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BPSU

BPSU Bulletin

The British Paediatric Surveillance Unit (BPSU) is part of the Research & Policy Division of the Royal College of Paediatrics and Child Health

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British Paediatric Surveillance Unit in 2012 and its long term future

A Message from the BPSU

Many of you will have been concerned to hear that the current grant for the BPSU from the Department of Health Policy Research Programme is due to conclude in late 2012. For most of its 25 year history the BPSU has relied on charitable donations and grants rather than government funding, so this funding scenario is nothing new. We have always had to be creative and resourceful in finding income without compromising our quality and independence. We are now working hard to secure the future of the BPSU in these difficult financial times.

The RCPCH, which hosts the surveillance unit, together with the parent bodies the Health Protection Agency and UCL Institute of Child Health remain committed to active paediatric surveillance of rare conditions and are continuing to review the best financial, operational and scientific model for the BPSU, with the aim of strengthening and securing its long term future.

In the meantime, the BPSU continues with active surveillance and welcomes new studies.

The BPSU is actively working with its partners to identify and secure new sources of financial support, as well as developing modern and cost-effective systems for electronic notification and online reporting, which have now been piloted and will be introduced in 2012. The BPSU will keep all paediatricians, partners, stakeholders and other contributors updated with progress throughout 2012.

The BPSU is recognised nationally and internationally as a model for the active surveillance of rare conditions in a population of 14 million children across the United Kingdom and the Republic of Ireland. The achievements of the BPSU have only been possible because of the sustained commitment of clinicians in completing and returning the Orange Cards over the last three decades.

Although this is a difficult funding environment, we are hopeful that we can take the BPSU forward into 2013 and beyond. Its continued success also depends on you – one of the 93% of BPSU clinicians who each month return an Orange Card.

PLEASE CONTINUE TO RETURN YOUR ORANGE CARDS AND REPORT CASES.

Prof Alan Emond
Chair, BPSU Executive Committee

Supported by the Department of Health

Study News

Study update

The **Gender Identity Disorder (GID)** surveillance study commenced in November 2011 and is a joint study between the BPSU and the Child and Adolescent Psychiatry Surveillance System (CAPSS).

We would like to thank all reporting clinicians for their support: 42 cases have been reported to date, 22 of these through the BPSU. Seven BPSU questionnaires remain outstanding and we would encourage respondents to return your completed questionnaires if you have not already done so. Please do not hesitate to contact the study team if you need a replacement questionnaire or have any questions regarding the study.

Please note: Several clinicians have asked whether they should notify us of historical cases of GID (diagnosed pre-November 2011). As this study is aiming to estimate the incidence of GID rather than prevalence, we are only able to include new cases where a putative diagnosis has been made since 1st November 2011. This will allow us to estimate the number of new cases per year. **However, please do report any cases of existing patients who have become eligible for reporting since 1st November 2011** (i.e. who did not meet case definition criteria when they first presented, but have fulfilled these criteria over time). Please direct any queries to our Research Assistant Faye Sweeney (f.sweeney@ich.ucl.ac.uk or 020 7905 2190).

Thanks again for your continued support!
Further details are available at www.rcpch.ac.uk/what-we-do/bpsu/current-studies/GID

Surveillance extension approved

The **PIND** study continues for a further year. In 1997 we commenced UK surveillance for variant Creutzfeldt-Jakob disease (vCJD) in children, funded by the Department of Health. Because there is no diagnostic test for vCJD we ask paediatricians to tell us about all the children that they see with progressive intellectual and neurological deterioration, even if a diagnosis has already been made locally. The strategy is to present the anonymised clinical details to a group of experts, so as to confirm the local diagnoses and review the undiagnosed cases to ensure that none of these have the clinical features of vCJD.

The PIND team: Lesley Stellitano, Chris Verity and Anne Marie Winstone

The good news is that we have identified just 6 children with vCJD, the last one developing symptoms in 2000. In all age groups the rate of presentation of vCJD has slowed and the total number of definite and probable UK cases was 176 by the 4th January 2012 (National CJD Surveillance Unit website).

Despite this encouraging news there are good public health reasons for continuing active PIND surveillance:

1. PIND surveillance is still working well. We receive 10-20 notifications per month; this has been consistent since the first months of the study. 3187 cases of suspected PIND had been reported to us by February 2012.
2. There is still no evidence of vertical transmission from mother to child but it will take many years of observation before we can be confident that this cannot happen. In the absence of a diagnostic test the PIND study is the only way to identify vCJD in children.
3. There is concern about secondary transmission through dental procedures in children.
4. Similarly there is the continuing risk of transmission to children via surgical instruments.
5. Transmission could occur via blood transfusion. High risk groups include premature infants having top-up transfusions and older children with coagulation defects, immune deficiencies and malignant disease.
6. The PIND study has provided unique data on the many causes of progressive neurological disease in children and the variation in their incidence in different ethnic groups. The findings are important epidemiologically and contribute to the appropriate planning of diagnostic tests, clinical management and provision of services.

For all these reasons the PIND study is on the card for another year. Many thanks to all of you for reporting PIND cases – even if a diagnosis has already been made locally. The support for our study has been tremendous and we hope that your enthusiasm will continue. Rest assured that we will make good use of the data that you provide!

For contact: Chris Verity, christopher.verity@addenbrookes.nhs.uk

Surveillance Ends

Dr Richard Reading

Surveillance for **Gonorrhoea, Syphilis, Chlamydia and Trichomonas surveillance in children under 13 years age** came to an end in January after two years. We have been trying to identify these conditions which are rarely encountered in paediatrics, because of their links with possible sexual abuse. In adults these conditions are all sexually transmitted, so we would expect a child protection assessment to have been undertaken in children with these conditions and we would be interested to learn the child protection outcomes. In a previous BPSU study on genital herpes, reported in the Archives last year (Reading R, Hughes G, Hill J, Debelle G. Genital herpes in children under 11 years and investigations for sexual abuse. Archives of Disease in Childhood. 2011;96:752-757) we showed that the quality of screening for other sexually transmitted infections was poor, and that relatively few cases had led on to a child protection assessment. We would hope in the case of the current infections being studied, that the quality of child protection assessment was better in view of the clearer association between these infections and sexual transmission.

Over the two years we have had relatively small numbers of confirmed and valid cases reported to us. We have no reason to suspect under-reporting so it looks like the identification of these conditions is extremely rare in UK and Irish clinical practice. We are currently completing our data collection and will be analysing the results over the next few months. We hope these results will inform forthcoming guidance on the management of sexually transmitted infections as a consequence of child sexual abuse. The investigators would like to thank all paediatricians who have reported cases over the past two years. The study has been funded by WellChild.

Contact: Richard Reading – Email: richard.reading@nnuh.nhs.uk

Dr I Okike

Bacterial meningitis in babies 0-90 days of age: burden of disease in UK and the Republic of Ireland

We are very grateful to all reporting clinicians who contributed cases to the above study. A total of 485 reports were received via BPSU, 418 (86%) returned, 261 (62%) met our analytical case definition, 64 (13%) reports without a completed study questionnaire and 3 reports classified as unable to verify.

Please complete and return any pending study questionnaires. If you do not have all the details at the moment, we would appreciate if you could at least confirm if this was a case of bacterial meningitis in a baby less than 90 days of age by sending to us via email the age, sex, gestational age at birth, birth weight, where admitted from, isolated organism if known and outcome and then complete the rest of the form at a later date. In order to de-duplicate cases, the date of birth, hospital and NHS numbers should be included and sent to iokike@nhs.net.

Please also complete the study questionnaire if we have informed you of a case under your care reported via other sources ie HPA or meningitis support charities to Dr I Okike, Vaccine Institute, St George's, University of London, 2nd Floor Ingleby House, Blackshaw Road, London, SW17 0QT

In order for us to do final analysis, we have set **28 February 2012** as the deadline for return of completed questionnaires.

Once again, thank you for all your help with this very important study.

E-card Reporting

E-card reporting: September saw the end of the 9 month e-card reporting pilot. 499 clinicians were initially sent an e-card, by the end of the pilot 433 were still in receipt. Response rates averaged 70% but this rose to 85% following reminders, slightly lower than our postal card response. Most of the e-cards were returned within 3 weeks of being sent. Problems with opening e-card due to firewalls and Blackberry compatibility were reported. Positive cases were reported at the same frequency as the postal card. Over 90% preferred the e-card to the postal card. An Aide memoir was identified as being important when reporting a case. Though the e-card was seen as being acceptable the postal system was still preferred by some. Poor responders to the postal system generally remained poor responders on the e-card. There was support for on-line data reporting following a case report. We are currently examining an alternate system and expect to roll out the e-card during the year. If you are interested in receiving an e-card email us at bpsu@rcpch.ac.uk.

Recent Publications

1. K N Ward, A Ohrling, NJ Bryant, JS Bowley. EM Ross, C Verity. Herpes simplex serious neurological disease in young children: incidence and long-term outcome. ADC 2012; 97: 162-165
2. L Samad, S Marvin, H ElBashir, A G Sutcliffe, J C Cameron, R Lynn, B Taylor. Prospective surveillance study of the management of intussusception in UK and Irish Infants. Briti Journ Surg 2011;Vol: doi: 10.1002/bjs.7821
3. J Khalid, JM Oerton1, C, PC Hindmarsh, CJ Kelnar, R L Knowles. Incidence and clinical features of congenital adrenal hyperplasia in Great Britain. ADC 2012; 97: 101-106
4. CL Townsend, Catherine S Peckham, Pat A Tookey. Surveillance of congenital cytomegalovirus in the UK and Ireland. ADC-FNN 2011; 96(6): 398-403
5. DE Nicholls, RM Lynn, RM Viner. Childhood eating disorders: British national surveillance study. British Journal of Psychiatry 2011; 198 (4): 295-301
6. M Knight, M Pierce, D Allen, JJ Kurinczuk, P Spark, DJ Roberts, MF Murphy. The incidence and outcomes of fetomaternal alloimmune thrombocytopenia: a UK national study using three data sources. Br J Haematol 2011; 152(4): 460-8

Analysis

E-card reporting

September saw the end of the e-card reporting pilot. Response rate has averaged 85%, slightly lower than our normal card response. We are currently evaluating the data and will be rolling out the e-card to during the year. If you are interested in receiving an e-card email us at bpsu@rcpch.ac.uk.

TABLE 1 - % RESPONSE RATE (for 6 months Apr-Aug 2011)

Region	% rtnd	Rank
EAngl	90.5%	12
Mersey	92.1%	9
NET	85.2%	20
NScot	96.3%	1
NWest	93.4%	5
North	92.1%	8
NIre	89.5%	15
NWT	89.5%	14
Oxfrd	90.3%	13
RIre	89.0%	17
SET	91.4%	11
SScot	93.6%	4
SWest	89.4%	16
SWT	86.3%	19
Trent	91.5%	10
Wales	94.9%	2
Wessx	92.8%	6
WMids	92.4%	7
WScot	87.0%	18
Yorks	94.0%	3
Average	**90.9%**	

DATE IS PROVISIONAL AND SUBJECT TO CHANGE

TABLE 2: Cases followed up to 10.10.2011

		VALID			INVALID		C&R	D&E	X
Condition	**Started**	**C/R**	**D**	**E**	**X**	**Total**	(as % of Total)		
AIDS/HIV	1986	7044	769	717	748	9,278	76	16	8
CR	1990	85	35	31	5	156	54	42	3
PIND	1997	1789	376	825	178	3,168	56	38	6
GBS	2009	104	32	7	61	204	51	19	30
GSCT	2010	14	2	32	12	60	23	57	20
Lead	2010	8	2	10	14	34	24	35	41
SYP	2010	30	5	6	14	55	55	20	25
Chylo	2010	120	15	13	70	218	55	13	32
GA1	2010	9	6	7	20	42	21	31	48
NeoMen	2010	193	33	53	206	485	40	18	42
ESRD	2011	0	0	0	61	61	0	0	100
CHT	2011	5	0	4	280	289	2	1	97
AAD	2011	4	0	0	16	20	20	0	80
VITD	2011	11	2	4	11	28	39	21	39
HUS	2011	0	0	0	33	33	0	0	100
GID	2011	0	0	0	21	21	0	0	100
Total		**9,416**	**1,277**	**1,709**	**1,750**	**14,152**	**67**	**21**	**12**

AIDS/HIV ..Human immunodeficiency virus in childhood
CR.....Congenital rubella
PIND .....Progressive intellectual & neurological deterioration
GBS .....Guillain-Barré syndrome / Fisher syndrome
GSCT.....Gonorrhoea, Syphilis, Chlamydia, Trichomonas infections
Lead.....Raised Blood Lead Levels in Children
SYP.....Congenital syphilis
Chylo.....Chylothorax in Infants and Children
GA1.....Glutaric Aciduria 1
NeoMen ....Bacterial meningitis in babies <90 days of age
ESRD.....End-Stage Renal Disease
CHT.....Primary Congenital Hypothyroidism
AAD .....Autoimmune Addison's Disease in Children
VITD.....Seizures Vitamin D Deficiency
HUS .....Haemolytic uraemic syndrome
GID .....Gender identity disorder

C confirmed/ already known

D duplicate

E reporting error or revised diagnosis

X status not yet reported to BPSU by investigator