



## 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

### Early onset eating disorders study

Commences this March

### Sir Peter Tizard Bursary 2005

Call for applications

### Study News

HIV/AIDS, Neonatal herpes simplex virus, new studies, RCPCH scientific meeting

### New Surveillance Units

British Paediatric Orphan Lung Disease, UK Obstetric Surveillance System

### Analysis

Regional and Study tables

## Surveillance of early onset eating disorders commences in March

A one-year surveillance of early onset eating disorder (EOED) in children less than 13 years of age commences this March. This study is being undertaken by Dr Dasha Nicholls, Consultant Child and Adolescent Psychiatrist at GOSH; Richard Lynn, BPSU Scientific Coordinator; Dr Russell Viner, Consultant Paediatrician at GOSH and Professor Paul Lelliott, Director of the Royal College of Psychiatrists Research Unit. This will be the first BPSU study to be undertaken with the involvement of child and adolescent psychiatrists as well as paediatricians. Funded by the Hyman Wingate Foundation the project has London MREC approval.

Dasha Nicholls and Richard Lynn explain the reasons for undertaking this project, "Epidemiological studies suggest that although the incidence of anorexia nervosa is relatively stable, there may be a trend towards earlier onset. There is wide variation in the few available estimates of incidence of eating disorders in children under 13 years of age. However, increasing numbers of patients appear to be presenting in childhood and early adolescence. The ambiguous position of EOED between paediatrics and mental health has led to significant gaps in knowledge about the extent of this problem, and there is no information on the scale of paediatric resource used by this patient group. Through this study we hope to be able to answer the following important research questions:

- To estimate the incidence of early onset eating disorders in children in the British Isles
- To describe the age, sex and family history
- To describe the range of clinical features at presentation including other psychiatric illness
- To delineate patterns of professional involvement (paediatric & child mental health)
- To characterise the range of acute medical complications experienced by children with early onset eating disorders
- To identify the range of therapeutic interventions used in management.

**Case Definition:** Any child aged less than 13 years of age newly diagnosed with early onset eating disorder, which is defined as:

#### TWO OR MORE OF THE FOLLOWING

- weight loss or failure to gain weight during a period of expected growth, not due to any identifiable organic cause
- determined food avoidance
- fear of weight gain
- preoccupation with body weight or energy intake
- self induced vomiting
- excessive exercising
- recurrent episodes of binge eating or abuse of laxatives

"Exercise may be considered to be excessive when it significantly interferes with important activities, when it occurs at inappropriate times or in inappropriate settings, or when the individual continues to exercise despite injury or other medical complications." (American Psychiatric Association. DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. Washington, D.C. American Psychiatric Association; 2004; pp. 590-591.)

Please report any new cases meeting the surveillance definition seen by you for the first time even if you believe the case may have been reported from elsewhere.

Further information is available on the white protocol card enclosed with this mailing or via the BPSU website at <http://bpsu.inopsu.com/current.htm#EOED>. Otherwise contact Dr Dasha Nicholls, E-mail: [NichoD@gosh.nhs.uk](mailto:NichoD@gosh.nhs.uk) or Richard Lynn, E-mail: [bpsu@rcpch.ac.uk](mailto:bpsu@rcpch.ac.uk).

## Sir Peter Tizard Bursary 2005/6 - 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**)

### Who is **NOT** eligible to apply for this bursary?

- Experienced consultants i.e. more than 5 years in post
- Those who have previously undertaken a major research project in epidemiology or held a major research grant (this excludes acting as a local investigator in a multicentre trial) by the closing date for applications
- Those with university or joint NHS/Academic appointments by the closing date for applications
- Those who have 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 scientific quality of the application, the justification for the study being carried out through the 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 a sole criterion.

Closing date for initial application is 16th June 2005.

We would be grateful if consultants could make junior staff aware of this application request for the 2005/06 Sir Peter Tizard 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](mailto:bpsu@rcpch.ac.uk).

## Vacancy on BPSU Executive

Since the December request for applicants to replace Dr Gabriel Laing on the BPSU Executive a second vacancy has arisen. This vacancy is to replace Dr Hugh Davies, who due to commitments with COREC and his Trust is no longer able to attend BPSU meetings. Hugh's advice especially in the area of ethics and consent has been invaluable to the committee and we hope to continue to call upon his services in this field in the future. In the Spring College Newsletter pack there is the appropriate application form for anyone interested in sitting on the BPSU Executive. The committee meets five to six times a year and under the chairmanship of Professor Mike Preece is very active in developing the work of the BPSU. We are inviting applications from consultant paediatricians in good standing with the College. Current experience of general or community paediatrics would be an advantage but applications from other disciplines will be considered. Experience of research design, carrying out and reporting research is required, together with an understanding of epidemiological principles. Enthusiasm and a willingness to contribute to the activities of the BPSU is essential.

If you are interested in finding out more please contact Richard Lynn, Scientific Coordinator on Tel: 020 7307 5671 or E-mail: [bpsu@rcpch.ac.uk](mailto:bpsu@rcpch.ac.uk). Application forms are available from Mr David Ennis, Head of Committees, on E-mail: [david.ennis@rcpch.ac.uk](mailto:david.ennis@rcpch.ac.uk).

## Study News

Dr Pat Tookey reports on the national surveillance of **HIV/AIDS** which has had its extension request approved for a further year: 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 system, is administered at ICH under the auspices of the Royal College of Obstetricians and Gynaecologists. Laboratory reports to HPA, 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.

6261 children had been reported to the National Study of HIV in Pregnancy in Childhood (NSHPC) by the end of 2004, nearly 5885 of whom (94%) were born to HIV infected women (Table 1). Most of the remaining 376 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 2004**

Region of first report	Infected	Intermediate	Uninfected	Total Reported
London	<b>797</b>	606	1895	<b>3298</b>
Rest of England	<b>342</b>	399	780	<b>1521</b>
Scotland	<b>54</b>	46	215	<b>315</b>
Wales and NI	<b>16</b>	20	24	<b>60</b>
Republic of Ireland	<b>68</b>	196	427	<b>691</b>
<b>Total</b>	<b>1277</b>	<b>1267</b>	<b>3341</b>	<b>5885</b>

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, the long term effects of maternal treatment during pregnancy on children and developments in the management of infected children.

Dr Pat Tookey also reports on the **Neonatal Herpes Simplex Virus** study: Now into its second year following an extension approval by the BPSU Executive this study was commissioned by the National Screening Committee. The study aims to estimate current birth incidence in the British Isles; explore presentation and management of diagnosed cases; assess morbidity and mortality through a one year follow up; compare findings with the 1986-91 BPSU cohort and with INoPSU studies currently being undertaken in Australia and Canada. On re-visiting this condition it was expected that a small rise in birth prevalence would be reported since the original study undertaken in 1986 and between 10 and 25 cases were expected annually. For 2004 about 60 reports were made through the BPSU, and about a third of these have so far been confirmed, which is greater than the number of confirmed reports in any of the 5 years when Neonatal HSV was previously under surveillance (1986-1991), and at the upper end of the range we expected.

We would like to thank everyone who has reported cases of HIV/AIDS and neonatal HSV and returned our forms; we really appreciate your continuing support and cooperation. Both studies have ethics approval from London MREC and have had their BPSU extension requests recently approved for a further year.

Contact: Dr Pat Tookey, Centre for Paediatric Epidemiology and Biostatistics, Institute of Child Health, 30 Guilford Street, London WC1N 1EH. Tel: 020 7829 8686. E-mail: [p.tookey@ich.ucl.ac.uk](mailto:p.tookey@ich.ucl.ac.uk)

**New Studies:** Studies on **childhood scleroderma**, principal investigators Dr Ariane Herrick and Dr Eileen Baildam, and **MRSA**, principal investigators Dr Alan Johnstone and Dr Mike Sharland, have been approved. These will commence once MREC approval has been received.

**RCPCH Scientific meeting 2005:** The BPSU will once again be prominent on the Research Division stand in Central Hall, York University Campus. If you would like to discuss potential projects or to pick up some literature please come along. Four BPSU studies are being presented at York. The severe complications of varicella and the PIND studies are being presented during the Monday and Wednesday plenary. Group presentations on severe hyperbilirubinaemia and HIV/AIDS are also taking place during the week. If you are unable to attend the sessions but would like a copy of the abstracts please contact the BPSU office, (E-mail: [bpsu@rcpch.ac.uk](mailto:bpsu@rcpch.ac.uk)).

## New National Surveillance Units

Two new national surveillance units have recently been launched. The **British Paediatric Orphan Lung Disease (BPOLD)** register was launched this January. BPOLD aims to establish a registry of nine rare lung diseases in children in the UK. The registry, funded by the British Paediatric Respiratory Society and the Cohen Zimble Family Trust, will provide epidemiological data on the prevalence and incidence of individual rare lung diseases and inform research projects which increase our understanding of these diseases and ultimately improve treatment strategies for these children. Reporting will be via the internet rather than via a monthly report card. For further information visit the BPOLD website at [www.bpold.co.uk](http://www.bpold.co.uk).

The **UK Obstetric Surveillance System (UKOSS)** was launched in February, the aim of UKOSS is to develop a UK-wide Obstetric Surveillance System in order to describe the epidemiology of a variety of uncommon disorders of pregnancy. The unit is run out of the National Perinatal Epidemiology Unit (NPEU) in collaboration with the Royal College of Obstetricians and Gynaecologists. Surveillance will follow the BPSU methodology of sending out a monthly report card with a menu of conditions. Unlike the BPSU all the data will be collected at the NPEU for analysis. Six conditions are on the first cards and these include TB in pregnancy, eclampsia and amniotic fluid embolisms. For further information visit the UKOSS website at [www.npeu.ox.ac.uk/UKOSS/](http://www.npeu.ox.ac.uk/UKOSS/).

## Monthly Analysis

As you will see from **Table 2** the response rate for the six months from June to November is only averaging 88.7%. The response rate continues to be much lower than expected. Northern Ireland has taken over from Wales as the highest-ranking region. Regionally within England, Trent and East Anglia have joined the London area in consistently having a response rate below 90%. We 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.

**TABLE 2 - % RESPONSE RATE**  
June - November 2004

Region	% rtnd	Rank (April-Sept 2004)
North	90.1	10 (13)
Yorks	91.6	5 (2)
Trent	87.7	15 (14)
EAnagl	88.5	13(12)
NWT	83.8	19 (19)
NET	80.6	20 (20)
SET	87.5	16 (15)
SWT	87.0	17 (16)
Wessex	90.5	7 (5)
Oxford	92.0	4 (6)
SWest	90.0	11 (10)
WMids	90.3	8 (11)
Mersey	90.6	6 (4)
NWest	92.3	3 (8)
Welsh	93.4	2 (1)
NScot	88.8	12 (9)
SScot	90.2	9 (18)
WScot	88.3	14(7)
NIre	93.6	1 (3)
RIre	85.8	18 (17)
Average	88.7	

**TABLE 3 - ALL CASES REPORTED AND FOLLOW-UPS TO 01/12/2004**

Condition	Started	I VALID					NYK	as % of total		
		I	IIa	IIb	III	Ttl		I	II	III
HIV/AIDS	1986	3205	464	517	328	4514	71	22	7	
CR	1990	70	26	50	3	149	47	51	2	
PIND	1997	1114	206	491	29	1861	60	37	3	
Se. Hyperbil	2003	85	13	33	19	150	57	31	13	
LCH	2003	46	20	26	29	121	38	38	24	
TB	2003	356	51	71	65	543	66	22	12	
NNH	2004	23	8	14	19	64	36	34	30	
MCADD	2004	43	7	6	13	69	62	19	19	
Thyrotoxicosis	2004	29	2	13	44	88	33	17	50	
Non type 1 diabetes	2004	31	2	0	57	90	34	3	63	
Total		5002	699	1221	627	7549	66	25	9	

I	= confirmed/already known	IIa	= duplicate
IIb	= reporting error or revised diagnosis	III	= status not yet reported to BPSU by investigator
AIDS/HIV	- Acquired Immunodeficiency Syndrome / Human Immunodeficiency Virus	TB	- Tuberculosis in Childhood
CR	- Congenital Rubella	NNH	- Neonatal Herpes Simplex Virus infection
PIND	- Progressive Intellectual Neurological Degeneration	MCADD	- Medium chain Acyl CoA dehydrogenase deficiency
Se. Hyperbil	- Severe hyperbilirubinaemia in the newborn		
LCH	- Langerhans cell histiocytosis		

**ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED**