APSU

Australian Paediatric Surveillance Unit

Celebrating

15 **years** of Surveillance 1993-2007

Australian Paediatric Surveillance Unit

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Australian Paediatric Surveillance Unit 15th Anniversary Publication 1993-2007

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Table of Contents

Foreword

Professor Fiona Stanley AC

Patron APSU

The APSU has created a powerful national data collecting capacity. It was established to respond to a need for accurate, total population data on those rarer paediatric problems and conditions for which no other regular national source of data was available. Parents of children with rare disorders should be pleased that the APSU is asking the same questions they do – how many children are affected, why did this happen and what can we do about it?

This celebration of 15 years of surveillance should reflect on the significant contribution the APSU has made to child health. I applaud their progress and wish them all the very best for the next 15 years!

Professor Neil Wigg

President, Paediatrics and Child Health Division
Royal Australasian College of Physicians

As a medical student I was taught that uncommon conditions occurred uncommonly. Rare conditions were even rarer. They tended to have exotic names and were relegated to the end of differential diagnosis lists. Rare conditions appeared in esoteric case series and often defied systematic study. Fifteen years of disease surveillance by the Australian Paediatric Surveillance Unit (APSU) demonstrates the enormous value of systematic study of rare and often "geographically dispersed" childhood disorders.

The successes of the APSU are recorded in this landmark publication. These successes have been achieved through dedicated quality research by a wide range of clinicians and researchers, superb leadership and support from APSU staff, and the near universal and continuing engagement and involvement of paediatricians across Australia over 15 years. The successes must be shared.

The Paediatrics & Child Health Division, RACP is proud to be associated with the APSU, to support this publication, and to recognise the APSU as a leader in paediatric disease surveillance worldwide. Congratulations to Professor Elizabeth Elliott and the APSU staff, present and past, whose achievements are reflected in this celebratory report.

Professor Carol Bower

APSU Board Chair

It has been a privilege to be associated with the APSU, as a study investigator and as a member of the Scientific Review Panel and the Board. The achievements of the APSU over its first 15 years are extensive and have had important clinical and public health implications. In the past 2-3 years, there has been an acceleration of activity, with the rapid response mechanism and the PAEDS pilot program and efforts to address gaps in surveillance as part of the NHMRC Enabling Grant.

The success of the APSU is dependent on the contribution of Australian paediatricians, month after month, as they return their notification cards and complete questionnaires. The APSU's success has also been heavily reliant on the tireless work of Professor Elliott in initiating and supporting studies and championing the APSU at every opportunity.

My congratulations to the APSU staff past and present and to paediatricians across Australia for 15 years of valuable work – may there be many more to come.

Elizabeth Elliott

Director, Australian Paediatric Surveillance Unit

It is estimated that between 6000 to 8000 rare diseases affect about 6-10% of all Australians in their lifetime (or ~400,000 children aged less than 15 years). Rare diseases are often chronic, disabling, and impact significantly on our children's lives, health care services and the wider community. Yet they are often neglected, being described by some as 'orphan' diseases. Many countries, including the USA, NZ and the UK have recently recognised the important burden of rare diseases and have formulated national plans that include development of centralised information resources, specialist clinics and respite services and have provided funding for research and advocacy. The APSU was founded in 1993 to address the lack of national data on rare diseases through involvement of clinicians nationwide.

Australian paediatricians have made a remarkable contribution to knowledge about rare childhood disorders in Australia, through their sustained participation in APSU surveillance activities over the last 15 years. APSU is a unique surveillance and research resource providing an 'active' mechanism for prospective, national identification and study of children with rare diseases. This mechanism involves sending a paper or e-mail report 'card' each month to approximately 1277 child health specialists servicing 4.1 million children aged <15 years. Clinicians are asked to indicate on the card whether or not they have seen a child newly diagnosed with a condition listed, and clinicians reporting cases are then asked to provide more detailed de-identified data on the case via a questionnaire. In some cases, clinicians also provide biological samples. Since 1993, the APSU has sent out approximately 300,000

cards, of which almost 282,000 have been returned – a participation rate of over 94%, which is unrivalled internationally and attests to the simplicity of the mechanism and the value with which clinicians regard their role.

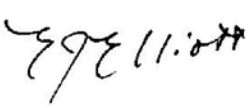
Since 1993, almost 350 investigators from across the nation have studied 45 conditions, including a range of rare, but important vaccine-preventable, communicable, genetic and mental health disorders and uncommon injuries. Previously unavailable data, derived from APSU studies, has provided a national 'snapshot' of the epidemiology, management and short-term outcomes of these disorders. Study data have also been invaluable for informing public health policy, as exemplified particularly by studies such as fetal alcohol syndrome, severe seat belt injuries, perinatal exposure to HIV and vaccine-preventable diseases. In the case of Rett syndrome, for example, data have also contributed to international databases, informed service development and improved our understanding of the genetics of the disease. APSU data have catalysed many other research studies using different methods.

The 2007 evaluation of the APSU suggested it meets its objectives with regard to the simplicity and cost of the mechanism and the quality, timeliness and representativeness of the data. In the evaluation, clinicians said they thought the APSU was valuable for generating knowledge (89%), guiding clinical practice (75%) and future research (80%), and informing public health policy (72%). The fact that data are supplied directly by clinicians caring for children with rare diseases enhances its quality.

Funding of the APSU has been an ongoing challenge and I am particularly grateful to the following for their support: the Clive and Vera Ramaciotti Foundation; Financial Markets Foundation for Children; Department of Health and Ageing (DoHA); National Health and Medical Research Council (NHMRC); Royal Australasian College of Physicians (RACP) and its Paediatrics and Child Health Division; the University of Sydney and the Children's Hospital at Westmead. Staffing and activities of the APSU have been expanded since the award of an NHMRC Enabling Grant in 2006. This grant has enabled us to address some of the limitations of the APSU, including inadequate surveillance coverage of children (often Indigenous children) living in remote and rural communities that are poorly serviced by paediatricians. The funding also allowed us to use the APSU for 'emergency' surveillance of severe influenza complications in 2007. This study, commissioned by the DoHA and mounted within 10 days, required weekly surveillance and demonstrated APSU's readiness for surveillance of outbreaks of emerging or imported infectious diseases. Also in 2007, in collaboration with the National Centre for Immunisation Research and Surveillance (NCIRS), APSU coordinated a pilot, paediatric active enhanced disease surveillance program (PAEDS) in four tertiary paediatric hospitals. This type of surveillance will potentially be useful when collection of timely or detailed data or of biological specimens is essential. Efforts are also underway to develop web-based reporting; to involve advanced trainees in APSU activities; to develop a web-based rare disease resource for parents and professionals; to provide education about rare diseases; and to foster international collaborative studies.

I thank all past and present clinicians who report to the APSU, study investigators, Presidents of the Paediatrics and Child Health Division (RACP), and members of the APSU Board, Scientific Review Panel and staff who have contributed to the success of the APSU.

I owe particular thanks to Drs Kerry Chant, Katrina Williams, Anne Morris, Greta Ridley and Yvonne Zurynski for their roles in assisting to develop and run the unit and the current Board Chair Professor Carol Bower for her support.



1992

- A planning meeting with national representation is convened by Dr Elizabeth Elliott at the Royal Alexandra Hospital for Children, Sydney to discuss the feasibility of developing an Australian Unit, modelled on the British Paediatric Surveillance Unit (BPSU), developed in 1996 by Dr Susan Hall from the Public Health Laboratory Service.
- Dr Elliott and Prof Kim Oates are awarded a grant from the Clive and Vera Ramaciotti Foundation for development of an Australian Paediatric Surveillance Unit.

1993

- Dr Susan Hall is guest speaker at a workshop on paediatric surveillance at the Australian College of Paediatrics (ACP) Annual Scientific Meeting.
- The APSU becomes a unit of the ACP in May 1993 and the ACP Council endorses a Steering Committee with representatives from each Australian State, New Zealand and chaired by the President of the ACP Dr Peter Procopis.
- APSU begins surveillance in May 1993 with eight studies and 992 contributing clinicians.
- First APSU Annual Report published.

1994

- Response rates for the return of monthly cards reaches a high of 90%, indicating clinicians' acceptance of the value of contributing to the APSU.
- APSU data are provided to the NHMRC, World Health Organisation (WHO), International Committee for Vitamin K Deficiency Surveillance, Australian Quarantine Inspection Service and Royal Life Saving Society of Australia.

1995

- The unit is at threat due to a lack of funding.
- A grant from Financial Markets Foundation for Children, providing funding from 1995-1997, keeps the unit alive.

1996

- To date 70 investigators have used the scheme, 11 studies are in progress, three studies are being developed for 1997 and five completed. The response rate rises to 93%.
- Formal evaluation of the APSU (the first of a national paediatric surveillance unit) is initiated to assess whether the unit is fulfilling its objectives and conforming to criteria developed by the Centre for Disease Control for evaluating surveillance systems.
- Proposal for an International Network of Paediatric Surveillance Units (INoPSU) is developed.

1997

- Email reporting is introduced, the first unit to do so internationally.
- A proposal is developed for the establishment of the APSU website.

1998

- The proposal for an INoPSU is formally ratified -The Amsterdam-Ottawa note.

1999

- APSU evaluation results, published in Archives of Diseases in Childhood, are very positive. The mechanism is found to be simple and flexible, data are representative and timely and the majority of clinicians find the workload acceptable and APSU

data educational and useful in informing clinical practices.

- Response rates reach an all time high of 98%.
- Additional funding from the Financial Markets Foundation for Children and DoHA consolidates a tripartite partnership between government, the business community and the APSU.

2000

- APSU data on acute flaccid paralysis (AFP) confirm no wild or vaccine-associated poliomyelitis in Australia and contribute to Australia and the Western Pacific Region being declared polio-free by the WHO in Kyoto.
- First INoPSU scientific and business meeting held in Ottawa, Canada. APSU Director elected as INoPSU Convenor, 2000-2004.

2001

- APSU is represented at the National Strategic Planning Workshop on Poliomyelitis Eradication and contributes data to a DoHA report highlighting issues relating to AFP surveillance and containment of poliomyelitis.

2002-2003

- Second INoPSU conference and business meeting held in York, UK.
- APSU celebrates 10 years with a special meeting in Hobart in association with the Annual Scientific Meeting of the RACP. The guest speaker is Dr Chris Verity, Chairman of the BPSU Executive Committee. The meeting showcases outcomes of studies conducted through the unit since 1993.
- Professor Fiona Stanley becomes APSU Patron.

2004

- The APSU leads the way internationally, by initiating surveillance for mental health disorders (childhood dementia, early onset eating disorder and conversion disorder). This reinforces the unit's preparedness to address Australia's health priorities and provides internationally unique data.
- Third INoPSU conference and business meeting held in Lisbon, Portugal.

2005 - 2006

- Five year funding is received from the Faculty of Medicine, The University of Sydney.
- APSU receives an NHMRC Enabling Grant of $1 million for 2006- 2010 to facilitate further development of the surveillance network.
- APSU delegates attend the 4th INoPSU conference in London and present a review of public health impacts of APSU studies.
- APSU in collaboration with the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases proposes a Paediatric Active Enhanced Disease Surveillance (PAEDS) network to enhance timely collection of clinical data and biological specimens from inpatients with selected conditions and pilot the scheme, funded by DoHA, in four tertiary hospitals.

2007

- New APSU website, hosted by the RACP is launched: www.apsu.org.au.
- PAEDS network commences data collection.
- APSU undergoes a Governance Review.
- Joint project to standardise classification of congenital anomalies initiated by APSU and National Perinatal Statistics Unit.

- Data from surveillance for serious seatbelt injuries informs consultation process for changes to child restraint laws in Australia.
- The APSU undertakes emergency, weekly surveillance of severe complications of influenza for one month at the request of the DoHA and in response to an epidemic that included several child deaths.
- Second evaluation of the APSU completed. Paediatricians report value of APSU in generating new information, guiding clinical practice and informing future research and public health policy.
- APSU represented on key committees including National Polio Expert Committee; National Polio Certification Committee; Inter-governmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders; New Zealand Paediatric Surveillance Unit Scientific Review Committee; Research Committee and Council of the Division of Paediatrics and Child Health, RACP; Scientific Influenza Advisory Group; NHMRC Alcohol Guidelines Review Committee; and National Birth Anomalies Committee.
- The APSU, in collaboration with the National Heart Foundation and Menzies School of Health Research, Darwin, initiates a study on acute rheumatic fever and explores mechanisms to enhance disease surveillance among Aboriginal and migrant communities.
- APSU Director awarded NHMRC Practitioner Fellowship to support APSU activities.
- Staff employed at the APSU reaches a record high, with the unit employing nine staff (7.2FTE).

2008

- The APSU celebrates 15 years of surveillance with two dedicated APSU Sessions at the Annual Scientific Meeting of the RACP in Adelaide.
- Launch of 15 year celebratory publication showcasing the APSU achievements.
- The fourth INoPSU conference and business meeting is scheduled for September in Munich, Germany.

APSU statistics

For the period 1993-2007:

- Forty-five studies have been undertaken by the APSU involving almost 350 investigators.
- Approximately 300,000 report cards have been sent and 282,000 returned, a 94% response rate.
- Approximately 170 original articles have been published in peer reviewed journals and 230 scientific presentations given.
- Grants totalling over $3 million have been awarded to the APSU.
- Approximately 1277 clinicians report monthly on a population of 4.1 million children aged <15 years.

The APSU

The APSU is a unique national research resource, established in 1993 to facilitate active surveillance of uncommon childhood diseases, complications of common diseases or adverse effects of treatment. Diseases are chosen for their public health significance and impact on health resources. A range of infectious, vaccine preventable, mental health, congenital and genetic conditions and injuries have been studied. For many of these conditions the APSU is the only mechanism for data collection.

The APSU had been used by almost 350 individual researchers to conduct 45 surveillance studies to date. APSU enables collection of detailed epidemiological and clinical data that are of direct relevance to clinical practice, clinical and public health policy and resource allocation and therefore impact on the health and wellbeing of Australian children. Details on demographics, diagnosis, investigations, management, use of health services and outcomes are collected on up to 16 rare childhood conditions simultaneously.

The APSU is a unit of the Division of Paediatrics and Child Health, Royal Australasian College of Physicians (RACP) and is based at the Children's Hospital at Westmead. The activities of the APSU are funded by:

- competitive research funding, including an NHMRC Enabling Grant No. 402784;
- the Australian Government Department of Health and Ageing, through their communicable diseases program and;
- the Faculty of Medicine, the University of Sydney;
- a range of granting bodies and industry.

APSU staff is supported by the Discipline of Paediatrics and Child Health, University of Sydney and the NHMRC (Elizabeth Elliott Practitioner Fellowship No. 457064)

The APSU Board oversees the management of the unit and the APSU Scientific Review Panel evaluates applications to conduct studies through the unit for suitability and scientific merit. The APSU has been influential in the development of international surveillance units and in the development and activities of the International Network of Paediatric Surveillance Units.

Mission

To improve the quality of life for Australian children and their families by being a reliable source of accurate, accessible, national data collected by clinicians, about child health problems with high impact, that will inform clinical practice, advocacy, policy, education and research.

Aims

1. To provide a national, active surveillance mechanism that can be used to:
   - Study the epidemiology, clinical features, management and short term outcomes of rare childhood conditions in Australia;
   - Respond to epidemiological emergencies such as disease outbreaks, importation of disease and emergence of new disease.
2. To initiate and facilitate national collaborative research consistent with national child health priorities, including a "healthy start to life" and to fill knowledge gaps.
3. To produce and disseminate evidence that will support development of:
   - effective educational strategies for health professionals and parents;
   - clinical practice guidelines;
   - appropriate prevention strategies;
   - community awareness campaigns;
   - evidence based policy.

APSU website - www.apsu.org.au

A new website launched in 2007 with the assistance of the RACP, houses information about APSU activities, publications and news and provides a quick and easy way for clinicians to access study protocols and questionnaires. In 2008 a web-based reporting mechanism will be trialled via a secure site. In the 2007 APSU evaluation 71% of clinicians said they would be willing to contribute questionnaire data on-line via a secure site. This mechanism would also allow clinicians and researchers to access summary data from APSU studies.

Contributors to the APSU

Data are reported to the APSU each month by approximately 1277 dedicated clinicians working in paediatrics and child health in Australia. These are predominantly general paediatricians (56%), with 44% paediatric sub-specialists. The latter include paediatric surgeons (who make up 3.8% of all contributors); geneticists (2.9%) and child psychiatrists (1.9%). Clinicians are identified through the list of Fellows of the Division of Paediatrics and Child Health of the RACP, the Australasian Association of Paediatric Surgeons and other subspecialty interest groups. In 2006, approximately 92% of all paediatricians on the RACP list of Fellows and in active clinical practice in Australia, participated in surveillance. Reporting by clinicians caring for children enables collection of enhanced data on diagnosis, clinical management, and short-term outcomes. The APSU focuses on surveillance of uncommon disorders minimising the workload for busy clinicians.

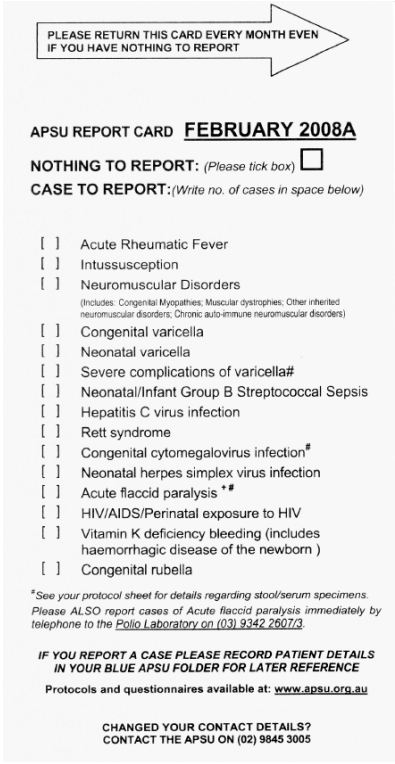
Operation of the APSU

Each month all contributing clinicians are sent a paper or e-mail report card and asked to report children newly diagnosed with any of the conditions listed on the card (Figure 1). Investigators conducting a study are informed weekly by the APSU of any new cases reported by contributors. The investigators then send a brief questionnaire to the clinician, requesting further de-identified information. Investigators are responsible for collation, analysis and publication in a peer reviewed journal as well as annually in the APSU Annual Report. The full process is summarised in Figure 2.

Electronic reporting

In 1997, the APSU was the first unit in the world to introduce e-mail reporting, an important innovation which made reporting fast and easy for paediatricians and significantly cut administrative and postal costs. In 1997, 101 (11%) of APSU contributors elected to report via e-mail and this number grew steadily to 811 (64%) by 2007. Currently 5460 paper cards are sent each year via "snail-mail" and 15,192 by e-mail.

Figure 1: APSU report card



PLEASE RETURN THIS CARD EVERY MONTH EVEN IF YOU HAVE NOTHING TO REPORT

APSU REPORT CARD **FEBRUARY 2008A**

NOTHING TO REPORT: *(Please tick box)* ☐

CASE TO REPORT: *(Write no. of cases in space below)*

[ ] Acute Rheumatic Fever
[ ] Intussusception
[ ] Neuromuscular Disorders
(Includes: Congenital Myopathies; Muscular dystrophies; Other inherited neuromuscular disorders; Chronic auto-immune neuromuscular disorders)
[ ] Congenital varicella
[ ] Neonatal varicella
[ ] Severe complications of varicella#
[ ] Neonatal/Infant Group B Streptococcal Sepsis
[ ] Hepatitis C virus infection
[ ] Rett syndrome
[ ] Congenital cytomegalovirus infection#
[ ] Neonatal herpes simplex virus infection
[ ] Acute flaccid paralysis +#
[ ] HIV/AIDS/Perinatal exposure to HIV
[ ] Vitamin K deficiency bleeding (includes haemorrhagic disease of the newborn)
[ ] Congenital rubella

