



### 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

#### Study News

Non-type 1 diabetes in children up to the age of 17 years

Early onset eating disorders (EOED) in children under 13 years of age

HIV in childhood study extension

Thyrotoxicosis in childhood study ends

#### In-House

BPSU Annual Report 2004-2005

BPSU and the Patient Information Advisory Group (PIAG).

#### Recent Publications

Listing

**Orange Cards Response Rate - We Need Your Help!**

Regional and Study tables

### Required - a new chair to head the BPSU Executive

The current chair of the BPSU Executive Committee, Professor Mike Preece, will be stepping down next year after five years in the post. Mike 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 and latterly Dr Chris Verity. The BPSU is grateful to Mike for all his hard work over the years in particular 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 will direct the future development of the Unit; represent it to the Department of Health and present 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 enters its 20<sup>th</sup> year of surveillance. 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 have been sent out with the September College newsletter pack. Alternatively please contact Mr David Ennis at the membership office (Tel 020 7307 5645). For further information on the post please contact Professor Mike Preece, BPSU Chair (Tel: 020 7405 9200 #5257) or Richard Lynn, BPSU Scientific Coordinator (Tel: 020 7323 7911).

### Happy 20th birthday to BPSU!

In June 2006 the BPSU will be turning 20 years old. Various activities will take place in 2006 to celebrate this momentous occasion, including a celebratory conference on Tuesday 30 May 2006 at the Institute of Child Health, London – **mark your diaries now!** The conference will provide an opportunity for college members, the BPSU Executive Committee, INoPSU (International Network of Paediatric Surveillance Units) members, representatives from other national surveillance units and patient support groups to come together and reflect upon 20 years of surveillance undertaken by the BPSU. The conference will consider the role of paediatric surveillance to date as well as possibilities for the future. Guest speakers have been selected to represent the successful surveillance activities of the unit over the past 20 years. A dinner will also be held in celebration of the achievements of the BPSU. The BPSU will also be hosting the fourth INoPSU conference in London in 2006. Watch this space for further details.

If you would like to be on our mailing list for details of the BPSU 20<sup>th</sup> Anniversary Conference please contact [Jennifer.Ellinghaus@rcpch.ac.uk](mailto:Jennifer.Ellinghaus@rcpch.ac.uk) (Tel: 020 7323 7912).

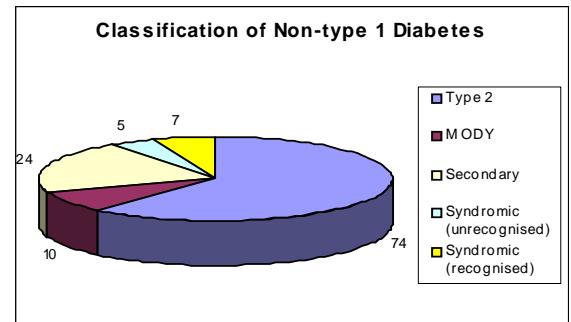
### Sir Peter Tizard research bursary - winner announced!

The BPSU received 5 bursary applications this year, all of a high standard. After a lengthy discussion the Committee awarded the bursary to Dr Yim-Yee Matthews, an SpR from Walsgrave Hospital. Dr Matthews wishes to study the epidemiology of Childhood Idiopathic Intracranial Hypertension (IIH). 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 BPSU Executive Committee will now work with Dr Matthews to develop the appropriate methodology to undertake this study, with the intention of commencing surveillance in 2006. 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.

## Study News

**Study Updates:** The **Non-type 1 diabetes in children up to the age of 17 years** study is now into its 11 month of surveillance. The project is being run out of the RCPCH Research Unit under the guidance of Linda Haines with the support of Dr Julian Shields (Bristol) and Dr Tim Barrett (Birmingham). The study has 4 main aims:

- 1) to ascertain the incidence of all non-type 1 diabetes in children up to the age of 17,
- 2) to ascertain the relative incidence of obesity-related type 2 diabetes, familial type 2 diabetes and other syndromic diabetes
- 3) to establish the clinical features at presentation that distinguishes type 2 diabetes from syndromic and type 1 diabetes
- 4) to determine how type 2 diabetes is being diagnosed and treated by paediatricians.



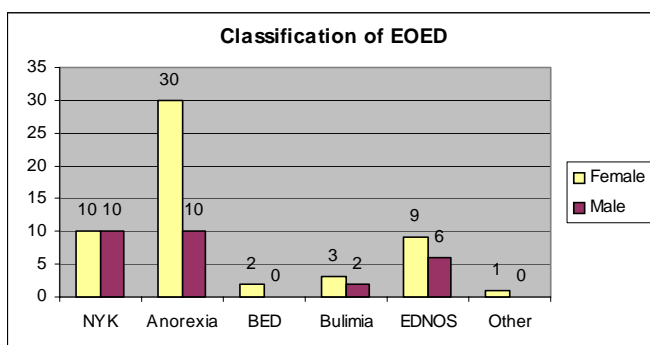
To date 222 cases have been reported. 120 have been confirmed as non-type 1 diabetes, whilst we await details of the remainder. Paediatricians have reported 92 of the cases whilst diabetic nurse specialists who are also receiving their own report card have reported 28 cases. Cases of type 2 diabetes are the most commonly reported (61%) followed by diabetes secondary to another condition (20%). Figure 1 shows the different categories of diagnosis amongst the 120 confirmed cases.

Contact: Mrs Linda Haines on Tel: 020 7232 7963 E-mail: [Linda.Haines@rcpch.ac.uk](mailto:Linda.Haines@rcpch.ac.uk)

Surveillance of **Early onset eating disorders (EOED) in children under 13 years of age** commenced in March of this year. This study is being carried out in collaboration with the Research Unit -Royal College of Psychiatrists and, as for the diabetes study; a dual reporting system has been set up, in this case with paediatricians and over 800 child & adolescent psychiatrists. The primary aims are:

- 1) to estimate the incidence of EOED in children
- 2) to describe the family history
- 3) to describe the range of clinical features at presentation including other psychiatric illness
- 4) to delineate patterns of professional involvement (paediatric and child mental health)
- 5) to characterise the range of acute medical complications experienced by children with EOEDs and
- 6) to identify the range of therapeutic interventions used in management.

To date we have had 186 reports, 53 reported by paediatricians and 133 reported by psychiatrists. Of the 133 questionnaires returned so far and after errors (29) and duplicates (19) are discounted 82 have fitted the case criteria. The level of card reporting by the psychiatrists has been impressive, over 50%, with a high percentage of positive case reports.



The median age of reported cases so far is 11¼ years, the youngest being a male of 5¾ years. Interestingly 33% (28) of reported cases are boys, suggesting quite a different demographic profile from that found in adolescent onset cases. All but three cases are ethnically white. The standard deviation score for BMI ranged between -4.3 and 2.75 with a median of -1.32. From our initial categorisation, 30 fit the definition for anorexia nervosa, 5 for bulimia nervosa, 2 for binge eating disorder (BED), 25 for eating disorder not specified (EDNOS) and one other. 20 further cases will be categorised once further data has been collected (Figure 2).

This study is proving that surveillance of psychological disorders in children is possible and mirrors what has been shown through the Australian Paediatric Surveillance Unit. It is hoped that once all the data has been analysed a comparison can be made with data from the other national units that have undertaken surveillance of this condition.

**Case definition for reporting** is - Any child aged from five to 13, **NEWLY** diagnosed with early onset eating disorder which is defined as **TWO OR MORE OF THE FOLLOWING:**

- |  |  |
|--|--|
| 1) weight loss or failure to gain weight during a period of expected growth, not due to any identifiable organic cause | 5) self induced vomiting                                     |
| 2) determined food avoidance   | 6) excessive exercising                                      |
| 3) fear of weight gain   | 7) recurrent episodes of binge eating or abuse of laxatives. |
| 4) preoccupation with body weight or energy intake   |  |

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## Study News Continued...

**Study extensions:** The BPSU Executive has approved surveillance for **HIV in childhood** for a further three years until March 2008. Paediatric reporting through the BPSU continues to play a central role in the paediatric and obstetric surveillance of HIV in the UK and Ireland, carried out at the Institute of Child Health (ICH) on behalf of a group including the Health Protection Agency (HPA) and the Health Protection Scotland (HPS). 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 HPA and to HPS are a third source of information, and data from all these sources are combined as the National Study of HIV in Pregnancy and Childhood (NSHPC).

All children with HIV infection should be reported, as well as all infants born to HIV infected women, regardless of their own infection status. About 6600 children had been reported to the NSHPC by the end of June 2005, of whom about half were born since the beginning of 2002.

Although there are more reports of HIV and AIDS than for other conditions on the orange card, paediatric HIV and exposure to maternal infection is still relatively rare. While management of infected children is concentrated in a few specialist centres, HIV infected children and infants born to HIV infected women are being identified and reported from all parts of the UK and Ireland, and from areas which have rarely or never seen cases in the past. The continuing co-operation of paediatricians in active national surveillance is extremely valuable and gratefully acknowledged by Dr Pat Tookey and the rest of the NSHPC team.

National HIV surveillance data are published regularly on the HPA and HPS websites. A quarterly Newsletter is produced by the NSHPC team, as well as a regularly updated powerpoint presentation; both can be obtained by email from the NSHPC.

London MREC reviewed and approved the NSHPC and associated paediatric HIV studies in 2004.

Contact: Ms J Masters or Dr P Tookey, Tel: 020 7829 8686 E-mail: [nshpc@ich.ucl.ac.uk](mailto:nshpc@ich.ucl.ac.uk)

**Study completion:** Surveillance of **thyrotoxicosis in childhood** will be ending in September 2005. This brings to an end 13 months the first surveillance study funded by the Sir Peter Tizard bursary.

The recipient Dr Scott Williamson stated *“this has been a very valuable experience for me. It has improved my understanding of epidemiology and the problems associated with data collection using surveillance techniques. The data we have collected will go a long way to answer questions on the incidence of Graves’ disease and other causes of thyrotoxicosis, and is giving valuable information on presenting features and management of this condition. Thanks to all those who have reported cases and completed the questionnaire. The next few months will see us tidying up the data reading for presentation and publication”*.

To date 203 cases have been reported of which 109 have been confirmed. Of these 36 were males and 73 females. The median age at diagnosis is 12.9 years. Further preliminary data are available in the recently published annual report.

Contact: Dr Scott Williamson, University of Dundee. Tel: 01382 660111 E-mail: [scott.williamson@tuht.scot.nhs.uk](mailto:scott.williamson@tuht.scot.nhs.uk)

## In-house

The BPSU **19th Annual Report 2004-2005** has recently been published. College members will receive their copies with the Autumn College Newsletter. The report contains feedback on the current projects underway, includes a detailed section on international activities and the yearly Unit analysis. The willingness of paediatricians to continue to contribute to the system is reflected in an average monthly response rate of 92% which has led to over 1800 case reports, one of the highest ever for a single year. Even so, case ascertainment is an area the BPSU is acutely concerned with and we encourage all to report cases even if they are not sure they fit the case definition or even if they feel a colleague may have already done so. This, with the increased use of alternate sources of ascertainment, will improve still further the number of cases reported. And remember, it is also important that you return the orange card if you have nothing to report.

A limited number of additional copies are available from the BPSU office. Alternatively the report can be viewed on the BPSU website at <http://bpsu.inopsu.com>. To increase circulation of the report we encourage you to place this link on your hospital website.

For some time now the BPSU has been involved in discussions with the **Patient Information Advisory Group (PIAG)**. PIAG was established to provide advice on issues of national significance involving the use of patient information and to oversee arrangements created under Section 60 of the Health and Social Care Act 2001. Membership is drawn from patient groups, healthcare professionals and regulatory bodies (<http://www.advisorybodies.doh.gov.uk/piag/>). Research that requires the collection of identifiable data without consent now needs PIAG approval as well as approval from an MREC. The BPSU methodology and the studies currently on the card have been given approval by PIAG and we will be liaising with PIAG over the appropriateness of future BPSU studies. For those of you who regularly report cases you will have noted that the level of identifiers sought by the investigators has been kept to an absolute minimum, only enough to allow de-duplication of case reports. It is therefore important for you to keep a record of the reported case on the clinicians tear off section of the orange card.

## Recent Publications

If you would like a hardcopy of these or any others arising from BPSU studies please contact the BPSU office, the authors directly or check out the BPSU website at <http://bpsu.inopsu.com/complete.htm>.

1. Childhood hemolytic uremic syndrome, United Kingdom and Ireland. Lynn RM, O'Brien SJ, Taylor CM, Adak GK, Chart H, Cheasty T, Coia JE, Gillespie IA, Locking ME, Reilly WJ, Smith HR, Waters A, Willshaw GA. *Emerg Infect Dis.* 2005;**11**(4):590-6.
2. Human herpesviruses-6 and -7 each cause significant neurological morbidity in Britain and Ireland. Ward KN, Andrews NJ, Verity CM, Miller E, Ross EM. *Arch Dis Child.* 2005;**90**:619-62233.
3. Unexpected Occasional Persistence of High levels of HHV-6DNA in Sear: Detection of Variants A and B. Ward KN, Thiruchelvam AD, Couto-Parada X. *Journ Med Virol* 2005. **76**:563-570.
4. Severe food-allergic reactions in children across the UK and Ireland, 1998-2000. Colver AF, Nevantaus H, Macdougall CF Cant AJ. *Acta Paediatrica* 2005; **94**: 689-695.
5. Subdural haematoma and effusion in infancy: An epidemiological study. C J Hobbs, A Childs, J Wynne, J Livingston, A Seal *Arch Dis Child* 2005; 90: 952-955.

## Orange Cards Response Rate – We Need Your Help!

As you will see from **Table 1** the response rate for the orange card is hovering around 88%. Wales continues to rank first with a response rate of 95.4%. The response rate for the return of questionnaire remains high at 92% (**Table 2**). 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, even if they are a couple of months late.

**TABLE 1 - % RESPONSE RATE**  
Jan –June 05

Region	% rtd	Rank (Oct-Mar 05)
North	88.4	9 (14)
Yorks	93.4	2 (2)
Trent	88.2	10 (13)
EAngl	88.2	10(8)
NWT	81.7	19 (19)
NET	81.6	20 (20)
SET	85.9	16 (15)
SWT	81.7	18 (18)
Wessex	92.0	5 (7)
Oxford	90.4	8 (3)
SWest	88.1	12 (12)
WMids	88.0	13 (11)
Mersey	86.2	15 (17)
NWest	91.3	6 (5)
Wales	95.4	1 (1)
NScot	93.3	3 (9)
SScot	86.2	14 (10)
WScot	92.8	4(6)
Nlre	90.5	7 (4)
Rlre	82.3	17 (16)
<b>Total</b>	<b>87.8</b>	

**TABLE 2 - ALL CASES REPORTED AND FOLLOW-UPS TO 01/09/2005**

Condition	Started						as % of total		
		I VALID	II INVALID		NYK		I	II	III
HIV	1986	3570	497	528	272	4867	73	21	6
CR	1990	71	28	52	3	154	46	52	2
PIND	1997	1123	221	519	78	1941	58	38	4
Se. Hyperbil	2003	107	21	46	2	176	61	38	1
LCH	2003	79	25	27	28	160	50	33	18
NNH	2004	40	9	15	23	87	46	28	26
MCADD	2004	59	14	7	24	114	61	18	21
Thyrotoxicosis	2004	110	8	27	59	204	54	17	29
Non type 1 diabetes	2004	55	1	39	108	203	27	20	53
EOED	2005	32	0	11	10	53	60	21	19
Scleroderma	2005	2	0	0	3	5	40	0	60
<b>Total</b>		<b>5262</b>	<b>824</b>	<b>1244</b>	<b>621</b>	<b>7949</b>	<b>66</b>	<b>26</b>	<b>8</b>

I = confirmed/already known  
Iib = reporting error or revised diagnosis

IIa = duplicate  
III = status not yet reported to BPSU by investigator

HIV Human Immunodeficiency Virus -  
In childhood -  
CR - Congenital Rubella  
PIND - Progressive Intellectual  
Neurological Degeneration  
Se. Hyperbil - Severe hyperbilirubinaemia in the newborn  
aureus.  
LCH - Langerhans cell histiocytosis

NNH - Neonatal Herpes Simplex Virus infection  
MCADD Medium chain Acyl CoA dehydrogenase  
deficiency  
EOED - Early onset eating disorders in children less than  
13 years of age  
MRSA methicillin-resistant Staphylococcus

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED