



Royal College of Paediatrics and Child Health

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

Editor

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BPSU Conference – Celebrating recent achievements

March 3rd 2009 the BPSU will hold its 6th scientific Conference at the Royal Institute of British Architects, London. It aims to highlight BPSU activities over the past five years. The selected programme reviews the contribution the BPSU has made to the understanding and control of uncommon childhood conditions, its impact on public health policy and its development of partnerships.

The conference will provide an opportunity for college members, researchers, representatives from other national surveillance units and patient support groups to come together to listen and discuss with our presenters the projects that they have been involved.

Speakers include Dr Allan Johnson (MRSA); Dr Hermione Lyall (HIV/AIDS); Dr Richard Reading & Dr Pat Tookey (herpes); Dr Delane Shingadia (emerging infections); Dr Claire Cameron (varicella infection); Dr Donal Manning (neonatal hyperbilirubinaemia); Dr Andrew McNinch (vitamin K deficiency bleeding); Dr Marian Knight (feto-maternal alloimmune thrombocytopenia) and Dr Dasha Nicholls (early onset eating disorders).

We are also delighted to have Dr Sheila Shribman attending in her capacity as National Clinical Director for Children, speaking on Child Health Policy in England and devolved UK countries.

Delegate fees are £99 with concessions for non-clinical/charity of £55, which includes buffet lunch from the award winning kitchens of RIBA. CPD points available

Details are available at http://bpsu.inopsu.com/home/2009_conference.htm Alternatively please contact Helen Friend helen.friend@rcpch.ac.uk Tel: 020 7092 6174 to register.



Required – a new chair to head the BPSU Executive

The current chair of the BPSU Executive Committee, Professor Allan Colver, will be stepping down this year after the completion of his three-year term in post. Allan follows a distinguished line of chairs, from Sir Peter Tizard in the early years followed by Professor David Baum, Professor Catherine Peckham, Professor Euan Ross, Dr Chris Verity and Professor Mike Preece. The BPSU is most grateful to Allan for all his hard work over the years in particular over recent weeks securing the financial future of the Unit.

The BPSU is a prestigious part of the College and is a nationally and internationally known and respected organisation in its own right. The Chair is very much a hands on post, directing the future development of the Unit; leading discussions with the Department of Health and presenting its work at national and international conferences. Applicants should ideally have experience of chairing committees and of conducting and presenting epidemiological research. This is a very exciting time for the BPSU as it takes forward the tasks outlined in its submission to the DH. If you feel that you could contribute to the BPSU's activities please do not hesitate to submit an application.

Nomination details for this position will be sent out with the March College newsletter pack, closing date for applications will be 24th April. Alternatively please contact David Ennis, Director of Policy and Standards (david.ennis@rcpch.ac.uk) intimating your interest to apply.

For further information on the post please contact Professor Allan Colver, BPSU Chair (allan.colver@ncl.ac.uk), or Richard Lynn, Scientific Coordinator (bpsu@rcpch.ac.uk).

In the News

Funding for BPSU secured: We are very pleased to announce that, after a year of discussions with the DH, the BPSU has secured a 3 year £700,000 grant extension to spring 2012. In conjunction with the DH policy unit the BPSU has drawn up a work program which will reflect the needs of those who wish to use the BPSU and research priorities within the DH.

New committee members: We welcome Dr Delane Shingadia and Dr Piers Daubeny to the BPSU Executive. Many of you will already know Delane who currently works at Great Ormond Street and was the lead investigator on the BPSU TB survey a couple of years back. Delane will give a clinical perspective on the infectious disease projects which we regularly discuss. Piers who is based at the Brompton Hospital has a experience in epidemiological research particularly in paediatric/fetal cardiac disease an area the BPSU has previously addressed. Can we take this opportunity to thank all those who applied, it was a difficult choice but do look out for calls for members in the future.

BPSU Evaluation Project: Over the past year, using CDC Atlanta guidelines on assessing surveillance systems, we have undertaken an internal evaluation of BPSU processes, outputs and the degree to which the BPSU meets its aims and objectives. As the views of paediatricians were a very important element of this internal evaluation we sent questionnaires to a random sample of 600 paediatricians who currently receive orange cards and also all investigators who have carried out a study since 2003. The evaluation of the BPSU processes will be presented in the next bulletin.

Feedback from the 79% who responded was on the whole was positive and the system is found to be both useful and valued by paediatricians.

- 84% paediatricians considered surveillance of rare paediatric disease to be important.
- 43% stated that they had changed their clinical practice following the outcome of BPSU studies.
- Over 90% accessed published papers, the BPSU bulletin and BPSU annual report reporting study outcomes, however, most (82%) had not used the BPSU website.
- 30% of clinicians would prefer an electronic reporting system to the current postal Orange Card.
- Of those reporting a case, 92% found the detailed case questionnaire easy to complete. Problems identified by reporting paediatricians included difficulty in re-identifying a patient (5%) when subsequently contacted for case details and retrieving hospital notes (17%).
- Of the 27 investigators contacted 24 responded. 83% felt supported by the BPSU during study development
- 92% considered that their research objectives could only have been achieved with national surveillance.
- 73% of studies resulted in future research being identified.

We can conclude that although participation requires effort, this does not appear to be unduly burdensome and the BPSU system is valued by both paediatricians and investigators.

These comments, along with the rest of the internal evaluation will be examined in the coming months to make recommendation for improvements to the BPSU system.

If you have any comments or questions about the evaluation process please contact Helen Friend (helen.friend@rcpch.ac.uk)

Intussusception

After 13 months of surveillance this survey will end in 31 March 2009. The aim was to describe the epidemiology of IS, identify variation in management AND monitor short term outcomes. Please continue to report any suspected or confirmed IS intussusception based on clinical, radiological and /or surgical findings. Cases are then being classified by the investigators as definite, probable, possible, or suspected IS cases according to internationally agreed and validated Brighton Collaboration criteria. If you have seen a case from 1 March 2008 which you have not yet reported could you please do so. To date we have received 106 IS case notifications from paediatricians, from 75 units; of which 65 are confirmed cases.

To maximise ascertainment we have for the first time involved members of the British Association of Paediatric Surgeons. They have been reporting on a separate report card with great success. Their compliance rate has been almost 70% with 96 case reports received to date. Clearly there will be some duplication with the paediatric reports and we are currently identifying this.

For more information contact Dr Lamiya Samad l.samad@ich.ucl.ac.uk or Professor Brent Taylor at b.taylor@ich.ucl.ac.uk

Sir Peter Tizard Research Bursary

The BPSU received 4 applications for the 2008-09 bursary, all of a high standard. After a lengthy discussion the Committee awarded the bursary to Dr Lleona Lee, a SpR from University Hospital of North Staffordshire. Dr Lee wishes to study the epidemiology of surgical ligation of the patent ductus arteriosus (PDA) in premature infants. The study will consider the incidence of this procedure in the British Isles; determine the indications for PDA ligation and outcome. The BPSU Executive Committee will work with Dr Lee to develop the appropriate methodology to undertake this study, with the intention of commencing surveillance in 2009. Thank you to all of those who applied for the bursary. We do hope that you do find a route to further your research interests.

2009-10 Call for bursary applications: Paperwork is already available on our website at http://bpsu.inopsu.com/home/tizard_bursary.html

5th INoPSU Conference

Following on from the successful 4th INoPSU meeting held in London during 2006, a fifth meeting was organised in Munich to coincide with the German Paediatric Society annual scientific conference. Thirteen representatives from 8 units attended the meeting only representatives from New Zealand, Wales, Ireland and Latvia were unable to attend.

The meeting allowed representatives from each of the national units to meet and exchange views on rare disease surveillance and issues that affect each of the units, particularly funding and the increasing need for confidentiality and consent. The morning session attended by over 30 conference delegates of the German Paediatric Society scientific meeting, allowed INoPSU the chance to showcase its work. Presentations on prevention of paraffin aspiration in children (Ger); rapid response to flu complications (Aus); mad cow disease (UK), seatbelt injuries; fetal alcohol (Aus); cerebral palsy (Por) and the impact of INoPSU on disease surveillance (Can) were given. The presentations can be downloaded from <http://www.inopsu.com/publications/index.html>



The afternoon saw the INOPSU business meeting, held in a local restaurant (inset). Here reports were received from the unit representatives. It was with concern we received news that several units are struggling; in fact it was noted that the Trinidad unit has not been developed; and that the Malaysia and Papua New Guinea units have ceased surveillance. All agreed that INoPSU needs to be stabilised before we attempt any further expansion. We were also disappointed to hear the news that EU Framework funding application had been rejected. All despaired at the EU's continued apparent lack of interest in supporting child rare disease epidemiology. A new work programme was agreed; one aim being to increase the profile of INoPSU work at international conferences.

Finally, Daniel Virella of the Portuguese Paediatric Surveillance Unit will be INoPSU convenor for the next 2 years, replacing Rob Pereira from the Netherlands who was thanked for his work along with Helen Friend and Richard Lynn who are administrating INoPSU works. Also a big thanks goes to Anja Boneberger for organising the conference.

For further information on INOPSU please contact the BPSU office (bpsu@rcpch.ac.uk)

Publications & Analysis

Publications: A one year follow up of the original **Non-type 1 diabetes** dataset by J P Hamilton Shield et al, entitled Management and one year outcome for UK children with type 2 diabetes was recently published on-line (Arch. Dis. Child., Oct 2008; doi:10.1136/adc.2008.143313). The authors conclude that the 3.8% mean reduction in BMI SDS in the first year after diagnosis indicates that many children find it hard to make the necessary lifestyle changes needed to positively impact upon metabolic health. That physicians are using a wide variety of treatment regimens which are relatively effective in achieving glycaemic targets but systematic screening for complications is incomplete. There is also an urgent need to develop an evidence base for effective treatment and management protocols to reduce the risks for long term micro- and macro-vascular complications.

**TABLE 2 - % RESPONSE RATE
(AS OF DEC 2008)**

Region	% rtnd	Rank
North	94.9%	3 (4)
Yorks	91.6%	11 (9)
Trent	90.5%	13 (7)
EAngl	92.6%	7 (8)
NWT	89.3%	15 (18)
NET	84.9%	19 (19)
SET	92.1%	8 (15)
SWT	89.3%	16 (17)
Wessx	95.7%	2 (5)
Oxfrd	94.8%	4 (2)
SWest	91.6%	10 (10)
WMids	90.3%	14 (11)
Mersey	84.8%	20 (16)
NWest	90.8%	12 (13)
Wales	95.9%	1 (1)
NScot	92.0%	9 (3)
SScot	93.5%	6 (14)
WScot	89.1%	18 (20)
Nlre	94.2%	5 (6)
Rlre	89.1%	17 (12)
	91.3%	

TABLE 3 - ALL CASES REPORTED AND FOLLOW-UPS TO JANUARY 2009

Condition	Started	VALID			INVALID		Total	as % of total		
		C/R	D	E	NYK	X		C&R	D&E	X
HIV/AIDS	1986	5,607	669	660	397	7333	76	18	5	
CR	1990	76	33	61	0	170	45	55	0	
PIND	1997	1,383	299	680	186	2548	54	38	7	
MCADD	2004	234	60	74	2	370	63	36	1	
VKDB	2006	5	8	8	24	45	11	36	53	
FMAIT	2006	94	16	17	34	161	58	20	21	
Genital Herpes	2007	17	0	9	7	33	52	27	21	
IIH	2007	60	16	39	155	270	22	20	57	
CAH	2007	78	25	26	79	208	38	25	38	
IS *	2008	69	18	6	124	217	32	11	57	
AP	2008	0	0	0	4	4	0	0	100	
CD~	2008	0	0	0	110	110	0	0	100	
SUPC	2008	2	0	0	10	12	17	0	83	
Total		7,625	1144	1580	1132	11481	66	24	10	

* Includes cases reported through the Paediatric surgeons surveillance system

~ Includes cases reported through the child and adolescent psychiatry surveillance system

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
MCADD Medium chain acyl CoA dehydrogenase deficiency
MRSA Methicillin-resistant Staphylococcus aureus
VKDB Vitamin K deficiency bleeding
FMAIT Fetomaternal alloimmune thrombocytopenia
IIH Idiopathic intracranial hypertension
CAH Congenital adrenal hyperplasia
IS Intussusception
AP Anaphylaxis following immunisation
CD Conversion Disorder
SUPC Sudden unexpected early postnatal collapse

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED

