

rare



Kids

Australian Paediatric Surveillance Unit NEWSLETTER September 2012

Welcome to the September Edition

As we head into the final quarter of 2012 we would like to take the opportunity to update you on the recent and upcoming activities of the unit and to thank you for your valuable contribution.

In this edition you will find updates on the following:

- The APSU on-line reporting system
- Selected APSU studies
- Grants and funding
- Conferences
- Reports, the website and latest publications.

We hope you enjoy this edition of Rare Kids. We are keen to hear what you think of the newsletter. If you have any comments or suggestions please contact us on apsu@chw.edu.au or call 02 9845 3005.

Thank you for your ongoing support

The APSU Team

APSU On-line Reporting System – NSW Clinicians

The APSU has trialled an on-line reporting system over the last 12 months in NSW. We wish to thank all NSW clinicians for using the on-line reporting system.

The system is undergoing an upgrade and hopefully, we will have an even better on-line reporting system. To minimise disruption during the upgrade period we have temporarily suspended the on-line system and we are working with the developers at the University of Sydney to bring you a better system by the end of the year.

In the meantime we value your feedback! All NSW clinicians who had been using the on-line reporting system have been sent a **blue evaluation report card** asking for your opinion about acceptability of the on-line system.

To date, the majority of comments received have been positive – it seems most clinicians found the system easy to use and not too burdensome. However, only 50% of the blue cards have been returned – we are keen to hear from the other 50% so please return your blue card as soon as possible! Thank you for your continued support!

APSU NEWS

Annual Report

The Annual Report 2009 to 2010 is available for viewing and download on the APSU website www.apsu.org.au

As the APSU will be celebrating 20 years of continued surveillance in 2013, we will be producing a comprehensive report of outcomes and impacts for the 20 year period with a view of launching this report at the International Paediatric Association Congress in 2013.

APSU Website Redevelopment

A new improved APSU website is planned for the beginning of 2013.

We wish to thank the RACP Division of Paediatrics and Child Health for supporting the development of the current site. Unfortunately the RACP are no longer able to support our current website.

If you have any suggestions to improve the website please don't hesitate to contact us at apsu@chw.edu.au or call 02 9845 3005.

During the transition to the new website there may be times when some content is not available. If you have any difficulties accessing or downloading content from our website please contact our office so that we can assist you.

APSU Studies Update

Severe Complications of Influenza

With your help we conducted surveillance for the serious complications of influenza for the 5th consecutive year. To date we have had over 50 notifications of children admitted to hospital with serious complications of influenza including pneumonia, encephalitis and encephalopathy. Five children died. These serious complications have occurred in previously healthy children as well as in those with chronic pre-disposing conditions.

We are still awaiting detailed questionnaires for several notifications. Please forward these as soon as possible. Please also continue to report children with severe complications of laboratory confirmed influenza and admitted to hospital. This surveillance will conclude on the 30th of September.

Neonatal and Infant Herpes Simplex Virus (HSV) Infection - new longer-term follow-up

It is well recognised that herpes simplex virus (HSV) infection in the newborn can be devastating with a high risk of death without treatment. Professor Cheryl Jones and colleagues recently completed a 13- year surveillance study on HSV infection in neonates (< 28 days of life) with the APSU. Key findings of the study were that while the reported incidence and clinical presentation remained relatively unchanged over the study period, the survival of newborn infants had improved. However, this study did not investigate HSV infection in young infants who acquired infection after the first 4 weeks of life. There is evidence to suggest that they too have heightened susceptibility to HSV, but information about how to investigate and manage these infants is limited, and their outcomes including recurrence are unknown. For this reason, we have commenced a new study that now includes all new HSV positive cases in infants up to one year of age through the APSU.

We plan to characterise morbidity in survivors and document the frequency and management of early viral recurrences, and presentations up to 12 months following the first infection. This new knowledge will better inform clinical practice guidelines, and provide further evidence of the efficacy of management and diagnostic changes. The national team of investigators welcome Dr Camille Raynes-Greenow an epidemiologist who has joined the team and will now manage this project.

For further information please contact:

Prof Cheryl Jones Cheryl.jones@health.nsw.gov.au, or

Dr Camille Raynes-Greenow Camille.raynesgreenow@health.nsw.gov.au

Sudden Unexpected Early Neonatal Death or Collapse in Previously Healthy Term Infants in the First 7 Days of Life

Thank you for reporting cases to this important study. In the absence of a population-based register, the APSU study will provide important data on early neonatal deaths in the first 7 days of life. In a recent retrospective review of sudden unexplained death in infants in NSW, 30% occurred in the first 7 days of life. Most definitions of SIDS commence after day 7 or 28 days of life and data collections for SIDS do not adequately capture information about deaths or collapse during the first 7 days of life.

The questionnaire for this study has been shortened by removing some questions. The new versions of the questionnaire will be available on the APSU website shortly. When you report a case of early neonatal death or collapse you will be sent this new version by APSU staff.

If you have any questions about this study please do not hesitate to contact the investigators: Professor Heather Jeffery heather.jeffery@sydney.edu.au or Dr Tracey Lutz lutz.tracey@gmail.com

Studies Concluding at the end of 2013

Subdural Haematoma and Effusion in Children < 2 years:

This study will finish in December 2012.

Food Protein Induced Enterocolitis Syndrome (FPIES):

This study will be reviewed in early 2013 to determine completion time.

Update on Grants and Funding

ARC Linkage Project Grant – Progress to date

The APSU in partnership with the following:
The Children's Hospital at Westmead
Royal Australasian College of Physicians
SMILE Foundation
Steve Waugh Foundation
AGSA (Association of Genetic Support of Australasia)

Have made the following progress in relation to the 3 key project aims:

Aim 1: A survey of families caring for a child with a rare disease will provide information on psychosocial, economic, educational and health and support service needs. Dr Sandra Johnson, has started a PhD on this part of the study. Following ethics approval this survey will be sent to families linked with our Partner Organisations

Aim 2: A survey of Australian paediatricians will highlight current awareness of rare diseases; needs for information about referral pathways and diagnostic and clinical services that can be accessed for their patients; needs for educational materials and opportunities and the preferred way to deliver these. Dr Arancha Gonzalez is the advanced trainee in the RACP Paediatrics and Child Health program and is currently conducting a literature review in relation to the educational needs of paediatricians in relation to rare diseases.

Aim 3: An audit of health service use and economic analysis. We will be analysing service use and costs of admissions and presentations to the Children's Hospital at Westmead for children living with rare diseases. We have developed a partnership with the Genetic Metabolic Disorders Service, the Management Support and Analysis Unit and Medical Records Department at the hospital in order to address this aim. Mr Troy Dalkeith from the Genetic Metabolic Disorders Service at The Children's Hospital at Westmead will be commencing a Masters related to this aim in January 2013. We are currently establishing project data requirements and consulting with health economists.

SMILE Foundation

A review and analysis of health services for children affected by rare diseases: Australian and International perspectives.

This project will be the first to provide a comprehensive description of health services for children with rare diseases in Australia including:

- Mapping available services, their scope and utility and their strengths and weaknesses.
- Detailed case studies of families accessing/using these health services to assist with raising awareness and advocacy.
- An audit of multidisciplinary services for rare diseases overseas and a comparison to models used in Australia

Thank you to the SMILE Foundation (<http://www.smilefoundation.com.au>) for their generous support.

DoHA Chronic Disease Prevention and Service Improvement Fund 2012-2015

APSU has secured funding from the Chronic Diseases Prevention and Service Improvement Fund at the Department of Health and Ageing. The project will address a number of knowledge gaps in the area of rare chronic childhood diseases.

The great majority of these conditions are chronic, continuing through the life-span, complex and disabling, requiring frequent, multidisciplinary, multi-service care. Despite this there are gaps in knowledge on the epidemiology, risk factors and prevention, best clinical practice and need for health and community services for rare chronic conditions of childhood.

The four conditions to be studied include:

- Obesity Hypoventilation Syndrome (OHS)
- Children's Interstitial Lung Disease (ChILD)
- Bronchiectasis and;
- Fetal Alcohol Spectrum Disorders

APSU will study these conditions by performing retrospective medical audits, conducting prospective national surveillance, and conducting surveys of patients/families to generate unique data describing the epidemiology, risk factors, health services use, and psychosocial and financial impacts on families.

In addition we propose to analyse services that support transition from child health services to adult health services for children with rare chronic conditions.

APSU STAFF UPDATE

The APSU would like to welcome its newest staff members. Jennifer Murphy and Jocelyne McRae have taken up the role of PAEDS Coordinator – Research Nurse within the Paediatric Surveillance Program at The Sydney Children's Hospital Network (Westmead).

Jennifer Murphy brings more than 20 years' paediatric nursing experience in clinical, educational and research fields.

Jocelyne has held clinical research appointments in areas including infectious diseases and childhood cancer & holds a Master of Health Science in Clinical Data Management from the University of Sydney. She is currently undertaking a Master of Public Health.

Conferences

RACP Congress – Brisbane 6-9 May 2012

The RACP hosted the Future Directions in Health Congress 2012 at the Brisbane Convention and Exhibition Centre, Queensland from the 6 – 9 May. The congress was attended by well over 1100 delegates including physicians, physician trainees, allied health professionals and industry professionals.

The Australian Paediatric Surveillance Unit showcased 4 presentations in the Paediatrics and Child Health Division.

The session, “You Can’t Always Kiss It Better! The Significance of Child Injury Surveillance Data in Australia and internationally; included:

1. Surveillance for Serious Seatbelt injuries and impacts on Child Restraint Policy in Australia.
A/Prof Yvonne Zurynski
2. Seatbelts in The Crash Lab – Do Parents Understand the Consequences of Using Inappropriate and Incorrect Child Restraints and Seatbelts. *Dr Julie Brown*
3. Subdural Haematoma in Children Aged < 2 years: What is APSU Data Telling us? *Dr Susan Marks*
4. Baby Walkers, Bouncy Swings, and Strollers: International Surveillance for Rare Injuries from Common Baby Products. -
Dr Greta Ridley



International Congress of Pediatrics 2013 (ICP)

The 27th Congress of the International Pediatric Association
“Bridging the Gaps in Child & Adolescent Health
24th – 29th August 2013 Melbourne, Australia.

There will be an **International Network of Paediatric Surveillance Units (INoPSU)** pre-congress workshop on **Saturday 24th August 2013**.

This session will include international speakers who will be presenting outcomes of international data collected by several paediatric surveillance units around the world. INoPSU, chaired by Yvonne Zurynski (APSU) and Danielle Grenier (Canadian Paediatric Surveillance Program) is a network of 10 national paediatric surveillance units which collect data on rare conditions. www.inopsu.com).

For more information please visit the website
(<http://www2.kenes.com/IPA/Pages/home.aspx>)

KEY PUBLICATIONS

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Australian Paediatric Surveillance Unit

Children’s Hospital, Westmead
Cnr Hawkesbury Road and Hainsworth Street,
Westmead, NSW 2145

t 02 9845 3005 f 02 9845 3082

e apsu@chw.edu.au www.apsu.org.au



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