



**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

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Inside this issue

**Sir Peter Tizard
Research Bursary**
Call for applications

Study news
HIV/AIDS
Severe hyperbilirubinaemia
Neonatal herpes simplex virus
Langerhans cell histiocytosis

Call for abstracts
HPA conference

Analysis
Regional and
Study tables

Bursary - in the name of Sir Peter Tizard

The newly introduced RCPCH- BPSU bursary is to be named after one of the innovators of the BPSU, Sir Peter Tizard. The first award, to be known as the Sir Peter Tizard Research Bursary, has been awarded to Dr Scott Williamson of Ninewells hospital to examine childhood thyrotoxicosis. We expect this study to commence in the early summer.

Application call for the 2004-05 bursary: Following its successful launch the RCPCH is again offering paediatricians the opportunity to apply for a Bursary in order to undertake research using the BPSU. The successful applicant will once again receive £15,000 towards costs for a thirteen-month 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**)
- ? Applicants should have access to administrative/research support for the duration of the study.

Who is NOT eligible to apply for this bursary?

- ? Experienced consultants i.e. more than 5 years in post
- ? Who have previously undertaken a major research project or held a major research grant (this excludes acting as a local investigator in a multicentre trial)
- ? Those with university or joint NHS/Academic appointments
- ? Those who previously undertaken a BPSU or similar surveillance study

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 merits of the candidate, the scientific quality of the application, the justification for the study being carried out through BPSU. The scientific and public health importance of the condition proposed will be taken into account but will not be a sole criterion. Paediatricians working in purely clinical setting are advised to establish links with clinical and scientific colleagues who would be able to provide advice and support at the planning stage and also when the project is underway.

Closing date for initial application is 24 June 2004.

We would be grateful if consultants could make junior staff aware of this call for the 2004-05 bursary.

Further information is available on the BPSU website at <<http://bpsu.inopsu.com/methodol.htm#bursary>> or from Richard Lynn, Scientific Coordinator, Tel: 020 7307 5671 or E-mail: bpsu@rcpch.ac.uk.

Study News

Dr Pat Tookey reports on the national surveillance of HIV/AIDS - The BPSU reporting scheme is the cornerstone of paediatric HIV surveillance in the UK and Republic of Ireland, which is carried out at the Institute of Child Health (ICH) on behalf of a group including the Health Protection Agency (HPA) and the Scottish Centre for Infection and Environmental Health (SCIEH). A parallel active quarterly obstetric reporting scheme, modelled on the orange card, is administered at ICH under the auspices of the Royal College of Obstetricians and Gynaecologists. Laboratory reports to PHLS CDSC and to SCIEH are a third source of information.

All infected children should be reported as well as all infants born to HIV infected women, regardless of their own infection status. Until recently subsequent follow up information has only been sought from paediatricians caring for confirmed infected children and those of indeterminate infection status. However, continued follow up of uninfected children born to HIV infected women, most of whom are now exposed to antiretrovirals in fetal life, is now being established so that any potentially related adverse outcomes can be identified and investigated.

Nearly 5000 children had been reported to the National Study of HIV in Pregnancy in Childhood by the end of 2003, nearly 4600 of whom (93%) were born to HIV infected women (Table 1) Most of the remaining 360 children were born before 1986 and infected during the course of treatment for haemophilia, or contaminated blood transfusion.

Table 1 – HIV Infection status of children born to HIV infected women & reported to RCOG or paediatric surveillance schemes by end December 2003

Region of first report	Infected	Intermediate	Uninfected	Total Reported
London	710	570	1356	2636
Rest of England/Wales/NI	288	269	510	1067
Scotland	50	36	198	284
Republic of Ireland	67	180	340	587
Total	1115	1055	2404	4574

Apart from providing up-to-date data on the prevalence of paediatric HIV infection in the UK and Republic of Ireland, the surveillance programme also monitors the impact of antenatal testing strategies, the uptake of interventions in pregnancy, and developments in the management of infected children.

Prevalence and detection of infection in pregnancy: Unlinked anonymous surveys of HIV infection indicate that the prevalence of infection in pregnant women continues to rise (Renewing the Focus 2003 - http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/). In London in 2002, approximately 1 in every 250 live born infants was born to an infected woman (350 in 2000), elsewhere in England it was approximately 1 in 1,15,80 (3,700 in 2000), and in Scotland 1 in 1,700 (2,100 in 2000).

HIV detection rates in pregnant women are monitored through the alignment of surveillance data with data from the unlinked anonymous surveys. A routine offer and recommendation of antenatal HIV testing has now been implemented almost everywhere in the UK, and the proportion of diagnosed pregnancies has increased substantially over previous years. In London at least 75% of infected pregnant women were diagnosed before delivery in 2002, and when late reports are incorporated into the data, the proportion is likely to rise to around 80%. Prior to 2000 routine antenatal testing was rare in lower prevalence areas in the rest of England and detection rates were poor, but in 2002 about 85% of infected women were diagnosed before delivery. These improvements are leading to substantial reductions in the proportion of infected infants born to HIV positive women.

BPSU workload: Although there are more reports of HIV and AIDS than there are for other conditions on the orange card, paediatric HIV infection and exposure to maternal infection is still relatively rare. While management of infected children tends to be concentrated in a few specialist centres, HIV infected children and infants born to HIV infected women are now being identified and reported from areas which have rarely or never seen cases in the past. This makes the continuing co-operation of paediatricians in active national surveillance more important than ever. In order to reduce the burden on the BPSU, we have set up direct reporting arrangements with several units caring for larger numbers of children.

We would like to thank everyone who has reported cases and returned our forms; we really appreciate your continuing support and cooperation.

This study has ethics approval from London MREC and has had its BPSU extension request recently approved for a further year.

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Study news, contd.

Dr Donal Manning reports on progress: of the survey into severe hyperbilirubinaemia in the newborn. This study started in June 2003, collecting information on cases presenting from 1st May 2003. I would like to report the returns for the first 8 months of surveillance.

To date 47 reports have been received of these 23 have met the case definition, 21 have been duplicate or error reports and data on 3 is still outstanding. Thus, we are receiving a mean of 3 cases per month meeting the definition (peak unconjugated serum bilirubin ≥ 510 micromol/L in the first month of life). While this is a gratifyingly small number, it renders complete ascertainment all the more important – even missing a single case will substantially affect the calculated incidence of severe neonatal jaundice. I would be very grateful, therefore, if all those paediatricians who have reported cases to BPSU would take the trouble to return the completed questionnaire.

Of the 23 cases (and 1 who died before serum bilirubin could be measured), 4 have suffered bilirubin encephalopathy/kernicterus, of whom 3 died. Two of these babies were actually born in April but presented in May, the first month of surveillance. Thus, while we will include them in our description of bilirubin encephalopathy, we will be unable to include them in calculating its incidence per total live births. If reports continue at the current frequency, we would expect to hear of 4 to 5 cases of bilirubin encephalopathy per year. This is consistent with the total of 10 cases in two years that we heard of when we surveyed members of BAPM informally while the BPSU study was in preparation. Because the numbers developing encephalopathy have been low, BPSU have agreed to support the study for a second year and MREC approval for this extension has been given.

I would like to thank all paediatricians who have taken the trouble to report cases and return completed questionnaires, and those who have shown a personal interest in the study. Could I again make a plea for complete returns, as any under-reporting could substantially alter the accuracy of calculation of the incidence of severe neonatal jaundice, which is the primary objective of the study.”

For further information contact Dr Donal Manning, Department of Paediatrics, Wirral Hospital, Arrowe Park, Wirral, Merseyside CH49 5PE. Tel: 0151 678 5111. Fax: 0151 604 7138, E-mail: donal.manning@whnt.nhs.uk

The survey of **neonatal herpes simplex virus (HSV) Infection** commenced in January 2004. Unfortunately due to an error in the production of the protocol card and the reporting instructions it was stated that cases seen between January 2003 – 2004 should be reported. This is to confirm that only infants born since **January 2004** should be reported. Apologies for any confusion this may have caused.

Please report: any liveborn or stillborn infant born since the beginning of 2004 in the UK or Ireland with confirmed or suspected neonatal HSV infection, seen by you for the first time in the last month.

Surveillance Definition

1. Any infant under one month
 - a) with a diagnosis of HSV infection, based on virus detection by culture, PCR or IF, or serology – IgM and/or seroconversion,
 - or** b) treated with antiviral drugs for suspected HSV infection
2. Any stillborn infant in whom HSV infection is suspected

For further information contact Dr Pat Tookey, Centre for Epidemiology and Biostatistics, Institute of Child Health, 30 Guilford Street, London WC1N 5EH. E-mail: p.tookey@ich.ucl.ac.uk

The survey of **Langerhans cell histiocytosis (LCH)** commenced in June last year with the aim of describing the epidemiology of LCH in children in the UK and Ireland. There have been few epidemiological studies of this disease but it is estimated that one in 200,000 children are affected each year, with between 50-100 new cases per year in the UK.

In addition to the BPSU survey, the study team at Newcastle University are also mailing pathologists, oncologists, dermatologists, orthopaedic surgeons and other clinicians who may see children with this condition, on a six-monthly basis. They have also contacted the UK Children's Cancer Study Group (UKCCSG) to cross-check case reports.

At the end of February, there had been 54 notifications to the BPSU and 50 notifications via Newcastle's mailing. Further information is awaited for about a third of these reports. Excluding duplicates and reports in error there are currently 16 cases. However, sources indicate that further cases will be confirmed shortly.

For further information contact Professor Louise Parker, Sir James Spence Institute, Royal Victoria Infirmary, Newcastle-upon-Tyne, NE1 4LP. E-mail: louise.parker@ncl.ac.uk

Conference call for abstracts

Abstracts for oral presentations and posters are now invited for the Health Protection Agency's Annual Conference 2004, taking place on 13-15 September at the University of Warwick. The main themes for this year are Children's Health, International Health and Risk Communication.

Abstracts may be submitted up until 22 April. Please visit the HPA website for further details of the wide range of abstract categories and submission details – <http://www.hpaconference.org.uk> kindly forward this information to any of your colleagues who may be interested.

Monthly Analysis

As you will see from **Table 2** the response rate for the six months to November is averaging just below 90%. Initial results for January are giving cause for concern so please return your cards even if you have nothing to report. Notable movements in the rankings over the ~~past quarter are South Western region with a rise of 5 places to 8th~~, and East Anglia, picking up to 15th after a previous fall to 19th. NWT continues its rise up to 9th and SET is up to 3 to 14th. However NET and SWT remain bottom of the rankings. Wales, as usual, is 1st. Can I remind you all to let us know if you have moved address or retired, we can then make the adjustment to the regional denominators. As the cards are printed a month in advance apologies if there is a delay in getting your newly addressed card to you. Also please could you let us know of any recently appointed consultants not yet receiving the orange card.

Table 3 highlights the returns for the current studies, of the conditions currently on the card, 1360 cases have been reported in the past 12 months of which 693 have so far been confirmed. The severe complications to varicella survey has now been completed. For those who have yet to do so, please return the proformas to the investigators as soon as possible. Two new studies have recently commenced, the study on childhood tuberculosis, which has received over 80 cases reports already, and neonatal herpes simplex virus infection which has had 9 reports in the first month.

TABLE 2 - % RESPONSE RATE

June-Nov 2003	% ret'd	Rank (May-Sept 2003)
North	90.2	12 (15)
Yorks	92.3	4 (5)
Trent	90.3	11 (9)
EAnagl	88.6	15(19)
NWT	90.7	9 (11)
NET	82.0	20(20)
SET	89.3	14 (17)
SWT	84.2	19 (18)
Wessex	90.6	10 (12)
Oxford	93.5	3 (2)
SWest	91.1	8 (13)
WMids	91.2	7 (8)
Mersey	89.5	13 (7)
NWest	91.9	6 (3)
Welsh	95.0	1 (1)
NScot	87.3	17(14)
SScot	88.0	16 (10)
WScot	91.2	6 (6)
NIRE	94.5	2 (4)
RIRE	85.2	18 (16)
Total	89.7	

TABLE 3 - ALL CASES REPORTED AND FOLLOW-UPS TO 25/02/2004

Condition	Started	I					Ttl	as % of total		
		VALID	II INVALID		NYK	I		II	III	
HIV/AIDS	1986	2657	408	499	246	3810	70	24	6	
CR	1990	67	24	49	7	147	46	50	5	
PIND	1997	980	181	408	128	1697	58	35	8	
Con Toxo	2002	6	1	17	8	32	19	56	25	
Varicella	2002	103	21	28	36	188	55	26	19	
IFInfect	2003	70	13	19	33	135	52	24	24	
Se. Hyperbil	2003	23	3	18	11	55	42	38	20	
LCH	2003	5	3	16	29	53	9	36	55	
Tuberculosis	2003	9	0	6	67	82	11	7	82	
NNH	2004	0	0	0	9	9	0	0	100	
Total		3920	654	1060	574	6208	63	28	9	

I = confirmed/already known

IIb = reporting error or revised diagnosis

IIa = duplicate

III = status not yet reported to BPSU by investigator

AIDS/HIV - Acquired Immunodeficiency Syndrome / Human Immunodeficiency Virus

CR - Congenital Rubella

PIND - Progressive Intellectual

Neurological Degeneration

Con Toxo - Congenital Toxoplasmosis

Varicella - Severe complications of varicella

IFInfect - Invasive fungal infections in VLBW infants

Se. Hyperbil - Severe hyperbilirubinaemia in the newborn

LCH - Langerhans cell histiocytosis

NNH - Neonatal herpes simplex virus infection

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED