



### Royal College of Paediatrics and Child Health

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

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## Guillain-Barré syndrome/Fisher syndrome Surveillance New study started

This summer saw, in response to the H1N1 pandemic, the setting up of a BPSU fast track committee to deal with potential surveillance enquiries. One such enquiry came from Dr Chris Verity, consultant paediatric neurologist at Addenbrooke's hospital, and his colleagues Lesley Stelitano and Anne Marie Winstone (inset) who proposed surveillance for Guillain Barré Syndrome/Fisher syndrome. With support from the committee they have obtained fast track approval from the relevant statutory bodies leading to a DH funded study appearing on the BPSU September card.



**Background:** Guillain-Barré (GBS) syndrome is an important cause of acute flaccid paralysis worldwide and it is believed that immune stimulation plays a central role in its pathogenesis. Fisher (FS) syndrome was described in 1956 and was thought to be a form of GBS. In some cases the clinical findings have features of both GBS and FS so it was decided to include both conditions in this study.

GBS was an identified risk with swine flu vaccines used in the United States in 1976 – it is thought that 1 extra case of GBS occurred with every 100,000 doses of vaccine. The exact reason why the 1976 vaccine increased the risk of GBS remains unknown. Since then many studies have looked for an association between other influenza vaccines and GBS and no robust evidence of a risk has been found. Recent epidemiological research in the UK found no evidence of an increased risk of GBS after seasonal influenza vaccine but there was an increased risk after influenza like illness. It is therefore possible that even if swine influenza vaccines do cause GBS, this risk may be offset by the protection they offer against influenza itself. Thus, both vaccination and swine influenza illness need to be evaluated as potential risk factors for GBS.

**Objective:** To determine how many new cases of Guillain-Barré syndrome/Fisher syndrome in children and young people (aged 16 years or under) are being seen by paediatricians each month and to determine the proportion of these that are temporally associated with a recent influenza infection or vaccination.

The surveillance was set up in conjunction with a similar adult study undertaken by Professor Elizabeth Miller at the Health Protection Agency (HPA). The HPA team will further enquire about the details of any vaccinations given to the child so that we can identify any temporal association between vaccination and GBS or FS.

**The reporting definition:** Please report any new suspected or confirmed cases of GBS/FS seen in the past month in children under the age of 16 years.

For more details visit: [www.bpsu.inopsu.com/studies/Guillain\\_Barre\\_Syn/index.html](http://www.bpsu.inopsu.com/studies/Guillain_Barre_Syn/index.html)  
Email: [annemarie.winstone@addenbrookes.nhs.uk](mailto:annemarie.winstone@addenbrookes.nhs.uk) or  
[lesley.stelitano@addenbrookes.nhs.uk](mailto:lesley.stelitano@addenbrookes.nhs.uk)

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### Swine Flu

The BPSU has set up a sub-committee, chaired by Dr Richard Pebody from the HPA to fast track the application process of any swine-flu related studies.

For more details please contact Richard Lynn, email: [richard.lynn@rcpch.ac.uk](mailto:richard.lynn@rcpch.ac.uk)

Further College information on swine flu is available at  
[www.rcpch.ac.uk/Policy/Swine-Flu](http://www.rcpch.ac.uk/Policy/Swine-Flu)

## Childhood CNS Inflammatory Demyelination Study Launched



The BPSU study on childhood CNS Inflammatory Demyelination (principal investigator Dr Michael Absoud - inset) launched in September 2009. This UK and Ireland wide study aims to determine childhood CNS inflammatory demyelination incidence, sex and ethnic distribution, age and clinical features at presentation, MRI findings, and short term outcome.

Acquired CNS Inflammatory demyelinating diseases are rare disorders manifesting in childhood but may culminate in physical and cognitive disability or ultimately be diagnosed as Multiple Sclerosis (MS). Children with MS present with a CNS inflammatory demyelinating episode prior to developing a second event (majority usually within two years) to then meet criteria for MS diagnosis. At first presentation children are diagnosed with acute disseminated encephalomyelitis (ADEM), optic neuritis, transverse myelitis, or another clinically isolated syndrome (CIS). It is not clear at the onset of symptoms which children will go on to develop MS.

Evidence from adult studies shows that the incidence and sex ratios of MS are changing and that 5% of MS cases manifest in childhood. Paediatric populations should be in the vanguard of such changes. The incidence of childhood demyelinating disease and MS is unknown, and is the subject of recent international interest and research (International Paediatric MS Study Group, [www.ipmssg.org](http://www.ipmssg.org)). This group recently published consensus definitions of paediatric CNS inflammatory demyelinating disorders to help facilitate uniformity in research. To our knowledge, this will be the first nationwide study since the proposal of new consensus definitions.

In children, for acute CNS inflammatory demyelinating illnesses, and relapses or attacks of MS, corticosteroids are the mainstay of treatment. Important newer disease modifying drugs, such as interferon and glatiramer acetate decrease relapses by modifying the immune system. There appears to be long term benefit in the early initiation of these therapies in adults, however, little is published on their use in children. The determination of the incidence and outcome of the first CNS inflammatory demyelinating episode in children is an essential pre-requisite for the design of future prevention or treatment trials.

Cases will be ascertained by the BPSU and British Ophthalmological Surveillance Unit (BOSU) –. An expert panel will meet on a quarterly basis to review cases and MRIs. Surveillance will be for a 13 month period. Clinicians will be asked to report outcomes using questionnaires sent at one and two years following diagnosis. The study team look forward to hearing of all cases.

For more details visit: [www.bpsu.inopsu.com/studies/CNS\\_ID](http://www.bpsu.inopsu.com/studies/CNS_ID) or email: Dr Michael Absoud, [michael.absoud@bch.nhs.uk](mailto:michael.absoud@bch.nhs.uk)

## New BPSU Chair

The BPSU is delighted to welcome Professor Alan Emond (inset) as its new Chair. Alan is a clinical academic paediatrician, who graduated from Cambridge University in 1977. After training in internal medicine and paediatrics in the UK, Jamaica and Australia he has been working in Bristol, England since 1985. He is Professor of Child Health at the University of Bristol, head of the Centre for Child and Adolescent Health in Bristol and consultant paediatrician at North Bristol Trust and University Hospitals Bristol. His clinical background is in general and community paediatrics, with over 30 years experience of children's medicine and child public health.



Prof Emond's research experience is in epidemiology and health service evaluation, including work on the Avon Longitudinal Study of Parents and Children (ALSPAC-Children of the Nineties), and in clinical trials. He has published widely on child growth and development, and advises the UK government on policy for children. He is an experienced educator, with a special interest in inter-professional teaching and learning. From 2005-9 he was chair of the British Association of Community Child Health (BACCH), the national organisation for community paediatricians in the UK.



In 2003 he set up the Centre for Child and Adolescent Health is a joint initiative between the University of Bristol and the University of the West of England, creating a multi-disciplinary academic group undertaking research and teaching in community child health. Alan is looking forward to working with the BPSU in his new capacity as Chair.

The BPSU Executive Committee (above) would like to thank the outgoing BPSU chair, Allan Colver for all his work for the BPSU over the last 8 years.

## Study News

### Anaphylaxis following immunisation

Anaphylaxis following immunisation is a rare event and it is not surprising that there have been relatively few reports from paediatricians over the last year. There have been 12 reports to date of which 6 have been confirmed. The aim of the study was to describe the clinical presentation, management and clinical pathway taken by children experiencing a reaction. Despite small numbers this will still be the most detailed study of this condition to date, and may identify risk factors that will enhance vaccine safety.

Please continue to report cases that you have seen during the study period. The September 2009 orange card was the last for this study. For more information contact Dr Mich Lajeunesse ([mich.lajeunesse@soton.ac.uk](mailto:mich.lajeunesse@soton.ac.uk)).

### Conversion disorder

The Conversion Disorder study, run jointly with Child and Adolescent Psychiatry Surveillance System (CAPSS) will continue surveillance to December 2009. The study aims to estimate incidence, describe features and presentation, co-morbidities and family psychiatric history. Current management and short-term outcome will also be investigated.

If you have seen a case of conversion disorder from 1 October 2008 which you have not yet reported, please report it with your next orange card. To date we have received 177 notifications from consultant paediatricians, and 169 from consultant psychiatrists. Of these 346 cases reported, 145 questionnaires have been returned, with over 58 confirmed cases.

With over **63% of questionnaires from consultant paediatricians outstanding**, we would be grateful if you could return your completed questionnaires as soon as possible. Please contact the research administrator if you need replacement questionnaires email: [v.james@imperial.ac.uk](mailto:v.james@imperial.ac.uk)

For more information on this study, please contact the Principal Investigator Dr Cornelius Ani: [c.ani@imperial.ac.uk](mailto:c.ani@imperial.ac.uk)

## New Surveillance Units Launched

### Child Adolescent Psychiatry Surveillance System (CAPSS)

May saw the official launch of CAPSS at the Royal College of Psychiatry Research Unit, where it is based. Overseen by an Executive chaired by Dr Dasha Nicholls, CAPSS has been set up in order to facilitate surveillance of rare child and adolescent psychiatric disorders. Based on the BPSU methodology over 600 psychiatrists are now receiving a monthly yellow report card which currently contains conversion disorder (CD) and early onset bipolar disorder. CAPSS card response rate is currently around 65%. Through representation on the Executive the BPSU will work with CAPSS to undertake studies that span the two specialties.

For more information contact [capss@cru.rcpsych.ac.uk](mailto:capss@cru.rcpsych.ac.uk)

or visit: [www.rcpsych.ac.uk/clinicalservicestandards/healthservicesresearch/capss.aspx](http://www.rcpsych.ac.uk/clinicalservicestandards/healthservicesresearch/capss.aspx)

### Scottish Paediatric Surveillance Unit

The ScotPSU aims to examine aspects of the epidemiology of some childhood conditions in Scotland. The system will provide epidemiological data on the prevalence and incidence of individual rare conditions or rare aspects of more common conditions. The unit is funded by the Scottish Paediatric Society and the management board is chaired by Professor Neil McIntosh. Studies under surveillance currently include coeliac disease in under 18 year olds; inflammatory bowel disease; physical signs associated with straddle injury; adverse drug reactions and symptomatic vitamin K deficiency. Reporting will be via a web based facility. Close links will be maintained with the BPSU in order to make sure that systems run smoothly. For further information visit [www.scotpsu.co.uk](http://www.scotpsu.co.uk)

## Bursary Winner

### Sir Peter Tizard Research Bursary – Winner Announced!

The quality of Bursary applications this year was again high. After lengthy discussion at the Executive Committee meeting in June, the bursary was awarded to Dr Hima Avatapalle, SpR's at Sheffield Children's Hospital to undertake a study on Autoimmune Addison's disease of childhood – a UK perspective. Dr Avatapalle will receive up to £15,000 to allow her to run the study and also to attend any training which would enable her to do this more effectively. The BPSU Executive Committee will now work with the winner to develop the appropriate methodology to undertake this study, with the intention of commencing surveillance in 2010.

Thank you to all of those who applied for the bursary. A call for the next bursary will be made in the New Year and details will be posted on our website at [http://bpsu.inopsu.com/home/tizard\\_bursary.html](http://bpsu.inopsu.com/home/tizard_bursary.html)

## BPSU News

### Annual Report

The BPSU 2008-9 has recently been published. The report contains feedback on the current projects underway, includes a detailed section on international activities and the yearly unit analysis. A hard copy of the report has been sent to all those who receive the orange card. The report can also be downloaded from [www.bpsu.inopsu.com](http://www.bpsu.inopsu.com). To increase awareness of the report we encourage you to place this link on your hospital website. A limited number of hard copied can be obtained from the BPSU office. Contact [helen.friend@rcpch.ac.uk](mailto:helen.friend@rcpch.ac.uk)



### New Consultants and Associate Specialities

The BPSU office has recently undertaken an audit of its systems, and this has identified some consultants who may be not receiving the orange cards. We would also like to improve the involvement of associate specialists, as some associate specialists with their own caseloads may be seeing children not known to the consultants, potentially resulting in under-reporting.

If you are a consultant or an associate specialist who does not receive the cards we will be in touch shortly. Alternatively you can email [helen.friend@bpsu.ac.uk](mailto:helen.friend@bpsu.ac.uk) including your hospital postal address, speciality and preferred email and we will add you to the system.

## Analysis

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

Region	% rtd	Rank
North	93.8%	8
Yorks	93.6%	9
Trent	93.0%	10
EAnGl	92.0%	15
NWT	90.3%	18
NET	86.5%	20
SET	92.1%	14
SWT	90.5%	17
Wessx	92.8%	12
Oxfrd	97.0%	1
SWest	94.0%	6
WMids	92.9%	11
Mersy	92.0%	16
NWest	95.3%	4
Wales	95.6%	2
NScot	94.8%	5
SScot	95.3%	3
WScot	92.2%	13
Nlre	94.0%	7
Rlre	89.8%	19
<b>Average</b>	<b>92.9%</b>	

**TABLE 2 - All Cases Reported and Follow-ups to September 2009**

Condition	Started	VALID			INVALID		as % of total		
		C/R	D	E	X	Total	C&R	D&E	X
HIV/AIDS	1986	5,986	705	674	434	7,799	77	18	6
CR	1990	78	33	31	3	145	54	44	2
PIND	1997	1,530	332	723	174	2,759	55	38	6
Genital Herpes	2007	22	2	10	6	40	55	30	15
IIH	2007	88	28	66	185	367	24	26	50
CAH	2007	132	52	31	55	270	49	31	20
IS	2008	50	17	7	87	161	31	15	54
AP	2008	4	0	1	9	14	29	7	64
CD	2008	31	5	2	147	185	17	4	79
SUPC	2008	17	3	13	39	72	24	22	54
TSS	2008	16	5	15	68	104	15	19	65
SNH	2009	10	0	1	13	24	42	4	54
<b>Total</b>		<b>7,964</b>	<b>1,182</b>	<b>1,574</b>	<b>1,220</b>	<b>11,940</b>	<b>67</b>	<b>23</b>	<b>10</b>

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 – Excludes reports from psychiatrists  
SUPC Sudden unexpected early postnatal collapse  
TSS Toxic Shock Syndrome  
SNH Severe Neonatal Hypernatraemia

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED

