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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

Editor
Richard Lynn
BPSU Scientific Coordinator

Tel: 020 7092 6173
Fax: 020 7092 6001
Email: bpsu@rcpch.ac.uk
Website: www.bpsu.inopsu.com

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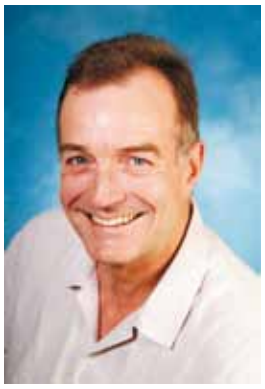

Alan Emond

We are pleased to announce that the BPSU has now secured funds to guarantee its financial viability for the next three years, and it will remain hosted by the RCPCH in London. Thanks to generous grants from Great Ormond Street Hospital Children's Charity and the UCL – Institute of Child Health, and committed support from the Health Protection Agency, the Scottish Executive and the RCPCH, the BPSU will continue to function with a full-time scientific co-ordinator (Richard Lynn) and a part-time research facilitator (Rachel Winch).

We hope to start negotiating a new long term contract with the new Public Health England when it comes into being in April 2013.

The RCPCH is still reviewing its governance structures, but at the moment the BPSU continues as a tripartite model between RCPCH, the HPA/HPS and UCL. Co-ordination of the international surveillance network (INoPSU) has been successfully transferred to Sydney, which enables the reduced staffing in the BPSU office in London to concentrate on surveillance studies in the UK and Ireland.

The strategic priorities of the BPSU over the next three years include moving to e-reporting and investigating online questionnaires to reduce costs and administration; and developing closer links with college speciality groups to encourage more surveillance projects initiated by practicing paediatricians. Researcher charges which were increased in 2011 to £10 000 for the first year and £5 000 for subsequent years will be held at this time. This still represents excellent value for money considering the research support provided and the data collection facilitated by the BPSU.

The BPSU Scientific Committee recruited 2 new members in 2012: Simon Nadel from St Mary's Hospital, London and Simon Lenton from Bath, to replace Shankar Kanumakala and Richard Reading. My thanks go to Shankar and Richard for all their work on the committee and their support for the BPSU over many years. Two new professional members and two lay members will be sought in 2013.

Please keep returning your orange cards, either by post or by email, as the unique strength of the BPSU is being able to mount surveillance studies and maintain a 90% response from paediatricians in the UK and Ireland.

With best wishes for 2013.

Alan Emond - Chair, BPSU Scientific Committee

BPSU E-reporting now available

Over 45% of BPSU respondents are now receiving our e-reporting card and the response rate is now up to 85%. We are pushing to raise this to our benchmark of 90% in the next few months. We are sending out regular reminders to those who have not responded to ensure the emails are not missed. It is very simple to report by email; you will receive a monthly email containing a web link. On clicking the link you will be transfered to our secure site called RedCap which is hosted by of UCL-ICH. Once the card is open you need to indicate whether you have a case to report or not. Please do let us know if you wish to transfer to the e-card by emailing bpsu.orangecard@rcpch.ac.uk

Supported by the Department of Health

Surveillance of Kawasaki Disease to begin January 2013

Dr. Robert Tulloh

Several studies are due to commence in the next few months. Kawasaki disease is making a return after an absence of 22 years for 13 months from January 2013. The project will be run by Dr Robert Tulloh, Bristol University Hospitals (inset).

In this article Robert describes the project:

Kawasaki disease is the commonest cause of acquired heart disease in children in the UK and USA. The serious sequelae of KD make it important to diagnose this condition early in order to treat it effectively and therefore minimise complications and long term ill health within the Paediatric population. The last BPSU survey of KD was in 1990 and since that time there has been increased awareness of the condition and treatment protocols.

The latest study will examine incidence in terms of demographics and changes since 1990; clinical representation; clinical treatment and outcomes in particular the prevalence of non-cardiac complications within 30 days following Kawasaki disease in the UK and Ireland. It will also consider how patients with diagnosed Kawasaki disease are being followed up within the UK and Ireland.

Case definition: Any infant or child up to the age of 16 years presenting for the first time with Fever of 5 or more days duration *plus* 4 of the following:

1. Conjunctivitis	Bilateral, bulbar, non-suppurative
2. Lymphadenopathy	Cervical > 1.5cm
3. Rash	Widespread, polymorphous. Not vesicular.
4. Lips and mucosa	Red cracked lips, 'strawberry tongue', erythematous oral cavity
5. Changes of extremities	Erythema, oedema of palms and soles initially, then peeling of skin at later stage.

Exclusion: Any child with proven evidence of streptococcal or staphylococcal infection

Funding: Kawasaki disease parent support group – www.kssg.org.uk

Ethics approval: This study has been approved by NRES Committee – South Central Bristol – (REC reference 11/EM/0149) and has been granted Section 251 NIGB permission under reference: ECC 6-02 (FT11)/2012

For further information about the study, please contact: Dr Robert Tulloh, Department of Paediatric Cardiology, University Hospitals Bristol NHS Foundation Trust, Upper Maudlin Street, Bristol, BS2 8BJ Email: Robert.Tulloh@UHBristol.nhs.uk

Acute Pancreatitis Surveillance to begin in February 2013

Surveillance of acute pancreatitis will commence in February 2013 for a period of 13 months with a 12 month follow-up (principal investigator Professor Julian Hamilton-Shield, inset – Bristol University Hospital). Acute pancreatitis is a rare condition in childhood in which the pancreas that is situated in the abdomen becomes inflamed and very painful. Children developing pancreatitis often need admission to hospital and may require surgical intervention.

Prof Julian Hamilton-Shield

There are many causes for this condition including: viral infections; trauma; gall-stones; congenital abnormalities in pancreatic anatomy (formation); inherited genetic conditions; alcohol misuse and iatrogenic drug side effects.

The treatment and management of children with pancreatitis is varied as the condition is quite Prof Julian Hamilton-Shield rare in childhood and it is currently difficult to know what constitutes the best management strategy for this condition for any given child.

This study has been designed to examine the epidemiology, medical management, surgical treatments and complications of acute pancreatitis with the aim of improving understanding of the condition and how best to treat it.

The British Association of Paediatric Surgeons (BAPS) is supporting this study and will be included in the reporting process.

Surveillance case definition: A child diagnosed for the first time with:

1) Upper abdominal pain

And at least one of the following

a) Serum amylase raised three times above the normal reference range for the local laboratory

and/or

b) Serum lipase raised three times above the normal reference range for the local laboratory.

Reporting instructions: Please report any newly arising cases of acute pancreatitis seen in a child less than 15 years in the past month fitting the surveillance case definition. Please report even if the case has now been referred to or from you paediatric/surgical colleagues.

Funding: University of Bristol

Ethics approval: NRES Committee – South West Central Bristol – (REC reference 11/SW/0132) and has been granted Section 251 NIGB permission under reference ECC 6- 02(FT12)/2012.

Further information and references are available on the BPSU website at www.rcpch.ac.uk/bpsu/ap or contact Professor Julian Hamilton-Shield. Email: j.p.h.shield@bristol.ac.uk or Dr Abdalmonem Majbar: am12337@bristol.ac.uk

Study News

Study extensions: Surveillance of **haemolytic uraemic syndrome** (principal investigator Dr Bob Adak - HPA) will continue for a further 2 years until September 2014. To date 208 reports have been received of which 46 have been confirmed; data on 120 outstanding. Almost half of these cases were not identified through other existing surveillance systems highlighting the importance of this study. An extension to the BPSU study will provide a longer period over which to cement relationships and maintain reporting systems whilst working through re-organisations in the NHS and the inception of Public Health England, securing a better future for surveillance networks, here and abroad.

Extended for a period of a further year is the Sir Peter Tizard bursary study on **hypocalcaemic seizures following vitamin D deficiency** (principal investigator Dr Emre Basatemur - UCL). The study commenced in September 2011, and to date 71 cases have been reported, of which 49 are confirmed. An extension of the study for a second year will facilitate more in-depth analysis, including breakdown of incidence estimates by ethnic group, and will strengthen conclusions drawn from the data. The study will continue until September 2013.

Finally the study on **gender identity disorder** (investigator Dr Sophie Khadr – UCL) has been given a 6 month extension. The study commenced in November 2011 and the response from Paediatricians (80) and Psychiatrists (194) has been excellent with 274 notifications to date. Although the number of notifications is high, the number of validated cases is much smaller due to a large number of exclusions. These have included prevalent cases, over 16s and notifications of children with disorders of sexual differentiation rather than GID. Whilst this is reassuring in that it suggests over-reporting rather than under-reporting, increasing the sample size of valid cases will allow the researchers to increase the accuracy of associations observed/conclusions drawn from the study data.

Preliminary descriptive data from the first nine months' surveillance (n=80 cases, 42 males) indicate that similar numbers of males and females are affected by this condition. There is a lag of several years between median [range] onset of symptoms (6y [1-14y]) and presentation to Paediatricians or Psychiatrists (13y [4-14y]), with high levels of psychiatric co-morbidity at presentation, particularly depression (n=15, 19%), Asperger syndrome or autistic spectrum disorder (n=16, 20%) and previous self-harm (n=24, 30%).

Surveillance ends: The surveillance period for several studies has recently ended. The raised blood lead levels in children study run by the HPA has recently completed surveillance, as have autoimmune Addison's disease, primary congenital hypothyroidism (UK only) and glutaric aciduria 1. If you still have outstanding questionnaires to complete and return we would be most grateful if you could do so as soon as possible. Updates on these and other BPSU surveillance studies are available in the BPSU annual report available to download at www.rcpch.ac.uk/bpsu

Congenital Rubella Update

Dr Pat Tookey updates on the **congeital rubella** study. WHO Europe has set 2015 as the target date for the elimination of endemic measles, rubella and congenital rubella (for congenital rubella this means <1 case of CRS per 100,000 live births) from the European Region. During 2012 there have been no confirmed cases of congenital rubella reported from the UK or Ireland. However, there was an upturn in the number of rubella infections in the community, with the HPA confirming about 60 cases by the end of September, exceeding the annual totals for each of the last nine years. Most cases were associated with importation of infection from Europe and there were two large clusters of cases in the South East of England in the first half of the year, (See Health Protection Report 6 (34) 2012, available at: www.hpa.org.uk/hpr/archives/2012/hpr3412.pdf). None of these infections were reported to have been in pregnant women. However, if any women were exposed in early pregnancy during these outbreaks, their infants would probably be due between October 2011 and February 2012. This is therefore just a reminder to paediatricians to be aware of the recent circulation of infection in the community, and to report any cases of confirmed or suspected congenital rubella on the orange card.

Publications and conferences

1. **Vitamin K deficiency bleeding after NICE guidance and withdrawal of Konakion Neonatal: British Paediatric Surveillance Unit study, 2006–2008.** A Busfield, R Samuel, A McNinch, et al. doi: 10.1136/archdischild-2011-301029. Arch Dis Child published online November 12, 2012. The authors' conclusions were IM Konakion MM is efficacious, but parents withholding consent for recommended IM prophylaxis reduces effectiveness. Reappraisal of NICE guidance would be appropriate. Prolonged jaundice demands investigation. Late VKDB occasionally occurs after IM prophylaxis.
2. **International Network of Paediatric Surveillance Units (INoPSU) Conference:** Following the success of the INOPSU meeting in Switzerland a 9th INOPSU meeting will be held in Melbourne Australia as part of the International Paediatric Association on 24th-29th August 2013. For further details contact bpsu@rcpch.ac.uk

Analysis

As you will see from Table 1 our response rate is still high but has fallen below our benchmark of 90%. Some regions have fallen considerably below this level. We know the e-card reporting has taken time to get up to speed but response rates for this is now at 85%. Please can I remind you to still return your cards and IMPORTANTLY the data collection questionnaires.

TABLE 1 - % response rate April-Sept 2012

Region	% rtnd	Rank
EAngl	95.4	1
Mersey	88.6	14
NET	81.1	18
NScot	89.4	8
NWest	88.8	13
North	90.4	5
NIre	85.2	16
NWT	84.7	17
Oxfrd	89.6	7
RIre	79.9	20
SET	87.8	15
SScot	88.8	12
SWest	90.6	4
SWT	88.9	11
Trent	90.3	6
Wales	89.0	10
Wessx	91.8	2
WMids	89.1	9
WScot	80.9	19
Yorks	91.6	3
Average	**88.0**	

DATA IS PROVISIONAL AND SUBJECT TO CHANGE

TABLE 2: Cases followed up to 02.12.2012

		VALID				INVALID		C&R	D&E	X
Condition	Start	C	R	D	E	X	TOTAL	(as % of total)		
AIDS/HIV	1986	7,194	113	782	730	961	9780	75	15	10
CR	1990	73	12	35	32	6	158	54	42	4
PIND	1997	1812	0	405	916	160	3293	55	40	5
Lead	2010	22	0	3	10	21	56	39	23	38
SYP	2010	37	0	5	6	28	76	49	14	37
GA1	2010	11	0	12	19	8	50	22	62	16
ESRD	2011	27	0	0	5	51	83	33	6	61
CHT	2011	192	0	9	28	290	519	37	7	56
AAD	2011	16	0	0	1	28	45	36	2	62
VITD	2011	42	0	4	14	12	72	58	25	17
HUS	2011	46	0	28	12	120	117	39	34	103
GID	2011	10	0	2	40	38	90	11	47	42
PDA	2012	0	0	0	0	72	72	0	0	100
Total		**9482**	**125**	**1285**	**1813**	**1795**	**14411**	**67**	**21**	**12**

AIDS/HIV ... Human immunodeficiency virus in childhood
CR ..... Congenital rubella
PIND ..... Progressive intellectual & neurological deterioration
Lead..... Raised Blood Lead Levels in Children
SYP ..... Congenital syphilis
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. Excludes psychiatry reports
PDA ..... Surgical ligation of patent ductus arteriousus

C confirmed/ already known

D duplicate

E reporting error or revised diagnosis

X status not yet reported to BPSU by investigator