



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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BPSU 15th Annual Report Published

The BPSU 15th Annual Report 2000-2001 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/library/BPSU/BPSU.htm>. 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.

For the first time, the report contains a contribution from the Professor Liam Donaldson, the Chief Medical Officer for England and Wales. Along with the recent renewal of the DH's grant to the Unit this very much reflects the importance and high esteem in which the BPSU is now held. To quote Professor Donaldson, *"it is a matter of pride that the innovative and scrupulous epidemiology of the BPSU has been emulated by several other countries in Europe and beyond."*

Elsewhere in the report, Dr Chris Verity reviews the achievements of the Unit over its first 15 years, highlighting the outcomes of some of the 50 completed studies. Not only has the BPSU aided in the collection of epidemiological data, but it has also assisted in developing management protocols and in one case - chemistry set poisoning - aided in changing law. Recently the BPSU has been at the forefront of discussion over consent and data confidentiality, and has taken a lead in involving parent organisations and leading the development of the International Network of Paediatric Surveillance Units. 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 cases reported, the highest ever for a single year. On behalf of the Unit and the BPSU investigators we thank you for this magnificent response.

New BPSU Committee Members Chosen

Following a call earlier on in the year for applicants to the BPSU Executive, four new members including a new chair have been chosen. Of particular importance was the choice of the new chair of the BPSU to replace Dr Chris Verity. To this end Professor Michael Preece, Professor of Child Health and Growth at the Institute of Child Health (London) was selected. Professor Preece has an extensive background in research and currently chairs the ICH/GOS Ethics Committee.

Following a difficult choice, Dr Allan Colver, Newcastle Royal Infirmary, Dr Martin Richardson, Peterborough General Hospital, and Dr William McGuire, Ninewells hospital were selected as new members of the committee. Each offers a level of interest and experience, which will complement the current committee membership.

To accommodate these new faces the BPSU Executive has to say farewell to several long-standing members. Dr Chris Kelnar, Professor Brent Taylor and Dr Angus Clarke along with Dr Verity are stepping down from the Committee this autumn. Without doubt their contribution has been a major factor in the successful development of the BPSU over the past eight years.

Study News

Professor Sibert reports on the progress of the survey into **internal abdominal injury due to child abuse in children under 14 years**: “This study began in March 2001 the inclusion criteria being 1) Children aged 0 – 14 years; 2) Internal abdominal injury due to child abuse, diagnosed at multidisciplinary meeting (case conference, strategy meeting or part 8 review).

To date we have received 30 notifications via the BPSU. In each of these cases, a questionnaire has been sent out collecting further information with regards to the child; the injuries identified; clinical management; family dynamics and outcome details, including the child protection investigation. Of the 30 notifications and hence questionnaires sent out, 12 replies are outstanding as of 31/08/01 (i.e. no further details yet available), 2 duplicate case notifications have been received, 9 notifications were made in error (injury accidental – not due to child abuse), 7 confirmed cases – similarities are emerging in the information that we are collecting in these confirmed cases. Sadly, three of these children died as a result of their injuries.

“We have also received information on a number of cases with internal abdominal injuries due to child abuse predating the onset of the study – information provided by paediatricians contacting us directly. Recently, changes have been made to the notification card by the BPSU, which should reduce the likelihood of notifications being made in error. We would like to thank all of those who have so far participated in this study.”

For further information contact JR Sibert, PM Barnes & C Norton, Department of Child Health, University of Wales College of Medicine, Academic Centre, Llandough Hospital, Penarth, Wales CF64 2XX. Email: sibert@cf.ac.uk

Dr Brenda Gibson reports on the first national prospective epidemiological study of **childhood thrombosis**, now into its eighth month of data collection: “It is hoped that this study will help to answer important questions related to the management of childhood thrombotic events, which, although rare, often raise difficult therapeutic issues. The study is designed to allow:-

- a) The evaluation of the role of acquired and inherited thrombophilia in childhood thrombosis.
- b) The validation of currently used therapeutic approaches, which have generally been extrapolated from adult practice, with no further validation.
- c) The design of controlled clinical trials appropriate to paediatric practice.

“In the past seven months, 75 cases of childhood thrombosis have been reported either via the BPSU or the British Society for Haematology. Of the 75 first mailing data collection forms sent to the reporting physicians, 53 have been returned completed, of which 32 have been confirmed as eligible by the entry criteria. Initially a number of reported cases were ineligible for the study because the reported event predated the start of the study, but since then the majority of reported cases have met eligibility criteria. Fewer cases have been reported than expected and because of concerns of under-reporting, we are directly targeting paediatric surgeons, intensivists and cardiologists/cardiac surgeons. Duplicate reporting is better than under-reporting.

“The criteria for entry is - any child aged between one month (or 44 weeks post conceptional age) and 16 years, newly diagnosed with an objectively documented venous or arterial thrombosis. Neonates and children with stroke are **excluded**, to prevent overlap with other ongoing BPSU studies, and this might, in part, explain the smaller than expected number of reported cases.

“A second mailing data collection form will be sent to reporting physicians at an interval of 6 months from the first, to collect information on progress and outcome. We are now more than six months into the study and the second mailing started in August.”

For further information contact Dr Brenda Gibson, Dept of Haematology, RHSC, Yorkhill, Galsgow G3 8SJ

Dr Andrew Williams reports on the **cerebral vascular disease/ stroke and like illness survey**: “We have now completed the eighth month of this 13 month descriptive epidemiological study. To date 200 reports have been received, so far 83 who have been confirmed as occurring on or after January 1st 2001. This sadly includes 4 deaths with different causes. In addition to this we have had 5 referrals for Vein of Galen and 4 for Sturge Weber. Data from a parallel surveillance system involving cardiologists, haematologists, radiologists and neurosurgeons is also currently being collated.

“It has become apparent that a few cases reported to us may overlap with the Vitamin K deficiency and the thrombosis studies both of which are also being run contemporaneously with us on the Orange Card. We would encourage discussion with these respective study groups if there any queries. Investigators in all the studies are prohibited from referring patients or transferring their data from one study to another. Instead we are obliged to contact the original referrer and politely suggest that they contact the other research group through the Orange Card.

“We have also received our first returns from the 6 month follow up, looking at stroke recurrence. The figure quoted for recurrence of childhood stroke varies widely in the literature and this study aims to give a clearer picture. The returns so far are encouraging and will hopefully be used to support funding for a larger multinational interventional study into infarctive childhood cerebrovascular disease.

Study News

We are delighted with the progress thus far of this study and are extremely grateful for the Stroke Association in supporting it. Our regional advisors and myself are only too pleased to discuss any possible referral.”

For details please contact Dr A N Williams, Dept, of Neurology, Institute of Child Health, Birmingham Children’s Hospital, Birmingham B4 6NH. Email: anw@doctors.org.uk

Dr Pat Tookey reports on the study into **congenital cytomegalovirus (cCMV)**: “Surveillance started in February of this year, and is continuing. We are seeking notification of all infants born in the British Isles since the beginning of 2001 with clinically recognised, confirmed and suspected cCMV infection. In the first six months of reporting (February to July) we received 73 reports through the BPSU, from all parts of the British Isles.

Our case definition for *confirmed cases* is: any infant with cCMV infection, confirmed by PCR or virus isolation from urine, blood, saliva or tissue taken at biopsy within 3 weeks of birth, and for *suspected cases*: any infant with symptoms compatible with cCMV infection aged under 12 months with CMV isolated from urine, blood, saliva or tissue taken at biopsy after 3 weeks of age, and/or with CMV specific IgM after 3 weeks of age. Our main aims are to ascertain the population prevalence of cCMV disease, describe current management strategies, and monitor the clinical outcome at the time of the child’s first birthday. We are also monitoring laboratory reports of CMV in infants under the age of one year made to the PHLS and Scottish Centre for Infection and Environmental Health.

Twenty-five of the 73 reports received in the first six months are currently outstanding, 17 were made in error (mostly infants born in 2000) and four are duplicates. Among the remaining 27 infants for whom we have received completed information there were two pairs of twins, one infant in one of the pairs was not infected. Diagnosis of cCMV was made in the first three weeks of life in 18 infants. The other eight were aged over three weeks at diagnosis, and have therefore been recorded as suspected cases. We plan to investigate the feasibility of tracking down the Guthrie cards and attempting to make a retrospective diagnosis for suspected cases.

Please continue to report cases of confirmed or suspected cCMV on the orange card. Thanks to all those who have already reported cases – and if you have not yet returned your form, please do so as soon as possible. Contact Dr. Pat Tookey on tel: 020 7905 2604 (Email: p.tookey@ich.ucl.ac.uk) for further information.”

On behalf of the above contributors and all the other investigators, can we thank you for your continued cooperation.

International Network of Paediatric Surveillance Units (INoPSU)

New national units: The newly formed **Portuguese Paediatric Surveillance Unit (PPSU)** commenced surveillance in April. Covering a child population of 1.8 million and involving 1500 clinicians studies to be surveyed include Kawasaki disease, haemolytic uraemic syndrome, group b streptococcal disease, and insulin dependent diabetes mellitus. Executive committee members were pleased to meet recently with representatives of the newly formed **Greece and Cyprus Paediatric Surveillance Unit (GPSU)**. Developed following a one-off email contact, members were delighted to hear plans for the establishment of this new unit. This will be the thirteenth national unit to develop such a system based on the BPSU methodology. The GPSU child population catchment is around 1.6 million, studies initially under surveillance include Kawasaki disease, nephrotic, aplastic and West syndromes, Q and endemic fever. The BPSU scientific coordinator will be liaising with these new units with the aim of seeking their affiliation to the INoPSU. The involvement of Portugal and Greece should also strengthen any future EU funding application for collaborative INoPSU projects. Talking of which, the INoPSU sent a delegation led by Professor Victor Marchessault from the Canadian Surveillance Programme to the International Paediatric Association conference in Beijing, China. The aim was to seek affiliation to the IPA, which I am pleased to announce was successful, and to raise the profile of the INoPSU.

INoPSU conference: Currently the BPSU is preparing to host the second INoPSU conference. Following on from a successful inaugural conference in Ottawa Canada last year, this conference will be at York University held on 14-15th April 2002. The meeting will directly precede the RCPCH scientific meeting. The first day will afford an opportunity to those involved in surveillance activities to meet and discuss matters of interest.

The morning of the second day will see a series of lectures open to all to attend. Topics include *Haemophilus b* vaccination strategies; MMR vaccination; reducing the risk of mother to child transmission of HIV worldwide; inflammatory bowel disease; hepatitis C virus surveillance; vCJD in UK children; and a parental support perspective on the need for surveillance.

The RCPCH plenary session on the Monday afternoon will continue the international theme with two INoPSU presentations entitled “Epidemiology of Haemolytic-uraemic syndrome - a worldwide perspective” by Professor Elizabeth Elliott (APSU) and “Vitamin K deficiency bleeding – international surveillance findings” by Professor Rudi von Kries. Further details on the meeting will be available in the winter bulletin and will be posted up on the website. If you wish to register an interest in attending the INoPSU session, which will be free to those attending the RCPCH session, we would be pleased to hear from you.

Recent Publications

- 1) The redeveloped BPSU website at <http://bpsu.inopsu.com>
- 2) BPSU summary paper on confidentiality; Verity C, on behalf of the BPSU Executive Committee available at <http://www.rcpch.ac.uk/library/index.htm>
- 3) *An international network of paediatric surveillance units: A new era in monitoring uncommon diseases of childhood.* Elliott E, Nicoll A, Lynn R, Marchessault V, Hirasig R (INoPSU Secretariat), on behalf of INoPSU members. Canadian Journal of Paediatrics 2001; **6**: No 5 pg 250-9
- 4) *Is regional paediatric surveillance useful? Experience in Wales.* R H J Morgan, O'Connell H, Sibert JR, Lynn RM, Z E Guildea, Palmer S. Arch Dis Child 2001; **84**: 486-487
- 5) *Prospective survey of childhood inflammatory bowel disease in the British Isles.* Sawczenko A, Sandhu B K Logan, R F A, Jenkins H, Taylor C J, Mian S, Lynn R. Lancet 2001; **357**, 1095-96
- 6) *The risk and outcome of cerebral oedema developing during diabetic ketoacidosis.* Edge J A, Hawkins M M, Winter D L, Dunger DB, Greene S Arch. Dis. Child. 2001; **85**: 16-22
- 7) *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

Monthly Analysis

As you will see from Table 1, the monthly card returns once again has fallen below 90%. To date the card return for March (85%), April (86%) and June (83.6%) are much lower than expected and have contributed significantly to this fall. If you are holding these or any other cards could you please return them as soon as possible. The end of year return for 2000 was 92.7% although down on 1999 (93.4%) we would very much like to maintain the current rate at this level. In Table 2 you can see that the questionnaire return rate is around 90%. With the Encephalitis study coming to an end in October, it would be helpful if any outstanding questionnaires could be returned.

Table 1:
% response rate Jan-June 2001

Region	% retd	Rank (Dec-May 2001)
North	90.1	6 (10)
Yorks	86.2	16 (17)
Trent	88.8	10 (3)
EAngl	85.5	18 (14)
NWT	85.1	19 (20)
NET	81.7	20 (19)
SET	86.0	17 (18)
SWT	88.9	9 (9)
Wessex	93.6	2 (15)
Oxford	88.4	11 (8)
SWest	86.7	15 (16)
WMids	89.3	7 (6)
Mersey	94.4	4 (6)
NWest	89.2	8 (12)
Welsh	94.7	1 (5)
NScot	92.3	3 (1)
SScot	88.1	13 (3)
WScot	88.0	14 (12)
Nlre	90.2	5 (2)
Rlre	88.3	12 (12)
Total	88.0	

Table 2: All cases reported and follow-ups to 28/08/2001

Condition	Started	I		II		Not Yet Known	Ttl	as % of total		
		VALID	INVALID	Ia	Ib			I	II	III
HIV/AIDS	1986	1445	283	343	151	2222	65	28	7	
CR	1990	65	24	32	3	124	53	45	2	
Reye's	1986	157	51	116	4	328	48	51	1	
SSPE	1986	108	48	36	24	216	50	39	11	
PIND	1997	715	125	271	59	1170	61	34	5	
Enceph	1998	133	30	135	84	382	35	43	22	
CVD/S	2001	70	3	20	91	184	38	13	49	
VKDB	2001	2	1	1	10	14	14	14	71	
Thrombosis	2001	23	4	10	27	64	36	22	42	
CMV	2001	17	3	13	40	73	23	22	55	
IAI	2001	8	0	9	13	30	27	30	43	
Total*		2743	572	986	506	4807	57	32	11	

* All data is provisional & continually being updated

Key to table / abbreviations

I	Confirmed/already known	HIV/AIDS	Acquired Immunodeficiency Syndrome
Ia	Duplicate		/ Human Immunodeficiency Virus
Ib	Reporting error or revised diagnosis	CR	Congenital Rubella
III	Status not yet reported to BPSU by investigator	Reye's	Reye's Syndrome
		SSPE	Subacute sclerosing panencephalitis
		PIND	Progressive Intellectual Neurological Degeneration
		Enceph	Encephalitis in children (2-36months)
		CVD/S	Cerebrovascular disease/stroke & like illness
		VKDB	Vitamin k deficiency bleeding
		CMV	Congenital Cytomegalovirus
		IAI	Internal abdominal injuries due to child abuse in children under 14 years