



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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Survey of internal abdominal injury due to child abuse commences

Surveillance of severe abdominal injuries in children up to 14 years through the BPSU commenced this March for 13 months initially. The surveillance team led by Professor Jo Sibert has much experience in this type of epidemiological investigation. Paediatricians are now well aware of the dangers of subdural haemorrhage from the shaken baby syndrome. There has been considerable work on the epidemiology of the condition from South Wales and Bristol, Scotland and of course the BPSU study delineating this problem as the commonest cause of death and disability from abuse in the UK. Paediatricians are also aware of the dangers of non-accidental suffocation and the difficulties of diagnosis. They may not be so aware however of the problem of internal abdominal injuries due to abuse, which in our experience may lead to death and disability usually from blows to the abdomen.

Work from the surveillance of severe physical child abuse in Wales suggests internal abdominal injury is the second most common cause of death in childhood from abuse after subdural haematoma. Although internal abdominal injury is a well-recognised form of child abuse, clinicians have little information on how to differentiate between accident and abuse, the prognosis for the abused child and the risks of further abuse. The inclusion criterion will be the holding of a case conference or other multidisciplinary meeting following the diagnosis of a child having internal injury of the abdomen due to child abuse. This would include traumatic damage or rupture of any abdominal viscera including deaths but exclude abdominal bruising alone. The study intends to compare the presentation and clinical findings with children with accidental internal abdominal injury derived from the major trauma outcome study. It will also investigate outcome clinically, legally and in child protection terms.

Further information is available from Professor J Sibert, Department of Child Health, University of Wales College of Medicine, Llandough Hospital, Penarth CF64 2XX Email: sibert@cf.ac.uk

BPSU Executive seeks new Chair and members

After five years as committee chair Dr Chris Verity will be stepping down from the post. Chris follows a distinguished line of clinicians that have chaired the BPSU Executive, from Sir Peter Tizard in the early years followed by Professor David Baum, Professor Euan Ross and Professor Catherine Peckham. Chris will be a hard act to follow – but somebody can do it!

The BPSU is a very prestigious part of the College and is a nationally and internationally known organisation in its own right. The Chair will direct 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 research.

The Committee itself also has spaces for new members particularly those in general and community paediatrics and infectious disease.

Nomination details for the Chairman and committee membership have been sent out with this month's College newsletter pack, alternatively contact Dr Patricia Hamilton c/o College committee department Tel: 0207 307 5600 or Dr Christopher Verity Tel: 01223 216662 for further details.

Sir Cyril Clarke - A tribute

It was with great sadness that the BPSU heard the news that Sir Cyril Clarke had passed away last November in his 94th year. Sir Cyril was chairman of the BPSU Joint Committee of Management from its inception in 1986 until 1994. As a past President of the Royal College of Physicians with a wealth of research experience, along with Sir Peter Tizard, there was no one better placed to guide the BPSU through its early years. Sir Cyril described his work as "fun", even though its purpose was extremely serious - a sentiment the BPSU is happy to continue.

BPSU secures further Department of Health funding

In recognition of the important work the BPSU facilitates in child and public health, the Department of Health (DH) have agreed to renew its contribution to the BPSU - a total of £170,000 over the next three years starting this September.

However, though this represents a substantial contribution towards the running costs of the BPSU, further funding is required to cover the full operating costs of the Unit. To this end the BPSU Executive have approved an increase in the contribution rates expected from investigators using the system. As from September 2001 the BPSU contribution rate will be increased to £7,000 a year from £5,040. This will apply to new applicants who are seeking funds through national grant giving bodies, including national charities. Those who have difficulty raising such sums or who intend to seek funds through smaller local sources or charities can apply to the BPSU Executive for the existing reduced rate of £3,600 (previously £2,520). It is regrettable that these contributions have to be raised but it is the first such increase since July 1997. In very exceptional circumstances the BPSU Executive can decide to waive investigators fees altogether. However this is only likely to happen for a study which has no external funding but which is considered to be of extreme public health importance and merits urgent investigation. Advice on where funding can be sought is also available. All studies will continue to be assessed on their scientific merit and not their ability to pay.

Study news

Study extensions: Surveillance of *paediatric and obstetric HIV* continues, being carried out through the BPSU and a parallel obstetrics reporting system administered under the auspices of the Royal College of Obstetricians and Gynaecologists; data are combined at the Institute of Child Health (London) by the national study of HIV in pregnancy and childhood.

Table 1: HIV infection status of children born to HIV positive women and reported to the RCOG or paediatric surveillance schemes by 31 January 2001

Region of first report	Infected	Indeterminate	Uninfected	Total reported	Known to have died~
Thames Regions	576	385	596	1557	125
Rest of Eng, Wales, NI	135	72	117	324	42
Scotland	39	35	149	223	20
Republic of Ireland	42	42	127	211	11
Total	792	534	989	2315	198

~ **Excluding deaths in children known not to be HIV infected**

Table 1 shows the infection status of the 2315 children at risk of vertical infection reported to date through the current surveillance system. Paediatricians caring for infected children and indeterminate children are contacted annually for follow-up information. Almost all survivors of the approximately 300 children infected through blood products are now over 15 and are no longer receiving paediatric care.

The unlinked anonymous surveys of HIV infection (UA surveys), which cover approximately 70% of births in the UK, show that the prevalence of infection in pregnant women continues to rise. In 1999 approximately 1 in every 400 births in London was to an infected woman, but this varied considerably by area, reaching 1 in 120 in one district. Elsewhere it was 1 in approximately 4,500, with the prevalence in Scotland remaining fairly stable, but slowly rising in England outside London.

HIV detection rates in pregnancy are monitored through the alignment of the confidential obstetric reports with results from the UA surveys. With the widespread introduction of routine antenatal testing, maternal diagnosis rates are now improving in all areas. In particular, antenatal detection rates (the proportion of previously undiagnosed women who are diagnosed antenatally) reached 61% in inner London in the first half of 2000, and 56% in outer London, and started to improve elsewhere in the UK where almost one-third of previously undiagnosed women were diagnosed antenatally. Overall in the first six months of 2000, about three-quarters of all HIV infected women in inner London and in Scotland were aware of their diagnosis before their baby was born (compared to about half in 1998), about two-thirds in outer London (one-third in 1998), and about half elsewhere (one quarter in 1998). There are encouraging signs of a corresponding reduction in the proportion of infants born to infected women who are themselves infected.

As well as contributing data to monitor antenatal detection rates, the surveillance programme also monitors the overall prevalence of HIV in pregnant women and children; the uptake of interventions in pregnancy and their effect on the rate of vertical transmission; developments in the management of infected children. Work is about to start on monitoring the long term effects of antiretroviral treatment taken during pregnancy and perinatally, on children born to infected women; the vast majority of these children are uninfected.

Paediatric HIV infection and exposure to maternal infection continues to be relatively rare, and most paediatricians see only the occasional case. However, management of these children is concentrated in a few centres, and therefore a minority of paediatricians have larger numbers of children to report. The investigators very much appreciate the continuing cooperation of paediatricians.

Dr Kate Ward principal investigator of the **encephalitis in childhood** study reports *"The survey has been extended for five months to the end of September 2001. Of the 318 cases reported so far, 122 cases fulfilled the analytical case definition, whereas 53 cases did not fulfil the analytical case definition and will serve as controls. As to the remaining 143 cases, 90 were invalid due to duplication or other error (including children too old or too young) and follow up has not yet been completed for 53 cases.*

As we are now in our third and final year, we would like to remind paediatricians that our case definition is clinical and we accept all cases regardless of whether the aetiology is known or unknown. Please keep reporting as early as possible without waiting for results from your local microbiology laboratory so that we can help with timely investigation for human herpesvirus-6 (HHV-6) and -7 (HHV-7) infections. This is especially important since we are finding, HHV-6 and HHV-7 infections as commonly as herpes simplex and varicella zoster virus infections. Finally we would like to thank all our contributors for their efforts so far and we look forward to hearing more from them over the coming months"

There have been several reports of **congenital rubella** births through the BPSU in the last months. Most are imported cases (woman acquired infection abroad, but baby born here). Further details on two cases which may or may not be imported cases are awaited. Respondents are reminded to report all confirmed or suspected cases of congenital rubella in babies born in the UK and the Republic of Ireland, regardless of where the mother acquired her infection.

Studies completed: Surveillance of **Group b streptococcal disease**, study investigator Dr Paul Heath, came to an end this February after 13 months. To date 438 cases have been reported and 260 confirmed. February also saw the end of the **haemolytic uraemic syndrome** survey, to date 415 cases have been confirmed. Concern is such that the PHLS with the support of members the British Paediatric Nephrology Association will continue sentinel surveillance of HUS. Whilst the surveillance protocol is prepared can we remind you that any new cases of HUS seen should still be telephone reported to Dr G K Adak at the PHLS Communicable Disease Surveillance Centre, Tel: 020 8200 6868 ext 4551, Email: BAdak@phls.org.uk, or alternatively inform the BPSU office.

New studies: Since the turn of the year five new studies have been added to the orange card. The aforementioned **abdominal injury** survey commences this March. January saw two studies commence - **vitamin k deficiency bleeding**, funded by the Department of Health, investigators Dr J Tripp and Dr A McNinch and the long awaited **cerebrovascular disease stroke and like illness** survey, supported by the Stroke Association, investigators Dr F Kirkham, Dr A Williams. This study aims to define the epidemiology of this fascinating group of conditions and in the first month the BPSU has received 26 notifications and 2 further cases from the parallel surveillance which covers adult haematologists and neurologists. February saw the commencement of surveys on **thrombosis in childhood**, investigator Dr B Gibson and **congenital cytomegalovirus**, investigator Dr P Tookey. Protocol cards for all these studies have been dispatched with recent orange card mailings. Additional copies are available from the BPSU office

Contact-a-Family Directory Launched

In January, the BPSU had the pleasure of being invited to the launch of the revised Contact-a-Family (CaF) directory of specific conditions and rare disorders. First published in 1991 the new version launched at the BMA will be produced as an A5 perfect-bound book. With over 750 pages the CaF Directory contains over 270 entries ranging from abdominal exstrophies to xeroderma pigmentosum. Many of the entries cover several related conditions and each one gives medical information as well as details of available support groups for both parents of affected children and for adults with late onset disorders. Dr Richard Smith, Editor, British Medical Journal stated *"It can provide people with information that is hard to find anywhere (even in medical textbooks) in a form that everybody can understand"*. At £30 this new version is half the cost of the original ring binder format, each year a new edition will be published so that details are kept up to date. CaF also have a free access website (<http://www.cafamily.org.uk>) containing much which is in the directory. Further information can be obtained from CaF on Tel: 020 7383 3555.

Held in conjunction with the Institute of Child Health (London), last December saw the first national conference of the UK Rare Disease Alliance. The conference, organised by CaF and entitled "Rare disorders - the need for a new approach", was attended by over 100 delegates including clinicians and those representing UK support groups from across the UK. The BPSU had a presence at the conference in the form of Dr Chris Verity, who presented work of the BPSU and Richard Lynn, the BPSU Scientific Coordinator. The conference heard from Professor David Hall who outlined the need for future partnerships between patients and doctors. The conference also received presentations from founders of the diamond blackfan anaemia support group and children living with inherited metabolic disease, formerly the Research Trust for Metabolic Disease in Children. Anders Olason spoke on The Agrenska Foundation based in Gothenburg, Sweden and a national centre for children with mostly rare disabilities and their families for whom he is director. Such was the success of the meeting that it is hoped to arrange another.

CaF also announced that they have recently been granted £1.5 million over three years from the DH to expand the work of the organisation. Subject to ratification it has also been agreed that Carol Youngs, assistant director of CaF, will represent the parent and carers group on the BPSU Executive.

Publications

Recent BPSU publications and presentations

- 1) Neonatal meningitis in England and Wales: 10 years on. Holt DE, Halket S, de Louvois J, Harvey D. Arch Dis Child Fetal Neonatal Period Ed 2001; **84**:F85-F89
- 2) Heath PT, Booy R, Azzopardi HJ, Slack MPE, et al. Non Type b Haemophilus influenzae Disease: Clinical and Epidemiological Characteristics in the Hib Vaccine Era. Paediatr Infect Dis J 2000; **20**:300-5.
- 3) Heath PT, Booy R, Azzopardi HJ et al. Antibody Concentration and Clinical Protection after Hib Conjugate Vaccination in the United Kingdom. JAMA 2000; **284**:2334-2340
- 4) Heath PT, Booy R, Griffiths et al. Clinical Immunological Risk Factors Associated with Hib Conjugate vaccine failure in Childhood. Clinical Infectious Disease 2000; **31**:973-80
- 5) Lynn RM. Key issues in child health surveillance. Proc R Coll Physicians Edinb 2001; **31**:39-45.

Six papers on BPSU surveys were presented at the RCPCH scientific meeting in York. 1) Antenatal HIV testing - making a difference. Tookey PA. 2) Are children in the UK developing vCJD? The BPSU study of progressive intellectual and neurological deterioration in children. Verity C. 3) Surveillance of haemolytic

uraemic syndrome in the UK and Ireland (1997-2000) Adak GK. 4) Group B streptococcal disease (GBS) in UK infants less than 90 days of age: a national surveillance study. Heath P. 5) Childhood encephalitis and human-herpesviruses-6 and-7 (HHV-6 & -7) infection. Ward K N. 6) Prospective national data on IBD in children aged less than five. Sawczenko A.

Abstracts can be viewed at <http://adc.bmjournals.com/>.

Analysis

As you will see from Table 2, the three monthly return has fallen below 90%. Reminders are being sent out, as much to check the postal system as to identify under reporting. Their return would be appreciated. Wales continues to consistently be the best reporting area, London being the worst. The North of Scotland and Mersey have improved dramatically whilst the fall noted in the Republic of Ireland continues to be of concern.

In order to examine returns further we are interested to correctly identify clinicians working substantively in a sub-specialty. If you are such a specialist please could you let the office know by amending your mailing address on the orange card. We will incorporate these and any other address amendments as soon as we can. Due to printing in advance there may be a months delay in doing so.

Analysis

Table 2:
% response rate June-Nov 2000

Region	% retd	Rank (Jan-June 2000)
North	93.3	4 (9)
Yorks	87.7	16 (8)
Trent	92.1	7 (5)
EAnGl	89.1	14 (15)
NWT	84.3	19 (19)
NET	83.5	20 (20)
SET	86.4	17 (16)
SWT	90.2	11 (17)
Wessex	90.5	10 (11)
Oxford	93.1	6 (1)
SWest	88.7	15 (18)
WMids	91.8	8 (12)
Mersey	93.2	5 (10)
NWest	89.2	13 (14)
Welsh	96.7	1 (2)
NScot	94.8	2 (13)
SScot	90.9	9 (3)
WScot	90.1	12 (6)
NIre	94.1	3 (4)
RIre	86.1	18 (7)
Total	89.6	

Table 3: All cases reported and follow-ups to 12/02//2001

Condition	Started	I			II			Not Yet Known			as % of total		
		VALID	INVALID	Not Yet Known	I	IIa	IIb	III	Ttl	I	II	III	
HIV/AIDS	1986	1313	266	318	110	2007	65	29	6				
CR	1990	61	24	32	4	121	50	46	3				
Reye's	1986	154	49	113	11	327	47	50	3				
Hi	1992	351	39	134	13	537	65	32	2				
SSPE	1986	104	42	35	31	212	49	36	15				
HUS	1997	448	213	34	33	728	62	31	7				
PIND	1997	658	106	229	74	1067	62	31	7				
Enceph	1998	122	26	107	64	319	38	42	20				
SVB	1999	233	27	118	244	622	37	23	39				
GBS	2000	260	49	52	77	438	59	23	18				
CVD/S	2001	0	0	0	29	29	0	0	100				
VKDB	2001	0	0	0	2	0	0	0	100				
Total*		3704	841	1172	675	6392	58	31	11				

* All data is provisional & continually being updated

Key to table / abbreviations

I	Confirmed/already known	AIDS/HIV	Acquired Immunodeficiency Syndrome / Human Immunodeficiency Virus
IIa	Duplicate	CR	Congenital Rubella
IIb	Reporting error or revised diagnosis	Reye	Reye Syndrome
III	Status not yet reported to BPSU by investigator	Hi	Haemophilus influenzae infection
		SSPE	Subacute sclerosing panencephalitis
		HUS	Haemolytic Uraemic Syndrome
		PIND	Progressive Intellectual Neurological Degeneration
		Eneph	Encephalitis in children (2-36months)
		SVB	Severe visual impairment & blindness
		GBS	Group B streptococcal disease
		CVD/S	Cerebrovascular disease/stroke & like illness
		VKDB	Vitamin k deficiency bleeding