



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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Surveillance of thyrotoxicosis commences in September 2004

The first survey funded by the Sir Peter Tizard bursary commences this month. Dr Scott Williamson is Principal Investigator for this 13 month study which will be based at Ninewells Hospital Dundee. The Scottish MREC has approved the study protocol.

One of the reasons for choosing this study as the Sir Peter Tizard Bursary was because the incidence of childhood thyrotoxicosis in the UK and Ireland is unknown. Studies in other countries show variable and changing incidences of Graves' disease (the commonest form of thyrotoxicosis) in childhood, but its cause remains unknown. Dr Williamson proposes to study the epidemiology of Graves' disease in childhood with particular emphasis on its incidence, the presenting features and the initial management of the condition, in order to define this group of children. This will provide a basis for any comparisons of incidence in the future, and will provide a useful data for future clinical trials. A consensus towards the best practice in initial management of the disease may be approached thereafter. As the presenting features of Graves' disease can sometimes overlap with those of other forms of thyrotoxicosis, which are likely to have a much lower incidence, the epidemiology of these will also be covered by this study.

The **case definition** is any child up to 16 years of age who in the opinion of the notifying paediatrician has thyrotoxicosis based on history, clinical and laboratory findings.

Please report any new or suspected case you may have seen in the last month on the BPSU orange card, irrespective of reason for referral or whether or not you are the main clinician responsible for the patient. Paediatricians who have reported a case that meets the case definition will be sent a questionnaire seeking demographic details and clinical features.

The British Thyroid Foundation, who support this survey, can give advice to parents and patients and can be contacted at PO Box 97, Clifford, Wetherby LS23 6XD Tel: 0870 770 7933 or <http://www.btf-thyroid.org>

The white protocol card with further details on the study is enclosed with this mailing and is also available at <http://bpsu.inopsu.com/current.htm#Thyro> A flyer which can be used to provide information about the project to clinicians and public can also be printed off from this site.

Dr Williamson stated to the bulletin *"I am honoured to be the first recipient of the Sir Peter Tizard bursary and I hope the study will shed new light on our understanding of childhood thyrotoxicosis in the UK and Ireland"*.

If you need any advice regarding the eligibility of a particular case for inclusion in the study, please contact: Dr Scott Williamson, Paediatric Academic Fellow, Maternal and Child Health Sciences, University of Dundee, Dundee, DD1 9SY Tel: 01382 660111 ext 33263
E-mail: s.y.williamson@dundee.ac.uk

BPSU Announces 2004/05 Sir Peter Tizard Bursary winner

The call for applications for the Sir Peter Tizard Bursary received a good response once again. The BPSU Executive considered 15 applications, all of a very high standard. After some deliberation, the winner was Dr Shamez Ladhani, Specialist Registrar from the Royal London Hospital. Dr Ladhani wishes to study the epidemiology of paediatric malaria in order to determine clinical features, management and outcome.

Dr Ladhani is currently developing the survey methodology and aims to commence surveillance in 2005. Many thanks to all those who applied this year.

Non-Type 1 diabetes survey to commence

A one-year surveillance of non-Type 1 diabetes will commence this Autumn. This study is being undertaken in a response to the growing body of evidence that the epidemic of obesity in UK children has resulted in a rising incidence of Type 2 diabetes. Type 2 diabetes is associated with greatly increased morbidity and mortality in adults and the prognosis is likely to be worse in those developing the disease at an early age. It is important to establish the incidence of Type 2 diabetes in UK children, to identify the proportion of cases attendant on obesity and to examine associated morbidity. As Type 2 diabetes is an evolving clinical problem for paediatricians it can be difficult to distinguish from both classical Type 1 and syndromic diabetes.

Run by RCPCH research division in collaboration with Dr Julian Shield (Bristol Children's Hospital) and Dr Tim Barrett, (Birmingham Children's Hospital) the study aims to identify a) the incidence of all non-Type 1 diabetes in children 0 - 16 years; b) the relative incidence of obesity-related Type 2 diabetes, familial Type 2 diabetes and other syndromic diabetes; c) the clinical features at presentation that distinguish Type 2 diabetes from syndromic and Type 1 diabetes in childhood; d) how Type 2 diabetes being diagnosed and treated by paediatricians; e) the short-term morbidity associated with obesity-related diabetes.

The **case definition** is "Any new diagnosis of non-Type 1 diabetes (suspected or confirmed) in a patient 0-16 years of age (i.e. up to but not including their 17th birthday). NB These may not be new cases of diabetes, but newly recognised as atypical for Type 1." Reported cases will be followed up one year later to confirm the diagnosis of non-Type 1.

The study has been funded by Diabetes UK and approval has been sought from South West MREC. Further details along with the protocol card will be supplied in the coming weeks. Free information on all forms of diabetes is available to the public from Diabetes UK, 10 Parkway, London NW1 7AA Tel: 020 7424 1000, www.diabetes.org.uk.

For more information please contact Mrs Linda Haines, Principal Research Officer, RCPCH, 50 Hallam Street London W1W 6DE. Tel 020 7 3075673 or visit <http://bpsu.inopsu.com/current.htm#NTD>

Study News

Dr Stephen Teo reports on the progress of the **Childhood tuberculosis (TB)** study: "This study commenced in December 2003 and is due for completion in December 2004. We have thus far received 160 reports which have met the case definitions. Most cases have been in England. While it seems that with areas outside London account for more than Greater London, (Table 1), this may change as further data are gathered. There have been cases across all age groups with no particular trend at this stage (Table 2). So far there have been 128 cases of pulmonary TB, i.e. with parenchymal changes visible on chest X-ray, hilar lymphadenopathy and/or pleural disease. We would like to thank you for taking the time to return the questionnaires. For those who have yet to return their questionnaire could we encourage you to do so."

Table 1 TB Cases by region and gender as of Sept 2004 **Table 2** TB cases by age and gender as of Sept 04

	Female	Male	NK	Total
Unknown	1			1
England not London	47	40		87
London	28	27	1	56
Northern Ireland	1	2		3
Republic of Ireland	2	1		3
Scotland	3	1		4
Wales	4	2		6
Total	86	73	1	160

Age (years)		< 3	4 - 7	8 - 11	12 - 15	Total
No of cases	Male	22	22	16	13	73
	Female	22	17	17	31	87
Total		44	39	33	44	160

Contact: Dr. Delane Shingadia. Tel: 0207 377 7000 ext 3368, E-mail d.v.shingadia@qmul.ac.uk

Study extensions: The BPSU's commitment to monitoring cases of **congenital rubella** was re-affirmed with the extension of this study for a further year. Dr Pat Tookey reviews the study to date. "National surveillance (England, Scotland and Wales) of congenital rubella began in 1971 with passive reporting. After the rubella vaccination programme was implemented, there was a dramatic decline in the number of cases from an average 50 births and 740 terminations a year in 1971-75 to 20 births and 55 terminations a year in 1986-90. Active surveillance was needed to monitor cases at this low level, and congenital rubella was put on the orange card in 1990. BPSU reports from Ireland are also followed up, but not usually included in published figures.

Ten confirmed congenital rubella births in the UK between 1999 and 2003 have been reported through the BPSU. Although six cases occurred in babies whose mothers acquired infection outside the UK, four infants were born to women whose infection occurred in the UK^(1,2,3). Rubella continues to circulate in many parts of the world and the decline in MMR uptake rates in the UK means that infection could once again start to circulate here. Awareness of rubella infection and congenital rubella among paediatricians, and health professionals looking after pregnant women must be maintained. Continued surveillance of congenital rubella is vital.

There were no reports of congenitally infected infants born in 2002, and so far there have been two for infants born in 2003 and none for 2004. The ten infants reported between 1999 and 2003 included six born to women who acquired infection in their countries of origin (Bangladesh, Pakistan, Sri Lanka, Nigeria, Zambia and Sudan). Another infant was epidemiologically linked to an outbreak of infection in Greece, although the maternal infection was acquired in Scotland⁽⁴⁾. Two of the ten were born to Asian women who came to the UK as young adults and acquired infection here.

The BPSU has proved to be a rapid and effective reporting system for congenital rubella and was particularly quick to identify the increase in cases in 1996 when all but two of the BPSU reports were made within two months of the infant's birth⁽⁵⁾. Although prospectively recognised maternal infections in pregnancy are reported through the Health Protection Agency, the majority of maternal infections resulting in live births of congenitally infected infants are not recognised antenatally but only retrospectively diagnosed. Few children with isolated hearing loss due to congenital infection have been reported in recent years (any such children would probably remain undiagnosed as they have vaccine-induced antibodies following MMR at 13 months). However, this may change with the implementation of routine neonatal hearing screening. It is obviously important to take such changes into account when looking at reporting trends."

1. Tookey P. Congenital rubella: down but not out (letter). *Lancet* 2002; **360**: 803
2. Rahi J, Adams G, Russell-Eggitt I, Tookey P. Epidemiological surveillance of rubella must continue (letter). *BMJ* 2001; **323**: 112
3. Tookey P. Surveillance Report: Rubella in England, Scotland and Wales. *Eurosurveillance* Monthly 9 (4) April 2004 21-22; accessed 10 May 2004. <http://www.eurosurveillance.org/em/v09n04/0904-231.asp>
4. Tookey P, Molyneaux P, Helms P. UK case of congenital rubella can be linked to Greek cases (letter). *BMJ* 2000; **321**: 766-6
5. Tookey PA, Peckham CS. Surveillance of congenital rubella in Great Britain, 1971-96. *BMJ* 1999; **318**: 769-70

Surveillance completed: The survey of **congenital toxoplasmosis** (principal investigator Dr Ruth Gilbert, ICH London), which commenced in July 2002, has now ended after 25 months of surveillance. To date 41 cases have been reported of which 12 have so far been confirmed. There are still several outstanding questionnaires awaited and we would be grateful if this could be returned to the investigators as swiftly as possible. If you have any cases seen during the study period that have gone unreported please could you let us know. On behalf of the investigators can we thank all those who reported cases and contributed data to this important study.

Publications

The BPSU **18th Annual Report 2003-2004** has recently been published. College members will receive their copies with the College newsletter that should be reaching you shortly. A limited number of additional copies are available from the BPSU office, alternatively the report can be viewed on the College's website at <http://www.rcpch.ac.uk/publications/bpsu.html>. We hope you will find this an interesting read and worthy of storage on your overcrowded bookshelves. Alternatively do feel free to circulate it within the department or pass it on to the hospital library.

This year's report contains feedback on the 11 studies undertaken over the past year, as well as 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 900 confirmed 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 would encourage all to report cases even if they are not sure they fitted the case definition and 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. On behalf of the Unit and the investigators we thank you for this magnificent response.

The BPSU has also produce **two information leaflets**, which we intend to widely distribute. The first is aimed at clinicians and professionals who wish to know more on the BPSU activities. This will be circulated in forthcoming BPSU mailings and will also be made available to the paediatric specialty groups for distribution among their non-RCPCH membership.

Our second and perhaps the more important leaflet (right) is that devised for circulation to the general public. This leaflet, approved by all the BPSU's parent bodies, the RCPCH, HPA and the ICH London, has been produced following wide consultation, including our colleagues at Contact a Family, the patient and carers committee representatives, and public information advisers from GOS. It is our intention to make this leaflet, which outlines the aims and objectives of the BPSU, available within paediatric departments across the country. Initially the leaflet is being circulated through the electronic bulletin produced by Contact a Family. Both leaflets can be viewed and downloaded as a pdf file from the Colleges website at <http://www.rcpch.ac.uk/publications/bpsu.html> and hardcopies are available from the BPSU office.

A copy of both leaflets will be included in a forthcoming orange card mailing and we would encourage you all to request further copies in order to make them available within your department. It would also be helpful if you could encourage your Trust/hospital Webmaster to upload the leaflets onto their websites, along with a hyperlink to the BPSU web page (<http://bpsu.inopsu.com>).

British Paediatric Surveillance Unit

Investigating rare
childhood conditions for
the future health
of the nation



A public
Information leaflet

Contact a Family

For the last 25 years Contact a Family has helped to put parents of disabled children in touch with one another, usually through a local or national support group. For families affected by a very rare disorder, there may be no suitable group. Contact a Family helpline will then try to link a family with another affected by the same condition. This process has often taken many months and even years, and in some cases no match has been found.

A new web-based linking service from Contact a Family is about to change things. On 1 July 2004, we saw the launch of www.makingcontact.org. This will enable families to link with one another across the world electronically. By logging on families can see if there is anyone else affected by the same condition that is looking for contact with others. It will be possible to contact other dads or mums or look for people in your area. Disabled adults may also use the service to contact one another. Registration, so that others can find the families, is free. The information given to Contact a Family will be held in the strictest confidence.

There is no charge to register details with the linking service however, if a family wishes to start to correspond with another family, Contact a Family will ask for credit card details and there will be a charge of £5 per year. This is partly to deter anyone who may cause a nuisance from registering and to try and ensure that children do not register, as the discussions between individuals are not monitored. Families who do not have access to the Internet, or who could not afford the £5 fee may register free of charge via the helpline (0808 808 3555, between 10am & 4pm Monday to Friday).

Monthly Analysis

Table 3 - % RESPONSE RATE

Jan-June 04	% retd	Rank (Nov-Apr 04)
North	89.6	10 (5)
Yorks	91.4	3 (2)
Trent	88.1	15 (7)
EAngl	88.5	13 (14)
NWT	82.6	19 (16)
NET	76.0	20 (20)
SET	86.0	16 (15)
SWT	88.9	11 (19)
Wessex	90.3	8(11)
Oxford	89.4	14 (13)
SWest	83.7	12 (8)
WMids	84.6	9 (4)
Mersey	87.1	4 (6)
NWest	86.1	6 (10)
Welsh	90.0	1 (1)
NScot	85.9	2 (12)
SScot	84.5	18 (17)
WScot	90.1	7 (9)
NIre	90.7	5 (3)
RIre	83.5	17 (18)
Total	88.3	

Table 4 - ALL CASES REPORTED AND FOLLOW-UPS TO 02/09/2004

Condition	Started	I					as % of total		
		VALID	INVALID		NYK				
		I	Ia	Ib	III	Ttl	I	II	III
HIV/AIDS	1986	2947	437	507	257	4148	71	23	6
CR	1990	70	26	50	1	147	48	51	1
PIND	1997	1063	200	469	51	1783	60	38	3
Con Toxo	2002	12	2	19	8	41	29	51	20
Se. Hyperbil	2003	42	5	26	20	93	45	33	22
LCH	2003	30	18	25	20	93	32	46	22
TB	2003	193	32	28	109	362	536	17	30
NNH	2004	11	51	12	12	40	28	43	30
MCADD	2004	7	1	1	12	21	33	9	58
Total		4375	726	1137	490	6728	65	28	7

I = confirmed/already known

Ib = reporting error or revised diagnosis

Ia = 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

Se. Hyperbil - Severe hyperbilirubinaemia in the newborn

LCH - Langerhans cell histiocytosis

TB - Childhood Tuberculosis

NNH - Neonatal herpes simplex virus infection

MCADD - Medium chain Acyl CoA dehydrogenase deficiency

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED