



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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Surveillance of genital herpes in children under 11 years of age to commence in April 2007

Genital herpes in prepubertal children is rare, but when it occurs it raises the question of possible sexual abuse. Paediatricians currently have very little evidence on which to base an opinion on possible mode of transmission, yet their advice is key to whether or not a child protection investigation proceeds. National guidelines are inconsistent and epidemiological evidence is weak¹.

This study will measure the incidence of genital herpes in young children in the UK and Ireland, and describe clinical, social and other features, which might point to possible modes of transmission. Although it will not be able to confirm whether sexual transmission has occurred, indicative data on any more than a handful of cases is currently not available. A national surveillance study will provide up to date population based evidence about genital herpes in children and may guide policy and practice in this difficult area.

BPSU surveillance will be undertaken for 13 months, commencing in April with the study first appearing on the orange card circulated at the end of April.

Please report any new cases seen within that month. Details of the study are included in the protocol card which has been circulated with the orange card and is also available at <http://bpsu.inopsu.com>

The **case definition** is any child age one month to ten years inclusive with typical herpetic vesicular lesions in genital or perineal area presenting as new cases to secondary care.

Paediatricians will be asked to report all possible cases first presenting to secondary care, including recurrences, which have not previously presented to secondary care. A short questionnaire will ask about associated clinical, social and demographic factors, virological confirmation of the diagnosis, and the outcome of any child protection investigation or court proceedings.

This study, which has MREC (Ref: 07/MRE02/9) and PIAG (Ref: 4-06(FT6)/2006) approval, is funded by Birmingham Children's Hospital and is being run from the Norfolk and Norwich University Hospital and the Health Protection Agency Centre for Infections in Colindale.

If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact:

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1. Reading R, Rannan-Eliya Y. Evidence for sexual transmission of genital herpes in children. *Arch. Dis. Child.* 2006 ADC Online First: 5 December 2006. <http://dx.doi.org/10.1136/adc.2005.086835>



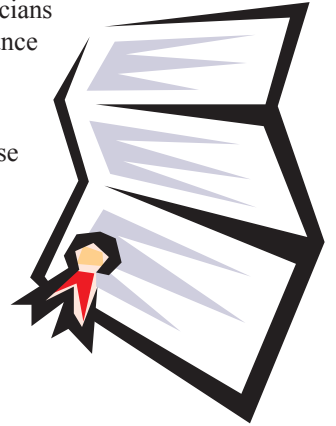
Dr Richard Reading,
Principal Investigator

Sir Peter Tizard – 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 initial application is Friday 15th June 2007.

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 or from Jennifer Ellinghaus, BPSU Research Facilitator, Tel: 020 7323 7912 or E-mail: Jennifer.Ellinghaus@rcpch.ac.uk.

Noticeboard

Commenting on the BPSU

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

Have you sent back all your **orange cards**, even if you have nothing to report?

To increase the profile of the

BPSU website

we encourage you to approach your webmaster to include the site address <http://bpsu.inopsu.com> on the links page of your institution/hospital: <http://bpsu.inopsu.com>

Are you a Consultant Paediatrician?

Not receiving the orange card? – then please contact the BPSU office and we will place you on our mailing list:

bpsu@rcpch.ac.uk
0207 323 7912

Don't forget the BPSU Workshop in April

There are a few places left so please book quickly!

Jennifer.Ellinghaus@rcpch.ac.uk

Involving the Public in Research

As previously reported, the BPSU Executive now has two patient/care representatives. Here Sue Banton (right) reports:

“Ann Seymour and I have recently been appointed as public (lay) representatives to the Executive Committee of the BPSU on behalf of the RCPCH Patient and Carers Committee replacing Carol Youngs who undertook the post for five years. Our remit is to help the BPSU to develop public involvement in its work and we are delighted to have this opportunity to share our views of involving the public in health related research.

My own experience began over 10 years ago when I was invited on to a MRC steering committee for the Hip Trip. The BPSU, through the congenital dislocation of the hip survey, helped to provide epidemiological data on this condition. At the time I was a very inexperienced member of the Trial Steering Committee, but on reflection my involvement helped to enhance the study. Through contact with the charity STEPS a parent focus group helped to formulate the psychosocial and economic questionnaires for the trial. The charity also disseminated the results to the public through a conference and article in their magazine and via their website (www.steps-charity.org.uk).

I am currently involved in an epidemiological and genetic study for clubfoot and a user led study looking at the effect that appearance and choice of a prosthesis have on a child's development. I am also a member of Involve, an organisation which promotes public involvement in NHS, Social Care and Public Health research. We believe that involving the public can only enhance the scope and relevance of the research. Members of the public can bring knowledge and experience of a particular condition or service and give a public perspective. They can help to improve the design and focus of the research, advise on the ‘best practice’ for public involvement throughout the research, advise on ethical issues and on effectively disseminating the results to the wider public.

Involving the public is part of the new national health research strategy (Best Research for Best Health, DOH, Jan 06), so consideration of public involvement should be undertaken at the proposal stage of any research study. To reflect this, the BPSU application forms will now specifically ask questions relating to public engagement and involvement.

Involving the public can take many levels from a simple consultation process to actively running the study and can involve diverse populations including carers, children and young people. Excellent information and guidance can be found on the Involve website (www.invo.org.uk) which includes downloadable guides. “Involving the public in NHS, public health, and social care research: Briefing Notes for Researchers” would be an excellent start. It is an introductory document designed for researchers with no previous experience of involving members of the public as active partners in research. We are here to assist those considering applying to the BPSU so if you wish to contact us please do so through the BPSU office.”



*Mrs Sue Banton,
BPSU Patient/Carer
Representative*



*Mrs Ann Seymour,
BPSU Patient/Carer
Representative*

Update – Surveillance of Childhood Scleroderma

Dr Anne Herrick reports on the first 18 months of the scleroderma survey: – “To date, 97 cases have been notified, and 60 questionnaires have been returned. Thirty-four questionnaires are currently outstanding. The remaining three cases were excluded for not meeting the study criteria. Of the 60 questionnaires returned, 42 valid cases have been identified. Several of the cases notified at the outset of the study were invalid because the child had presented prior to the study period. As anticipated, most of the notifications for the study are coming via the BPSU. Although we are also mailing members of the UK Systemic Sclerosis Study Group, of the British Association of Dermatologists and the British Society for Paediatric and Adolescent Rheumatology, only 13 notifications have come via these organisations, perhaps reflecting how paediatricians are more practiced than other groups in regularly reporting cases.

Of the 42 valid cases, 39 (93%) are of localised scleroderma and three (7%) are of systemic sclerosis. Sixteen have been male and 26 have been female. The median age of valid cases so far has been 10 years (range 4 to 16 years).

An important part of the study is the 12-month questionnaire, which asks for follow-up data and (if appropriate) whether a rheumatologist or dermatologist has confirmed the diagnosis. From the data obtained from the initial and 12-month questionnaires we shall obtain information not only on incidence, but also on the nature of presenting symptoms, the delay between symptom onset and diagnosis, and the types of care received.

The low number of notifications has been a little disappointing. One interpretation is that childhood scleroderma, at least linear scleroderma and systemic sclerosis, is even more rare than previously believed. The study is due to end in July 2007 so if anyone reading this article is aware of a case presenting since July 2005 but not yet notified, please contact us, as we are very keen to ensure that we receive as many notifications as possible. We are extremely grateful to all those who have already notified cases and completed the questionnaires.



*Dr Adriane Herrick,
Principal Investigator*

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Publications

- The UK case-control study of cerebral oedema complication diabetic ketoacidosis in children. Edge JA et al. *Diabetologia*. **49**: 2006; 2002-09
- Prospective surveillance study of severe hyperbilirubinaemia in the newborn in the United Kingdom and Ireland. [Manning DJ, Maxwell MJ, Todd PJ, Platt MJ](#). *Arch Dis Child Fetal Neonatal Ed*. 2006 Oct 30; [Epub ahead of print].
- Rising incidence of type 2 diabetes in children in the United Kingdom. Haines L, Wan KC, Lynn R, Barrett TG, Shield JPH. *Diabetes Care* in Press, published online on January 26 2007 as dc06-1813

International: The **Australian Paediatric Surveillance Unit** annual report 2004 is now available online at www.apsu.org.au. The report highlights such studies as early onset eating disorder, fetal alcohol syndrome, HIV, neonatal herpes simplex virus infection, hyperinsuaemic hypoglycaemia, haemoglobinopathies and neonatal Group B *streptococcus*. The **New Zealand Paediatric Surveillance Unit** annual report 2005 is available online at <http://www.paediatrics.org.nz> and includes reports on inborn errors of metabolism, foregut and hindgut malformations, pneumococcal meningitis and vitamin k deficiency bleeding. The 10th annual report of the **Canadian Paediatric Surveillance Programme** is also available on-line at <http://www.cps.ca/English/Surveillance/CPSP/index.htm> and highlights recent findings in acute flaccid paralysis, acute rheumatic fever, CMV infection, MCADD, osteogenesis imperfecta, SCID, transfusion related acute lung injury and congenital myotonic dystrophy.

In-house

The response rate over a 13-month period from January 2006 to January 2007 sits just under 92% (Table 1). This is an excellent rate, especially considering that January 2007 cards are still trickling in and reminders have not yet been sent for all of 2006. Please don't forget to send in any old cards that you might find when cleaning out your in trays! Wales again ranks first for this period, with a response rate of 96.3%. Well done paediatricians in Wales for your excellent contribution to the BPSU surveillance programme in 2006. The response rate for the return of questionnaires remains high at 93% (Table 2) but please do remember to use the tear off section of the orange card, writing down the child's details so you will not forget when being contacted by the investigators. And finally please also send in any late questionnaires as late is always better than never. Thank you again to all paediatricians for your contribution to surveillance of rare childhood disease.

TABLE 1 - % RESPONSE RATE
Jan 06 – Jan 07

Region	% rtd	Rank (previous rank)
North	92.6	17 (16)
Yorks	93.7	11 (9)
Trent	94.7	6 (7)
EAnGl	94.8	5 (6)
NWT	93.6	13 (15)
NET	90.7	20 (20)
SET	93.7	12 (14)
SWT	92.7	16 (17)
Wessex	93.8	9 (8)
Oxford	94.6	7 (4)
SWest	95.4	2 (3)
WMids	93.9	8 (10)
Mersey	92.8	15 (12)
NWest	95.1	4 (2)
Wales	96.3	1 (1)
NScot	91.8	19 (19)
SScot	92.1	18 (18)
WScot	93.0	14 (11)
Nlre	95.4	3 (5)
Rlre	93.8	10 (13)
Total	91.6%	

TABLE 2 - ALL CASES REPORTED AND FOLLOW-UPS TO 01/03/07

Condition	Started	VALID			INVALID		NYK	Total	as % of total		
		C/R	D	E	X	C&R			D&E	X	
HIV	1986	4432	571	588	395	5986	74	19	7		
CR	1990	72	30	53	5	160	45	52	3		
PIND	1997	1291	259	599	48	2197	59	39	2		
NNH	2004	75	24	22	68	189	40	24	36		
MCADD	2004	171	47	30	26	274	62	28	9		
MRSA	2005	71	9	22	32	134	53	23	24		
Scleroderma	2005	37	2	18	27	84	44	24	32		
Malaria	2006	129	7	2	67	205	63	4	33		
VKDB	2006	1	-	4	3	8	13	50	38		
FMAIT	2006	7	-	5	9	21	33	24	43		
Total		6286	949	1343	680	9258	68	25	7		

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
NNH Neonatal Herpes Simplex Virus infection
MCADD Medium chain Acyl CoA dehydrogenase deficiency
MRSA Methicillin-resistant Staphylococcus aureus
VKDB Vitamin K Deficiency Bleeding
FMAIT Fetomaternal Alloimmune Thrombocytopenia

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED