



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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## Sir Peter Tizard Bursary – Final Call for applications

The RCPCH is once again inviting applications for the Sir Peter Tizard Research Bursary from paediatricians wishing to undertake an epidemiological surveillance study through the British Paediatric Surveillance Unit. The successful applicant will receive up to £15,000 towards the costs of a surveillance study.

### The purpose of the bursary:

- To encourage paediatricians who are not research active to undertake a study of a rare disease or condition which affects children and which is of scientific or public health importance.
- To enable paediatricians to further develop their research knowledge and skills.
- To add to the body of knowledge of rare childhood diseases and conditions.
- To promote the role of the BPSU in the surveillance of rare diseases affecting children.
- To support the Royal College of Paediatrics and Child Health's objective of building and strengthening research in paediatrics.

### Who is eligible to apply for this bursary?

- Applicants must be members of the RCPCH
- Paediatricians with NHS contracts (PT or FT) who are
  - a) Specialist Registrar/Staff /Associate Specialist grade
  - or
  - b) Consultant grade (**less than five years in post**)
- Only one application may be submitted per year by each applicant
- Two candidates may submit an application together, but the Committee will consider both applicants' criteria during the review process
- Priority will be given to encouraging young clinicians in training.

### What are the selection criteria?

The purpose of the bursary award is to encourage paediatricians to develop skills and experience in epidemiological research. Applications will be judged on; the scientific quality of the application, the justification for the study being carried out through BPSU and the likely benefits to the candidate in terms of developing their research knowledge and skills. The scientific and public health importance of the condition proposed will be taken into account but will not be the sole criterion.

### Closing date for application is Friday 13th June 2008.

We would be grateful if consultants could make junior staff aware of this application request for the 2006/07 Sir Peter Tizard bursary. Further information is available on the BPSU website at [http://bpsu.inopsu.com/home/tizard\\_bursary.html](http://bpsu.inopsu.com/home/tizard_bursary.html) or from Aaron Barham, Education Dept, Tel: 020 70926011 or E-mail: [aaron.barham@rcpch.ac.uk](mailto:aaron.barham@rcpch.ac.uk)

### Office Re-location

Along with the rest of the RCPCH the BPSU office has now re-located to 5-11 Theobalds Road, Holborn, London WC1X 8SH. Our new telephone number is 020 7092 6193/4. Please continue to return the orange cards; we have a redirect mailing system set up so they will reach us but it would be helpful if you could send any outstanding cards you may have back to us as quickly as possible.

## In the News

**Committee update:** Dr Colin Campbell (inset) has recently been appointed as the new BPSU medical adviser for infectious diseases, taking over from **Chikwe Ihekweazu**.



Speaking to the bulletin Colin said *"I am delighted to have the opportunity of working with the BPSU as medical adviser for the next couple of years, taking over from Chikwe in providing infectious disease support to applicants to the BPSU. I have worked in a wide variety of specialties, including paediatrics and also spent 3 years working in HIV in Central America and Africa before settling down to Public health. I joined the Public health training scheme in 2006 as a Health protection trainee in Colindale and have worked on a national contamination incident of blood cultures as well as reviewing the zoonoses acquired from pets and pet shops. I am currently working in North West London HPU and will hopefully be looking at TB in Schools."* If you are interested in submitting an application Colin can be contacted via [colin.campbell@hpa.org.uk](mailto:colin.campbell@hpa.org.uk) for advice.

Two other members of the BPSU Executive will also stand down this summer. **Donal Manning** who joined the Executive in 2005 has been invited to join the NICE Guideline Development Group for Neonatal Jaundice. Many of you will remember that Donal, as an investigator undertook surveillance of hyperbilirubinaemia through the BPSU, the findings of which I am sure will contribute to the NICE discussions. **Professor Adam Finn**, due to pressure of work, has with some reluctance, also had to step down. Thanks to all three both for their contribution.

## Conference news

The BPSU was again well represented with papers at this years RCPCH scientific meeting in York. Four papers, 2 at plenary, were presented. For those who could not attend but would like copies of the abstracts please contact us at [bpsu@rcpch.ac.uk](mailto:bpsu@rcpch.ac.uk)

Two of the presentations were on **HIV**. Monday saw the HIV team present a paper entitled "very low risk of mother to child transmission (MTCT) of HIV in women on HAART achieving viral suppression". The second HIV paper entitled "congenital abnormalities and in-utero exposure to antiretroviral therapy" was presented at the Infectious disease group meeting. An update on the HIV study can be read overleaf.

The second plenary, on **PIND**, entitled "A spectrum of neurodegenerative disease in UK children" was presented on Tuesday by Dr Chris Verity. It was reported that 2345 children had met the criteria of PIND. Among them were six with probable or definite variant Creutzfeldt – Jacob disease. 996 children had other confirmed diagnoses and in these there were 116 known neurodegenerative conditions. The study concluded that long-term surveillance has provided unique epidemiological data about the distribution of neurodegenerative disease in UK child population.

Finally, a paper, also in the infectious disease meeting, was presented by Dr Shamez Ladhani on the true burden of **malaria** in the UK and Ireland. It was reported that 188 confirmed cases of imported malaria in children under 16 years were reported to the BPSU a further 117 cases were reported through the malaria reference laboratory. The vast majority of cases were imported from West Africa, primarily from Nigeria and are caused by *P. falciparum*.

Also at the conference Dr Beth Chessbrugh (inset), winner of the 2007 Sir Peter Tizard Bursary for her application to undertake surveillance of Glutaryl-Coenzyme A dehydrogenase deficiency (GDD) picked up her award.

## BPSU Evaluation underway

We are currently undertaking an internal evaluation of BPSU processes, outputs and the degree to which the BPSU meets its aims and objectives. This is good practice for any such Unit and it will also be important to demonstrate such internal scrutiny when the Unit applies for further funding.

The views of paediatricians are a very important element of this internal evaluation therefore we have sent questionnaires to a random sample of 600 paediatricians who currently receive orange cards in the UK and Ireland. Two - thirds of the questionnaires have been returned to date, thank you to all those who have done this so promptly. We are hoping to achieve a high return rate so **we would be very grateful if those of you who are yet to complete the survey could do so**. The results of this questionnaire along with the rest of evaluation will be available later in the year.

If you have any questions or have any views you would like to express about the Unit and its activities please contact [helen.friend@rcpch.ac.uk](mailto:helen.friend@rcpch.ac.uk)



## Study Updates

### National Study of HIV in Pregnancy and Childhood



Although mother to child transmission rates of HIV are very low now in the UK, some perinatal transmissions still occur. We (the NSHPC, together with the Children's HIV Association [CHIVA, [www.chiva.org.uk](http://www.chiva.org.uk) ] and the Audit Information and Analysis Unit of the Specialised Commissioners) carried out an audit to explore the circumstances of perinatal transmissions in England 2002-2005; the Executive Summary and Recommendations are available at [www.nshpc.org.uk](http://www.nshpc.org.uk) .

We identified 87 infected infants in time for the audit, although another 34 who were diagnosed later on but born 2002-2005, have been reported since then. Among the approximately one third of infected babies whose mothers were diagnosed before delivery, there was usually a combination of factors which probably contributed to transmission, including late diagnosis, receipt of little or no ART and concurrent infections. However, delay in acting on test results, inadequate monitoring, or poor communication between health professionals, or between them and the mother, were also evident in some cases. Two-thirds of infected infants were born to undiagnosed women, and most of these were only identified when they presented with symptoms or their mother or another family member was diagnosed – seven of these 54 babies died under the age of 12 months, two more during their second year, and 60% of the survivors have already had an AIDS defining illness. Although less than 10% of infected women remain undiagnosed by the time of delivery, they account for most perinatal transmissions in the UK and Ireland – maintaining and improving antenatal detection rates remains a priority.

Since 2003 over 1200 births to HIV infected pregnant women have been reported each year, from all over the British Isles, and the majority of these births now occur outside London and the South East of England. This underlines the importance of continuing comprehensive coverage through the BPSU. Two NSHPC papers are due out any time now; we'd like to thank the BPSU and all contributing paediatricians and colleagues for their invaluable support! Look out for:

- Townsend et al. Low rates of mother-to-child transmission of HIV following effective pregnancy interventions in the United Kingdom and Ireland, 2000-2006. *AIDS* 2008, *in press*
- Townsend et al. Trends in management and outcome of pregnancies in HIV infected women in the United Kingdom and Ireland, 1990-2006. *BJOG* 2008, *in press*

For a full list of publications and conference presentations drawing on NSHPC data, and much more information, including downloadable slides, visit [www.nshpc.ucl.ac.uk](http://www.nshpc.ucl.ac.uk)

Contact: Dr P Tookey/Ms Janet Masters. E-mail: [nshpc@ich.ucl.ac.uk](mailto:nshpc@ich.ucl.ac.uk) or [p.tookey@ich.ucl.ac.uk](mailto:p.tookey@ich.ucl.ac.uk)

### Study ends: After 4 years, May will see the final surveillance month for MCADD

The UKCSNS-MCADD is a research evaluation of a pilot newborn screening service for MCADD introduced in 2004 in six centres in England screening about half of all UK births. This evaluation was commissioned by the Department of Health to inform a review of newborn screening policy in the UK.

The study aimed to ascertain all cases of MCADD diagnosed in the study period, and determine outcome of MCADD two years following clinical diagnosis or diagnosis through newborn screening. Since 2004, well over one million babies have been screened for MCADD in England. From preliminary data comparing screened and unscreened populations in the UK, the estimated prevalence of MCADD identified after clinical diagnosis appears to be a half to two-thirds identified through newborn screening. This suggests under-diagnosis and/or variable penetrance – similar to that reported from screening programmes in other countries. The study has also shown that newborn screening reliably identifies affected children before they are likely to develop symptoms, enabling parents to use simple measures to avoid fasting and thereby reduce the chances of severe illness or death.

A report of the evaluation including findings from the BPSU study was presented to the National Screening Committee as part of a fast track policy review in May 2006. Subsequently, in February 2007, the Department of Health announced that screening for MCADD is to be added to newborn bloodspot screening in England in a phased roll out during 2007/8 and 2008/9 with continuation of screening in existing pilot sites (Gateway reference number:7801). Implementation of screening for MCADD in England is being managed by the UK Newborn Screening Programme Centre. Details are available at [www.newbornbloodspot.screening.nhs.uk](http://www.newbornbloodspot.screening.nhs.uk).

Contact: Professor Carol Dezateux, Ms Juliet Oerton, Ms Mona Khalid. Tel: 0207 905 2605/2241/2141  
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## Recent Publications & Analysis

**BPSU bulletin:** The Bulletin will now be produced 3 times a year in January, May and September and the circulation of hardcopies will be reduced. Copies of the bulletin, as all our publications, will be placed on the website at [http://bpsu.inopsu.com/publications/quarterly\\_bulletin.html](http://bpsu.inopsu.com/publications/quarterly_bulletin.html). However, we will provide updates of our activities through the President's email, circulated to all College members, more regularly with lead headlines being hyperlinked to articles on the BPSU website.

**Recent paper:** Cameron JC, Allan G, Johnston F, Finn A, Heath PT, Booy R. Severe complications of chickenpox in hospitalised children in the UK and Ireland. *Arch Dis Child*. 2007 Dec;**92(12)**:1062-6.

### You can still have you say

We welcome ALL comments about BPSU activities and publications. If you have any queries or concerns why not write/email us so we can address them, perhaps in this bulletin. What would YOU like to see in this bulletin? Send your comments to [bpsu@rcpch.ac.uk](mailto:bpsu@rcpch.ac.uk)

TABLE 2 - % RESPONSE RATE

Region	% rtrnd	Rank
North	93.0	7 (5)
Yorks	91.5	11 (6)
Trent	94.4	3 (7)
EAnGl	93.8	6 (8)
NWT	88.4	19 (18)
NET	85.8	20 (19)
SET	89.2	16 (14)
SWT	88.9	17 (20)
Wessex	94.1	4 (3)
Oxford	93.9	5 (13)
SWest	92.8	8 (12)
WMids	91.8	10 (9)
Mersey	89.8	15 (10)
NWest	90.2	14 (17)
Wales	95.9	1 (1)
NScot	95.5	2 (2)
SScot	88.7	18 (15)
WScot	90.7	13 (11)
NIre	92.0	9 (4)
RIre	91.1	12 (16)
<b>Total</b>	<b>91.6%</b>	

TABLE 3 - ALL CASES REPORTED AND FOLLOW-UPS TO DECEMBER 2007

Condition	Started	VALID		INVALID		NYK	Total	as % of total		
		C/R	D	E	X			C&R	D&E	X
HIV	1986	5152	614	631	439	6836	75	18	6	
CR	1990	75	31	59	3	168	45	54	2	
PIND	1997	1363	296	676	93	2428	56	40	4	
MCADD	2004	171	47	31	104	353	48	22	29	
Scleroderma	2005	56	11	25	11	103	54	35	11	
VKDB	2006	5	8	8	14	35	14	46	40	
FMAIT	2006	60	8	14	34	116	52	19	29	
Genital Herpes	2007	5		7	7	19	26	37	37	
IIH	2007	23	6	29	91	149	15	23	61	
CAH	2007	22	7	8	85	122	18	12	70	
<b>Total</b>		<b>6761</b>	<b>997</b>	<b>1450</b>	<b>7127</b>	<b>9920</b>	<b>68</b>	<b>25</b>	<b>7</b>	

C/R = confirmed/already known  
 E = reporting error or revised diagnosis  
 D = duplicate  
 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

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED

