



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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## BPSU to hold 2<sup>nd</sup> Workshop

Following the success of the first Users' workshop held in October 2005 (inset) the BPSU are to hold a second workshop in April 2007. The first workshop was aimed at bringing investigators from the various projects together to exchange views on how surveillance can be developed and improved. The aims of the second workshop will be 1) to allow junior researchers on the projects experience in presenting data 2) to encourage applications from clinicians and researchers who are interested in using the BPSU system.



Mr R Lynn and Dr R Knowles,  
BPSU Workshop 2005

The 2007 workshop will be in 2 sessions. The morning session will consist of presentations from the investigators on their projects. Each presentation will examine different aspects of surveillance. Ann-Marie Winstone will present the PIND study concentrating on the use of expert groups to determine an analytic case definition. Dr Pat Tookey will explain how data linkage through the HIV survey is undertaken; Ms Catherine Goodall will discuss how laboratory surveillance supports BPSU infectious disease projects such as the MRSA study; Dr Eileen Baidam of the scleroderma study will explain how adult specialty groups can help in maximising ascertainment and Dr Marian Knight will consider the potential for collaboration between the BPSU and the obstetric surveillance system, UKOSS.

After lunch the second session will consist of 4 workshops on the themes of patient and carer involvement in paediatric research; setting up alternative reporting sources; developing a good questionnaire and ethics, consent and data handling. Delegates will have the option of choosing 2 of the 4 themes.

There will also be a variety of posters on display from current projects. No doubt you will agree that this varied programme will assist those thinking of applying to undertake surveillance through the BPSU. The full programme and registration form will be included with the January 2007 orange card mail out, and can also be downloaded from the BPSU website at <http://bpsu.inopsu.com>. Registration will be £30 and will attract CPD points. Only 50 spaces are available so please book early to secure your place. For further information or to request a registration form please contact [Jennifer.Ellinghaus@rcpch.ac.uk](mailto:Jennifer.Ellinghaus@rcpch.ac.uk) (Tel: 020 7323 7912).

## Sir Peter Tizard Research Bursary – Winner Announced!

The BPSU received 17 bursary applications this year, far more than the number received in previous years. After shortlisting by the medical advisors and scientific coordinator and lengthy discussion at the Executive Committee meeting in July, the bursary was awarded to joint applicants Dr Tom Dawson and Dr Shazia Adalat, both SpR's at Heartland Hospital Birmingham. The bursary has been awarded on the proviso that the study passes the phase 2 application process. Dr Dawson and Adalat wish to study the epidemiology of Toxic Shock Syndrome (TSS). The study will 1) consider the incidence of this rare condition in children in the UK and the spectrum of clinical presentations; 2) identify the source of toxin secreting organism (e.g. burn) 3) assess initial clinical management and 4) examine clinical outcome. The BPSU Executive Committee will now work with Dr Dawson and Adalat to develop the appropriate methodology to undertake this study, with the intention of commencing surveillance in 2007. Thank you to all of those who applied for the bursary. A call for the next bursary will be made early in the New Year and details will be posted on our website at [http://bpsu.inopsu.com/home/tizard\\_bursary.html](http://bpsu.inopsu.com/home/tizard_bursary.html).



2006 Joint Bursary Winners  
Pictured (l-r): Dr Shazia Adalat  
and Dr Tom Dawson

## News in Brief – Neonatal Herpes, Malaria, MRSA, IIH

Dr Pat Tookey reports on the current surveillance of **Neonatal Herpes Simplex Virus**, which commenced in 2004, and will continue until February 2007. We are seeking notification of all infants with confirmed or suspected neonatal HSV, born in the British Isles during the three years 2004 to 2006.

About 75 cases have been confirmed to date, and a substantial number of reports are outstanding for the latter half of 2006, as well as a few from earlier on. Reports to date are consistent with an estimated prevalence of about 4/100,000 births; this is about double that previously reported through a similar BPSU study carried out 1986-1991, and similar to the reported prevalence in Scandinavian countries and Australia. To date, just over half of all infections are attributable to HSV-2, typical lesions were absent in over a third of all cases, and about 25% of infants have died. Diagnosis of maternal infection prior to delivery is rare, although after the neonatal diagnosis evidence of likely maternal infection was retrospectively recognised in about 20% of cases.

Once the status of all reports has been clarified, we'll be able to explore the relationship between virus type, presentation, timing of diagnosis and treatment, and outcome. We also intend to contact notifying paediatricians for follow up information on all infants who survived the neonatal period. Follow up forms were previously sent out for those born in the first half of 2004, and we will request follow-up data on those born in the latter half of 2004 and in 2005 as soon as possible after primary data collection closes. Thanks to everyone who has reported cases and completed forms – and if you have any outstanding forms to return (or indeed cases to report) please do so as soon as possible. Please note data is preliminary and has yet to be peer reviewed. Contact Dr Pat Tookey on 020 7905 2604 (E-mail: [p.tookey@ich.ucl.ac.uk](mailto:p.tookey@ich.ucl.ac.uk)) for further information.

The **Malaria in Children** bursary study (investigator Dr Shamez Ladhani) ends in February 2007. In the previous bulletin Dr Ladhani outlined the study to date in some detail. To bring you all up to date, 11 months into the survey 167 cases have been reported. Overall, 83% of cases were from the UK, 15% from Ireland and 2% from Scotland. Completed questionnaires have been returned for 102 cases. Of these 96 have been confirmed as malaria (87% *P. falciparum*), while 5 were duplicates and 1 a false positive malaria antigen test case. The UK number of cases reported is still lower than expected. This may be due to cases being seen by paediatric trainees. We urge you to inform your consultants of all confirmed cases of paediatric malaria.

It is important that we identify all cases of imported malaria in children in order to obtain accurate estimates of incidence, complications and outcome. So please could you remember to report any outstanding cases and complete and return your questionnaires. For further information please contact: Dr Shamez Ladhani. Tel: 020 7882 2615. E-mail: [s.ladhani@qmul.ac.uk](mailto:s.ladhani@qmul.ac.uk). Please note data is preliminary and has yet to be peer reviewed.

The **MRSA bacteraemia** study commenced in June 2005 with the aims of obtaining a robust estimate of the incidence of infection in children, and defining the demographic and clinical features of the patient population, with particular regard to the proportion of cases that are healthcare-associated or community-acquired. Following lower than expected levels of reporting, the BPSU and the Department of Health agreed to extend the study for an additional 12 months, which takes the data collection period to the end of June 2007.

At the end of November 2006, 112 notifications have been received from the BPSU. Of these, 63 have been confirmed, 28 were error or duplicate reports and 21 are outstanding. Of the 63 confirmed cases reported by paediatricians, 79% (50/63) were submitted by paediatricians in England, 8% (5/63) from Scotland, 6% from the Republic of Ireland (4/63) and 5% and 2% from Northern Ireland and Wales respectively. Sixty-nine isolates have been received by the HPA Staphylococcal Reference Laboratory and voluntary routine reporting from hospital microbiologists to LabBase 2 has identified 103 cases; 10 cases were confirmed by all 3 reporting routes.

Clinical information derived from completed questionnaires indicates that cases are concentrated in children less than 1 year old (73%), with almost half of the total group aged less than 1 month on the date of their first MRSA-positive blood culture. The majority were resident in SCBU/NICU or PICU units at the time of diagnosis and 28 were described by paediatricians as premature.

Interestingly, data on the isolates submitted to the HPA Staphylococcal Reference laboratory suggests that the majority of isolates are of the UK epidemic MRSA strain, EMRSA-15, which is associated with the hospital setting and is one of the predominant strains in the UK adult population. It is hoped that these data will inform policy to reduce the burden of invasive infection with MRSA in children. Please note data is preliminary and has yet to be peer reviewed. Contact: Catherine Goodall: E-mail: [catherine.goodall@hpa.org.uk](mailto:catherine.goodall@hpa.org.uk).

The **Idiopathic Intracranial Hypertension (IIH)** phase 2 application has now been approved. The study investigator, Dr Yim Yee Mathews, was the 2005 Sir Peter Tizard Research Bursary winner. The study will consider the incidence of this rare condition in children in the UK, the spectrum of clinical presentations, initial clinical management and clinical outcome. The applicant is in the process of obtaining MREC and PIAG approval for the study and it is anticipated that the surveillance will commence by early Spring 2007. Watch this space for further information.

## In-House News – BPSU on the Road

In September 2006 the BPSU exhibited at two key paediatric conferences; the British Association of Paediatric Medicine (BAPM) in Nottingham and the British Association for Community Child Health (BACCH) in Reading. The BPSU displays were well received at both events and provided an excellent opportunity for delegates considering undertaking a study through the BPSU to chat informally about their ideas. The BACCH conference also included two workshops run by the BPSU Scientific Coordinator, Mr Richard Lynn, discussing 'The BPSU and Community Paediatrics'. The BPSU will continue to attend similar conferences in 2007 so do look out for us and come and say hello – your feedback and ideas are always welcome. The importance of BACCH and BAPM members to the BPSU system cannot be understated. The BPSU and its investigators thank you for your ongoing support.



*J Ellinghaus and R Lynn,  
BAPM Conference 2006*

The BPSU has also been represented and its activities discussed at several meetings recently. Dr Richard Pebody, member of the BPSU Executive Committee as representative of the Health Protection Authority (HPA), presented at the HPA conference in September 2006 on the impact of the BPSU on infectious disease surveillance. Richard Lynn attended the Faculty of Paediatrics meeting at the Royal College of Physicians of Ireland in October to discuss the Irish contribution to the BPSU. Richard also attended a meeting of the Child Psychiatry Research Society in November to discuss the potential for development of a surveillance system for psychiatric disorders in children. And finally, Professor Allan Colver, Chair of the BPSU Executive, was invited to speak at a meeting of the Ulster Paediatric Society in Belfast to discuss the BPSU and its activities.

## Yearly Review

Once again we have reached the time of year when it is traditional to look back over the year's activities. Being the BPSU's 20<sup>th</sup> anniversary year, 2006 has been a particularly active one for the Unit. Three studies commenced this year: the Sir Peter Tizard bursary study on Malaria in Children (January 2006), Vitamin k Deficiency Bleeding (VKDB, October 2006) and Fetomaternal Alloimmune Thrombocytopenia (FMAIT, October 2006). Only one study, Early Onset Eating Disorders (May 2006) ended this year. The willingness of the child psychiatrists to contribute to this study was very pleasing and perhaps paves the way for a child psychiatric surveillance system. There are now 10 studies currently being undertaken through the BPSU.

During 2006 the BPSU Executive Committee met 6 times to discuss surveillance proposals and applications. This year 12 phase one and 6 phase two applications were considered, along with 17 bursary applications – a record number. The application paperwork has been revised and simplified and can be downloaded from the BPSU website at <http://bpsu.inopsu.com/apply/index.html> for those interested in applying. This year we formalised the BPSU's arrangements with the Patient Information Advisory Group (PIAG) and all of the BPSU's studies have applied for and been granted PIAG approval. Following consultation with the BPSU, PIAG have streamlined their application process for BPSU applicants so that the delay in commencing studies should be considerably reduced.

Following the BPSU strategy meeting in 2005 it was agreed that the BPSU needed to 1) improve the response rate – achieved 2) improve the number of study/bursary applications – achieved 3) increase awareness of the BPSU activities. The orange card response rate for 2005 was excellent at 93.6% – up 2.4% on 2004. There have been nearly 1,600 cases reported for the 12 months to October 2006 of which nearly 1000 have been confirmed. The last aim has been achieved through the re-launch of the expanded and improved BPSU website (<http://bpsu.inopsu.com>); through the holding of a very successful one day conference and through exhibiting and presenting at relevant conferences and meetings such as BACCH and BAPM. At the RCPCH scientific meeting there were 7 plenary and 9 group presentations – again a record for the BPSU.

Internationally 2006 has also been a very busy year. The BPSU hosted the 4<sup>th</sup> INoPSU conference at the ICH (London) in June 2006. The conference was attended by 12 of the 15 national units; only representatives from New Zealand, Papua New Guinea and Malaysia were not able to attend. The morning session saw presentations on fetal alcohol syndrome from Australia and New Zealand; the Canadian unit presented data on neonatal herpes and hyperbilirubinaemia and there were also talks on Type 2 diabetes (Latvia), VKDB (Netherlands) and acute flaccid paralysis (Switzerland). The afternoon business meeting saw the BPSU reaffirmed as the central liaison for the Units and the BPSU continues to maintain the INoPSU website at [www.inopsu.com](http://www.inopsu.com). The site lists over 120 rare conditions that have been surveyed by the now 15 countries in the network. Future funding and international collaboration were also discussed. A venue for the 5<sup>th</sup> conference has yet to be confirmed.

Finally we say a fond farewell to Professor Mike Preece after serving on the BPSU Executive as Chair these past five years. Professor Allan Colver took over as Chair and several new members have also joined the committee this year; Professor Adam Finn, Dr Simon Mitchell, Dr Colin Michie and Dr Chikwe Ihekweazu as medical adviser (infectious disease). The BPSU Executive also welcomes Mrs Sue Banton and Mrs Ann Seymour to replace Mrs Carol Youngs as patient/carer representatives. Sue started a self-help group 27 years ago when her son was born with clubfoot. This group has since become an international charity (STEPS). It is through this charity that Sue initially became involved with research, then as an advisor for the National Paediatric Epidemiology Unit and more recently with INVOLVE which promotes public involvement in NHS, public health and social care research. Ann became interested in child welfare whilst working for the National Association for the Welfare of Children in Hospital. She then spent 6 years working for the Royal College of Anaesthetists and then joined the board of the Confidential Enquiry into Maternal and Child Health and most recently sat on a working group regarding the care of critically ill children. Both will contribute significantly from child, parent and public perspective of child health.



*BPSU Executive Patient/Carers  
Pictured (l-r): Mrs Sue Banton*



## BPSU Prize Draw

From January 2007, the BPSU will be randomly selecting paediatricians with a 100% orange card response rate to receive a prize in the form of Marks & Spencer vouchers. A winner will be drawn in July 2006 and January 2007 and will be announced in the Autumn 2006 and Spring 2007 BPSU Quarterly Bulletin issues. In order to be eligible for the prize, you will need to have a complete response record for the 6 month period prior to the draw – that is January to June or July to December. We do understand that cards can go missing in the post, so to be eligible to enter the draw you will need to have returned all of your orange cards and/or reminder letters to ensure that your response rate is 100%. Naturally if you are ever concerned that your response rate might not be complete, you are more than welcome to call or email the BPSU office (0207 323 7912 / [Jennifer.Ellinghaus@rcpch.ac.uk](mailto:Jennifer.Ellinghaus@rcpch.ac.uk)) to update your record. If you have any queries about the competition do contact the BPSU office on the details listed above.

## In-house

As you will see from **Table 1** the response rate for the orange card is hovering at around 92%. Wales continues to rank first with a response rate of 96.1%. We are currently chasing up those apparently not returning the cards in order to see if there are any particular difficulties we can address. The response rate for the return of questionnaires remains high at 92% (**Table 2**), however even here there have been difficulties, particularly with reporting clinicians not being able to recall which child they have reported. **Please** remember to use the tear off section of the orange card, writing down the child's details so you will not forget when being contacted by the investigators. We do appreciate that there is an ever-increasing workload on clinicians but the validity of the BPSU as a surveillance system depends wholly on your support and involvement, so please keep those cards and questionnaires coming in, even if they are a couple of months late. Finally, from all here at the BPSU office can we wish you a healthy and happy 2007.

**TABLE 1 - % RESPONSE RATE**  
Jan – Sept 06

Region	% rtrnd	Rank (Jan- June 06)
North	91.7	16 (6)
Yorks	93.5	9 (8)
Trent	93.8	7 (12)
EAnagl	93.9	6 (4)
NWT	91.8	15 (16)
NET	89.9	20 (20)
SET	92.0	14 (15)
SWT	91.1	17 (13)
Wessex	93.5	8 (11)
Oxford	94.6	4 (2)
SWest	94.7	3 (5)
WMids	93.2	10 (9)
Mersey	92.3	12 (18)
NWest	94.9	2 (7)
Wales	96.1	1 (1)
NScot	90.9	19 (14)
SScot	91.0	18 (17)
WScot	92.4	11 (10)
Nlre	94.3	5 (3)
Rlre	92.2	13 (19)
<b>Total</b>	<b>91.5%</b>	

**TABLE 2 – ALL CASES REPORTED AND FOLLOW-UPS TO 14/11/2006**

Condition	Started	VALID				Total	as % of total		
		C/R	D	E	X		C&R	D&E	X
HIV	1986	4258	553	575	363	5749	74	20	6
CR	1990	71	28	52	6	157	45	51	4
PIND	1997	1243	246	583	77	2149	58	39	4
NNH	2004	75	24	21	45	165	45	27	27
MCADD	2004	156	45	11	41	253	62	22	16
MRSA	2005	62	7	20	21	110	56	25	19
Scleroderma	2005	25	5	1	74	78	32	26	42
Malaria	2006	83	5	1	74	163	51	4	45
VKDB	2006	-	-	-	7	7			100
FMAIT	2006	-	-	-	6	6			100
<b>Total</b>		<b>5973</b>	<b>910</b>	<b>1281</b>	<b>673</b>	<b>8837</b>	<b>68</b>	<b>25</b>	<b>8</b>

C/R = confirmed/already known

E = reporting error or revised diagnosis

D

X

= duplicate

= status not yet reported to BPSU by investigator

HIV Human Immunodeficiency Virus In Childhood

CR Congenital Rubella

PIND Progressive Intellectual Neurological Degeneration

NNH Neonatal Herpes Simplex Virus infection

MCADD Medium chain Acyl CoA dehydrogenase deficiency

MRSA Methicillin-resistant Staphylococcus aureus

VKDB Vitamin K Deficiency Bleeding

FMAIT Fetomaternal Alloimmune Thrombocytopenia

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED