Australian Paediatric Surveillance Unit
Biennial Research Report 2009 and 2010

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The Hon Tanya Plibersek MP
Minister for Health

John Dewey said that what the best and wisest parent wants for their child, society should want for all its children. Good health is first among these desires, and good information is vital to protect and build the health of our children.

The Australian Paediatric Surveillance Unit continues to demonstrate its expertise in collecting data to better understand the extent and impact of uncommon childhood diseases, rare serious complications of common diseases and rare adverse effects of treatment through the engagement of 1,300 paediatricians and other health physicians around Australia.

The APSU has demonstrated the value of a flexible system which can be adapted for potential emerging infectious diseases threatening Australian children. It also provides a platform for rapid response in times of need such as in 2007 when influenza surveillance was added to the APSU data collection following a number of childhood deaths. This in turn allowed the APSU, in 2008, 2009 and 2010, to provide the Australian Government with important paediatric hospitalisation data before, during and after the influenza (H1N1) 2009 pandemic.

The APSU data provides useful clinical and public health insights relating to infectious diseases in Australian children and APSU studies of the impacts of rare diseases on families, clinicians and health services provide important information to policy makers, planners, educators and service providers.

I commend the APSU for and its role in public health and in the health of our children through the long-time success of this important national paediatric surveillance system.

The Hon Tanya Plibersek MP
Minister for Health
Foreword

Dr Gervase Chaney
President, Paediatrics & Child Health Division, RACP

On behalf of the Paediatrics and Child Health Division of the Royal Australasian College of Physicians (RACP), I would like to commend and congratulate the Australian Paediatric Surveillance Unit on this Biennial Research Report 2009 and 2010. The APSU continues to be a leader in paediatric research and evidence in Australia and its growing activity, collaborations and surveillance programs are a testament to its success and status.

The Division and the College are delighted to continue what has been a very successful partnership with the APSU. This has been enhanced by the successful securing of the Australian Research Council (ARC) Linkage Grant by the APSU with the input of the support of the RACP and other partners. In addition the APSU and the RACP have been formalising their relationship with the development of a memorandum of understanding.

It is reassuring to see the ongoing high level of engagement by clinicians with the APSU, with the well over 90% response rate being maintained. This is a reflection of the reputation of the APSU and its contribution to child and youth health among paediatricians and other clinicians.

I was fortunate to be in Warwick at the Royal College of Paediatrics and Child Health Annual Scientific Meeting in April 2011 and enjoy the recognition of the British Paediatric Surveillance Unit at its 25th Anniversary Symposium and celebrations. It was fitting that Elizabeth Elliott was one of the guest speakers – there to present the APSU (Australian) experience. It is clear that the two organisations share much and continue to learn from each other’s experiences and it was very satisfying to see that the APSU is at least the equal of its British predecessor in its scope, outputs and influence.

APSU continues to be very well led by the Director Professor Elizabeth Elliott and Deputy Director Yvonne Zurynski. I would like to again commend them, the other APSU staff, the board and all the researchers and contributors for the ongoing success of APSU and its contribution to the health of children, young people and their families in this country.

Gervase Chaney
President
Paediatrics and Child Health Division
Royal Australasian College of Physicians
Paediatricians are responsible for the ongoing success of the Australian Paediatric Surveillance Unit (APSU) and the quality of surveillance data it collects. Monthly report cards have become a ‘way of life’ for those of us in clinical paediatric practice and a vehicle through which even the most isolated paediatrician can contribute new knowledge about disease epidemiology, influence clinical care, and inform health policy. Paediatricians say they find the educational materials provided by the APSU useful and that monthly reporting is no burden. The latter is reflected in the persistently high reporting rate, for which we are envied internationally.

Over the last few years, the APSU has extended its activities to include leadership in raising awareness of the need for a national plan for rare diseases. A National Rare Disease Working Group convened by APSU in 2008 outlined the principles of a national plan and gained endorsement for a plan from individuals and agencies nationally. With colleagues in Western Australia, APSU planned a national conference on rare disease (Awakening Australia to Rare Diseases) to progress the notion of a plan and a scoping paper on a national plan is soon to be submitted to the Australian Health Ministers Advisory Council. With the National Centre for Immunisation Research, APSU jointly oversees the Paediatric Active Enhanced Disease Surveillance (PAEDS) System, through which data are collected from inpatients in tertiary/quaternary hospitals in four Australian States, with funding from the Department of Health and Ageing. APSU is also represented on the advisory board of the Australian Maternity Outcomes Surveillance System.

APSU has strengthened its relationships with, and contribution to, parent support groups – including the Steve Waugh Foundation (SWF), SMILE Foundation and the Association of Genetic Support for Australasia (AGSA). We are delighted that the Australian Research Council has recently funded a study on the impacts of rare diseases on families, health services and health providers - a collaboration between APSU, SWF, SMILE, AGSA, the Royal Australasian College of Physicians and The Sydney Children’s Hospitals Network. I congratulate Associate Professor Yvonne Zurynski, APSU’s Assistant Director, on her ARC grant, her election to Co-Chair of the International Network of Paediatric Surveillance Units, promotion to Associate Professor. I congratulate the BPSU, the first of the paediatric surveillance units, on their 25th anniversary and was delighted to be asked present the keynote address at their celebration in Warwick.

We are grateful for financial support received from the Department of Health and Ageing and the National Health and Medical Research Council (NHMRC) of Australia for APSU activities. The NHMRC Enabling scheme has now been discontinued and we are currently seeking infrastructure funding to take APSU into its 20th year. I thank the APSU staff for their dedication and members of the Board and Scientific Review Panel for their support, and commend paediatricians for their remarkable ongoing contribution to child health research.

Director, Australian Paediatric Surveillance Unit
Professor, Discipline of Paediatrics and Child Health
The University of Sydney
Foreword

Professor Carol Bower
Board Chair, Australian Paediatric Surveillance Unit

Once again, the APSU Biennial Report clearly demonstrates the clinical and public health value of this unique resource. In infectious disease, the APSU has made a major contribution to being able to declare Australia polio-free, has recorded the effectiveness of rubella and varicella vaccination and has documented the serious consequences of influenza infection in childhood and the need for children with chronic conditions to be vaccinated against influenza. Importantly, data have also been collected to monitor the incidence of intussusception following rotavirus vaccination. Surveillance activities are not limited to infectious diseases. Valuable research on neuromuscular disorders, Rett syndrome, systemic lupus erythematosus, vitamin K deficiency bleeding and seatbelt injuries has been conducted, contributing to our understanding of these conditions and how they can be diagnosed, managed and prevented.

The move to electronic notification, involvement in the development of a rare diseases policy and the extensive community and consumer involvement are additional aspects of the APSU that increase the ease of use and relevance of the surveillance system.

The APSU is a national treasure. Paediatricians can be justly proud of their contribution to it and of the work done by APSU staff and investigators.

Professor Carol Bower
Head of Epidemiology, Division of Population Sciences,
Telethon Institute for Child Health Research,
The University of Western Australia.
Patron

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Professor, School of Paediatrics and Child Health, The University of Western Australia. Director, Telethon Institute for Child Health Research, Perth

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APSU Staff 2009-2010

Professor Elizabeth Elliott, Director (Jan 1993 – )
Associate Professor Yvonne Zurynski, Deputy Director (Feb 2005 – )
Ms Nicole McKay, Data Manager (Apr 2006 – Aug 2011)
Ms Karen Pattinson, Office Manager (Aug 2006 – Jan 2011)
Ms Ingrid Charters, Administration Officer (Oct 2004 – )
Ms Trudy Butlin, Administration Officer (2010 – May 2011)
Ms Sarah Srikanthan, Publications Project Officer (Aug 2007– Apr 2011)
Dr Greta Ridley, Senior Research Officer (Sep 2010 – )
Ms Leanne Vidler, Coordinator, Paediatric Active Enhanced Diseases Surveillance System (June 2009 – Dec 2011)

Ms Kirrilee Drew, Office Manager (Feb 2011 – )
Mr Tim Groenendyk, Publications Project Officer (May 2011 – )
Blanche Baker, Administration Officer (June 2011 – Aug 2011)

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James Fitzpatrick, PhD, Sydney Medical School
Kate Larkins, Honours, Sydney Medical Program
Emily Fitzpatrick, Masters, Sydney Medical Program
Matilda Anderson, Honours Sydney Medical Program
Michael Smith, Honours Sydney Medical Program
Nicola Benwell, Honours Sydney Medical Program
### National Organisations
- Australian Maternity Outcomes Surveillance System (AMOSS)
- Association for Genetic Support Australasia (AGSA)
- Association for the Welfare of Children in Hospitals (AWCH)
- Australia and New Zealand Paediatric Nephrology Association
- Australian CHARGE Association
- Australian Enteric Pathogens Surveillance Scheme
- Australian Polio Expert Committee
- Australasian Paediatric Endocrine Group
- Australian Institute of Health and Welfare
- Australian National University Medical School
- Australian Research Alliance for Children and Youth (ARACY)
- Australian Society of Clinical Immunology and Allergy
- Intergovernmental Committee on Drugs: Working party on FASD
- Commonwealth Department of Health and Ageing
- National Births Anomalies Steering Committee
- National Centre in HIV Epidemiology and Clinical Research
- National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases
- National Heart Foundation of Australia
- National Notifiable Diseases Surveillance System
- National Perinatal Statistics Unit
- National Polio Reference Laboratory
- OzFoodNet: Australian Enhanced Foodborne Disease Surveillance
- WHO Regional Commission for the certification of poliomyelitis eradication
- Rett Syndrome Association of Australia & AussieRett
- Royal Australasian College of General Practitioners (RACGP)
- Royal Australasian College of Physicians, Paediatrics and Child Health Division (RACP)
- SMILE Foundation
- Steve Waugh Foundation

### New South Wales
- Anti-Discrimination Commission of New South Wales
- Child and Adolescent Mental Health Statewide Network (CAMHSNET)
- Centre for Kidney Research
- Centre for Mental Health, New South Wales Health
- Gastroenterology and Liver Unit, Prince of Wales Hospital
- Hunter Genetics
- Institute for Neuromuscular Research
- Liverpool Health Service
- Macleay Hastings Health Service
- Macquarie Group Foundation
- Millennium Institute of Health Research
- NSW Birth Defects Register
- NSW Centre for Perinatal Health Services Research
- NSW Commission for Children
- NSW Department of Health
- NSW Hospitals: Bankstown, John Hunter, Nepean, Royal Prince Alfred, Royal North Shore, Sydney Children’s, Westmead. The Children’s Hospital at Westmead
- Paediatric HIV Services Unit, Sydney Children’s Hospital
- Prince of Wales Medical Research Institute
- The University of Sydney
- The University of New South Wales
- South Eastern Sydney and Illawarra Area Health Service
- South Eastern Area Laboratory Services
- Sydney South West Area Health Service

### Victoria
- Australian Mycobacterium Reference Laboratory Network
- Centre for Adolescent Health, Royal Children’s Hospital
- Victorian Infectious Diseases Reference Laboratory
- Monash Medical Centre
- Murdoch Children’s Research Institute
- Public Health Group, Department of Human Services
- The University of Melbourne
- Victorian Hospitals: Royal Women’s, Royal Children’s, Mercy Hospital

### Queensland
- Queensland Hospitals: Mater Children’s, Princess Alexandra, Royal Children’s
- Queensland University of Technology
- Tropical Public Health Unit
- The University of Queensland

### South Australia
- Flinders Medical Centre
- Institute of Medical Veterinary Science
- Mycobacterium Reference Laboratory, Adelaide
- South Australian Health Commission
- Women’s and Children’s Hospital, Adelaide
- University of Adelaide
- Children Youth and Women’s Health Services

### Western Australia
- Curtin University
- Disability Services Commission
- Pathcentre, Queen Elizabeth II Medical Centre
- Telethon Institute for Child Health Research
- WA Hospitals: King Edward Memorial, Princess Margaret Hospital for Children, Royal Perth

### Tasmania
- Royal Hobart Hospital

### Australia Capital Territory
- Canberra Hospital

### International Organisations
- Canadian Immunisation Monitoring Program Active
- European Organisation for Rare Diseases, Paris, France
- Great Ormond St Hospital, London, UK
- Hospital for Sick Children, Toronto, Canada
- New Zealand Organisation for Rare Diseases
- Oakland Children’s Hospital, USA
- Orphanet, Paris, France
- Rare Diseases, London, UK
- UK Obstetric Surveillance System
- Westkids, Auckland, NZ

### International Network of Paediatric Surveillance Units (INoPSU)
- British Paediatric Surveillance Unit
- Belgian Paediatric Surveillance Unit
- Canadian Paediatric Surveillance Programme
- German Paediatric Surveillance Unit
- Greek Paediatric Surveillance Unit
- Latvian Paediatric Association
- Netherlands Paediatric Surveillance Unit
- New Zealand Paediatric Surveillance Unit
- Portuguese Paediatric Surveillance Unit
- Swiss Paediatric Surveillance Unit
- Republic of Ireland Paediatric Surveillance Unit
- Welsh Paediatric Surveillance Unit
Acknowledgements

Funding and Sponsorships 2009 and 2010

The National Health and Medical Research Council of Australia supports the APSU:

Enabling Grant entitled “Australian Paediatric Surveillance Unit: A collaborative network for child health research” (Grant No. 402784; Principal Investigators: Elliott EJ, Bower C, Kaldor J, Booy R, Sullivan E) and a Practitioner Fellowship: Elliott EJ (Grants Nos. 457084 and 1021480).

Characterisation of H1N1 Influenza 09 in hospitalised children using Paediatric Active Enhanced Diseases Surveillance (grant no. 633028)

The Australian Government Department of Health and Ageing, provides infrastructure support for APSU activities that relate to communicable and vaccine-preventable surveillance and for the Paediatric Active Enhanced Diseases Surveillance system.

The Sydney Medical School, University of Sydney provides in-kind support and is the main fundholder. The APSU Director and Deputy Director are members of the Discipline of Paediatrics and Child Health, Faculty of Medicine.

The Division of Paediatrics and Child Health of the RACP provides support for special projects including production of the bi-ennial report.

The Children’s Hospital at Westmead provides office space, IT services and research infrastructure support for the APSU.

Additional financial supporters for individual surveillance studies include:

- Acute intussusception: CSL Biotherapies, GlaxoSmithKline (GSK).
- Acute rheumatic fever: National Heart Foundation of Australia
- Congenital cytomegalovirus infection: Virology Division, Dept of Microbiology, South Eastern Area Laboratory Service, Sydney Children’s Hospital.
- HIV/AIDS and perinatal exposure to HIV: National Centre in HIV Epidemiology and Clinical Research.
- Neonatal herpes simplex virus infection: Department of Immunology and Infectious Diseases, The Children’s Hospital at Westmead, Herpes Simplex Virus Research Unit.
- Neuromuscular disorders of childhood: Department of Neurology and Neurosurgery, Royal Children’s Hospital, Melbourne.

Mount Majura Wines continues to generously sponsor the APSU wine prize draw.
The APSU

The Australian Paediatric Surveillance Unit (APSU) is a national research resource, established in 1993 to facilitate active surveillance of uncommon childhood diseases, rare serious complications of common diseases or rare adverse effects of treatment. Conditions are chosen for their public health importance and impact on health resources. A range of infectious, vaccine-preventable, mental health, congenital and genetic conditions, and injuries have been studied (Table 1 and Table 8). For many childhood conditions, the APSU provides the only mechanism for national data collection.

To the end of 2010, the APSU has been used by over 300 individual researchers to run 48 surveillance studies. Epidemiological and clinical data collected through the APSU are of direct relevance to clinical and public health policy and resource allocation, and thus impact on the health and welfare of Australian children.¹

The APSU is affiliated with the Division of Paediatrics and Child Health, Royal Australasian College of Physicians (RACP) and the Discipline of Paediatrics and Child Health, Sydney Medical School, the University of Sydney. It is based at The Children's Hospital at Westmead. The APSU Board oversees the management and policy directions of the unit, while the APSU Scientific Review Panel (SRP) determines which studies are suitable to run through the APSU mechanism and provides advice on surveillance methods. The activities of the APSU are funded in part by the Australian Government Department of Health and Ageing (Communicable Disease and Health Risk Policy Section), the Sydney Medical School, The University of Sydney, The National Health and Medical Research Council of Australia (NHMRC Enabling Grant 402784), and other competitive research funding.

Contributors to the APSU

Contributors to the APSU are clinicians working in paediatrics and child health in Australia. Most (about 80%) are general paediatricians with or without a special interest. In addition, 6% are neonatologists, 3.5% are surgeons, 2.6% are geneticists and 2% are emergency physicians. Clinicians are identified through the Division of Paediatrics and Child Health of the RACP, the Australasian Association of Paediatric Surgeons and other paediatric special interest groups. In 2010 an estimated 91% of all paediatricians listed on the RACP list of Fellows and in active clinical practice in Australia participated in APSU surveillance.

Aims of the APSU

1. To provide a national active surveillance mechanism that can be used to:
   • estimate the incidence, epidemiology, clinical features, current management and short-term outcomes of rare childhood conditions in Australia
   • respond to epidemiological emergencies such as outbreaks, emerging or imported diseases.
2. To initiate and facilitate collaborative, national, child health research consistent with national health priorities, including ‘a healthy start in life’ and to fill knowledge gaps.
3. To produce and disseminate evidence that will support development of:
   • the most effective educational resources and clinical guidelines for clinicians
   • the most appropriate prevention strategies and community awareness campaigns.

Operation of the APSU

Individuals or organisations may apply to study a rare condition through the APSU. Applications undergo a process of peer review by the SRP and must have ethical approval from a properly constituted ethics committee before being listed on the monthly report card. All studies must have the potential to contribute significant new knowledge about rare childhood conditions and to influence policy, clinical practice or resource allocation.

Conditions are usually studied for two to three years, although provision for ongoing surveillance may be granted for diseases of particular public health significance or with very low incidence (e.g. HIV/AIDS, congenital rubella).

Each month all clinicians participating in APSU surveillance are sent a report card listing up to 17 different conditions under surveillance and asked to return the report card indicating whether they have seen a case or not. All positive reports of cases generate a brief questionnaire requesting de-identified information about the child’s demographics, details of diagnosis, management and short-term outcome from the clinician. For more detail on APSU methodology please see the APSU website: www.apsu.org.au.

INTERNATIONAL COLLABORATIONS

In October 2010, Yvonne Zurynski represented the APSU at the 6th International Network of Paediatric Surveillance Units (INoPSU) meeting held in Dublin, where eight other countries were represented. Yvonne Zurynski and Danielle Grenier, of the Canadian Paediatric Surveillance Unit (CPSP) were elected co-chairs of INoPSU for the next three years. The co-Chairs are working towards strengthening INoPSU governance and management, increasing the network membership, as well as encouraging publication of international results on conditions that have been recently studied by several national surveillance units, e.g. Early Onset Eating Disorders (Australia, Canada, Britain); Acute Flaccid Paralysis (Australia, Britian, Netherlands, Canada, Germany).

As part of her Creswick Foundation Fellowship, Yvonne Zurynski was able to travel overseas to visit patient organisations which provide support and resources for families who have a child affected by a rare disease: Contact-a-Family; INVOLVE; Rare Diseases UK; Eurodis; and the rare diseases information service for clinicians, Orphanet. A comparison of rare diseases resources, policy, research infrastructure and awareness in Australia and Europe was presented at the 2009 RACP Congress. Given that information about rare diseases for Australian parents and the community is often lacking, the APSU provides patient accessible summaries for conditions studied, including clinical features, links to other information resources, and to support groups if these exist, and educational opportunities for patients. These summaries are available on the APSU website www.apsu.org.au.

SUPPORTING THE DEVELOPMENT OF NEW SURVEILLANCE SYSTEMS

The Paediatric Active Enhanced Disease Surveillance system (PAEDS) is an inpatient surveillance system involving specialist paediatric centres in NSW (the Children’s Hospital at Westmead), VIC (Royal Children’s Hospital, Melbourne), SA (Women’s and Children’s Hospital, Adelaide), and WA (Princess Margaret Hospital, Perth) jointly managed by the APSU and the National Centre for Immunization Research and Surveillance (NCIRS). PAEDS was successfully piloted in 2007 and 2008, and has now received funding to mid 2014 from the Department of Health and Ageing. This allows PAEDS to gather unique linked clinical and laboratory data in hospitalised children which is not available through other surveillance systems. The surveillance focus for PAEDS has been conditions relevant to vaccine preventable diseases or potential adverse events following immunization. (to read more please go to page xx)

APSU supported the development of the Australian Maternity Outcomes Surveillance System (AMOSS) which was launched in June 2009. AMOSS is modelled on APSU methodology and informed by the UK Obstetric Surveillance System (UKOSS). AMOSS is managed by the National Perinatal Statistics Unit and funded by a project grant from the NHMRC. AMOSS aims to provide detailed, systematically collected data on serious but rare outcomes related to birth and pregnancy. Surveillance commenced in the second half of 2009. For more information on AMOSS go to: www.amoss.org.au (check this link)

MAKING APSU REPORTING EASIER FOR CLINICIANS

The number of clinicians reporting via e-mail has increased from 68% in 2008 to 83% in 2010.

In late 2010 APSU received support from the Information and Communication technology department of the University of Sydney under their e-Research platform to develop a web-based reporting system. This has made reporting more efficient for clinicians and for APSU staff who previously had to manually enter 1340 responses into the APSU database each month. The web-based reporting system is currently being trialled in NSW and we plan to roll it out to other states over the next year.
**WORKING WITH FAMILY SUPPORT GROUPS AND CHARITIES**

The APSU helped raise awareness of rare childhood diseases by participating in Rare Diseases Day activities in 2009. The APSU joined the global effort by the National Organization of Rare Diseases (NORD) and the European Organisation for Rare Diseases, Eurodis, who coordinated the day.

In 2010, to mark International Rare Diseases Day, the APSU hosted a Workshop on the 27th of February at the Children's Hospital at Westmead, Sydney with the aim of raising awareness of rare disease impacts and to outline key points to for a national plan for rare diseases in Australia. Workshop attendees supported a coordinated response to rare diseases in Australia and the development of a National Plan. Delegates also supported the need to establish an umbrella organisation for rare diseases in Australia that brings together support groups, researchers and health professionals.

Steve Waugh, the Walker family and Prof Elizabeth Elliott at the “Zebras on the Commons” APSU Rare Diseases Workshop in February 2010

The APSU and the Steve Waugh Foundation collaborated in 2009, to establish the Medical Health Advisory Committee and to develop criteria that the Foundation can apply when making decisions about funding appreciations by families who have a child with a rare disease. Prof Elliott and A/Prof Zurynski serve on this committee. The Steve Waugh Foundation focuses on supporting families who have nowhere else to turn www.stevewaughfoundation.org.au

The APSU also has strong links with the SMILE Foundation which provides emergency grants to families in crisis and supports medical research into rare diseases www.SMILE.org.au . Prof Elliott is serves on the Board of SMILE.

**DEVELOPING A RARE DISEASES PLAN**

Following the publication of a literature review, the APSU convened a National Rare Diseases Working Group in February 2009. This group comprised researchers, child health advocates, clinicians and consumer support groups including: The Steve Waugh Foundation; SMILE Foundation; Association for the Welfare of Children in Hospitals; Association for Genetic Support Australasia; European Organisation for Rare Diseases (Eurodis); New Zealand Organisation for Rare Diseases; Royal Australasian College of Physicians, Paediatrics and Child Health Division; Royal College of General Practitioners; The Children’s Hospital at Westmead; NSW Health; NSW Commission for Children; Australian Research Alliance for Children and Youth (ARACY); and the Anti-discrimination Commission of NSW. With support from a small grant from ARACY, this Working Group and the APSU achieved the following four outcomes:

1. Draft of 8 key points to be addressed by a National Plan for Rare Diseases:
   - Raise awareness of the burden of rare diseases on patients, families, health professionals and the community
   - Provide educational resources and networking opportunities for health professionals to allow them to better identify and manage rare diseases
   - Improve health care for people with rare diseases through access to diagnostic tests, new drugs and other treatments, improved primary care and specialised services
   - Promote research on rare diseases through advocacy for targeted research funds and development of national and international multidisciplinary research partnerships
   - Increase knowledge of the epidemiology and impacts of rare diseases in Australia through research
   - Develop and disseminate information to educate patients, parents, carers and the general public, about rare diseases that is relevant in the Australian context
Major Achievements 2009–2010

- Develop an umbrella organisation to support people affected by any rare disease by linking existing organisations to facilitate the co-ordinated development of integrated peer support networks, contact among families and contact among rare diseases interest groups.
- Advocate to government in partnership with families, for people affected by rare diseases

2. A strategy to attract funding to develop a National Plan for Rare Diseases;
3. A strategy for raising community awareness of International Rare Diseases Day 28\textsuperscript{st} of February 2009;
4. A publication and presentations about the impacts of rare diseases and the need for a national plan.\footnote{Zurynski Y, Beville L, Elliott E. Call for a national plan for rare diseases. J Paediatr Child Health 2010; 46:2–4}

Prof Elizabeth Elliott and A/Prof Yvonne Zurynski participated in the National Organising Committee for Rare Diseases Symposium held in Fremantle WA in April 2011. This symposium brought together national and international experts on rare diseases to meet with parents, researchers, clinicians, policy makers, people living with rare disease and support groups. A strategy for the adoption of a National Plan for Rare Diseases in Australia was set and subsequently operationalized. The National Rare Diseases Coordinating Committee was established and is working towards the further development of a National Plan for Rare Diseases for Australia.

APSU recently secured a highly competitive three year Australian Research Council (ARC) Linkage Grant. The ARC funding will enable Australia to lead the international research effort on rare diseases by using a coordinated approach to study the impacts of rare diseases on children, families, clinicians and health services. Data obtained will improve psychosocial, health and economic outcomes for children and families and will inform the development of new health service models. This grant brings together many partners including the Royal Australasian College of Physicians, The University of Sydney, University of Western Australia, SMILE Foundation, Steve Waugh Foundation and the Association of Genetic Support of Australasia.

INFORMING PUBLIC HEALTH POLICY

Child restraint and seatbelt safety
An APSU study of seatbelt related injuries informed national policy on child restraints by highlighting severe injuries occurring among young children travelling while restrained by adult seatbelts. Reported injuries included abdominal crush injuries, lumbar spine Chance fractures, cervical spine and brain injuries, many of which could have been prevented if the child had travelled in an Australian standards approved car seat or booster seat. Children aged less than 7 are too small to be effectively restrained by an adult seatbelt, where the lap-belt sits on the abdomen rather than the hips and the sash belt sits on the neck rather than shoulder. Furthermore, many of the injured children were misusing their restraint or seatbelt. The new child restraint laws were first introduced in Victoria in xxxx and in NSW in April 2009. All states and territories of Australia now have child restraint laws covering children aged up to 7 years.

Influenza vaccination policy
APSU was able to rapidly respond to the H1N1-2009 Influenza pandemic, having conducted seasonal influenza surveillance since 2007. The APSU protocols were also adapted for use by the PAEDS system during the 2009 pandemic after receiving emergency funding from the NHMRC. Although serious complications occur in children who have underlying chronic conditions very few had been vaccinated for influenza despite this being recommended by the National Immunisation Programme. We also found that even previously healthy children develop serious life threatening complications such as encephalitis, rhabdomyelitis and severe pneumonia due to influenza infection. (These findings informed influenza vaccination policy.

Varicella vaccination policy
The surveillance study of neonatal and congenital varicella showed that the rates of these most serious of outcomes of varicella infection have fallen significantly since the introduction of universal vaccination for varicella in Australia. This finding supports the continuation of the varicella vaccination programme and has raised awareness of the potential benefits of vaccinating for varicella in countries that do not have a varicella vaccination policy.

Alcohol in Pregnancy Policy
Although the APSU surveillance study of Fetal Alcohol Syndrome concluded in 2004, this study raised many questions and acted as impetus for health professional education, informed policy and catalysed new research. A national Alcohol in pregnancy research group was formed and further research included studies on: health professionals attitudes and knowledge regarding alcohol use in pregnancy, women’s knowledge about Fetal Alcohol Spectrum Disorders (FASD), and communication of public health messages about alcohol and pregnancy. Research conducted by the APSU informed the revision of the NHMRC Guidelines on Alcohol use in pregnancy in 2009 and tools for screening and diagnosis have been developed. With the support of the Federal Government. The Lillivian Project aims to determine the prevalence of FASD in the Fitzroy Valley, Kimberley, WA and is providing new insights into the reasons for alcohol use in pregnancy among Aboriginal women and potential strategies for the prevention of FASD in these high risk populations.

<table>
<thead>
<tr>
<th>Conditions Under Surveillance</th>
<th>Dates of Study</th>
<th>Key findings, implications and publications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infectious/vaccine preventable conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute flaccid paralysis (AFP)</td>
<td>Mar 1995–</td>
<td>Surveillance for AFP has a central role in monitoring Australia’s polio-free status. Results of this study support the need for a national approach to ARH/RHD control. The establishment of RHD Australia is a significant step forward to achieving this national approach. This study has supported a proposal by Australian Maternal and Obstetric Surveillance System (AMOSS) which will investigate the existence and impact of RHD in pregnancy. There is a need for improved education for health professionals to support them in recognising and treating ARF as early as possible to prevent the development of valve damage and rheumatic heart disease.</td>
</tr>
<tr>
<td>Acute rheumatic fever (ARF)</td>
<td>Oct 2007–Dec 2010</td>
<td>ARF occurs not only across northern Australia but also in southern states including NSW, Victoria, SA and southern WA, and it occurs in urban settings as well as rural and remote regions. Results from this study support the need for a national approach to ARH/RHD control. The establishment of RHD Australia is a significant step forward to achieving this national approach. This study has supported a proposal by Australian Maternal and Obstetric Surveillance System (AMOSS) which will investigate the existence and impact of RHD in pregnancy. There is a need for improved education for health professionals to support them in recognising and treating ARF as early as possible to prevent the development of valve damage and rheumatic heart disease.</td>
</tr>
<tr>
<td>Congenital cytomegalovirus (cCMV) infection</td>
<td>Jan 1999–</td>
<td>This study continues to inform the ongoing debate about the need for routine screening of mothers and infants for CMV as women tend to be asymptomatic and unaware of their infection, and the majority of infants are asymptomatic at birth and are unlikely to be captured without routine screening. Approximately 13.5% of infected infants will develop permanent sequelae. Despite APSU capturing only a portion of cCMV cases, national surveillance of cCMV remains important in the absence of screening programs and prior to the introduction of therapeutic agents which are currently being developed. The roll-out of newborn hearing screening programs, use of PCR and retrospective analysis of newborn screen cards is likely to lead to the identification of additional cases.</td>
</tr>
<tr>
<td>Neonatal herpes simplex virus infection (HSV)</td>
<td>Jan 1997–</td>
<td>Although the incidence and mode of presentation of neonatal HSV infection has remained relatively similar since 1997, there is a trend to improved survival of infants. One possible explanation for this is that international guidelines have recommended larger doses of antiviral agents (parenteral acyclovir) for longer durations. We have observed that HSV-1 is now the major serotype that causes neonatal HSV disease in Australia, and importantly, adolescent mothers (i.e. less than or equal to 20 years of age) are more likely to transmit genital HSV-1 infection to their newborns than adult mothers.</td>
</tr>
<tr>
<td>HIV/AIDS, perinatal exposure to HIV</td>
<td>May 1993–</td>
<td>HIV infection among children remains a rare occurrence in Australia. The increasing number of reports of perinatal exposure to HIV may be partly attributed to the availability of interventions for minimising the risk of mother-to-child transmission. Complete documentation of the use of interventions is required to provide evidence of their effectiveness in the Australian population.</td>
</tr>
<tr>
<td>Severe complications of influenza</td>
<td>Sep 2007; Jul 2008–Sep 2008; Jun 2009–Sep 2008; Jun 2010–Sep 2010.</td>
<td>Pandemic influenza H1N1 2009 led to many more admissions when compared with the previous and subsequent year. Severe complications, in particular pneumonia and encephalitis were more common in 2009, leading to lengthy hospital stays, PICU admissions and ongoing problems on discharge. There were six deaths in 2009, but only two deaths were reported in 2010. Few children with underlying chronic conditions and eligible for vaccination according to the NIP were vaccinated for seasonal influenza, suggesting the need for education and raising awareness among clinicians and parents. Despite the number of confirmed cases decreasing in 2010, children experienced serious complications including pneumonia and encephalitis.</td>
</tr>
</tbody>
</table>
### Conditions Studied 2009–2010: Key Findings

<table>
<thead>
<tr>
<th>Conditions Under Surveillance</th>
<th>Dates of Study</th>
<th>Key findings, implications and publications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute intussusception (IS)</td>
<td>May 2007–May 2010</td>
<td>The increased risk of IS in relation to rotavirus vaccination is evident in infants &lt;3 months of age that have been shown to develop IS within 1–7 days following one dose of rotavirus vaccination. This risk disappears as age increases in affected children that have received up to three doses of the vaccine. The level of intervention required to resolve IS was similar to that observed in the VAERS data and no deaths occurred as a result of IS.⁹</td>
</tr>
<tr>
<td>Congenital rubella</td>
<td>May 1993–</td>
<td>The one notification received in 2010 highlights the need for immigrant women from countries with poorly developed vaccination programs to be serologically tested for rubella after arrival in Australia and vaccinated where appropriate. Continued vigilance for this rare congenital infection is essential given the seriousness of congenital rubella syndrome which is characterised by deafness, cataracts, growth retardation, mental handicap and cardiac abnormalities.¹⁰</td>
</tr>
<tr>
<td>Congenital varicella</td>
<td>May 2006–</td>
<td>There have been no cases of congenital varicella in recent years, 2008-2010, supporting the effectiveness of the vaccination program in preventing severe outcome due to varicella infection in pregnancy.¹¹</td>
</tr>
<tr>
<td>Neonatal varicella</td>
<td>May 2006–</td>
<td>Our study shows that there has been a significant reduction in the incidence of neonatal varicella in Australia following the introduction of the varicella vaccine to the National Immunisation Program in 2005. Countries considering the routine use of varicella vaccine need to consider both direct and indirect effects (including clinical and economic benefits beyond the neonatal period) of universal varicella vaccination.¹²</td>
</tr>
<tr>
<td>Severe complications of varicella</td>
<td>May 2006–</td>
<td>Despite the inclusion of varicella vaccination on the National Immunisation Program cases of severe complications of varicella continue to be reported, predominately among non-immunised children, 20% of which also had underlying medical conditions.¹³</td>
</tr>
<tr>
<td><strong>Congenital/genetic disorders</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuromuscular disorders of childhood (NMD)</td>
<td>Jan 2007–</td>
<td>The most common forms of neuromuscular disease in childhood are muscular dystrophy, followed by SMA, congenital myopathies and inherited neuropathies. Surprisingly, myotubular myopathy appears to be the most common congenital myopathy in the Australasian population. Increasing focus on epidemiological studies of common and severe diseases such as Duchenne muscular dystrophy (DMD) has led to establishment of a working group which has successfully worked toward establishment of Australasian registries for DMD and SMA, and is now working to establishment of a registry for myotonic dystrophy.¹⁴</td>
</tr>
<tr>
<td>Rett syndrome</td>
<td>May 1993–Apr 1995; Jan 2000–</td>
<td>This study enables continuing enrolment of new cases of Rett syndrome into the Australian Rett Syndrome Database. The Guidelines for Management of Scoliosis in Rett Syndrome will assist clinicians and families working with children with Rett Syndrome.¹⁵ Analytical investigations using data relating to different aspects of the study continue to be undertaken and during 2009/10, 18 articles relating to the study were either published or accepted for publication. Collaborative research between Australia and Israel has identified the brain-derived neurotrophic factor (BDNF) polymorphism as another genetic modifier of Rett syndrome severity.¹⁶</td>
</tr>
<tr>
<td><strong>Other injury/illness</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin K deficiency bleeding (VKDB)</td>
<td>May 1993–</td>
<td>The majority of infants with VKDB had late onset disease and approximately half of them had liver disease. Compared with early/classical disease, ongoing morbidity was more frequent with late onset disease and deaths only occurred in this group. In the period 2005-2010, parents refused consent for Vitamin K administration at birth in 50% the reported cases. There is a need to educate parents about the serious potential consequences of refusing vitamin K at birth.</td>
</tr>
<tr>
<td>Systemic lupus erythematosus</td>
<td>Oct 2009–</td>
<td>This study provides the first estimate of incidence of SLE in Australian children. Despite the rarity of SLE, the incidence of SLE in indigenous children (30% of all reported cases) is much greater than that of the overall population.¹⁷</td>
</tr>
</tbody>
</table>
Conditions Studied 2009–2010: Key Findings

References


13. Ryan MM. Clinical trials for paediatric neuromuscular disorders in the Australian context. Presentation, Awakening Australia to Rare Diseases, Perth Australia 2011.


Response Rates
In 2009, 1329 clinicians participated in the monthly surveillance of 15 conditions, with an overall response rate of 94% (Figure 1). In 2010, 1344 clinicians participated in the monthly surveillance of 17 conditions and the overall response rate was 95% (Figure 1). This maintains the excellent participation level by contributing clinicians since APSU’s inception in 1993. In 2009 and 2010 approximately 83% of clinicians reported by e-mail.

Figure 1. APSU annual response rate (%) 1993-2010

New South Wales (NSW) has the greatest proportion of the national population of children aged less than 15yrs (32.0%), Victoria has 24.1% and Queensland 21.3%. Correspondingly, NSW has the greatest number of participating clinicians. Response rates to the monthly report card have remained high in all states, with ACT and Tasmania recording the highest rates in 2009 and SA and Tasmania recording the highest rates in 2010 (Table 2).

Table 2. Response rates to monthly report card, number of clinicians reporting to the APSU and proportion of all children < 15yrs of age for each state for 2009 and 2010.

<table>
<thead>
<tr>
<th>STATE</th>
<th>RESPONSE RATE (%)</th>
<th>CLINICIANS REPORTING N (%)</th>
<th>NUMBERS AND PROPORTION OF AUSTRALIAN CHILDREN &lt;15yrs N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>96 94</td>
<td>21 ( 1.6) 21 ( 1.6)</td>
<td>64,993 ( 1.6) 46,553 ( 1.1)</td>
</tr>
<tr>
<td>NSW</td>
<td>94 95</td>
<td>501 (37.7) 505 (37.6)</td>
<td>1,345,199 (32.1) 1,355,146 (32.0)</td>
</tr>
<tr>
<td>NT</td>
<td>84 91</td>
<td>18 ( 1.4) 17 ( 1.3)</td>
<td>52,993 ( 1.3) 53,101 ( 1.3)</td>
</tr>
<tr>
<td>QLD</td>
<td>93 93</td>
<td>233 (17.5) 236 (17.6)</td>
<td>886,975 (21.2) 901,542 (21.3)</td>
</tr>
<tr>
<td>SA</td>
<td>94 99</td>
<td>101 ( 7.6) 104 ( 7.7)</td>
<td>291,178 ( 7.0) 293,153 ( 6.9)</td>
</tr>
<tr>
<td>TAS</td>
<td>100 100</td>
<td>22 ( 1.7) 23 ( 1.7)</td>
<td>97,698 ( 2.3) 97,648 ( 2.3)</td>
</tr>
<tr>
<td>VIC</td>
<td>94 94</td>
<td>307 (23.1) 309 (23.0)</td>
<td>1,007,452 (24.1) 1,017,271 (24.1)</td>
</tr>
<tr>
<td>WA</td>
<td>94 96</td>
<td>126 ( 9.5) 129 ( 9.6)</td>
<td>438,600 (10.5) 445,818 (10.5)</td>
</tr>
<tr>
<td>Australia</td>
<td>94 95</td>
<td>1329 (100) 1344 (100)</td>
<td>4,185,598 (100) 4,230,205 (100)</td>
</tr>
</tbody>
</table>

Respondent Workload
Workload continued to be low for most clinicians who participate in APSU surveillance. During 2009 the majority of clinicians (79.5%) had no cases to report and therefore no case questionnaires to complete; 12.9% reported one case, 3.6% reported two cases and 4% reported three or more cases. During 2010, 84.4% of clinicians had no cases to report; 11.5% reported one case, 2.7% reported two and 1.4% reported three or more cases.

Summary of surveillance study results 2009-2010
A summary of the classification of all case reports received for the period 2009-2010 is presented in Table 3. Duplicate reports are identified using the child’s date of birth, first two letters of the first name and first two letters of the surname. After duplicates are identified, all data are completely deidentified and stored securely. Errors include cases that do not meet case definition criteria or administrative errors including ‘report made by mistake’. Case classifications are provided after review by the expert investigators responsible for each surveillance study and are accurate at December 2010. However, it is possible that some notifications may be reclassified at a later date as additional clinical data for existing notifications, or additional notifications, are received.
An estimate of incidence is calculated using the reported number of newly diagnosed cases of disease in a defined population seen by paediatricians in a defined period of time. As 100% case ascertainment is unlikely to be achieved by any one surveillance scheme, ‘reported rate’ is used in this report to represent estimates of minimum incidence. The reported rate of each condition is expressed either as the number of new cases per 100,000 live births per annum (for conditions diagnosed before 12 months of age) or per 100,000 children in the age range specified in the study protocol (Tables 4a and 4b). Population figures for the denominator are obtained from the Australian Bureau of Statistics.

Tables 4a and 4b show the reported rate of conditions studied through the APSU during 2009-2010. For conditions where cases were also ascertained through complementary sources e.g. mandatory reporting systems and laboratory surveillance (including perinatal exposure to HIV, acute flaccid paralysis and Rett syndrome), cases from more than one source have been included to estimate the rate of disease.

* Includes notifications from APSU and other sources (e.g. laboratory). § Includes errors and unclassified cases

Table 4a. Reported rate for each condition studied to December 2009

<table>
<thead>
<tr>
<th>Conditions Under Surveillance</th>
<th>Study period</th>
<th>Duration of study (years)</th>
<th>Total notifications</th>
<th>Questionnaires returned, n (%)</th>
<th>Total confirmed cases for duration of study*</th>
<th>Reported Rate for duration of study (per 10^5 per annum)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Infectious/vaccine preventable conditions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute flaccid paralysis</td>
<td>Mar 1995 ongoing</td>
<td>15</td>
<td>876</td>
<td>809 (92)</td>
<td>557</td>
<td>0.94^[d]</td>
</tr>
<tr>
<td>Acute rheumatic fever</td>
<td>Oct 2007 ongoing</td>
<td>2.5</td>
<td>185</td>
<td>169 (91)</td>
<td>111</td>
<td>1.19^[b]</td>
</tr>
<tr>
<td>Congenital cytomegalovirus infection</td>
<td>Jan 1999 ongoing</td>
<td>11</td>
<td>399</td>
<td>296 (74)</td>
<td>160</td>
<td>5.37^[a]</td>
</tr>
<tr>
<td>Neonatal herpes simplex virus infection</td>
<td>Jan 1997 ongoing</td>
<td>13</td>
<td>233</td>
<td>223 (96)</td>
<td>117</td>
<td>3.35^[a]</td>
</tr>
<tr>
<td>Perinatal exposure to HIV infection</td>
<td>May 1993 ongoing</td>
<td>16.5</td>
<td>595</td>
<td>527 (89)</td>
<td>367</td>
<td>8.26^[a]</td>
</tr>
<tr>
<td>Congenital rubella (with defects)</td>
<td>May 1993 ongoing</td>
<td>16.5</td>
<td>110</td>
<td>106 (96)</td>
<td>51</td>
<td>0.08^[a]</td>
</tr>
<tr>
<td>Congenital varicella</td>
<td>May 2006 ongoing</td>
<td>3.5</td>
<td>12</td>
<td>12 (100)</td>
<td>2</td>
<td>0.19^[a]</td>
</tr>
<tr>
<td>Neonatal varicella</td>
<td>May 2006 ongoing</td>
<td>3.5</td>
<td>26</td>
<td>23 (88)</td>
<td>17</td>
<td>1.58^[a]</td>
</tr>
<tr>
<td>Severe complications of varicella infection</td>
<td>May 2006 ongoing</td>
<td>3.5</td>
<td>58</td>
<td>47 (81)</td>
<td>36</td>
<td>0.24^[a]</td>
</tr>
<tr>
<td><strong>Congenital/genetic disorders</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuromuscular disorders</td>
<td>Jan 2007–Dec 2009</td>
<td>3</td>
<td>386</td>
<td>306 (79)</td>
<td>198</td>
<td>1.49^[a]</td>
</tr>
<tr>
<td>Systemic lupus erythematosus</td>
<td>Oct 2009 ongoing</td>
<td>0.25</td>
<td>7</td>
<td>5 (71)</td>
<td>4</td>
<td>†</td>
</tr>
<tr>
<td>Rett syndrome</td>
<td>Jan 2000 ongoing</td>
<td>10</td>
<td>295</td>
<td>288 (98)</td>
<td>161</td>
<td>0.35^[a]</td>
</tr>
<tr>
<td><strong>Other injury/illness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin K deficiency bleeding</td>
<td>May 1993 ongoing</td>
<td>16.5</td>
<td>142</td>
<td>139 (98)</td>
<td>32</td>
<td>0.72^[a]</td>
</tr>
</tbody>
</table>

* Total confirmed cases according to case definition in the study protocol
a. Reported incidence per 100,000 live births
b. Reported incidence per 100,000 children < 15 years
c. Reported incidence per 100,000 children ≤ 24 months
d. Reported incidence per 100,000 children < 16 years
e. Reported incidence per 100,000 females < 16 years
† Due to limited surveillance period a reported rate cannot be calculated
Table 4b. Reported rate for each condition studied to December 2010

<table>
<thead>
<tr>
<th>Conditions Under Surveillance</th>
<th>Study period</th>
<th>Duration of study (years)</th>
<th>Total notifications</th>
<th>Questionnaires returned, n (%)</th>
<th>Total confirmed cases for duration of study*</th>
<th>Reported Rate for duration of study (per 10⁵ per annum)</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute flaccid paralysis</td>
<td>Mar 1995 ongoing</td>
<td>16</td>
<td>933</td>
<td>866 (93)</td>
<td>598</td>
<td>0.94b</td>
</tr>
<tr>
<td>Acute rheumatic fever</td>
<td>Oct 2007–Dec 2010</td>
<td>3.2</td>
<td>241</td>
<td>223 (93)</td>
<td>151</td>
<td>1.11b</td>
</tr>
<tr>
<td>Congenital cytomegalovirus infection</td>
<td>Jan 1999 ongoing</td>
<td>12</td>
<td>441</td>
<td>339 (77)</td>
<td>191</td>
<td>5.83a</td>
</tr>
<tr>
<td>Neonatal herpes simplex virus infection</td>
<td>Jan 1997 ongoing</td>
<td>14</td>
<td>242</td>
<td>232 (96)</td>
<td>121</td>
<td>3.2a</td>
</tr>
<tr>
<td>Perinatal exposure to HIV infection Perinatal HIV infection</td>
<td>May 1993 ongoing</td>
<td>17.5</td>
<td>681</td>
<td>612 (90)</td>
<td>437</td>
<td>9.22a</td>
</tr>
<tr>
<td>Serious complications of seasonal influenza</td>
<td>Jul 2008–Sep 2008</td>
<td>0.25</td>
<td>42</td>
<td>38 (90)</td>
<td>25</td>
<td>†</td>
</tr>
<tr>
<td>Intussusception</td>
<td>May 2007–May 2010</td>
<td>3</td>
<td>303</td>
<td>245 (81)</td>
<td>163</td>
<td>5.17c</td>
</tr>
<tr>
<td>Congenital rubella (with defects)</td>
<td>May 1993 ongoing</td>
<td>17.5</td>
<td>110</td>
<td>106 (96)</td>
<td>52</td>
<td>0.07d</td>
</tr>
<tr>
<td>Congenital varicella</td>
<td>May 2006 ongoing</td>
<td>4.5</td>
<td>12</td>
<td>12 (100)</td>
<td>2</td>
<td>0.15a</td>
</tr>
<tr>
<td>Neonatal varicella</td>
<td>May 2006 ongoing</td>
<td>4.5</td>
<td>28</td>
<td>24 (86)</td>
<td>18</td>
<td>1.31a</td>
</tr>
<tr>
<td>Severe complications of varicella infection</td>
<td>May 2006 ongoing</td>
<td>4.5</td>
<td>71</td>
<td>59 (83)</td>
<td>45</td>
<td>0.23a</td>
</tr>
<tr>
<td><strong>Congenital/genetic disorders</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systemic Lupus Erythematosus</td>
<td>Oct 2009 ongoing</td>
<td>1</td>
<td>27</td>
<td>23 (85)</td>
<td>20</td>
<td>0.36a</td>
</tr>
<tr>
<td>Rett syndrome</td>
<td>Jan 2000 ongoing</td>
<td>9</td>
<td>302</td>
<td>294 (97)</td>
<td>166</td>
<td>0.35a</td>
</tr>
<tr>
<td><strong>Other injury/illness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin K deficiency bleeding</td>
<td>May 1993 ongoing</td>
<td>17.5</td>
<td>148</td>
<td>145 (98)</td>
<td>34</td>
<td>0.72a</td>
</tr>
</tbody>
</table>

* Total confirmed cases according to case definition in the study protocol
a. Reported incidence per 100,000 live births
b. Reported incidence per 100,000 children < 15 years
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d. Reported incidence per 100,000 children < 16 years
e. Reported incidence per 100,000 females < 16 years
† Due to limited surveillance period a reported rate cannot be calculated
Acute Flaccid Paralysis (AFP)
BR Thorley, M Ryan, E Elliott

**Case Definition:** Any child less than 15 years of age newly diagnosed with acute flaccid paralysis in one or more limbs or acute onset of bulbar paralysis. All cases are reviewed by the National Polio Expert Panel (PEP) and classified as: confirmed poliomyelitis, non-polio AFP, polio-compatible AFP or non-AFP. [AFP cases with lack of clinical information are reported as “polio compatible, zero evidence”].

**Background:** For the complete study protocol including rationale and objectives please see www.apsu.org.au

**Results:** The AFP surveillance system in Australia follows the World Health Organization (WHO) international standard for a polio-free country by focussing on AFP cases in children <15 years of age, the age group at highest risk of poliovirus infection. The APSU and PAEDS systems were used to ascertain cases of AFP in 2009 and 2010 and the notifications from both systems were combined. The surveillance system relies on two information sources for enteroviruses to determine whether poliovirus is the causative agent of AFP: (i) completion of a clinical questionnaire by the clinician who notified the AFP case and (ii) collection of two stool specimens within 14 days of the onset of symptoms for testing at the WHO Victorian Infectious Diseases Laboratory Reference Laboratory (VIDRL). The WHO AFP surveillance performance indicators are (i) one case of AFP per 100,000 children <15 years of age per annum, and (ii) testing of two stool specimens from 80% of the AFP cases. The clinical and laboratory data are reviewed by the Polio Expert Panel, convened by the Department of Health and Ageing, and the final case classifications are reported to the WHO.

In 2009, 48 children were classified as non-polio AFP. This gave an AFP rate of 1.15 per 100,000 children <15 years of age per annum, thus meeting the WHO surveillance performance indicator as a sensitive system to detect an imported case of polio in children. In 2010, 41 children were classified as non-polio AFP and an additional two children as “polio compatible, zero evidence” giving an AFP rate of 1.00 per 100,000 children <15 years of age per annum. It continues to be difficult to meet the WHO surveillance performance indicator for adequate stool specimens. Specimens were referred from 16 children (32%) in 2009 and 12 (29%) in 2010. The most common diagnoses for AFP in 2009 and 2010 were Guillain Barré syndrome in 30 children (33%) and acute disseminated encephalomyelopathy in 12 (13%).

For case classification details and reported rates please see Tables 3 and 4, pages 16–18.

**Study Highlights and Impacts:**
- The AFP surveillance system has a central role in monitoring Australia’s polio-free status.
- The data generated by the surveillance system are referred to the Polio Expert Panel and reported to the Department of Health and Ageing and the World Health Organization.
- Australia has reported an AFP rate of >1.00 per 100,000 children <15 years of age in 2008, 2009 and 2010.

*For more information on the PAEDS system please refer to page 48.

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**Original Articles:**

**Presentations:**
3. Thorley B. Australia’s response to a wild poliovirus importation and Australia’s country report. 16th meeting of the Regional Commission for the Certification of poliomyelitis eradication in the Western Pacific region. Manila, October 2010.
5. Thorley B. Surveillance for poliovirus: wild, vaccine-like and vaccine derived. Alfred Hospital, Melbourne, August 2009.
Acute Rheumatic Fever (ARF) – Final Report
J Carapetis, S Noonan, E Elliott, Y Zurynski, B Currie, McDonald, G Wheaton, D Isaacs, J Ramsay, P Richmond, N Curtis, M Nissen

Case Definition: Any new episode of Acute Rheumatic Fever (even if there is a history of previous episodes) in any child <15 years of age and diagnosed according to the criteria provided by the National Heart Foundation Guidelines for Diagnosis and Management of ARF and RHD.

Background: For the complete study protocol including rationale and objectives please see www.apsu.org.au

Results: During the study period October 2007 to December 2010, 151 cases were confirmed, the majority (64%) from the NT and QLD, where ARF and RHD (Rheumatic heart disease) burden is known to be high, particularly among Indigenous children (see figure). Aboriginal and Torres Strait Islander children represented the majority of cases (87%) however, 5% were Pacific Islanders and 7% were non-Indigenous and non-Pacific Islander. Six of the 10 Caucasian children lived in rural eastern Australia (NSW and south east QLD), the remainder were from suburban Melbourne and Adelaide. The Pacific Islander children tended to be from urban regions. No cases were reported in the ACT or Tasmania. Delays in diagnosis were common and tended to be slightly longer for children living in rural and remote regions. Only 8.7% of children were reported as having recurrent ARF, however, this may be due to the unavailability of a complete medical history or lack of recognition of previous episodes. The median age at diagnosis was 10.2 years.

All children were prescribed secondary penicillin prophylaxis following the ARF illness; 92% were prescribed injections of Benzathine penicillin G, 1% were prescribed twice daily Erythromycin (presumably due to penicillin allergy), and 7% were prescribed twice daily oral penicillin – a therapy known to be less effective mainly due to difficulties with adherence with this regimen.

In addition to the APSU surveillance, audits of admissions for ARF and RHD were conducted at the Children’s Hospital at Westmead (2008-2010) and all cases identified had been reported to the APSU. However, a comparison between APSU cases and notifications to the Queensland Notifiable Diseases database showed that only 62% of locally reported cases had been reported to the APSU. This suggests that there may be systematic under-reporting and that clinicians may be less likely to report cases to the APSU in areas where a mandatory reporting system already exists.

The most common presenting symptoms included carditis, polyarthritis and fever. Skin manifestations such as erythema marginatum and subcutaneous nodules were uncommon.

For case classification details and reported rates please see Tables 3 and 4, pages 16–18.
ARF Study Highlights and impacts:

- This is the first national study of the epidemiology and impacts of ARF in Australian children.
- ARF occurs not only across northern Australia but in southern states including NSW, Victoria, SA and southern WA, and in urban as well as rural and remote regions. Both Indigenous and non-indigenous cases were reported.
- Results from this study support the need for a national approach to ARF control. The establishment of RHD Australia is a significant step towards achieving this national approach. This study has supported a proposal by the Australian Maternity and Obstetric Surveillance System (AMOSS) to investigate the existence and impact of RHD in pregnancy.
- There is a need for improved education for health professionals to support early recognition and treatment of ARF to prevent the development of valve damage and rheumatic heart disease.


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Email: sara.noonan@menzies.edu.au Ph: 08 8132 6311.

Original Articles:

Abstracts:

Presentations:
Congenital Cytomegalovirus Infection (cCMV)

W Rawlinson, G Scott, P Palasanthiran, M Ferson, D Smith, G Higgins, M Catton, A McGregor, D Dwyer, A Kesson, C Jones

Case Definition: **Definite cCMV:** Any child from whom CMV is isolated in the first three weeks of life from urine, blood, saliva or any tissue taken at biopsy. **Suspected cCMV:** Any child up to 12 months of age, in whom CMV is isolated from urine, blood, saliva or any tissue taken at biopsy and/or a positive serum IgM is found and in whom clinical features exist that may be due to intrauterine CMV infection. **Clinical features associated with cCMV infection include:** prematurity, low birth weight, sensorineural deafness, other neurological abnormalities (encephalitis, microcephaly, developmental delay, seizures), microphthalmia, chorioretinitis, cataracts, hepatitis, hepatosplenomegaly, thrombocytopenia, pneumonitis or myocarditis.

**Background:** For the complete study protocol including rationale and objectives please see [www.apsu.org.au](http://www.apsu.org.au).

**Results** Of 94 notifications received in 2009 and 2010, 82 (87%) questionnaires were returned – an improvement on return rates when compared with 2008 (79%). Over the two years, 64 reports met case definition criteria, either definite (60 cases) or suspected (4 cases). Cases were reported from all states and territories except the ACT in 2009 and ACT and Tasmania in 2010. Representing approximately one-third of Australia’s births annually, NSW continues to report the most cases of cCMV (34). In contrast, only six cases were reported from Victoria, which represents one-quarter of Australia’s births annually. Retrospective analysis of blood spots on Newborn Screen cards identified almost half (30) of the infants affected by cCMV, 25 of whom were investigated for sensorineural hearing loss. Twenty-two of these were from NSW. In total, 32 of the 64 infants confirmed with cCMV had hearing loss; 20 of these were identified at more than 30 days old and five were between 12 and 18 months old. Five infants were identified through retrospective analysis of Newborn Screen cards. Eleven infants, all from NSW, received treatment with Ganciclovir in the Newborn period.

For case classification details and reported rates please see Tables 3 and 4, pages 16–18.

**Study Highlights and Impacts:**
- This study continues to inform the ongoing debate about the need for routine screening of mothers and infants for CMV as women tend to be asymptomatic and unaware of their infection, and the majority of infants are asymptomatic at birth and are unlikely to be captured without routine screening.
- Approximately 13.5% of infected infants will develop permanent sequelae1 ~ 50% with hearing impairment.
- There is a need for education and awareness raising among women and health professionals about simple hygiene measures that can be used to prevent vertical transmission of CMV from mother to fetus2,3.
- Given the disproportionate reporting of cCMV cases to birth rates between states, it seems likely that APSU surveillance captures only a portion of cCMV cases nationally.
- Despite likely under-ascertainment through the APSU, national surveillance of cCMV remains important in the absence of screening programs and prior to the introduction of therapeautic agents currently being developed.
- In response to an article published in the *Medical Journal of Australia*, an ABC news report, ‘Doctors urge screenings to prevent cytomegalovirus spread,’ highlighted the need for routine screenings in newborns, and education for doctors.
- The roll-out of newborn hearing screening programs, use of PCR and retrospective analysis of newborn screen cards is likely to lead to the identification of additional cases.

**References:**

**Correspondence to:** Professor William Rawlinson, Virology Division, Department of Microbiology, Prince of Wales Hospitals, High Street, Randwick NSW 2031. Email: w.rawlinson@unsw.edu.au Ph: 02 9382 9113 Fax: 02 9398 4275

**Original Articles:**
Neonatal Herpes Simplex Virus (HSV)
C Jones, D Isaacs, P McIntyre, T Cunningham, S Garland

Case definition: Any child aged ≤28 days (regardless of gestation) with clinical evidence of HSV infection* and either:
- HSV isolated from the baby or
- HSV detected in CSF by PCR in association with CSF pleocytosis or other evidence of HSV encephalitis or
- Specific HSV-IgM detected in baby’s serum or
- Mother seroconverted or IgM positive and baby has typical clinical manifestations or
- HSV isolated from mother around delivery and baby has typical clinical manifestations.

*Clinical manifestations may be localised (herpetic lesions of the skin, eye or mouth) or disseminated including encephalitis, pneumonitis, or hepatitis (manifest by coagulopathy, jaundice, hepatosplenomegaly).

Background: For the complete study protocol including rationale and objectives please see www.apsu.org.au

Results: This study has identified important trends and significant knowledge gaps in the epidemiology, management and outcome of HSV infection in the newborn period. This new knowledge will better inform clinical practice guidelines, and provide indirect evidence of efficacy of treatment, management and diagnostic changes. However, confirmation of these trends requires follow up, and the surveillance study was not adequately designed to characterise morbidity in survivors or to document the frequency or management of early viral recurrences. There is also a paucity of data about both the initial presentation of and recurrences of HSV in early infancy but beyond the neonatal period. This has led to poorly informed management guidelines with inadequate data to inform risks of dissemination and sequelae. In view of this, we propose to commence a new APSU study of HSV infection in neonates and infants to better define the incidence of HSV infection from birth to 12 months of age in Australia and to document management of initial and recurrent infections and outcomes.

For case classification details and reported rates please see Tables 3 and 4, pages 16–18.

Study Highlights and Impacts: 2010 marks 14 years of active surveillance of HSV through the APSU. Although the incidence and mode of presentation of neonatal HSV infection has remained relatively similar over this period, there is a trend for improved survival of infants. One possible explanation for this is that international guidelines recommend larger doses of antiviral agents (parenteral acyclovir) for longer durations. Evaluation of the efficacy of this intervention in a randomised clinical trial remains problematic due to the rarity of the condition. Our national study has documented the uptake of this changed management since 2003 and an associated improvement in short term survival, although a causal relationship between the two findings cannot be proven. The method of diagnosis of neonatal HSV has also changed over the 14 year period, with a move to use of highly sensitive molecular techniques over virus isolation potentially resulting in earlier diagnosis and treatment.

Ongoing surveillance is needed to determine whether new diagnostic methods translate into earlier detection and thus earlier institution of antiviral therapy after infection, which may be an explanation for enhanced survival in recent years. The APSU study also highlights important epidemiological changes in the condition. In the past, HSV-2 was the main cause of genital herpes. However, in recent years there has been an increase in genital herpes in Australia caused by HSV-1. We have observed that HSV-1 is now the major serotype that causes neonatal HSV disease in Australia. Importantly, adolescent mothers (i.e. less than or equal to 20 years of age) are more likely to transmit genital HSV-1 infection to their newborns than older mothers. Differences in the mortality and morbidity between the two HSV serotypes have been reported. We therefore need ongoing surveillance to determine the causes and consequences of this epidemiological change.

Correspondence to: Prof. Cheryl Anne Jones, Head, Centre for Perinatal Infection Research, The Children’s Hospital at Westmead, Locked Bag 4001, Westmead NSW 2145 Email: cheryl.jones@health.nsw.gov.au Ph: 02 9845 3382 Fax: 02 9845 3389.

Original Articles:
HIV Infection, AIDS and Perinatal Exposure to HIV
A McDonald, L Mackey, J Kaldor, J Ziegler, E Elliott, D Wilson

Case definition: Any child under 16 years of age who is found to be HIV antibody positive or have positive virus culture, polymerase chain reaction (PCR) or antigen. It is important that these reports include children born with maternal antibodies even if they are subsequently found not to have HIV infection.

Please report any neonate or child who meets the case definition who you have seen in the last month and have not previously reported to the APSU. This includes both old and new patients, even if they have been reported to the national HIV registry or the national AIDS register.

Background: For complete study protocol including rationale and objectives please see www.apsu.org.au

Results: During 2009 and 2010, there were 123 notifications of perinatal exposure to HIV and 120 (98%) questionnaires were returned. In both years 52 infants reported through the APSU met the criteria for perinatal exposure to HIV. A completed questionnaire was received for almost all cases in both 2009 (98%) and 2010 (97%). HIV infection was diagnosed in eight of 52 (15%) perinatal exposed children in 2009 and in five of 52 (10%) perinatally exposed children reported in 2010. For two cases of paediatric HIV infection reported in 2010, HIV exposure was attributed to medical care in countries other than high HIV prevalence countries.

The mother’s HIV infection was diagnosed prior to or on the date of the child’s birth in 41 of 52 (79%) perinatally exposed children reported in 2009 and in 46 of 52 (88%) perinatally exposed children reported in 2010. Antiretroviral treatment during pregnancy was reported by 35 mothers in 2009 and by 45 mothers in 2010; information on antiretroviral use was not reported for six mothers in 2009 and one mother in 2010. Avoidance of breastfeeding was reported by 31 mothers in 2009 and 43 in 2010, and mode of infant feeding was not reported for 15 mothers in 2009 and two mothers in 2010.

Among children born to mothers whose HIV infection was diagnosed antenatally, no cases of mother-to-child transmission occurred among 41 exposed children in 2009, and one (2%) case was reported among 46 exposed children in 2010. Four cases of mother-to-child transmission among eight children born to mothers whose HIV infection was diagnosed postnatally were reported in 2009. In 2010, no cases of perinatal exposure among children born to mothers whose HIV infection was diagnosed postnatally were reported. Four (67%) and two (33%) cases of mother-to-child transmission among six children seen in 2009 and 2010, respectively, were born to mothers whose date of HIV diagnosis was not reported.

For case classification details and reported rates please see Tables 3 and 4, pages 16–18.

Study Highlights and Impacts: HIV infection among children remains a rare occurrence in Australia. The increasing number of reports of perinatal exposure to HIV may be partly attributed to the availability of interventions for minimising the risk of mother-to-child transmission. Complete documentation of the use of interventions is required to provide evidence of their effectiveness in the Australian population.

Correspondence to: Ms Ann McDonald, National Centre in HIV Epidemiology and Clinical Research, 376 Victoria Street, Darlinghurst, NSW 2010 Email: amcdonald@kirby.unsw.edu.au Ph: 02 9385 0900 Fax: 02 9385 0920.

Surveillance Reports:
Severe Complications of Influenza

Y Zurynski, David Lester-Smith, R Booy, M Festa, A Kesson, E Elliott

**Case definition:** Any child aged <15 years with laboratory confirmed influenza AND admitted to hospital AND with any of the following complications:

- Pneumonia (X-ray confirmed)
- Requirement for ventilation
- Encephalitis / encephalopathy with or without seizures
- Myocarditis; Pericarditis; Cardiomyopathy
- Rhabdomyolysis
- Purpura fulminans
- Disseminated coagulopathy
- Transverse myelitis
- Polyneuritis
- Guillain-Barré
- Shock (requiring >40 ml/kg fluid resuscitation)
- Acute renal failure
- Reye’s Syndrome
- Laboratory proven secondary bacterial infection; Bacteraemia; Septicaemia; Bacterial pneumonia
- Myocarditis; Pericarditis; Cardiomyopathy
- Death
- Exclusion: Simple febrile seizures

**Background:** For complete protocol including rationale and objectives please see [www.apsu.org.au](http://www.apsu.org.au)

**Results:** Surveillance was conducted from June to September in 2009 in response to the H1N1 2009 influenza pandemic. There were 100 confirmed cases: 39 (NSW), 34 (QLD), 9 (VIC), 8 (WA), 5 (SA), 4 (NT) and 1 (TAS). Admissions peaked in the second week of July and earlier than the expected peak for seasonal influenza in most years. The median length of stay was 4 days (range 1-53 days). All children had influenza A: 77 H1N1 2009; six type A but not H1N1; two H3N2 and 15 had an unknown subtype. The median age was 2.8 years (range 0-14.5) and 53% were male. Forty-five per cent of children had an underlying chronic condition. Of these, 39 children were >6 months old and therefore recommended for seasonal influenza vaccination under the National Immunisation Program (NIP). Only two of the 39 had been vaccinated. Sixty-five children received Oseltamivir (Tamiflu). Pneumonia (69%) was the most common complication reported. Thirty children had encephalopathy, nine with associated seizures and two with ongoing neurological problems at discharge. Eleven had a laboratory proven co-infection, five had rhabdomyolysis and five had hypovolaemic shock. Thirty-eight children (median age 5 years; range 0-13) were admitted to PICU with a median length of stay of 6.5 days (range 2-51) and 28 required ventilatory support. Eighteen of the 38 (47%) children had an underlying chronic illness.

Six (6%) children died (age 6.3-12.9 years), and all had influenza A H1N1 2009. Of these, two had an underlying chronic illness, four were admitted to PICU and two required ventilation. None of the deceased had been vaccinated for seasonal influenza. One previously healthy child was discharged home, developed serious pneumonia and died at home two days after discharge.

In 2010, from June to September there were only 25 confirmed cases: 12 (QLD), five (NSW), four (VIC), three (WA) and one (NT). Admissions peaked in the fourth week of August and the median length of stay was seven days (range 1-37 days). Twenty-three children had influenza A: 17 H1N1 2009, one type A but not H1N1, and five were not further subtyped. Two children had influenza B. The median age was 1.7 years (range 0-14.5) and 48% were male. Six (24%) children had an underlying chronic condition. Of those children eligible for vaccination according to the NIP, none had been vaccinated. Only 10 (40%) children received Oseltamivir. Pneumonia (56%) was the most commonly reported complication and six children had laboratory proven co-infection. Five children had encephalopathy, two with associated seizures, three had hypovolaemic shock and three had pericarditis/myocarditis. Eleven (44%) children (median age 5 years; range 0-13) were admitted to PICU with a median length of stay of 15 days (range 3-37) and eight required ventilatory support. Three of the 11 children had an underlying chronic illness. Two (8%) children died. One of these children was an infant with severe congenital heart and lung disease and influenza was unlikely to have been the main cause of death.

*For case classification details and reported rates please see Tables 3 and 4, pages 16–18.*

**Study highlights and Impacts:**

- Pandemic influenza H1N1 2009 led to many more admissions when compared with the previous and subsequent year.
- Severe complications, in particular pneumonia and encephalitis were more common in 2009, leading to lengthy hospital stays, more PICU admissions and ongoing problems on discharge.
- There were six deaths in 2009 during the pandemic, but only two deaths were reported in 2010, however, the proportions were similar in both years.
- Few children with underlying chronic conditions and eligible for vaccination according to the NIP were vaccinated for seasonal influenza, suggesting the need for education and awareness raising among clinicians and parents.
- Despite the number of confirmed cases decreasing in 2010, children experienced serious complications including pneumonia and encephalitis.

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Surveillance Study Reports

Original Articles:

Abstracts:

Presentations:
Acute Intussusception (IS) – Final Report
M Danchin, J Buttery, C Lloyd-Johnsen, D Strong, E Elliott, R Booy, P Richmond, V Krause, S Beggs, M Nissen, M Gold, J Bines, H Cook

Case Definition: Any case of newly diagnosed acute intussusception in any child aged ≤24 months where intussusception is confirmed on air/liquid contrast enema, ultrasound or surgery. If diagnosis is by ultrasound, this should include the demonstration of an intra-abdominal mass by abdominal ultrasound with specific characteristic features (target sign or doughnut sign on transverse section and a pseudo-kidney or sandwich sign on longitudinal section) that are proven to be reduced by hydrostatic enema on post-reduction ultrasound.

Background: For complete protocol including rationale and objectives please see www.apsu.org.au

Results: From May 2007 to May 2010, there were 303 notifications of intussusception and the questionnaire return rate was 81%. There were 163 children confirmed with IS, of which the majority were male (65%). Five (4%) children were identified as indigenous. The mean age at episode was 8.9 months (range: 2.2-24.0). The diagnosis of IS was mostly confirmed by ultrasound (68.5%), the rest by either enema or X-ray or a combination of these examinations. Four cases were diagnosed after surgery. In 40 cases (25%), lead points were identified and overall, no deaths occurred. Fifty-four stool samples were collected; however, results were only available for 42 of these samples. Only one sample was positive for rotavirus and 8 (19%) were positive for adenovirus. Of those that reported on immunisation (129), 84% reported that the child’s immunisation schedule was up to date. Out of 80 cases with complete immunisation data, 47 (44%) children had received a rotavirus vaccine; 14 received the vaccine within 14 days prior to the diagnosis of IS and for seven of these children, it was after the first dose of vaccine (usually three doses given). These children were significantly younger (median age 3.8 months) than those who did not receive a rotavirus vaccine before developing IS (median age 8.9 months).

In 59 (36%) children the IS was resolved using surgical intervention. This is slightly higher than previously reported in an Australian study however lower than other overseas experiences. Among the 14 cases that had received a rotavirus vaccination, six (43%) required surgery and three (21%) required resection. This is comparable to the US Vaccine Adverse Event Reporting System (VAERS) data obtained following RotaTeq vaccination, of which 47% required surgery and 23% required intestinal resection. Although the numbers are small, these vaccine-related cases are occurring in younger infants and the risks associated with surgery are greater.

The number of cases reported to the APSU is likely to be an underestimate. This was recognised at the outset of this study and a separate hospital based surveillance system, the Paediatric Active Enhanced Disease Surveillance (PAEDS) system developed by the APSU and the National Centre for Immunisation Research and Surveillance (NCIRS) was used to identify additional cases (for details on PAEDS please see page 48 in this report). The data from APSU when combined with data from PAEDS showed some evidence of an elevated risk of IS following the first dose of rotavirus vaccines, Rotateq® and Rotarix®. Among the 14 cases that had received a rotavirus vaccine, six (43%) required surgery and three (21%) required resection. This is comparable to the US Vaccine Adverse Event Reporting System (VAERS) data obtained following RotaTeq vaccination, of which 47% required surgery and 23% required intestinal resection. Although the numbers are small, these vaccine-related cases are occurring in younger infants and the risks associated with surgery are greater.

For case classification details and reported rates please see Tables 3 and 4, pages 16–18.

Study Highlights and Impacts:
- The increased risk of IS in relation to rotavirus vaccination is evident in infants <3 months of age that have been shown to develop IS within 1-7 days following one dose of rotavirus vaccination. This risk disappears as age increases in affected children that have received up to three doses of the vaccine.
- The level of intervention required to resolve IS was similar to that observed in the VAERS data and no deaths occurred as a result of IS.

References
Correspondence to: Professor Julie Bines, Dept of Gastroenterology, Royal Children's Hospital, Flemington Road, Parkville, VIC. Ph: 03 9345 4107, Fax: 03 9345 6449.

Original Articles:

Abstracts:

Presentations:
Neuromuscular disorders of childhood (NMD) – Final Report

M Ryan, A Kornberg, P Lamont, K North, P Rowe, K Sinclair

**Case definition:** Any child aged 15 years or less, seen in the previous month with a newly diagnosed, inherited or chronic auto-immune neuromuscular disorder (see table on APSU website: www.apsu.org.au).

Inherited neuromuscular disorder refers to any genetic disorder of the lower motor neuron i.e. disorders of anterior horn cell, motor and/or sensory peripheral nerve, neuromuscular junction or muscle. Chronic auto-immune neuromuscular disorders are acquired immune-mediated disorders of peripheral nerve, neuromuscular junction or muscle, causing permanent or persistent (>3 months duration) symptoms. These disorders include chronic inflammatory demyelinating polyneuropathy (CIDP), myasthenia gravis and dermatomyositis.

**Background:** For complete protocol including rationale and objectives please see www.apsu.org.au

**Results:** During the period 2007-2009, a total of 386 notifications were received with a total of 198 confirmed cases of paediatric neuromuscular disorders. These included 80 infants diagnosed at less than two years of age, 66 children diagnosed at 2-5 years, and 48 children at ages 6-15 years (4 were age-unspecified). Fifty-nine (30%) cases had a positive family history. Eighty-three (42%) presented with a classic ‘floppy infant’ presentation, while 110 (56%) were referred for delayed motor development. Antenatal diagnosis was made in only two cases. Targeted genetic testing was diagnostic in 132 (67%) children. Neurophysiological study was undertaken on 52 children (26%), and 53 (27%) required muscle biopsies for establishment of a specific diagnosis.

Neuromuscular disorders are a relatively common cause of chronic severe illness in childhood. In the Australasian population, spinal muscular atrophy (SMA) (40, 20%) and the muscular dystrophies (71, 36%) are the most common NMDs. Inherited neuropathies are more common than is often recognised - particularly Charcot-Marie-Tooth (CMT) type 1A (25, 13%).

Epidemiological studies such as this are the first step towards natural history and other research studies, and facilitate inclusion of Australasian subjects in multicentre international clinical trials.

For case classification details and reported rates please see Tables 3 and 4, pages 16–18.

**Study Highlights and Impacts:**
- The most common forms of neuromuscular disease in childhood are muscular dystrophy, followed by SMA, congenital myopathies and inherited neuropathies.
- Surprisingly, myotubular myopathy appears to be the most common congenital myopathy in the Australasian population.
- Increasing focus on epidemiological studies of common and severe diseases such as Duchenne muscular dystrophy (DMD) has led to establishment of a working group which has successfully worked toward establishment of Australasian registries for DMD and SMA, and is now working to establishment of a registry for myotonic dystrophy.

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**Presentations:**
3. Ryan MM. Clinical trials for paediatric neuromuscular disorders in the Australian context. Awakening Australia to Rare Diseases, Perth Australia 2011.
Surveillance Study Reports

Rett Syndrome

H Leonard, J Downs, J Christodoulou, C Ellaway, H Woodhead, G Baikie, M Davis

Case definition: A child <16 years age with newly diagnosed or possible Rett syndrome according to the clinical criteria tabled below or by genetic testing.

- Apparently normal prenatal and perinatal history
- Psychomotor development largely normal through the first 6 months or may be delayed from birth
- Normal head circumference at birth
- Postnatal deceleration of head growth in the majority
- Loss of achieved purposeful hand skill between ages 1/2 – 2 1/2 years
- Stereotypic hand movements such as hand wringing/squeezing, clapping/tapping, mouthing and washing/rubbing automatisms
- Emerging social withdrawal, communication dysfunction, loss of learned words, and cognitive impairment
- Impaired (dyspraxic) or falling locomotion

Background: For complete protocol including rationale and objectives please see www.apsu.org.au

Results: The contribution of new cases of Rett syndrome via the APSU to the population-based and longitudinal Australian Rett Syndrome Database has been critical to our recent research on diagnosis, survival, function, comorbidities and genetics. Since the discovery of the association between MECP2 mutation and Rett syndrome in 1999, the median age of diagnosis in Australia has decreased from 4.5 years to 3.5 years. However, a proportion of cases, particularly those with a p.R133C or p.R294X mutation, are still being diagnosed later, suggesting that less typical presentations are more difficult to diagnose. We also compared survival of the original cohort of patients diagnosed by Dr Andreas Rett with those in the Australian Rett syndrome database. Dr Rett’s Austrian patients lived to an average of 13.5 years - only three of the original cohort of 22 are still alive. Nearly 80% of children in our Australian study were still alive at 20 years of age, likely attributable to improved medical care over time.

Data from repeated video recordings in children diagnosed with Rett syndrome suggests that gross motor skills were more likely to be stable over time in females who maintained the ability to walk, and hand function was more likely maintained in the presence of the ability to walk.

Using a cohort study design, we found that children who had surgery for their scoliosis maintained functional skills post-operatively. On average, bone density was lower in females with Rett syndrome than in the general population, especially in those who were less mobile, with epilepsy, or in the presence of the p.R168X or p.T158M mutation. Use of sodium valproate for epilepsy was found to be associated with greater risk of fracture compared with other antiepileptic medications. We advocate the need for active preventive strategies to optimise bone health, especially if sodium valproate is prescribed. Clinical management guidelines for scoliosis have been developed and highlight the need for comprehensive management over the course of childhood. Finally, by combining data in the Australian cohort with Israeli subjects, we have been able to show that the common brain-derived neurotrophic factor (BDNF) polymorphism appears to be another genetic modifier of Rett syndrome severity.

References


For case classification details and reported rates please see Tables 3 and 4, pages 16-18.

Study Highlights and Impacts:

This study enables:

- Continuing enrolment of new cases of Rett syndrome into the Australian Rett Syndrome Database.
- The Guidelines for Management of Scoliosis in Rett Syndrome will assist clinicians and families working with children with Rett Syndrome.
- Analytical investigations using data relating to different aspects of the study continue to be undertaken and during 2009/10, 18 articles relating to the study were either published or accepted for publication.
- An article in The West Australian Newspaper on 28 April 2009, “Mother puts hope in gene therapy for Mikayla”, was in response to one article published after collaborative research was done between Australia and Israel, investigating the effect of a modifier of severity of Rett syndrome other than MECP2 mutation.

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32
Original Articles:


Presentations:

International


24. Helen Leonard How can we be successful and make a difference in international collaborative clinical research; RettSearch Meeting; June 2009, Chicago; United States.
Surveillance Study Reports

25. Jenny Downs InterRett, a model for international data collection in a rare intellectual disability disorder; International Association for the Scientific Study of Intellectual Disability Asia-Pacific Regional Congress; 2009 Singapore


27. Jenny Downs Clinical guidelines for scoliosis and related projects; 3rd RettSearch Consortium Meeting; 2009 Chicago; United States


National


**Congenital Rubella**

C Jones, P McIntyre

**Case Definition:** Any child or adolescent <16 years of age who in the opinion of the notifying paediatrician has definite or suspected congenital rubella, with or without defects, based on history, clinical and laboratory findings.

**Background:** For the complete protocol including rationale and objectives please see [www.apsu.org.au](http://www.apsu.org.au)

**Results:** Childhood vaccination for rubella and maternal antenatal screening has made congenital rubella a rare occurrence in Australia. In 2010, the APSU was notified of an infant with laboratory confirmed congenital rubella born in late 2007 and also identified by the Victorian Department of Health. Similar to the other confirmed cases since 2004, the infant’s mother was born overseas, and had not been vaccinated against rubella. The infant presented at seven weeks of age with bilateral cataracts, and was subsequently found to have a cardiac defect and bilateral sensorineural hearing loss.

*For case classification details and reported rates please see Tables 3 and 4, pages 16-18.*

**Study Highlights and Impacts:**

- The one notification received in 2010 highlights the need for immigrant women from countries with poorly developed vaccination programs to be serologically tested for rubella after arrival in Australia and vaccinated if appropriate.
- Continued vigilance for this rare congenital infection is essential given the seriousness of congenital rubella syndrome which is characterised by deafness, cataracts, growth retardation, mental handicap and cardiac abnormalities.

**Correspondence to:** A/Prof Cheryl Jones, Head. Centre for Perinatal Infection Research Unit, The Children’s Hospital at Westmead, Locked Bag 4001, Westmead NSW 2145 Email: cheryl.jones@health.nsw.gov.au Ph: 02 9845 3382 Fax: 02 9845 3389.

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**Congenital Varicella**


**Case definition:** Any stillbirth, newborn infant, or child <2 years who, in the opinion of the notifying paediatrician has definite or suspected congenital varicella syndrome, with or without defects and meets at least one of the following criteria:

- Cicatricial skin lesions in a dermatomal distribution and/or pox-like skin scars and/or limb hypoplasia
- Development of herpes zoster in the first year of life
- Spontaneous abortion, termination, stillbirth or early death following varicella infection during pregnancy

**Background:** For the complete protocol including rationale and objectives please see [www.apsu.org.au](http://www.apsu.org.au)

**Results:** During 2009-2010 there were three notifications of congenital varicella; one was an error and two had been notified previously (one child in 2006 and the other in 2007). These two cases followed antenatal maternal infection at 12 and 20 weeks respectively. The incidence of congenital varicella 2006-2010 was 0.15/100,000 live births per annum compared to 0.8/100,000 live births per annum (six cases) in 1995-1997, which is a non-significant reduction.

*For case classification details and reported rates please see Tables 3 and 4, pages 16-18.*

**Study Highlights and Impacts:** There have been no cases of congenital varicella reported in 2008-2010, supporting the effectiveness of the vaccination program in preventing severe outcomes due to varicella infection in pregnancy.

**Correspondence to:** Professor Robert Booy, Director, NCIRS, The Children’s Hospital at Westmead. Locked Bag 400, Westmead NSW 2145. Email: robert.booy@health.nsw.gov.au Ph: 02 9845 1415.

**Original Articles:**


**Presentations:**


Neonatal Varicella

Case definition: Any infant who, in the opinion of the notifying paediatrician, has neonatal varicella based on history, clinical and/or laboratory findings in the first month of life without features of congenital varicella syndrome. Features of neonatal varicella infection include pox-like rash which may be papulovesicular, vesiculopustular or haemorrhagic, and fever. Other systemic symptoms may be present. Complications of neonatal varicella include bacterial superinfection, neurological and haematological problems and general visceral involvement. The diagnosis of neonatal varicella can be made when an infant in the first month of life presents with clinical features of varicella infection. There may be a history of maternal varicella infection in the last 1–4 weeks of pregnancy or contact with a varicella infected person after birth.

The diagnosis can be confirmed by laboratory tests to detect:
- viral antigen/viral isolate from scrapings of the skin lesions or viral DNA from lesion fluid
- varicella specific IgM in a serum sample from the infant (or from the contact)

Background: For the complete protocol including rationale and objectives please see www.apsu.org.au

Results: From May 2006 to December 2010, there have been 18 confirmed cases of neonatal varicella with an estimated incidence of 1.31/100,000 live births per annum. The incidence was significantly lower (p=0.000001) during this study period (2006-2010) compared to an incidence of 5.8/100,000 live births per annum reported in 1995-1997 (previous APSU surveillance on neonatal varicella). Furthermore, looking at the incidence for the most recent years (2008 - 2010) the incidence rate was only 0.5/100,000 live births per annum, a reduction of more than 90% compared to both pre-vaccination surveillance (1995-1997) and the first year of the vaccination program (2006).

For case classification details and reported rates please see Tables 3 and 4, pages 16-18.

Study Highlights and Impacts: Our study shows that there has been a significant reduction in the incidence of neonatal varicella in Australia following the introduction of the varicella vaccine to the National Immunisation Program in 2005. Countries considering the routine use of varicella vaccine need to consider both direct and indirect effects (including clinical and economic benefits beyond the neonatal period) of universal varicella vaccination.

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Original Articles:

Presentations:
Severe Complications of Varicella Infection


Case definition: Any child aged 1 month or more, and less than 15 years, hospitalised with varicella AND one or more of the following complications:

- Bacteraemia / septic shock
- Toxic shock syndrome/ toxin mediated disease
- Septic arthritis or other local purulent collection
- Necrotising fasciitis
- Encephalitis
- Purpura fulminans/disseminated coagulopathy
- X-Ray evidence of pneumonia
- Fulminant varicella (multi-organ involvement)
- Reye’s syndrome
- Ataxia

Virological testing: In order to confirm varicella we recommend collection of a sample of vesicle fluid. Please Collect the sample and send to your local laboratory for culture or PCR or IF as per usual practice. The investigators will liaise with your virology laboratory regarding transporting the samples for genotyping.

Background: For the complete protocol including rationale and objectives please see www.apsu.org.au

Results: During the study period (2009-2010) there were 28 reports of severe complications of varicella, and we have received 26 (92.8%) completed questionaries. Among these were 20 confirmed cases, 4 duplicates and 2 errors. The following severe complications of varicella infection were reported during the study period:

- Focal purulent collection (8; 40%)
- Ataxia (5; 25%)
- Toxic shock/toxin mediated disease (5; 25%)
- Bacteraemia/septic shock (4; 20%)
- X-Ray evidence of pneumonia (2; 10%)
- Hepatitis (2; 10%)
- Disseminated coagulopathy (2; 10%)
- Encephalitis (1; 10%)

Of the confirmed cases, 85% were born in Australia. NSW and QLD had the most cases (30% each), followed by Victoria (20%) and Western Australia (10%); whilst Tasmania and South Australia had 5% each. The median age at diagnosis was 6 years (range 1 to 12 years) and 55% were female. Four infants (20%) had underlying medical conditions and none had had a previous varicella infection. The median length of stay (LOS) in hospital was 5 days (range 2 to 40 days). Six children (30%) were admitted to ICU (median LOS 4 days). Two children died. One was a one year old boy who had bacteraemia and sepsis secondary to varicella infection (Genotype A, Africa/Asian strain) was admitted to ICU and treated with Acyclovir, but died after 5 days. The second child was a12 year old boy who developed encephalitis and died of an intra-cerebral haemorrhage. A limited autopsy showed varicella in the CSF.

For case classification details and reported rates please see Tables 3 and 4, pages 16-18.

Study Highlights and Impacts:

- Despite the inclusion of varicella vaccination on the National Immunisation Program cases of severe complications of varicella continue to be reported, predominately among non-immunised children. This highlights the importance of universal vaccination.

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Abstracts:

Vitamin K Deficiency Bleeding (VKDB)

B Jalaludin, K Chant, P Loughnan, L Taylor, E Elliott

Case definition: Any infant <6 months of age with spontaneous bruising/bleeding or intracranial haemorrhage associated with prolonged clotting time, not due to an inherited coagulopathy or disseminated intravascular coagulation.

Background: For complete protocol including rationale and objectives please see www.apsu.org.au

Results: Since 1993, 148 notifications of Vitamin K Deficiency Bleeding (VKDB) have been received and the questionnaire return rate was 98%. There were 34 infants confirmed with definite VKDB and eight with probable VKDB. In 2009, there was one probable case in VIC and in 2010 there were two definite cases, one in VIC and one in WA. The infant confirmed in 2009 had early onset/classical VKDB and had received the recommended 1mg vitamin K IM at birth. This child had mild gastrointestinal bleeding which was resolved after a second dose of Vitamin K on day three of life, and there was no ongoing morbidity. The two infants confirmed in 2010 had late onset VKDB and both had received vitamin K at birth. Both were given a standard dose of Vitamin K at birth (1mg IM). One infant had biliary atresia and suffered an intracerebral haemorrhage and seizures on day three of life and received a dose of Vitamin K when bleeding noted. The second child reported in 2010 died after suffering an intracranial haemorrhage on day 100 after birth. This child received a dose of Vitamin K at birth (1mg IM) and at the time of the cerebral haemorrhage (2.5mg IV).

Of the 42 definite and probable cases, the majority were male (60%). Most (93%) infants were born at term gestation and the majority (93%) were breast fed. Eleven infants (26%) had early onset/classical VKDB and 31 (74%) had late-onset VKDB. The main sites of bleeding in early/classical cases were the gastrointestinal tract (14%), skin (7%), umbilicus (5%) and the Guthrie heel prick site (5%). In late onset cases, the most common bleeding sites were skin (38%), intracranial (24%) and gastrointestinal (21%) and umbilicus (12%). Of the 31 late-onset cases of VKDB, 15 (49%) infants had evidence of underlying liver disease and five infants died. These five infants had intracranial haemorrhage and two had underlying liver disease. Eighteen of the 31 (58%) infants with late onset VKDB received vitamin K at or near birth, however only 11 (36%) received the recommended dose or course of vitamin k prophylaxis. Only two of the five infants with late onset VKDB that died received vitamin K at birth. Eight of the 11 (73%) infants with early/classical VKDB received vitamin K at or near birth, although only two (18%) infants received the recommended dose or course of vitamin K. None of these infants had liver disease or died.

Parents of 15 (38%) infants refused consent to administer Vitamin K at birth over the whole time period; seven out of 14 cases identified since 2005. There was a higher incidence of VKDB (2.63/100,000 live births per annum) during the period when oral administration of vitamin K was recommended (Jan 1993-Mar 1994) compared to VKDB incidence of 0.66/100,000 live births per annum when intramuscular administration was recommended (April 1994 onwards).

For case classification details and reported rates please see Tables 3 and 4, pages 16-18.

Study Highlights and Impacts:
- The majority of infants with VKDB had late onset disease and approximately half of them had liver disease. Compared with early/classical disease, ongoing morbidity was more frequent with late onset disease and deaths only occurred in this group.
- There is still the need to educate parents during the antenatal period about the serious potential consequences of refusing vitamin K administration at birth, with 38% of parents withholding consent during the period 1993-2010 and during 2005-2010, parents refused consent in 50% the reported cases.
- There is also a need for increased awareness among health professionals of clinical recommendations on vitamin K prophylaxis.
- Oral prophylaxis of vitamin K increased the rate of VKDB, particularly late onset disease, however this rate was not significantly different to that observed for IM prophylaxis.

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Surveillance Study Reports

Systemic Lupus Erythematosus
F Mackie, G Kainer, J Munro, K Murray, AR Rosenberg, B Wainstein, J Ziegler, D Singh-Grewal, C Boros, N Adib, R Fahy

Case definition:
Any child ≤ 15 years of age who meets any of the 3 definitions below:
1. Any child ≤ 15 years of age fulfilling the clinical diagnostic criteria for SLE i.e. presenting with 4 or more of the 11 following symptoms:
   1. Malar rash
   2. Discoid rash
   3. Photosensitivity
   4. Oral ulcers
   5. Arthritis
   6. Serositis
   7. Renal disorder
   8. Neurological disorder
   9. Haematological disorder
   10. Immunological disorder
   11. Antinuclear antibody
   OR
2. Any child ≤ 15 years of age who presents with 1 or more of the above clinical features AND a positive antinuclear antibody >1:320.
   OR
3. Any child ≤ 15 years of age who presents with a tissue diagnosis of SLE renal biopsy diagnostic of SLE or skin biopsy consistent with SLE.

Background: For complete protocol including rationale and objectives please see www.apsu.org.au

Results: Cases notified to the APSU from October 2009 to December 2010 were collated and questionnaires regarding presenting symptoms, laboratory investigations, initial treatment, adverse events, ethnicity and geographic location were sent to reporting physicians. In the 12 months, 27 cases were reported (with one error) and completed questionnaires were received in 23 of the 27 cases giving a response rate of 85%. Seventeen fitted the case definition for SLE > 4/11 criteria. Two children fulfilled diagnostic criteria with >1 clinical criteria with antinuclear antibody (ANA) titre >1:320. One child did not meet criteria but had a renal biopsy diagnostic of SLE. Median age at diagnosis was 10.3 years (2.7-14 years); and the female: male ratio was 5.5:1. NSW recorded the most cases (46%), followed by QLD (23%) and then WA, NT, SA and Victoria with one case each. The most common ethnic background was Caucasian (38%) followed by indigenous (30%) and Asian (23%). However, the incidence of SLE for indigenous children was 4.0 per 100 000 <15 years per annum compared to the overall incidence of 0.3 per 100 000 children < 15 yrs per annum. Arthritis was the commonest presenting symptom (9/13) followed by malar or photosensitive rash. Six cases proceeded to renal biopsy with class IV nephritis the most common finding. At presentation, 77% received daily oral prednisone, 38% methylprednisolone, 25% cyclophosphamide, and 50% of patients received hydroxychloroquine. No patients received rituximab initially. The majority of newly diagnosed SLE cases were inpatients (9/13) with an average length of stay of 14 days. There were no deaths but one patient required dialysis and ICU admission. Two experienced significant drug related events: cardiomyopathy from hydroxychloroquine and a rash from ACE inhibitors.

For case classification details and reported rates please see Tables 3 and 4, pages 16-18.

Study Highlights and Impacts: Prior to this initial report there were no data on incidence of SLE in Australia. This study provides the first estimate of incidence of SLE in Australian children. Despite the rarity of SLE in Australian children the incidence of SLE in indigenous children is much greater than that of the overall population.

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Abstracts:
Severe Neonatal Hyperbilirubinaemia or Exchange Transfusion
N Evans, A McGillivray, P Beeby, N Badawai, R Haslam, A Kent, A Watkins, N French, P Gray, P Dargaville

BACKGROUND
There is concern internationally that the number of babies affected by severe neonatal hyperbilirubinaemia may be increasing. Cases of cerebral palsy caused by severe jaundice have been reported with increasing frequency in Europe and North America.1-4 Currently, there is a paucity of accurate severe hyperbilirubinaemia incidence data in Australia and it is of concern that unless this information is gathered urgently an increasing number of Australian children and their families could be affected by athetoid cerebral palsy.

Extremely high circulating levels of unbound bilirubin in the newborn period can have detrimental effects on the developing brain. Kernicterus, or bilirubin encephalopathy may result from severe neonatal hyperbilirubinaemia and cause athetoid cerebral palsy, deafness and paralysis of ocular muscles in surviving infants.1,5,6 Timely recognition and appropriate treatment of newborn babies with hyperbilirubinaemia prevents these sequelae and thus, cases of cerebral palsy due to hyperbilirubinaemia may be preventable.7,8 Reasons postulated for the re-emergence of kernicterus in an age of advanced neonatal care are multifactorial and include: early hospital discharge, inadequate community newborn surveillance and deficiencies in education programs concerning jaundice and its potential consequences among parents and care-providers.8,9 On review of the root cause of 125 cases of kernicterus in the United States, Johnson et al. found that health-system failings included: failure to recognise the significance of early jaundice, failure to institute appropriate monitoring and treatment in addition to inadequate post-discharge follow-up and lactation support.10 We aim to establish in Australia the current incidence of severe neonatal hyperbilirubinaemia and its sequelae including cerebral palsy and to document the underlying causes and associated clinical risk factors. It is anticipated that these data will inform the development of important future prevention strategies such as screening initiatives and education programs for parents, care-providers and health professionals. This study will also inform future improvements to the continuity and co-ordination of newborn care, particularly after hospital discharge. Ultimately, our study strives to inform risk reduction strategies for severe neonatal hyperbilirubinaemia and associated disabilities.

Commenced April 2010.

For complete protocol and questionnaire please see www.apsu.org.au

STUDY OBJECTIVES
The study aims to describe:
- The current incidence of severe neonatal hyperbilirubinaemia in Australia
- The associated diagnosis in affected infants and clinical risk factors
- The type and timing of treatment received
- The short-term* outcomes for each infant

*Long term sequelae including developmental outcome will be determined via a separate study.

REPORTING INSTRUCTIONS
Please report any neonate with severe hyperbilirubinaemia according to the case definition below.

CASE DEFINITION
A newborn infant born after 34 weeks gestation and up to 1 month post-delivery with severe hyperbilirubinaemia defined by:
A total serum bilirubin ≥ 450μmol/L
OR
needing an exchange transfusion for prevention or treatment of bilirubin encephalopathy
OR
clinical and/or MRI imaging evidence consistent with bilirubin encephalopathy

INVESTIGATOR CONTACT DETAILS (*Principle investigator and contact person)
*Associate Professor Nick Evans, Head of Neonatology, Newborn Care, Royal Prince Alfred Hospital, Missenden Rd, Camperdown, NSW 2050
*Dr Angela McGillivray (Clinical Neonatology Fellow and study coordinator/contact person) Tel 0403 786 298 or email: angela.mcgillivray@sswahs.nsw.gov.au
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CO-INVESTIGATORS
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A/Prof Ross Haslam, Women’s and Children’s Hospital, Adelaide, SA
A/Prof Alison Kent, Canberra Hospital, ACT
Dr Andrew Watkins, Mercy Hospital, Melbourne
Dr Noel French, King Edward Maternity Hospital, Perth, WA
Dr Peter Gray, Mater Hospital, Brisbane, QLD
Dr Peter Dargaville, Royal Hobart Hospital, Tasmania
REFERENCES


Subdural Haematoma and Effusion in Children < 2 years

Y Zurynski, S Marks, A Stachurska, R Chaseling, D Tizoumi, A Stephens, C Molly, A Piper, J Bragg, G Cole, M Vonau, P Winterton, G Vimpani

BACKGROUND

Subdural haematoma and effusion (SDH/E) is a rare but significant cause of morbidity and mortality in infancy. SDH/E has been described in neonates after traumatic delivery and in a very small group of infants it has been described prior to birth as a result of trauma in utero. Other causes may include accidental trauma due to falls or motor-vehicle accidents, congenital malformations, inborn errors of metabolism, or coagulopathy.

Studies from overseas and an Australian study based on an audit of admissions to the Children’s Hospital at Westmead, have shown that SDH/E is predominantly due to inflicted non-accidental injury. Hallmark signs include: retinal haemorrhages and the presence of intracranial haemorrhages of different ages. Other intracranial injuries including subgaleal bleeding, intracerebral bleeding, cerebral oedema and axonal shearing injury may also be present. Multiple skeletal injuries are also common and may include fractures or contusions of the ribs, metaphyses of long bones, skull, vertebrae, and almost any other site. History of family disruption, substance abuse and deprivation is commonly reported.

Outcome following SDH/E is poorly reported, but one study suggests that neuro-developmental impairment is likely in at least 20% of survivors, this leading to life-long consequences. In our study, outcome will be determined at the time of discharge and at six months. Such data is likely to support the development of future research including longitudinal cohort studies to determine the longer-term health and social consequences of SDH/E among Australian children.

Paediatric Surveillance Units in Britain and in New Zealand have estimated the incidence of SDH/E in children aged < 2 years at 12.5/100,000 in the United Kingdom and 14.7/100,000 in New Zealand². In a Scottish study of infants aged < 1 year, it was 24.6/100,000. There are no national data on SDH/E in Australian children, and this study will provide the first national estimate of the incidence of SDH/E and its causes. Based on the incidence reported in Britain and in New Zealand, and an estimated Australian population of 563, 800 children aged < 2 years, we expect ~60 cases per year. The case definitions and questionnaires used in our study are based on methods and materials used successfully in Britain and in New Zealand.

International literature recognises the difficulties that face clinicians when considering a diagnosis of inflicted brain injury, and the involvement of child protection teams and child protection statutory agencies. Infants often initially present with no history of injury or a history of only trivial trauma and the true history may only come to light at a later date. Our study will provide information on the presentation and diagnosis of SDH/E to inform clinical practice when investigating young children presenting with signs and symptoms of SDH/E, and may also inform educational materials for clinicians as well as community awareness campaigns to prevent SDH/E.

Commenced July 2010.

For complete protocol and questionnaire please see www.apsu.org.au

STUDY OBJECTIVES

We aim to determine the incidence of SDH/E in Australian children aged < 2 years and to describe the following:

- Causes of SDH/E.
- Demographics of children presenting with SDH/E.
- Presenting symptoms, associated medical conditions and injuries, investigations, treatments and referral patterns.
- Outcome at discharge from hospital and at six months.

CASE DEFINITION & REPORTING INSTRUCTIONS

Please report any child aged <2 years and newly diagnosed with a subdural haematoma or effusion (SDH/E) as confirmed by CT, MRI, head ultrasound, subdural tap or on post-mortem examination.

FOLLOW-UP OF REPORTED CASES

A 2-page questionnaire requesting further details will be forwarded to clinicians who report a case of subdural haematoma/effusion. An additional one page questionnaire will be sent six months after the initial diagnosis to obtain any additional information about the diagnosis and outcome for the child.
INVESTIGATOR CONTACT DETAILS (Principal Investigators and contact person)

A/Prof Yvonne Zurynski, Assistant Director APSU and Senior Lecturer, Faculty of Medicine, University of Sydney, The Children’s Hospital at Westmead, Locked Bag 4001, Westmead NSW 2145, Tel: 02 9845 1202; Fax: 02 9845 3082; email: Yvonne.zurynski@health.nsw.gov.au

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Anne Piper, Child protection Unit, John Hunter Hospital, Newcastle
Judy Bragg, Child at Risk Health Unit, Canberra Hospital
Glen Gole, Ophthalmologist, Royal Children’s Hospital, Brisbane
Marianne Vonau, Paediatric Neurosurgeon, Royal Children’s Hospital, Brisbane
Peter Winterton, Child Protection Unit, Princess Margaret Hospital Perth
Anne Smith, Victorian Forensic Paediatric Medical service, Royal Children’s Hospital, Melbourne
Prof Graham Vimpani, Head, Discipline of Paediatrics and Child Health, University of Newcastle and Medical Director of the Child Protection Team, John Hunter Children’s Hospital, Newcastle.

We acknowledge the support of the RACP Child Protection Special Interest Group in the development of this study.

REFERENCES


### Upcoming studies for 2011-2012

Please go to [www.apsu.org.au](http://www.apsu.org.au) to download all study materials including detailed case definitions and questionnaires.

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<th>Condition approved for study</th>
<th>Commencement date</th>
<th>Study summary</th>
<th>Investigators (<em>Principal investigator</em>)</th>
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<tbody>
<tr>
<td><strong>Cryopyrin-Associated Periodic Syndrome (CAPS)</strong>&lt;br&gt;(Once-off report card only)</td>
<td>June 2011</td>
<td>Cryopyrin-Associated Periodic Syndromes (CAPS) are extremely rare, potentially life threatening auto-inflammatory disorders. Three separate CAPS are recognised: Familial Cold-Auto-Inflammatory Syndrome (FCAS), Muckle Wells Syndrome (MWS) and Neonatal Onset Multi-Inflammatory Disorder (NOMID). The conditions represent a continuum of disease, with FCAS being the mildest and NOMID being the most severe. The disorders are associated with mutations of the NLRP3 gene (also known as CIAS1). However a mutation may be only found in up to 60% of patients, suggesting genetic heterogeneity. Early recognition and treatment with anti-IL-1 receptor antagonists is paramount to preventing joint, hearing and brain injury. This once-off APSU study will estimate the number of cases currently in Australia, and provide detailed information about presentation, treatment, complications and outcomes and will enable correlates between genetic mutations and presenting features.</td>
<td><em>Dr Sam Mehr, Dr Navid Abid, Dr Roger Allen, Dr Christina Boros, Dr Davinder Singh Grewal, Dr Alyson Kakakios, Dr Maurine Rogers, Dr Paul Turner, Dr Yvonne Zurynski</em></td>
</tr>
<tr>
<td><strong>Juvenile Onset Recurrent Respiratory Papillomatosis – JoRRP</strong></td>
<td>October 2011</td>
<td>Juvenile onset Recurrent Respiratory Papillomatosis (JoRRP) is a condition in which benign papillomata develop and recur in the larynx. RRP usually develops in infancy or early childhood (median age - 4 years). It is the most common benign neoplasm of the larynx in children and the second most frequent cause of childhood hoarseness. Common presenting symptoms include: stridor, chronic cough, recurrent pneumonia, failure to thrive, dysphagia and acute respiratory distress in children with upper respiratory tract infection. Asthma, croup and bronchitis need to be excluded before RRP is diagnosed. In about one third of children with RRP the disease spreads into the trachea and bronchi, with the risk of respiratory obstruction. It is currently not known which HPV genotypes are mainly responsible for JoRRP, and whether the current HPV vaccination program will reduce the incidence of JoRRP. The APSU study will enable the collection of detailed data including child and maternal history, symptoms, clinical presentation and treatment of JoRRP in Australia. HPV genotypes will be identified where possible and may inform future vaccine development.</td>
<td><em>Dr Daniel Novakovic, Dr Alan Cheng, Dr Julia Brotherton, A/Prof Yvonne Zurynski, Prof Robert Booy, Prof Elizabeth Elliott, A/Prof Paul Walker, A/Prof Robert Berkowitz, Dr Henley Harrison, A/prof Robert Black, A/Prof Chris Perry, A/Prof Shyan Vijayasekaran, Dr Davud Wabnitz</em></td>
</tr>
<tr>
<td>Condition approved for study</td>
<td>Commencement date</td>
<td>Study summary</td>
<td>Investigators (*Principal investigator)</td>
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<tr>
<td>Food protein induced enterocolitis syndrome – FPIES</td>
<td>January 2012</td>
<td>FPIES is a paediatric non-immunoglobin E mediated allergic disorder triggered by ingestion of certain food protein(s). The majority of children present with their first FPIES episode when less than 12 months of age. The diagnosis of FPIES remains a clinical one, with children presenting typically 2-4 hours after ingestion of a food protein recently introduced into the diet, with profuse vomiting and some subsequently develop diarrhoea. Some children present in a moribund state, with pallor, flippiness, reduced body temperature, hypovolemic shock and/or metabolic acidosis. Early and accurate diagnosis is important to enable appropriate dietary advice and prevention of recurrences. The APSU study will facilitate better understanding of the demographics of affected children, clinical features, causative foods, and clinical practices of clinicians caring for children with FPIES, thereby informing the development of educational materials for clinicians and families.</td>
<td>*Dr Sam Mehr, A/Prof Katie Allen, Prof Dianne Campbell, Dr Katie Frith, A/Prof Michael Gold, Dr Preeti Joshi, A/Prof Alyson Kakakios, A/Prof Richard Loh, A/Prof Peter Smith, A/Prof Mimi Tang, Dr Melanie Wong, A/Prof Yvonne Zurynski, Dr Brynn Wainstein.</td>
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<tr>
<td>Sudden unexpected early neonatal death or collapse in previously healthy term infants in the first 7 days of life</td>
<td>January 2012</td>
<td>The incidence of sudden unexpected and unexplained death or neonatal collapse is reported as between 0.035/1000 to 0.4/1000 live births. Although rare, greater than half of these infants die and the majority of survivors have significant long term neurodevelopmental morbidities. There is currently no National system available in Australia for investigating and reporting these cases. We aim to establish the current incidence of sudden unexplained death or collapse in the early neonatal period (first 7 days of life) in Australia. The APSU study will also enable a detailed description of known risk factors to inform prevention strategies.</td>
<td>*Professor Heather Jeffery Professor Elizabeth Elliott Dr Tracey Lutz, Dr Rod Hunt, Prof Nadia Badawi, Dr David Cartwright, Dr Zsuzsoka Kecskes</td>
</tr>
</tbody>
</table>
### Conditions Studied
Between 1993 and 2010, the APSU has facilitated 47 studies which are listed in Table 8.

#### Table 8. Conditions studied from 1993-2010.

<table>
<thead>
<tr>
<th>Condition under surveillance</th>
<th>Dates of study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Infectious/vaccine preventable conditions</strong></td>
<td></td>
</tr>
<tr>
<td>Acute flaccid paralysis</td>
<td>Mar 1995–</td>
</tr>
<tr>
<td>Acute rheumatic fever</td>
<td>Oct 2007–</td>
</tr>
<tr>
<td>Congenital cytomegalovirus infection</td>
<td>Jan 1999–</td>
</tr>
<tr>
<td>Hepatitis C virus infection</td>
<td>Jan 2003–Dec 2007</td>
</tr>
<tr>
<td>Neonatal herpes simplex virus infection</td>
<td>Jan 1997–</td>
</tr>
<tr>
<td>HIV/AIDS, Perinatal exposure to HIV</td>
<td>May 1993–</td>
</tr>
<tr>
<td>Hospitalised pertussis in infancy</td>
<td>Jan 2001–Dec 2001</td>
</tr>
<tr>
<td>Intussusception</td>
<td>May 2007–</td>
</tr>
<tr>
<td>Invasive <em>haemophilus influenzae</em> infection</td>
<td>Jan 1998–Dec 2000</td>
</tr>
<tr>
<td>Kawasaki disease</td>
<td>May 1993–June 1995</td>
</tr>
<tr>
<td>Non tuberculous mycobacterial infection</td>
<td>July 2004–Sep 2007</td>
</tr>
<tr>
<td>Congenital rubella</td>
<td>May 1993–</td>
</tr>
<tr>
<td>Congenital varicella</td>
<td>May 2006–</td>
</tr>
<tr>
<td>Neonatal varicella</td>
<td>May 2006–</td>
</tr>
<tr>
<td>Severe complications of varicella</td>
<td>May 2006–</td>
</tr>
<tr>
<td><strong>Congenital/genetic disorders</strong></td>
<td></td>
</tr>
<tr>
<td>CHARGE association</td>
<td>Jan 2000–Dec 2002</td>
</tr>
<tr>
<td>Extrahepatic biliary atresia</td>
<td>May 1993–Dec 1996</td>
</tr>
<tr>
<td>Fetal alcohol syndrome</td>
<td>Jan 2001–Dec 2004</td>
</tr>
<tr>
<td>Haemoglobinopathies</td>
<td>July 2004–Mar 2006</td>
</tr>
<tr>
<td>Hirschsprung disease</td>
<td>Jan 1997–Dec 2000</td>
</tr>
<tr>
<td>Hyperinsulinaemic hypoglycaemia of infancy</td>
<td>Jan 2005–Mar 2007</td>
</tr>
<tr>
<td>Neuromuscular disorders of childhood</td>
<td>Jan 2007–Dec 2009</td>
</tr>
<tr>
<td>Primary immunodeficiency disorders</td>
<td>Jan 1997–Dec 1999</td>
</tr>
<tr>
<td>Rett syndrome</td>
<td>May 1993–Apr 1995; Jan 2000–</td>
</tr>
<tr>
<td>Severe combined immunodeficiency</td>
<td>May 1995–Dec 2001</td>
</tr>
<tr>
<td><strong>Mental health issues</strong></td>
<td></td>
</tr>
<tr>
<td>Childhood conversion disorder</td>
<td>Jan 2002–Dec 2003</td>
</tr>
<tr>
<td>Childhood dementia</td>
<td>May 1993–Jun 1995</td>
</tr>
<tr>
<td>Early onset eating disorder</td>
<td>Jul 2002–Jul 2005</td>
</tr>
<tr>
<td>Munchhausen by proxy syndrome</td>
<td>Jan 2000–Dec 2003</td>
</tr>
<tr>
<td><strong>Other injury/illness</strong></td>
<td></td>
</tr>
<tr>
<td>Adverse reactions to complementary and alternative medicines</td>
<td>Jan 2001–Dec 2003</td>
</tr>
<tr>
<td>Anaphylaxis following food ingestion</td>
<td>Jul 2002–Dec 2003</td>
</tr>
<tr>
<td>Near drowning</td>
<td>May 1993–Dec 1996</td>
</tr>
<tr>
<td>Serious seatbelt injuries</td>
<td>Jan 2006–Dec 2007</td>
</tr>
<tr>
<td>Simple vitamin D deficiency rickets</td>
<td>Jan 2006–Aug 2007</td>
</tr>
<tr>
<td>Subdural haematoma and effusion in children</td>
<td>July 2010–</td>
</tr>
<tr>
<td>Systemic lupus erythematosus</td>
<td>Oct 2009–</td>
</tr>
<tr>
<td>Vitamin K deficiency bleeding</td>
<td>May 1993–</td>
</tr>
<tr>
<td>Severe Neonatal Hyperbilirubinemia or Exchange Transfusion</td>
<td>April 2010–</td>
</tr>
</tbody>
</table>
The International Network of Paediatric Surveillance Units (INoPSU) supports “the advancement of knowledge about rare and uncommon childhood infections and disorders through the participation of paediatricians in the surveillance on a national and international basis” and facilitates collaboration and information sharing among 12 active Paediatric Surveillance Units (PSUs) around the world. INoPSU member PSUs communicate regularly via e-mail and a bi-annual face-to-face meeting provides opportunity for networking, and exchange of ideas and experiences of rare disease surveillance.

The 6th Biennial Meeting of INoPSU was held in Dublin, Ireland on the 8th of October 2010, and provided an opportunity for PSUs to present results of surveillance at a special session of the Faculty of Paediatrics Ireland Annual Scientific Conference:

- Surveillance and beyond: the Canadian experience. Danielle Grenier
- Paediatric TB across Europe. Delane Shingadia
- Sexually transmitted infections in children. Richard Reading
- Toxic shock syndrome in children. Shazia Adalat
- Paediatric surveillance of HIV. Karina Butler
- Lead poisoning in children. Dominique Crowley
- Eating disorders in children: are the numbers really increasing? Richard Lynn
- Pandemic influenza H1N1 in children. Yvonne Zurynski
- Fast track surveillance for public health emergencies – is it possible? Anne-Marie Winstone

At the business meeting it was reported that a database which lists all 200 individual conditions that INoPSU units have surveyed, along with the researchers, their contact details and publications has now been established. This will be an invaluable resource to enable collaboration across units. A number of publications are planned, bringing together international data to highlight international comparisons and impacts on clinical and public health policy. Articles will include an international comparison of haemolytic uraemic syndrome and surveillance for acute flaccid paralysis according to WHO guidelines.

A new work programme was also agreed on with the main aim being to increase the profile of INoPSU. Initiatives to do this include collaborating with international organisations for rare diseases such as Orphanet (www.orpha.net) and Eurodis (www.eurordis.org). INoPSU’s profile will also increase through participation in Rare Disease Day activities in February each year as demonstrated by the APSU and CPSP.

A/Prof Yvonne Zurynski from the APSU and Dr Danielle Grenier from the Canadian Paediatric Surveillance Program and were elected as the new INoPSU co-chairs from 2010 to 2013. We look forward to further developments of INoPSU under their leadership. INoPSU acknowledged and thanked Dr Daniel Virella, from the Portuguese Paediatric Surveillance Unit for the leadership he provided, as Convenor of INoPSU for 2008-2010, and Helen Friend and Richard Lynn who provide the administration hub for INoPSU.

All delegates expressed their thanks to Robert Cunney and Sandra Morgan from the Irish Paediatric Surveillance Unit for organising the 2010 Biennial INoPSU meeting and for their generous hospitality.

The Swiss Unit will host the next INoPSU meeting from the 1st to the 3rd of September, 2011 coinciding with the Swiss Paediatric Society Meeting in Montreux, Switzerland.

The 10th meeting of INoPSU is to be held in Australia in 2013 to coincide with the 30th meeting of the International Paediatric Association and APSU’s 20th anniversary. Importantly, 2013 will see INoPSU celebrate 15 years of international paediatric surveillance.
International Network of Paediatric Surveillance Units (INoPSU)

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Although excellent national laboratory and public health surveillance systems are currently operating in Australia, very few provide timely, detailed clinical data or the opportunity for simultaneous collection of biological specimens. To address this gap, the Australian Paediatric Surveillance Unit (APSU) and the National Centre for Immunisation Research and Surveillance (NCIRS) developed a hospital-based active surveillance system: Paediatric Active Enhanced Disease Surveillance (PAEDS) which is modelled on the Canadian Immunisation Monitoring Program Active (IMPAct) system which includes all 12 tertiary care paediatric centres in Canada.

The Australian Department of Health and Aging (DoHA), provided support to enable the implementation and evaluation of the pilot PAEDS network. There are plans to extend the network nationally however, currently there are four paediatric centres in four states participating in PAEDS:

- The Children’s Hospital at Westmead, Sydney, NSW
- The Royal Children’s Hospital Melbourne, Victoria
- The Women’s and Children’s Hospital, Adelaide, SA
- Princess Margaret Children’s Hospital, Perth, WA

Dedicated research teams and surveillance nurses ensure timely and complete case ascertainment, collection of biological samples where relevant, and collection of detailed clinical data which is managed in a central database in the APSU (Figure 3).

One of the major drivers for the PAEDS initiative was a long-standing problem in attaining acceptable rates of reporting of acute flaccid paralysis (AFP), a clinical manifestation of polio virus infection. In order to maintain polio-free certification, Australia must reach the World Health Organisation (WHO) surveillance target of at least one AFP case per 100,000 children aged <15 years per annum, and a stool specimen collection rate of 80% of identified cases. The addition of varicella vaccination to the National Immunization Program in late 2005 prompted surveillance for varicella hospitalizations. Intussusception (IS) has been reported as a potential AEFI following rotavirus vaccination and was therefore included in PAEDS after the introduction of new rotavirus vaccines in Australia. Protocols for AFP, IS and varicella had already been developed and used by APSU in collaboration with teams of expert clinicians and researchers. A protocol for another potential rare AEFI, infantile seizures, was developed by the PAEDS Study Group. Furthermore, with support from an NHMRC special grant PAEDS was able to respond rapidly to the H1N1-2009 pandemic.

Data obtained through PAEDS may inform planning and policy development for diseases soon to become vaccine preventable. Surveillance for hospital admissions allows better assessment of disease severity in determining the need for future vaccines and provides background rates of severe disease enabling assessment of the subsequent impact on severe disease rates after introduction of vaccines into the National Immunisation Program.

Figure 3. The PAEDS mechanism

Data collection: history, immunization status, presentation, treatment, outcome. Biological sample collection, dispatch and follow-up of results. Sample relevant laboratory (e.g. Virology). Database at each hospital. Weekly export of data. Central PAEDS database in APSU. Data extraction and analysis. Reports and Publications.

References:
Journal articles

2010 - 2011


2009


Publications, Presentations and Media Impacts

Books and reports that include APSU data

2010


2009


Abstracts

2010-2011


7. Kesson A, Benwell N, Elliott E. Nor virus infection in hospitalized Australian children. *Clinical Microbiology and Infection* 2010; 16(supp. 2); S49.


Publications, Presentations and Media Impacts

2009


Presentations

2010-2011


5. Elliott EJ. Developing a rare diseases national plan for Australia. Rare Diseases symposium. Awakening Australia to rare diseases: Global perspectives on establishing a coordinated approach to a national plan. Fremantle, 2011.


16. Elliott EJ. Fetal alcohol spectrum disorders. Graduate Diploma of Indigenous Health (Substance Abuse), University of Sydney, October 2010.


32. Zurynski Y. Research gaps and needs in the Australian context. Rare Diseases symposium. Awakening Australia to rare diseases: Global perspectives on establishing a coordinated approach to a national plan. Fremantle, April, 2011.
Publications, Presentations and Media Impacts

2009


Community and Media Impacts

2010-2011

1. AAP. Clinic to target baby alcohol disorders (Elizabeth Elliott). The Australian. June 20, 2011.


10. Kenny, K. Duo wins top professional award. (The Royal Australasian College of Physicians awards the John Sands Medal to Elizabeth Elliott.) The University of Sydney News June 8, 2011.


2009


32. Elliott EJ. Call for centres to deal with 'alcohol' babies. Lateline ABC News. Tuesday, March 17, 2009.


Publications, Presentations and Media Impacts

Workshops and Policy Development

1. Zebras on the Commons – Rare Disease Workshop, Children’s Hospital at Westmead, Sydney, February 2010 (convened and coordinated by APSU).

2. National Plan for Rare Diseases (Draft) www.apsu.org.au

Awards


2. Smith M. Dean’s Summer Scholarship Award, University of Sydney Summer Scholarship Scheme. March 25, 2009.

3. Zurynski Y. Awarded Creswick Foundation Fellowship for travel to Europe, 2009
Clinicians Reporting Cases in 2009

ACT
Paul J Jenkins
Alison Kent
George Malecky
Abdel-Latif Mohamed
Suzanna Powell
Graham J Reynolds

NSW
Susan Adams
Wendy Allen
Rosemary Ambler
Elizabeth Argent
John D Arnold
Nadia Badawi
Robert Booy
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Ian Wilkinson
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Lisa Catherine Worgan
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Anita Lucia D'Aprano
Rosemary E Fahy
Deborah Fearon
Louise Martin
Kathryn Roberts
Annie Whybourne

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Donal B Appleton
Ruth Barker
Christopher Bourke
Richard P B Brown
Anita Cairns
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Richard E Cherry
John Coghlan
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Marse G Crawford
Penelope Cruckshanks
Catherine Dawson
Peter J DeBuse
Timothy John Donovan
Nigel David Dore
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Ronald W James
Helen Liley
Elena J Mantz
Andrea McClade
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Susan Moloney
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Peter C Richmon
Peter W Rowe
Jacqueline M Scurlce
Mary J Sharp
Clinicians Returning 100% Monthly Report Cards in 2009

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Amelia M Herath
Hilary A Holmes
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Habitur Rehan Bhurawala
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(Alise) Bijou Bick
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Robert Booy
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Margot McIver
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Anne Morris
Angela M Morrow
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Craig Munns
David N Murphy
Marea W Murray
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Ranjit Nanra
Kathryn North
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Megan Phelps
Susan Phin
Elizabeth Pickford
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Tamás Révész
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Jacqueline Kaye Schutz
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Neil Smith
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Catherine Marralga
R John H Massie
Catherine McAdam
Zoe McCullum
Joanna McCubbin
Peter N McDougall
Karen McLean
John A McNamara
Kathy McMahon
Neil D McMullin
R B McNeill
David Meldrum
Samuel Menahem
John F Mills
P T Monagle
Martina Morkamp
Margot Nash
Terence M Nolan
M J Nowotny
Frank Oberkland
Shane O'Dea
Anne O'Neill
Carl J Orkin
Greg M Pallas
Chris Pappas
Campbell Paul
George Paxton
Roderic J Phillips
Harley R Powell
Jenny Prioros
Ian D Rawlinson
Dinah S Reddihough
Gehan Roberts
Colin F Robertson
Philip James Robinson
Christine Rodda
Sheryle Rogerson
Robert Roseby
Phillip Rosengarten
Elisa Rough
Margaret Rowell
Braunwyn M Srou"
Clinicians Returning 100% Monthly Report Cards in 2009

Michaela McGregor
Fiona McKenzie
Judy E McMichael
Helen J Mead
Divyas Mehta
Corrado Minutillo
Kevin J Murray
Lakshmi Nagarajan
Rama Naidoo
Murali Narayanan
Flemming H Nielsen
Mark Parker
Aida Partridge
Sheveta T Patel
Sanjay Patole
Dorothy Payne
Bronwyn Peirce
Marianne Phillips
Susan L Prescott
P James S Price
James Ramsay
Christianne Remke
Steven Resnick
Peter C Richmond
David E Roberts
Peter W Rowe
Andrew Neil Savery
Mary J Sharp
Aris Siafakakis
Peter J Silberstein
Desiree Silva
M Slattery
Jennie Slee
Aide Smit
Colin Somerville
Johana Stefan
Russell G Troedson
Jack B Vercoc
Iain R Walpole
Michael Watson
Amanda Wilkins-Shurmer

ACT
Alison Kent
Abdel-Latif Mohamed
NSW
Wendy Allen
Jacqueline Kay Andrews
Nadia Badawi
Philip J Beeby
Gilda B Bonacruz-Kazi
Adam Buckmaster
Kathryn Carmon
Jeffrey Chaitow
Raymond Chaseling
Robin K C Choong
Paul Craven
Russell Dale
John A De Coursy
Mark De Souza
Barry John Duffy
Anne Maria Durkan
Jonathan Egan
Peter D Eisman
Carolyn Jane Ellaway
Philip John Emder
Adrienne Eips
Anthony D Epstein
Nick Evans
Marino Festa
Dominic A Fitzgerald
Joanne Ginn
Helen Margaret Goodwin
Adrienne Gordon
Doaa Habashy
David Hartshorn
Jason Harris
David Isaacs
Mary Iskander
Stephen Jacob
Cheryl Anne Jones
Allan Kelly
Sean Kennedy
Alison M Kesson
Jan Klimek
Stephen Knipe
Ian D Lennon
Michael LonerGAN
Kei Lui
Melissa Christine Luig
Larissa Mackey
Albert Mansour
Susan M Marks
Kieran T Moran
Desmond L Mulcahy
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Anandhan P Naidoo
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Ken Peacock
Elizabeth Peardon
James P Pendergast
Nick Pigott
Jason Pinner
Susan Piper
Karen M Power
Marilyn Rochfort
David N Schell
Davinder Singh-Grewal
Soundappan Soundapann
Anna Stachurska
Jacqueline A Stack
David R Starke
Lee Sutton
Juliana Tze
Khiang Tze
Rodney L Tobiansky
Dimitra Tzioumi
Maureen van Rossum du Chatel
Meredithe Ward
Murray T Webber
Richard Webster
Mark A Westphalen
Barry Wilkins
Caroline Williams
John B Ziegler
NT
Jonathan R Carapetsis
Carolyn Maclean
Louise Martin
Peter S Morris
Monique Stone
Annie Whybourn
QLD
Donald B Adsett
Robyn M Brady
Richard P B Brown
David W Cartwright
Maree G Crawford
Alison Cupitt
Mark W Davies
Peter J DeBuse
Timothy John Donovan
Aaron Mark Easterbrooks
Lesley B Everard
Peter H Gray
Leonie M Gray
Alison Harris
Katrina Harris
Richard Headlewood
Helen S Heussler
Elizabeth M Hurion
Susan Ireland
Peter Dominic Jones
Pieter Koorts
Helen Liley
Julie McEneny
Andrea McGlade
David McMaster
Steven McGattar
Ryan Mills
Susan Moloney
David J Moore
Anthony Morosini
Claire Nourse
Mark Painter
Brian R Patten
Jeffrey J Prebble
Ian F Robertson
Patrick J Ryan
Wei Seto
Rachel Susman
Clare Thomas
Claire E Wainwright
Timothy H Warmock
Andrew White
Jason Wildschutz
Michael L Williams
SA
Christina A Boros
Terence George Donald
Philip R Egan
Vanessa J Ellison
Paul N Goldwater
Ross R Haslam
Malcolm A Higgins
David B Ketteridge
Maria Kirby
Jan Liebelt
Scott Morris
Peter C Prager
Suzanna Thompson
M W Yung
TAS
Christopher J Bailey
Peter A Dargaville
David Strong
VIC
Jim Buttery
Elizabeth A Carse
A G Catto-Smith
Jeanie L Y Cheong
Tracey Coleman
Tom Connell
Noel E Cranswick
Richard R Doherty
Maurice Kelvin Easton
Austen Lawrence Erasmus
Mike Forrester
Michelle Giles
Julia Gunn
Dennis Hain
Simon Harvey
Sari Hayllar
Ralf Heine
Susen E Jacobs
Diana Lynne Johnston
Lilian Johnstone
Andrew William Lovett
Thao Lu
Lionel Lubitz
Gideon Lurie
Michael K Marks
Catherine McAdam
Kathy McMahon
Margot Nash
Carl J Orkin
Nico Le Claire Robins-Browne
Eliza Rough
Monique Ryan
Lara S Shekerdemian
Peter Jason Vuillermin
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Christopher Blyth
Andrew M Bullock
Catherine H Cole
Simon J Erickson
Katharine Gardiner
Andrew Gill
Geraldine Goh
Refin Hemani
Louise Hoolston
Farhat Hussain
Christine A Jeffries-Stokes
Mohammad Jehangir
Alice Johnson
Geoffrey J Knight
Helen Leonard
Flemming H Nielsen
Aida Partridge
Donald Payne
P Jams S Price
James Ramsay
Shripada Rao
Steven Resnick
Jacqueline M Scullock
Jack B Vercoc
Iain R Walpole
Andrew Michael Wawryk

Clinicians Reporting Cases in 2010

ACT
Alison Kent
Abdel-Latif Mohamed
NSW
Wendy Allen
Jacqueline Kay Andrews
Nadia Badawi
Philip J Beeby
Gilda B Bonacruz-Kazi
Adam Buckmaster
Kathryn Carmon
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Raymond Chaseling
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Mark De Souza
Barry John Duffy
Anne Maria Durkan
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Stephen Knipe
Ian D Lennon
Michael LonerGAN
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Melissa Christine Luig
Larissa Mackey
Albert Mansour
Susan M Marks
Kieran T Moran
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Steven Resnick
Jacqueline M Scullock
Jack B Vercoc
Iain R Walpole
Andrew Michael Wawryk
Clinicians Returning 100% Monthly Report Cards in 2010

ACT
Judith L Bragg
Ann Crawshaw
Ian F Crawshaw
G David Croaker
Amelia M Herath
Hilary A Holmes
Paul J Jenkins
Penelope J Johnson
Zsuzsoka (Susanne) Kecskes
Alison Kent
Antony Lafferty
Timothy McDonald
Abdel-Latif Mohamed
Suzanne M Packer
Suzanna Powell
Graham J Reynolds
Yvonne J Rosier
Erroll Simpson

NSW
C Abkiewicz
Julie C Adamson
Shirley Alexander
Hugh D W Allen
Wendy Allen
Geoff Amblert
Rosemary Amblert
Alan F Amos
Jacqueline Kay Andrews
Michael Anscombe
Jayne H Antony
Elizabeth Argent
John D Arnold
Bindu Baburaj
Nadia Badawi
Lynn Banna
Peter A Barr
Louise A Baur
Vivian V Bayl
Philip J Beeby
Yvonne Belessis
Graham J Bench
G P Bent
Jennifer Berg
Andrew Berry
Vivek Bhatti
Rani Bhatia
Habibur Rehman Bhurawala
Stewart Birt
Roger Blackmore
(Alice) Bijou Blick
Paul Bloomfield
Gilda B Bonacruz-Kazzi
Robert Booy
Jennifer R Bowen
Nick Boyd
Kerry Brown
Gary Brown
Michael P Brydon
Adam Buckmaster
P Buckner
Vicki Buneikis
Donald L. Butler
Anne M E Bye
Patrina Ha Yuen Caldwell
Ian Callander
Peter J Campbell
Dianne Campbell
Thomas Arthur Campbell
Jeffrey Chaitow
Janis D Chamberlain
Browny J Chan
Paul C Chay
Kity Chee
Alan Cheng
Howard W Chilton
Raymond Chin
Alan Y H Chong

David Christie
John Christodoulou
Robert Sin Liang Chu
Yew-Wee Chu
Simon D Clarke
John G Cooley
Ralph C Cohen
Des Cohen
Simon Cohen
Richard J Cohn
Alison F G Photography
Felicity A Collins
Anne F Collins
James S Colquhoun-Kerr
J R Coomansamy
Peter John Cooper
Stephen Geoffrey Cooper
Carolyn Cooper
Elizabeth A M Cotterell
Carolyn Cottier
Eric S Courtarakis
Heather Coughtrey
Jonathan Craig
Maria Craig
Paul Craven
Stuart Crice
Genevieve E Cummins
John Curotta
Shane Curran
Bruce Currie
Julie A Curtin
Jacqueline Dalby-Payne
Russell Dale
Patricia Davidson
Robert Davies
Robert Day
John A De Courcy
Mark De Souza
Koert De Waal
Michael J Deloughery
Anthony Dilley
Kim Donaghe
Peter John Donald
Ana Maria Dosen
David Dossetor
John Robert Douglas
Barry John Duffy
Scott Dunlop
Linda Durojaiye
Shoma Dutt
Peter William Ebeling
Matthew J Edwards
Fergus Elder
Carolyn Jane Ellaway
Philip John Emder
Adrienne G Epps
Anthony D Epstein
John B Erikson
Nick Evans
Robert H Farsworth
Bruce J Fashner
Michael Fashner
John M Feiler
Penelope Field
Michael J Field
Dominic A Fitzgerald
Fiona Fleming
Jeff Fitcher
Bob K J Fonseca
Michael R Freelander
Stuart M Gadd
Andrew J Gardiner
Madlenian Jan
Maurice D Geth
Sondhya Ghedia
Henry J Gilbert
Deepak Gill
Anne Clare Gill
Joanne Ging
Neil D Ginsberg
Chin Lum Goh
Safak Goktogan
Maria Linette Gomes
P M Goodwin
Linda Louise Goodwin
Helen Margaret Goodwin
Thomas M Grattan-Smith
Padaic Grattan-Smith
Toby D R Greenacre
Robert Guaran
Maree Guizzo
Hasantha Gunasekera
Julie M Haas
Dooa Habashy
Anna Hackett
Robert J Halliday
Robert F Hanson
Ralph M Hanson
Robert J Hardwick
Richard K Hart
David Hartshorn
John G Harvey
Richard E Hawker
Philip L Hazel
Guy Henry
Steven Hing
Ken Ho
Yoon Mei Ho
Peter Hogan
Andrew Holland
James C S Hong
Maxwell Hopp
Jason Hort
Keith M Howard
Neville J Howar
Robert Howman-Giles
Christine Hughes
Paul Hutchins
Christopher B Ingall
Michelle M Jack
Reuben Jackson
Adam Jaffe
Allan James
Con A James
Robyn Jamieson
Kim Duff
Colin Kable
G M Kainer
Alys Alexy
Cheryl Anne Jones
Kristi J Jones
Preeiti Joshi
David J Fasher
Lisa J Johnson
Patricia M Johnson
Owen Jones
Cheryl Anne Jones
Kristi J Jones
Preeiti Joshi
Kathryn North
Ranjit Nanra
A S C Lim
David N Murphy
Marea W Murray
Patricia Mutton
Anandhan P Naidoo
Ralph Nanan
Ranjit Nanra
Kathryn North
Ju Oei
Stephen J O’Flaherty
Fenton O’Leary
Stephen J O’Flaherty
Ju Oei

John A Lawson
Joanne Leal
J Lemoi
Ian D Lennon
Garth I Leslie
Jane Mary Lesslie
David Lester-Smith
Florence Levy
Deborah J Lewis
David Lillystone
A S C Lim
Daniel C S Lim
Anthony Jun Wing Liu
B H Lo
Michael Loneragan
Alison Loughran-Fowlds
O Lozynsky
Melissa Christine Luig
Kristine Macartney
John Macdessi
Kerrie T MacDonald
Sloane Madden
Annabel K Magoffin
Albert Mansour
Glenn M Marshall
Frank J Martin
HUGH O Martin
Bradley Martin
Tania May
Emma McCahon
Robert McCarthy
Mary McCaskill
C R (Rod) McClymont
Tim McCrossin
David T McDonald
Jennifer L McDonald
Ann McDonald
Anne McGeechan
Gayle Mclnerney
Peter B McIntyre
Margot McIver
Patricia McVeagh
Sam Mehr
Michael Melamadowitz
Tracey Merriman
Susan M Messner
Browny Milne
Joseph P Moloney
Anne Morris
John R Morton
David R Mowat
Desmond L Mulcahy
Crag Munnis
David N Murphy
Marea W Murray
Patricia Mutton
Anandhan P Naidoo
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Fenton O’Leary
Matthew W O’Meara
David A Osborn
Pamela Palasanthiran
Con Papadopoulos
Dimitrios Papadopoulos
Mary Paradissis
Julianne Parle
Patrick Patradoon-Ho
Ken Peacock
Elizabeth Peacon
James P Pendegast
Deborah G Perkins
Megan Phelps
Susan Phin
Elizabeth Pickford
Clinicians Returning 100% Monthly Report Cards in 2010

Jason Pinner
Susan Piper
Michael Piaister
Jaqueline C Pollack
Melvyn Polon
Christopher C Poon
Alison Poulton
Keith M Power
Peter G Procopis
Karina L Proudman
Stephen D Pryde
Kerry Quinn
Patrick M Rahilly
Shanti Raman
Andrew Rechman
Rebecca Richardson
Ingrid D Riegler
Suzanne I Robertson
Peter Robinson
Paul Robinson
Marlyn Rochefort
Laurence G Roddick
A Ronan
Andrew R Rosenberg
Greg Rowell
Gerard Roy
Sharon Ryan
Peter J Ryan
Terry M Sands
Vanessa Sarkozy
Charles M Scarf
Mark Selikowitz
Christopher Seton
Arun S Shanker
Peter Shaw
Gary F Sholler
Albert Shun
Martin Slinik
David O Silence
Natalie Silove
John K H Sinn
Ingrid Sinnerbrink
Jacqueline E Small
Grahame Smith
Robert Smith
Soundappan Soundappan
Shubha Srinivasan
Bernard J N St St George
Anna Staczkowa
Jacqueline A Stack
Jean Starling
David R Starte
Kate Steinbeck
Glenn Stephens
Michael M Stevens
H Victor Storm
Gopinath Musuwadi
Subramanian
Lee Sutton
Paul R Tait
Arthur Teng
Julianna Tze
Khiang Teo
Andrew Terrey
Kathryn Thacker
Ganesha Thambipillay
Ronda L Triechurst
Rodney L Tobiasky
Susanne J Towns
Mark B Tracy
Toby Trahair
Javeed Travadi
Anne M Turner
Dimitra Tzioumi
A B Underwood
Duc Ngoc Van
Peter Van Asperen
Maureen Van Rossum du Chattel
Charles Verge
Graham V Vimpani
Anne F Vimpani
Bryn Wainstein
Chris Wake
J L Walker
Annabel Wark
Meredith Ward
Philip Watt
Mary-Clare Waugh
Christopher F Webber
Mark A Webster
Richard Webster
Dylan Wesley
Carolyn M West
Mark A Westphalen
Bruce Whitehead
Catherine R Wiles-Harrell
Barry Wilkins
George L Williams
Gary Williams
Meredith Wilson
Carola Withfield
Nicholas Wood
Lisa Catherine Worgan
Ian Wright
Barry E Wyeth
Kylie F Yates
Berinda Yeoh
Suky Yim
Terence Yoong
Simon Young
Andrea Zalan
John B Ziegler
David Ziegler
Karen Zwi
Jonathan R Carapetis
Anita Luci D'Aprano
Rosemary E Fahy
Raj (Anjrag) Khilani
Carolyn Maclean
Louise Martin
Peter S Morris
Victor Nossar
Susan Skull
Monique Stone
Annie Whybourn
QL
Jason Acworth
Donald B Adsett
Leslie Ah Yui
Gary S Alcock
Donald A Appleton
Erica Baer
Deborah Bailey
Sasa Bandaranayake
Ruth Barker
Jennifer A Batch
Donna Bostock
Christopher Bourke
Michelle Boyd
Robyn M Brady
Richard P B Brown
Helena M Muntain
Scott Burgess
John R Burke
Anita Cairns
Leisha A Callaghan
Lazarus M Carpon
Gregory I Carman
Theresa A Carroll
David W Cartwright
Richard E Cherry
Ronald E Clark
Geoffrey J Cleghorn
John Coghlan
Paul B Colditz
Timothy Colen
Frances L Connor
Louise Conwell
Lucy Helen Cooke
Lisa Copeland
Andrew Cotterill
John W Cox
Maree G Crawford
Penelope Cruickshanks
Jan A Cullen
Armando Da Silva
Mark W Davies
Neville G Davis
Mark Davoren
Catherine Dawson
Peter J DeBuse
Apaks Dede
Maureen Dingwall
R D Diplock
Tanya Dodman
Timothy John Donovan
Nigel David Dore
Aaron Mark Easterbrook
Prinia Edwards
Lou Jee
Ian J Findlay
Catriona Fleming
William Frischman
Michael Gabbett
Donna Gandini
Michael R Gattas
Yuri Gilhofra
Glen A Gole
Bruce Goodwin
Peter H Gray
Simon Grew
Keith Grimwood
Andrew R Hallahan
Alison Harris
Margaret-Anne Harris
Glenn J Harte
Phillip J Harvey
Tim E G Hassall
Richard Heazlewood
Shivanand Hebbandi
Anthony Herbert
Margaret Holloway
Johanna M Holt
Thomas M Hurley
Elizabeth M Hurrian
Garry Inglis
Susan Ireland
Helen Irving
Ronald W James
Luke Jardine
Christopher M Johansson
Robert J Justo
Lisa Kane
Sumant Kevat
Paul Koch
Guan Koh
Pieter Koorts
J Anne Kynaston
Peter J Lewindon
Bruce R Lewis
Bruce G Lister
Liane R Lockwood
Gillian Mahy
Elena J Mantz
Vesna Markovic
Louise Suzannie Marsh
John R Mcleanor
David B McCrossin
Michael McDowell
James J McGill
Michael McGill
Andrea McGlade
Lynne McKinlay
Kim Alison McLennan
Sarah McMahon
David McMaster
Steven McTaggart
Julian D Mellick
Hilary P Mercer
Ross D Messer
Malcolm N Miller
Ryan Mills
Haseena Mohamed
Susan Moloney
David J Moore
Anthony Morosini
Richard Mulcahy
Gary Niven
Clare Nourse
Michael J O'Callaghan
Trevor E Olsen
Mansu Fabari
Brian R Patten
Jane E Peake
James T Pelekanos
David R Pincus
Ross Pinkerton
Jeffrey J Preble
Nicola Previtera
Darrell A Price
Marlon Radcliffe
Fergus A C Ring
Ian F Robertson
Jeremy Robertson
Peter Roddenby
David A Rogers
Peter C Roger
Richard F Royleneye
Patrick J Ryan
Phil Sargent
James A Scorer
Geoffrey Seet
Wei Selo
Doug C Shelton
E Shi
Katharine G (Kate) Sinclair
Alain A Sive
Catherine Y Skellem
Anthony J Slater
B David Slaughter
Peter Kenneth Smith
Jennifer B Smith
Velencia Soutter
Harry Stakeski
S L Stathis
Lila Stephens
Mark Stretton
David Symmons
Donna Taylor
Clare Thomas
Susan Thornton
Alison Tigg
Ottile Adrienne Tork
Uyen Tran
David I Tudhope
Claire E Wainwright
Rosslyn M Walker
Geoffrey B Wallace
Cameron J B Ward
Christopher Ward
Timothy H Warnock
John H N Wau
Cameron Webb
Sarah Whitefield
Neil R Wigg
Michael L Williams
Judy A Williams
Sue Wilson
David O Winkle
Geoffrey Withers
Stephen Withers
David Wood
Paul G Woodgate
Elisa Rough
Katherine S Rowe
Margaret Rowell
Suba Rudolph
Monique Ryan
Luke P Sammartino
Christine Sanderson
Kerryn R Saunders
R Savarirayan
Susan Sawyer
Ingrid E Scheffer
Adam M Scheinberg
Jill R Sewell
David Sholl
Peter Simm
Ian J Skelton
Robert A Sloane
Joanne Smart
Elizabeth Smibert
Lindsay J Smith
Christopher Smith
Jennifer A S Smith
Andrea Smith
Mike South
John Stevens
Michael J Stewart
Amanda Stock
Terry G Stubberfield
Robert Stundon
Joseph Tam
Mimi Tang
Russell G Taylor
Nick H Thies
Katherine Thomson
David Tickell
Karín Tiedemann
Margarette Tilders
Brian J M Timms
David Gerald Tingay
Jacinta M Tobin
Sophie C Treleaven
Anne-Marie Turner
Martin Tuszyński
Friedericke C M Veit
Peter Jason Vuillermin
Rowan G Walker
Amanda M Walker
Garry L Warne
Keith D Waters
Andrew M C Watkins
Peter W Wearne
Annette N Webb
Robert G Weintraub
Anthony P Weldon
George Werther
Susan White
Sumitra F Wickramasinghe
Katrina J Williams
Joshua Wolf
Martin C Wright
Joy Yapito-Lee
Margaret Zacharin
WA
Sabine Afchani
Angela J Alessandri
Gareth Baynam
Christopher Blyth
Andrew M Bullock
Mark Burrows
Carole Caccetta
Lynda M Chadwick
Gervase M Chaney
Catherine Choong
Richard J Christie
Hock Leng Chua
Barr S Clements
Harvey L C Coates
Catherine H Cole
Joanne Colvin
Charles Crompton
Riva Curtis
Elizabeth Davis
Luigi D’Orsogna
Tonia Douglas
Harry Dumbell
Jean Henri DuPlessis
Simon J Erickson
Ian James Everitt
Annette M Finn
Philoena Fitzgerald
Noel P French
Katharine Gardiner
Andrew Gill
Ian J Gollow
Anna Gubbay
Linda A Harris
Petra Hartmann
T Rex Henderson
Louise Houliston
Michelle Howell
Christine A Jeffries-Stokes
Mohammad Jehangir
Kay H Johnston
Timothy W Jones
Bradley Jongeling
Gareth Kameron
Andrew Douglas Kennedy
Blanche Khaw
C Kikiros
Cathy Kiraly-Borri
Geoffrey J Knight
Rolland Kohan
Hamant Anant Kulkarni
Katherine M Langdon
Peter N Le Souef
Helen Leonard
Dominic Mallon
Cherry Martin
Andrew Martin
Robert McClure
Michaela McGregor
Fiona McKenzie
Judy E McMichael
Helen J Mead
Divyesh Mehta
Catherine F Mews
Corrado Minutillo
Jagapathireddy Mokala
Kevin J Murray
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Peter C Richmond
David E Roberts
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Thank you to every clinician for your continued support of the important work of the APSU.
We look forward to your ongoing participation.

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