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BPSU Bulletin

BPSU

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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Severe Neonatal Hypernatraemia Study Launches

The BPSU study on severe neonatal hypernatraemia launches in May 2009. This study aims to capture all severe neonatal hypernatraemia, except those attributable to either prematurity or urinary concentrating defects.

The study's development follows publication of many case reports and case series where hypernatraemia has followed unsuccessful attempts to establish breastmilk transfer. The study will not however, attempt to establish a causal link between such attempts at breastfeeding, and hypernatraemia.

The study team have a long interest in both hypernatraemia, and breastfeeding promotion, and are aware of both the recently published Dutch Paediatric Surveillance Unit study, and the Welsh study. There has been significant national and international press interest in the issue following a piece by the BBC, with articles in national press and on BBC radio.

Dr Oddie said *"We are very excited to be launching this study. Hypernatraemia is an important condition, and we hope to be able to describe the incidence as well as report clinically useful information about how these infants present and are managed."*

The aim is to describe the incidence of severe hypernatraemia (Na>160mmol/l), any associated mortality, its associations in terms of feeding weight loss and time of presentation and to review the approaches taken to treatment.

Cases will be notified initially to the BPSU in the usual way, and the study team look forward to hearing of any cases, and will particularly welcome duplicate reporting of cases seen in more than one hospital. Please contact sam.oddie@bradfordhospitals.nhs.uk with any questions.

British Paediatric Surveillance Unit Conference

On the 3rd March 2009 the BPSU held a successful one day conference at RIBA London. The event was attended by almost 100 delegates. Feedback from the event was very positive with delegates rating the quality of presentations and choice of speakers highly.

The conference provided an opportunity to celebrate some of the recent work of the BPSU. The programme reviewed the contribution which the BPSU has made to the understanding and control of uncommon childhood conditions, its impact on public health policy and its development of partnerships.

Talks included a Key Note lecture by Dr Shelia Shribman, National Clinical Director, Children, Young People and Maternity Services. The BPSU was also delighted to welcome speakers from other surveillance units who have used the model developed by the BPSU to influence the establishment of their own systems. Dr Knight from the UK Obstetric Surveillance System and Dr Nicholls from the very recently established child and adolescent psychiatry reporting scheme both presented at the event

If you would like details of any the presentations made at the conference contact Helen Friend helen.friend@rcpch.ac.uk

Supported by the Department of Health

DH Department of Health

Study News

Genital Herpes study

After 26 months of surveillance Genital Herpes study will end in 31 April 2009. The investigators are aware of several lab notifications to the HPA of cases that have not been reported through the BPSU system. The investigators are not permitted any identification details of those cases, but are asking the lab directors to liaise with their local paediatrician, or other specialist, to request that these cases are notified directly to them – therefore some paediatricians may have been approach to notify patients to us. We are very grateful to those that have already done so, and hope others may feel able to do so if requested.

To date 20-25 cases have been received with very few of these cases being associated with any other overt features of sexual abuse, and few have resulted in child protection investigations. Full analysis of the data will enable comments to be made on possible modes of transmission and make suggestions about appropriate child protection measures when genital herpes is identified in a young child.

Please continue to report any suspected or confirmed Genital Herpes cases seen up until the end of April through the BPSU system. For more information on this study contact Dr Richard Reading E-mail: richard.reading@nnuh.nhs.uk

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Congenital rubella study

Two infants with congenital rubella are known to have been born in England at the end of 2008, but unfortunately only one has so far been reported through the BPSU. Congenital rubella remains extremely rare – 17 infants have been reported from the British Isles in the last 10 years, and ten of their mothers caught rubella abroad. However, it seems likely that the two most recent cases both had mothers who were infected here in the UK.

Although there doesn't seem to be much rubella infection circulating in the British Isles at present, there is potential for outbreaks to occur. Uptake of MMR has been at sub-optimal levels for 10 years now, and a substantial minority of children have not had rubella vaccine or been exposed to the disease. Areas of low vaccine uptake – for example London where about a quarter of 5 year olds have not had even one dose of MMR1– also tend to have substantial ethnic minority populations. Recently published data from North Thames suggests that while overall 2.7% of newly delivered mothers are susceptible to rubella, women born abroad, particularly in Sub-Saharan Africa and South Asia, are 4 and 5 times respectively more likely to be seronegative than UK-born women; mothers under the age of 20 years were also at higher risk.2

So keep rubella in mind – and if you suspect congenital rubella in a baby or young child, please report it promptly on the orange card. It's much better for us to have duplicate reports or to have reports subsequently withdrawn than to miss cases!

1. NHS Immunisation Statistics, England 2007-08, available at www.ic.nhs.uk/statistics-and-data-collections/health-and-lifestyles/immunisation
2. Hardelid P, Cortina-Borja M, Williams D, Tookey PA, Peckham CS, Cubitt WD, Dezateux C. Rubella susceptibility in pregnancy: estimates based on new born screening samples. J Medical Screening 2009;**16**(1):1-6

New Projects

To start this autumn
Several new projects are being scheduled to start this autumn; Neonatal meningitis (investigator Dr P Heath), Childhood demyelination (Dr M Absoud) and the Sir Peter Tizard sponsored Glutaric aciduria type 1 (investigator Dr B Cheesebrough). It is also hoped that studies on congenital syphilis, sexually transmitted infections in children under eleven years and raised blood lead levels in children will commence by the end of the year. More details about these will be sent out with the Orange cards and in future newsletters. Details will also be placed on the BPSU website once they become available

Sir Peter Tizard research bursary 2009-10 Call for bursary applications
Paperwork is already available on our website at http://bpsu.inopsu.com/home/tizard_bursary.html Deadline for applications is Friday June 5th 2009

National Information Governance Board Established

Until the beginning of this year all BPSU studies in England and Wales were required to seek under the Health and Social Care Bill 2001 'Section 60' approval from the Patient Information Advisory Group (PIAG), before collecting patient identifiable data without consent. Now responsibility for approving studies has been delegated to the Ethics and Confidentiality Committee (ECC) which is accountable to the new National Information Governance Board (NIGB).

The powers under Section 251 (S251) of the NHS Act 2006, which replaced Section 60 remain unchanged and will continue to apply to patient data generated in England and Wales. The NIGB, chaired by Harry Cayton, will provide leadership and promote consistent standards and information governance across health and social care.

Along with appropriate ethics approval each BPSU study will still be required to seek approval under the Act in order to collect patient identifiers e.g. NHS number, sex, dob without the need for individual consent.

These are important data for matching and de-duplication of reported cases, as well as subsequent analyses, but are also restricted to minimise or remove the likelihood of identification of any individual case and thus to ensure that only the paediatrician who is treating the child knows the child's identity.

The BPSU had with the support of PIAG developed a fast track process for S251 approval. The application paperwork for this is still valid (http://bpsu.inopsu.com/apply/piag.html) though we plan to update these following discussions with ECC. Applications can also be made using the Integrated Research Application System (IRAS) whilst submitting your ethics documentation.

For advice the ECC secretariat can be contacted directly at Tel: 020 7633 7011 E-mail: eccapplications@nhs.net and the NGIB at E-mail: NIGB@nhs.net

RCPCH Conference

The BPSU contributed to a successful RCPCH conference. The Unit had 6 papers presented which are listed below. Abstracts are available from the BPSU office.

1. Prevalence and clinical features of newly diagnosed congenital adrenal hyperplasia in the UK.
2. Monitoring cancer and death in uninfected children born to HIV-infected women in England and Wales 1996-2006.
3. Incidence of childhood scleroderma in the UK and Ireland.
4. Evaluating the British Paediatric Surveillance Unit: Views from users of the system
5. The British Paediatric Surveillance Unit: A public health evaluation.
6. Leigh syndrome – a familiar phenotype but a disappearing disease?

For the first time the BPSU had a stand in the Exhibition hall. We had an excellent response from those visiting the stand and we appreciated the opportunity to discuss potential projects and exchange information. Thank you for those who took time to come over and chat.

Using the tear off section of the orange card: A reminder

Please remember that if you report a case to note the patients name or other identification on the tear off section of the orange card and keep this to refer back to when you are contacted by the investigator. Please do not return this part of the card to the BPSU office.

British Paediatric Surveillance Unit Report Card

NOTHING TO REPORT ☐

April 2009[0904]
CODE No [13495AB]

Specify in box the number of cases seen

- HIV & AIDS
- Progressive Intellectual & Neurological Deterioration
- Congenital Rubella
- Genital Herpes in Children Under 11 Years (presenting to secondary care)
- Idiopathic Intracranial Hypertension under 17 years
- Congenital Adrenal Hyperplasia (excl. Northern & Republic of Ireland)
- Anaphylaxis following immunisation
- Conversion Disorder
- Sudden unexpected early postnatal collapse
- Toxic Shock Syndrome

Clinicians Section - Please Keep if Necessary
British Paediatric Surveillance Unit Report Card
for cases seen in April 2009
Please NOTE the patient's names(s) or other identification and KEEP THIS SLIP for easy reference when you are contacted by the investigator

Condition	Patient	Hospital No.

DETACH THIS SECTION BEFORE POSTING

Publications & Analysis

Publications:
1. Salotti J A, Nanduri V, Pearce M S, Parker L, Lynn R, Windebank K P. Incidence and clinical features of Langerhans cell histiocytosis in the UK and Ireland. Arch Dis Child; May 2009; 94: 376 – 380.
2. Teo S S S, Riordan A, Alfaham M, Clark J, Evans M R, Sharland M, Novelli V, Watson J M, Sonnenberg P, Hayward A, Moore-Gillon J, Shingadia D, and for the British Paediatric Surveillance Unit Childhood Tuberculosis Study Group
Tuberculosis in the United Kingdom and Republic of Ireland. Arch Dis Child; Apr 2009; 94: 263 - 267.
3. Shield JP, Lynn R, Wan KC, Haines L, Barrett TG. Management and 1 year outcome for UK children with type 2 diabetes. Arch Dis Child; 2009 Mar; 94(3):206-9.
4. Judd A, Ferrand R, Jungmann E, Foster C, Masters J, Rice B, Lyall H, Tookey P, Prime K. Vertically acquired HIV diagnosed in adolescence and early adulthood in the United Kingdom and Ireland: findings from national surveillance. HIV Medicine 2009; 10:253-256.
5. Townsend CL, Willey BA, Cortina-Borja M, Peckham CS, Tookey PA. Antiretroviral therapy and congenital abnormalities in infants born to HIV-infected women in the UK and Ireland, 1990-2007. AIDS 2009; 23:519-524.
6. Riordan A, Judd A, Boyd K, Cliff D, Doerholt K, Lyall H, Menson E, Butler K, Gibb D; Collaborative HIV Paediatric Study. Tenofovir use in human immunodeficiency virus-1-infected children in the United Kingdom and Ireland.

TABLE 1 - % RESPONSE RATE (for 6 months as of May 09)

Region	% rtnd	Rank
North	92.6%	9
Yorks	94.0%	5
Trent	92.4%	10
EAngl	91.7%	11
NWT	89.4%	19
NET	85.2%	20
SET	90.6%	16
SWT	91.4%	12
Wessx	94.1%	4
Oxfrd	93.5%	6
SWest	90.8%	15
WMids	90.3%	17
Mersey	91.1%	14
NWest	93.2%	8
Wales	97.3%	1
NScot	91.3%	13
SScot	94.2%	3
WScot	93.5%	7
NIre	94.5%	2
RIre	89.7%	18
North	92.6%	9
TOTAL	**92.0%**	

TABLE 2 - ALL CASES REPORTED AND FOLLOW-UPS TO MAY 2009

		VALID	INVALID		NYK		as % of total		
Condition	**Started**	**C/R**	**D**	**E**	**X**	**Total**	**C&R**	**D&E**	**X**
HIV/AIDS	1986	5,585	113	676	661	513	75	18	7
CR	1990	64	12	33	31	1	54	45	1
PIND	1997	1530	0	332	722	35	58	40	1
Genital Herpes	2007	17	0	0	9	12	45	24	32
IIH	2007	87	1	28	66	134	28	30	42
CAH	2007	97	0	27	35	67	43	27	30
IS	2008	50	0	17	7	87	31	15	54
AP	2008	0	0	0	0	9	0	0	100
CD	2008	16	1	0	2	88	16	2	82
SUPC	2008	6	0	2	8	28	14	23	64
TSS	2008	13	1	0	6	45	22	9	69
Total		**7465**	**128**	**1115**	**1547**	**1019**	**67**	**24**	**9**

C = confirmed/already known
D = duplicate
E = reporting error or revised diagnosis
X = status not yet reported to BPSU by investigator

HIV	Human immunodeficiency virus in childhood
CR	Congenital rubella
PIND	Progressive intellectual neurological degeneration
IIH	Idiopathic intracranial hypertension
CAH	Congenital adrenal hyperplasia
IS	Intussusception
AP	Anaphylaxis following immunisation
CD	Conversion Disorder
SUPC	Sudden unexpected early postnatal collapse
TSS	Toxic Shock Syndrome

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED