children

The BPSU study on chylothorax in infants and children (investigators Caroline Haines and Dr Peter Davis – inset) launches in June 2010. Over the next 13 months the study aims to capture and collect information on all infants and children with a first presentation of chylothorax.



The study's development follows the clinical

experiences of the team from the Paediatric Intensive Care Unit at Bristol Royal Hospital for Children in caring for children with chylothorax, the difficulties of managing what can be an extremely challenging condition, yet what is a relatively well-known condition. Additionally, the relative lack of published evidence on the incidence of the condition, its management and its outcome, beyond some small case series and individual case reports, heightened the team's interest.

Although it is thought that the majority of cases occur as a complication of cardiothoracic surgery, a large number of different non-surgical conditions have been reported as resulting in the accumulation of chyle in the pleural space. This can be potentially life-threatening and it can lead to serious metabolic, immunological and nutritional complications.

Cases will be notified initially to the BPSU in the usual way, and the study team look forward to receiving this information. As it is possible that some cases of chylothorax may not be primarily managed by paediatricians, agreement has also been reached to search the datasets of the Paediatric Intensive Care Audit Network (PICANet), the Central Cardiac Audit Database (CCAD) and the Hospital Episode Statistics (HES) for potential cases to maximise ascertainment. For any case presentation identified through this route for which a corresponding BPSU notification cannot be located, the relevant hospital will be contacted and orange notification cards supplied for completion.

The study is being undertaken by Dr Peter Davis and Miss Caroline Haines (inset) from Bristol Royal Hospital for Children. REC and NIGB-ECC approval has been granted (Ref:10/H0713/27).

If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact either of the study investigators. We would particularly welcome duplicate reporting of cases seen in more than one hospital or suspected cases of chylothorax, the clinical details of which will be reviewed by our multi-disciplinary expert panel of clinicians as part of the study.

Contact: peter.davis@uhbristol.nhs.uk Tel: 0117 3428843 or
caroline.haines@uhbristol.nhs.uk Tel 0117 3428380

Surveillance of Raised Blood Lead Levels in Children

The BPSU study on raised blood lead levels in children (investigator Dr Ruth Ruggles - inset) will be launched in June 2010. Data gathered during this surveillance study will enable the Health Protection Agency (HPA) to estimate the incidence of clinically recognised elevated blood lead concentrations in children in the UK and Ireland, report the distribution in the population and describe the possible sources of environmental exposure.

The findings will inform health promotion policy and the development of clinical guidelines for paediatricians for the investigation and management of such cases in future. Data obtained through a 12 month follow-up questionnaire will enable the HPA to describe short-term outcomes, including changes in blood lead concentrations, and improve the involvement of wider professionals in remediation of the source of exposure. This information will be used to inform future health protection strategies.

Public health interventions have succeeded in removing most sources of lead from the environment. However, a small proportion of children continue to be exposed to harmful levels of lead, usually in the home. Exposure to lead in children is associated with a range of adverse health effects, from sub-clinical neurodevelopmental impairment to encephalitis.

There are no reliable data on the incidence or prevalence of clinically significant lead toxicity or the prevalence of elevated blood lead concentrations in children in the UK. Currently, the UK has no formal monitoring of childhood blood lead concentrations within laboratory or clinical systems and the public health response to such cases is likely to be sub-optimal. A recent case series indicates that significant obstacles are often encountered in the effective and timely management of cases.

For further information, please contact the project team on slic@hpa.org.uk or visit the study website www.hpa.org.uk/chemicals/slic



Bacterial meningitis in babies <90 days of age: The current burden of disease



The BPSU study on neonatal bacterial meningitis in babies less than 90 days of age in the UK and the Republic of Ireland launches in July 2010 and is planned to run for a 13 month period

Bacterial meningitis is associated with significant mortality and morbidity in infants in the first 3 months of life. The most recent national surveillance study (1996-7) showed an incidence of 0.2 per 1000 live births and identified an overall mortality of 10% with 50% of cases having some form of disability at 5 year follow-up (24% serious); a risk of serious disability 16-fold higher than that of GP-

matched controls. There are a number of reasons why the epidemiology and management of meningitis in this age group may have changed over the last 10 years and an accurate picture of this is needed to allow prioritisation and development of new strategies.

The objectives of this study are:

- To define the minimum incidence of meningitis in the UK and Ireland in infants aged less than 90 days
- To define the bacterial pathogens that cause meningitis in this age group (and the antibiotic resistance profiles of these pathogens).
- To describe the clinical presentation of cases of meningitis in this age group.
- To describe the mortality and short-term (at hospital discharge or date of BPSU notification) complication rates of meningitis in this age group

If you would like any advice regarding eligibility of a particular case for inclusion in the study or any general questions regarding the study please contact: Dr. Ifeanyichukwu O Okike (inset), Research Fellow Tel 020 8725 3887, or Email: meningitis@sgul.ac.uk or Dr Paul T Heath (inset) Study Principal Investigator Tel: 020 8725 5980 or Email: pheath@sgul.ac.uk

Study Ending

Severe Neonatal Hypernatraemia

Many thanks to all respondents to this study, which closes with cases reported who were seen in May 2010. The study has gone very well, with 89 paediatricians reporting having seen a case so far, and excellent "new case questionnaire" completion. New data is arriving all the time and we are enthusiastically looking forward to analysing the data once the study is complete. We remain extremely grateful for every piece of data about every case; please do complete any outstanding forms you have with us, and don't hesitate to get in touch if there are issues we can assist with. sam.oddie@bradfordhospitals.nhs.uk

We hope to present the data in the autumn, and to be able to contrast our findings with those from a similar project carried out in a European country with higher breastfeeding initiation rates than the UK.

We thank those of you who have reported cases, Christine Peel who has administered the study so effectively, and the BPSU and Bradford Teaching Hospitals for supporting the study.

BPSU News

RCPCH Conference

The BPSU contributed to a successful RCPCH conference. We had an excellent response from those visiting the stand and we appreciated the opportunity to discuss potential projects and exchange information.



The Unit had 8 papers presented which are listed below, 3 of which were presented in plenary sessions. Abstracts are available from the BPSU office.

1. Children Born Abroad And Diagnosed With HIV Infection In The UK/Ireland
2. Clinical Outcome At 2 Years Following Diagnosis Of Medium Chain Acyl Coenzyme A Dehydrogenase Deficiency Through Newborn Screening: Findings From The Prospective UK Collaborative And British Paediatric Surveillance Unit Studies
3. Clinical Presentation Of Older Children With Congenital Adrenalhyperplasia: An Important Outcome For Newborn Screening Policy
4. Demyelinating disease in childhood.
5. Early postnatal collapse in the term newborn
6. Intussusception In The First Year Of Life: A UK National Surveillance Study
7. The Clinical Presentation And Diagnosis Of Juvenile Neuronal Ceroid Lipofuscinosis: A Prospective National Study
8. Vitamin K prophylaxis and Vitamin K deficiency Bleeding in the UK

BPSU News

Using the tear off section of the orange card: A reminder

Please remember that if you report a case to note the patients name or other identification on the tear off section of the orange card and **keep this** to refer back to when you are contacted by the investigator.

Please **do not** return this part of the card to the BPSU office.

New Consultant or Associate Specialists

If you are a Consultant or an Associate Specialist who does not receive the orange cards and you think you should please contact Helen Friend email: Helen.Friend@bpsu.ac.uk including your hospital postal address, speciality and preferred email and we will add you to the system. Please also let us know if your details have changed.

British Paediatric Surveillance Unit Report Card
April 2009 [9004]
CODE No [13495AB]

NOTHING TO REPORT

Specify in box the number of cases seen

HIV & AIDS
 Progressive Intellectual & Neurological Deterioration
 Congenital Rubella
 Genital Herpes in Children Under 11 Years (presenting in secondary cases)
 Idiopathic Intracranial Hypertension under 17 years
 Congenital Adrenal Hyperplasia (not, Normal & Reversible of blood)
 Anaphylaxis following immunisation
 Commission Disorder
 Sudden unexpected early postnatal collapse
 Toxic Shock Syndrome

Clinicians Section - Please Keep if Necessary
for cases seen in April 2009
Please NOTE the patient's name(s) or other identification and
KEEP THIS SLIP for easy reference when you are contacted by
the investigator.

Condition	Patient	Hospital No

DETACH THIS SECTION BEFORE POSTING

Upcoming Events

The BPSU commences 25th year of surveillance.

June sees the BPSU enter its 25th year of surveillance. As the figures in Table 1 (below) illustrate the involvement and willingness of College members to contribute remains undiminished. To celebrate this milestone the BPSU intend to hold several events during the year. We will be part of the INoPSU conference (see below) and are in discussions with the RCPCH, HPA and ICH with regards to holding symposia at their conferences. We also hope to hold a training workshop. Furthermore, if you would like any of our investigators to present to your department please let us know and we will try and arrange it, contact: bpsu@rcpch.ac.uk

Whilst we celebrate there is however, one sad note to acknowledge the recent death of Professor David Harvey. David was instrumental in setting up the BPSU, we are very grateful for his work and involvement.

International Network of Paediatric Surveillance Units (INoPSU) Conference

The International Network of Paediatric Surveillance Units (INoPSU) are holding their 6th conference in Dublin on Thursday 7th October in conjunction with the Royal College of Physicians (Ireland) Faculty of Paediatrics Scientific Meeting. Topics to be discussed will include HIV, toxic shock syndrome, TB across Europe, eating disorders, H1N1 and Guillain Barré Syndrome. The conference is organised by the Irish Paediatric Surveillance Unit and is free to attend. For more details contact Dr Rob Cunney robert.cunney@mailx.hse.ie or contact the BPSU.



Analysis

**TABLE 1 - % RESPONSE RATE
(for 6 months)**

Region	% rtd	Rank
North	93.8%	8
Yorks	93.7%	9
Trent	91.4%	16
EAnGl	95.0%	5
NWT	92.2%	14
NET	84.4%	20
SET	92.5%	13
SWT	90.2%	18
Wessx	93.8%	7
Oxfrd	95.8%	3
SWest	92.8%	12
WMids	93.6%	10
Mersy	90.6%	17
NWest	94.5%	6
Wales	98.4%	1
NScot	93.4%	11
SScot	98.3%	2
WScot	91.9%	15
Nlre	95.6%	4
Rlre	89.7%	19
Average	93.1%	

TABLE 2 - All Cases Reported and Follow-Ups to June 2010

Condition	Started	VALID			INVALID		C&R	D&E	X
		C/R	D	E	X	Total			
HIV/AIDS	1986	6,294	719	720	539	8,041	77	17	6
CR	1990	78	34	31	2	145	53	45	2
PIND	1997	1,707	352	751	57	2,809	60	38	2
CD	2008	76	8	11	159	252	30	7	63
SUPC	2008	39	7	25	20	91	43	35	22
SNH	2009	44	0	11	34	89	49	12	38
GBS	2009	14	2	1	72	89	16	3	81
CNS	2009	16	7	8	110	141	11	11	78
SYP	2010	0	0	0	18	18	0	0	100
GSCT	2010	0	0	0	0	4	0	0	100
Total		8,268	1,129	1,558	1,011	11,679	69	22	8

C = confirmed/already known
D = duplicate
E = reporting error or revised diagnosis
X = status not yet reported to BPSU by investigator

HIV Human immunodeficiency virus in childhood
CR Congenital rubella
PIND Progressive intellectual neurological degeneration
CD Conversion Disorder - Excludes reports from psychiatrist
SUPC Sudden unexpected early postnatal collapse
CNS CNS Inflammatory Demyelinating Disease
SNH Severe Neonatal Hypernatraemia
GBS Guillain-Barré syndrome / Fisher syndrome
SYP Congenital syphilis
GSCT Gonorrhoea, Syphilis, Chlamydia, and Trichomonas infections

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED