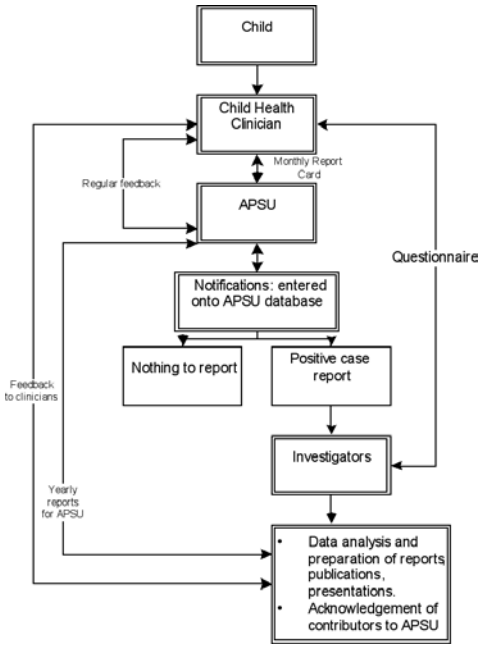
#*See your protocol sheet for details regarding stool/serum specimens. Please ALSO report cases of Acute flaccid paralysis immediately by telephone to the Polio Laboratory on (03) 9342 2607/3.*

IF YOU REPORT A CASE PLEASE RECORD PATIENT DETAILS IN YOUR BLUE APSU FOLDER FOR LATER REFERENCE

Protocols and questionnaires available at: www.apsu.org.au

CHANGED YOUR CONTACT DETAILS? CONTACT THE APSU ON (02) 9845 3005

Figure 2: Reporting process summary



Selection of studies

Individuals or organisations may apply to study a condition through the APSU and applications undergo a process of peer review and revision by the Scientific Review Panel before being listed on the monthly card.

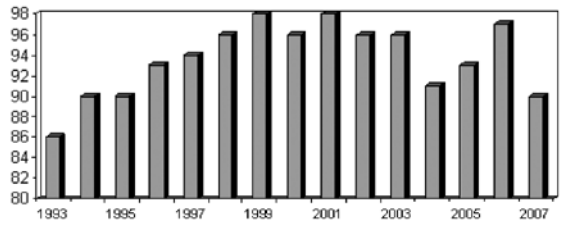
To satisfy the criteria for a study a condition must:

- be sufficiently uncommon so that the system is not over-burdened;
- usually result in referral to a paediatrician or related specialist;
- provide information that satisfies the study aims and that is not available from other sources.

Response rates

High response rates (return rate of monthly cards) have been maintained during the period 1993-2007, ranging from 85% to 90% (Figure 3). This attests to the robustness of the APSU scheme and more generally the commitment of participating clinicians. In 2006 a response rate of 96% was achieved, with over 90% of clinicians notifying a case complete and returning detailed questionnaires.

Figure 3: Response rates from 1993-2007



Respondent workload

Workload is acceptable to clinicians. During the period 1993-2006, the majority of clinicians (73%) had no cases to report, 16% had reported one case, 9% had reported between two and four cases and only 2% had reported five or more cases.

Collection of biological samples

Although collection and processing of biological samples has been facilitated by some APSU studies some clinicians report that requests for specimens is a significant burden, which may influence their willingness to report. For some conditions, timeliness of reporting is essential. In 2007-2008, in collaboration with the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases, the APSU is piloting the PAEDS (Paediatric Active Enhanced Disease Surveillance) program, which involves active case-finding by infectious diseases nurses based in four tertiary hospitals and is funded by the Department of Health and Ageing (DoHA). The pilot study suggest this system could improve the timeliness and completeness of data for selected conditions, including provision of biological samples, and would complement existing surveillance systems including the APSU.

Rapid response surveillance

APSU can respond rapidly in the event of an outbreak, emergence or importation of diseases. In 2007, weekly surveillance for severe complications of influenza was rapidly initiated after several deaths were reported among Australian children. Within 10 days of receiving a request from DoHA a study protocol and questionnaire was developed, clinicians were reporting by e-mail or fax and data on children admitted to hospital with severe complications of influenza were being collected.

Surveillance coverage – scope and limitations

Gaps in surveillance occur because many rural, remote, Indigenous and refugee communities are poorly served by paediatricians and because some children are treated by adult physicians. Using the National Health and Medical Research Council Enabling Grant the APSU is addressing these limitations by developing complementary surveillance methods that reach Indigenous and refugee children.

Financial support

Funding for the unit is required for program management such as administration, research and financial support. The unit is funded through a combination of government funds, competitive grants and sponsorships. (See page 33)

Studies Timeline

Table 1: APSU studies timeline

Study	Duration	Reported Rate for duration of study (per 10^5 per annum) to Dec 31, 2006	Total confirmed cases to Dec 31, 2007*
Infectious/vaccine-preventable conditions, including congenital infections			
Acute flaccid paralysis	Mar 1995 - ongoing	0.9 [b]	438
Congenital cytomegalovirus	Jan 1999 - ongoing	3.7 [a]	89
Congenital rubella	May 1993 - ongoing	0.1 [b]	50
Congenital varicella	Mar 1995 – Dec 1997	0.8 [a]	6
Congenital varicella (study reactivated)	Apr 2006 – ongoing	†	2
Neonatal varicella	Mar 1995 – Dec 1997	5.8 [a]	44
Neonatal varicella (study reactivated)	May 2006 – ongoing	†	14
Haemolytic uraemic syndrome	Jul 1994 - Dec 2001	1.1 [f] 0.5 [b]	146
Hepatitis C virus infection	Jan 2003 - ongoing	0.3 [b]	46
HIV infection, AIDS and perinatal exposure to HIV**	May 1993- ongoing	8.0 [a]	349
Hospitalised pertussis in infancy	Jan 2001-Dec 2001	56 [a]	128
Invasive *haemophilus influenzae* infection	Jan 1998 - Dec 2000	0.5 [b]	51
Kawasaki disease	Apr 1993 – Jun 1995	3.7 [e]	139
Neonatal group B streptococcus sepsis	Jul 2005 - ongoing	23.2 [a]	140
Neonatal herpes simplex virus infection	Jan 1997 - ongoing	3.5 [a]	92
Non-tuberculous mycobacterial infection	Jul 2004 – Sep 2007	0.3 [b]	44
Severe complications of varicella infection	May 2006 – ongoing	†	13
Severe complications of influenza	Sep 2007 – Oct 2007	n/a	19
Subacute sclerosing panencephalitis	Jan 1995 – Dec 1998	0.02 [b]	4

Study	Duration	Reported Rate for duration of study (per 10^5 per annum) to Dec 31, 2006	Total confirmed cases to Dec 31, 2007*
Congenital/genetic disorders			
Arthrogryposis multiplex congenita	Jan 1996 – Dec 1998	6.2 [a]	47
CHARGE association	Jan 2000 – Dec 2002	2.8 [a]	23
Congenital adrenal hyperplasia	Aug 1995 – Dec 1997	5.9 [a]	55
Congenital and idiopathic nephrotic syndrome	Jul 1998 – Jun 2001	1.2 [b]	135
Extrahepatic billiary atresia	May 1993 - Dec 1996	5.4 [a]	110
Hyperinsulinaemic hypoglycaemia	Jan 2005-Apr 2006	0.8 [e]	43
Fetal alcohol syndrome	Jan 2001 - Dec 2004	0.48 [b]	76
Haemoglobinopathies	Jan 2004 - Mar 2006	0.7 [b]	52
Hirschsprung disease	Jan 1997 – Dec 2000	10.8 [a]	108
Prader-Willi syndrome	Jan 1998 – Dec 2000	0.4 [b]	42
Primary immunodeficiency diseases (including SCID)	Jan 1997 – Dec 1999	1.1 [b]	126
Rett Syndrome	Jan 2000 - ongoing	8.8 [c]	308
Severe combined immunodeficiency disorder	May 1995 - Dec 2001	1.7[a]	33
Mental health issues			
Childhood dementia	May 1993 – Jun 1995	2.6 [b]	148
Childhood conversion disorder	Jan 2002 – Dec 2003	2.44 [b]	194
Munchausen by proxy syndrome	Jan 2000 – Dec 2003	0.4 [b]	58
Early onset eating disorder	Jul 2002 – Jun 2005	1.4[d]	101
Other injury/illness			
Anaphylaxis following food ingestion	Jul 2002 – Dec 2003	1.84 [b]	110
Adverse effects of complementary and alternative medicine	Jan 2001 - Jun 2004	0.24 [b]	39

Studies Timeline

Study	Duration	Reported Rate for duration of study (per 10^5 per annum) to Dec 31, 2006	Total confirmed cases to Dec 31, 2007*
Near drowning	May 1993 – Dec 1996	5.1[f]	202
Serious seatbelt injuries	Jan 2006 - Dec 2007	0.7[e]	41
Simple vitamin D deficiency rickets	Jan 2006 - Dec 2007	0.5[b]	393
Vitamin K deficiency bleeding	May 1993 - ongoing	0.7[a]	25
Intussusception	May 2007 - ongoing	n/a	45
Neuromuscular disorders	Jan 2007 - ongoing	n/a	74
Acute rheumatic fever	Oct 2007 – ongoing	n/a	10

* Total confirmed cases according to the study protocol and available at time of printing
a. Reported incidence per 100,000 live births
b. Reported incidence per 100,000 children <15 years
c. Reported prevalence per 100,000 females aged 5-18yrs
d. Reported incidence per 100,000 children 5-13 years
e. Reported incidence per 100,000 children <10 years
f. Reported incidence per 100,000 <5 years
** HIV infection includes cases due to perinatal exposure and from other sources
† Due to the limited surveillance period a reported rate has not been be calculated
NA – Not available

In 1997, the APSU was the first paediatric surveillance unit in the world to undergo systematic evaluation using guidelines proposed by the Centers for Disease Control and Prevention (CDC). The APSU was found to be a simple, flexible mechanism that provides timely data and is acceptable to the majority of its users. The APSU fulfilled most of its objectives and met CDC criteria salient to these.

Clinicians reporting to the APSU were overwhelmingly supportive and provided excellent constructive feedback. The evaluation underpinned recommendations for improvements. These included:

- systematic revision for completeness and accuracy of the reporting clinicians' contact list;
- improved dissemination of knowledge generated by APSU studies to guide translation into clinical practice, public health policy, and community awareness;
- shortening the data collection forms; and
- minimising requests for biological specimens to decrease workload for reporting clinicians.

The first evaluation also recognised gaps in surveillance conducted by the APSU:

- lack of coverage among rural, remote and indigenous communities poorly served by paediatricians;
- lack of alternative sources of case ascertainment to allow for calculation of sensitivity.

The second APSU evaluation was conducted in 2007. Again, the CDC criteria for an effective surveillance system (usefulness, simplicity, flexibility, data quality, acceptability, sensitivity, representativeness and timeliness) were met. The APSU reporting mechanism was acceptable to the 1277 clinicians who voluntarily return an average of 96% of monthly report cards, and 94% did not find the monthly reporting burdensome.

A review of the Royal Australasian College of Physician's list of paediatricians showed that 92% actively practising in Australia are reporting to the APSU.

Of reporting clinicians, 95% believe that the work of the APSU is valuable, specifically for:

- generating knowledge (89%) – "Improved knowledge e.g. diagnostic criteria/ management of rare disease";
- guiding clinical practice (75%);
- informing public health policy (72%);
- identifying research priorities (80%).

Dissemination of results has increased with the inclusion of APSU data in almost 175 journal articles, 200 presentations and 85 media items since the first evaluation, and these data have informed policy and practice.

The second evaluation specifically asked clinicians about the limitations of the APSU reporting system. Of the 122 clinicians that commented on limitations the most common limitation was clinician time involved in reporting: "reporting is easy, but filling in the details takes time", "reporting can be onerous", "time availability – I think you make it as easy as possible".

Looking to the future - issues to be addressed

Future challenges for the APSU will include acquisition of long term funding. Although the APSU provides excellent value for money it receives less money than other similar units overseas. Addressing gaps in surveillance of disease in children, particularly in remote and rural communities, is another issue that needs to be further explored. The PAEDS system, currently being piloted, will facilitate the collection of biological specimens and more timely detailed data than is currently available through the APSU. As well, a rapid response surveillance system has been trialled for potential use for monitoring outbreaks, emergence or importation of infectious diseases.

Between 1993 and 2007, the APSU has facilitated over 40 studies. The major findings and impacts of these studies are documented in Table 2.

Table 2: Key findings of National Surveillance conducted through the APSU

Conditions Under Surveillance	Key findings, implications and publications
Monitoring existing public health interventions and informing public health policy	
Acute flaccid paralysis Mar 1995 - ongoing	APSU reports cases of acute flaccid paralysis (AFP) via the Department of Health and Ageing to World Health Organisation and contributes to "polio-free" certification. The primary diagnoses for AFP are due to Guillain-Barre syndrome or transverse myelitis; since 2000 there have been 9 cases of infant botulism. Sixteen countries, including Indonesia, reported importations of wild poliovirus in 2005. Continued surveillance for AFP in Australia is essential to enable detection of imported poliovirus, in view of the recent outbreak in Indonesia and importation of an adult infected with polio to Australia in 2007. (1)
Infants hospitalised with pertussis Jan 2001 – Dec 2001	Identified adults as main source of infection and informed revision of immunisation schedule in 2003 to recommend vaccination of teenagers. Identified children less than 2 months at most risk and led to development of trials of vaccination at birth. (2)
Congenital rubella May 1993-ongoing	Although the incidence of congenital rubella has declined, the risk remains particularly among immigrant women born in countries with poorly developed vaccination programs. Study identified gaps in vaccination program, need for education of women and health professionals, and the need for targeted immigrant screening. (3)
Congenital varicella infection May 1993-Dec 1997	First study completed in 1997 showed that birth defects may occur even with 3rd trimester maternal infection. Study highlighted the need to monitor women infected in pregnancy and to perform eye examination in infants to detect defects. (4,5,6,7)
Invasive *haemophilus influenzae* infection Jan 1998-Dec 2000	Surveillance of *haemophilus influenzae* infection provided detailed clinical information not available from laboratory notification. Confirmed success of *haemophilus influenzae* Type B vaccination; influenced infection prevention policy. (8)
Intussusception May 2007 – ongoing	Rates of intussusception are monitored and temporal association with rotavirus vaccination established.
Simple vitamin D deficiency rickets Jan 2006–December 2007	Highlighted vitamin D deficiency rickets as a common problem among refugee children.
Subacute sclerosing panencephalitis Jan 1995-Dec 1998	Very rare, reflecting high uptake of measles vaccination. (9)

Conditions Under Surveillance	Key findings, implications and publications
Informing public health responses to emerging diseases	
HIV/AIDS, Perinatal exposure to HIV May 1993-ongoing	The APSU enhances mandatory reporting, identifies perinatal exposure and maternal risks. Most cases of HIV are due to perinatal transmission. The main source of infection in the mother was through heterosexual contact with a high risk partner. The transmission rate of infection has declined with increased use of interventions (including anti-retrovirals, elective caesarean section and avoidance of breastfeeding) in women diagnosed antenatally. Study has informed new antenatal screening policy. (10)
Haemolytic uraemic syndrome Jul 1994 – Dec 2001	APSU study identified Shiga-toxin producing *E.coli* prevalent in Australia, provided national data during HUS outbreak and informed code of production for fermented meats. (11,12)
Hepatitis C virus infection Jan 2003-ongoing	The APSU is monitoring an emerging disease of national significance. It is anticipated that the results from this study will impact on screening policy. HCV infection is usually acquired through perinatal exposure. There is need for a systematic diagnostic approach in identifying cases.
Congenital adrenal hyperplasia Jan 1995- Dec 1997	APSU methodology has high sensitivity for case ascertainment and has enabled cross-validation of potential neonatal screening programs. (13)
Congenital cytomegalovirus infection Jan 1999-ongoing	Provides the only national data collection for congenital cytomegalovirus infection (cCMV). CMV continues to be the most common infectious cause of congenital malformation in Australia. CMV is not associated with maternal illness in approximately 30% of cases and should be considered regardless of maternal history. CMV remains under-diagnosed. Although most cases are diagnosed by urine culture, use of PCR for urinary screening for cCMV may increase diagnostic yield. Universal neonatal hearing screening programs may also help identify new cases.
Neonatal herpes simplex virus infection Jan 1997 –ongoing	Herpes simplex virus (HSV) type 1 is identified as the cause of neonatal infection in 50% of Australian cases. Typical skin or mucosal lesions are not evident in about a half of the infants affected. Disseminated HSV infection may present with pneumonitis which requires early antiviral therapy.
Congenital varicella (Reactivated) Apr 2006 - ongoing	Study reactivated after inclusion of varicella vaccine on the National Vaccine Schedule in 2006. One case of congenital varicella was reported in NSW. Further analysis is currently being completed by the investigators. (7)
Neonatal varicella Mar 1995 – Dec 1997	Early identification, treatment (acyclovir, IgG) recommended. (4)

Public Health Outcomes and Impacts of APSU Studies

Conditions Under Surveillance	Key findings, implications and publications
Neonatal varicella (Reactivated) May 2006 - ongoing	Early identification is important. 14 cases of neonatal varicella are reported so far. Further analysis of the data is currently being completed by the investigators.
Severe complications of varicella May 2006-ongoing	Preliminary results show that during seven months of surveillance, 14 children were hospitalised with complications of varicella. Complications included bacteraemia, osteomyelitis, cellulitis, pneumonia, hepatitis, encephalitis and ataxia. Only one child had been vaccinated against varicella.
Neonatal group B streptococcus sepsis Jul 2005 –ongoing	APSU study will document the incidence, morbidity and mortality of GBS while identifying genotype distribution. Preliminary results show that over half of the cases have been early onset at less than 8 days of age.
Severe complications of influenza Jul 2007 – Oct 2007	Following a number of child deaths due to influenza across Australia in 2007, the Department of Health and Ageing approached the APSU to conduct short-term national surveillance for severe complications of influenza. Clinical data were provided on 88% of all notified cases and 15 children met the case criteria for severe complications of influenza. This study demonstrates the feasibility of using the APSU mechanism for enhanced emergency surveillance.
Describing the epidemiology and features of child mental health disorders	
Early onset eating disorders Jul 2002-Jun 2005	First national study of children under 13 years. Contributing to debate on relevance of adult diagnostic (DSM) criteria to children. Simultaneous Canadian and British study allowed for international comparison.
Childhood conversion disorder Jan 2002 – Dec 2003	First study to document the national burden of illness and to clarify psychosocial and other associated risk factors. (14)
Childhood dementia May 1993- Jun 1995	First national study world-wide. Study clarified the diagnostic criteria and identified a substantial group with no identified cause. (15)
Munchausen by proxy syndrome Jan 2002-Dec 2003	First study of its kind to document impact of diagnosis on clinicians; data has informed development of management policy.
Facilitating molecular epidemiological studies	
Rett syndrome May 1993-Apr 1995; Jan 2000 – ongoing	Enabled molecular epidemiological study of national cohort, phenotype/genotype correlation, establishment of international database. (16)
CHARGE association Jan 2000 – Dec 2002	Increased awareness of diagnostic criteria for CHARGE; diagnosis of 87% of cases in first year of life.
Hyperinsulineamic hypoglycaemia of Infancy Jan 2005-Apr 2006	First Australian study to document epidemiology and record known risk factors and outcomes.

Conditions Under Surveillance	Key findings, implications and publications
Guiding paediatric policy and clinical practice	
Vitamin K deficiency bleeding May 1993 – ongoing	Monitoring disease during policy changes to vitamin K prophylaxis and universal use of new vitamin K preparation. (17)
Fetal alcohol syndrome Jan 2001-Dec 2004	Indigenous children over-represented; high rate of affected siblings indicate missed prevention opportunities; children often in foster care and have affected siblings. Informed causal pathways and educational strategies. (18)
Non-tuberculous mycobacterial infection Jul 2004-Sep 2007	Usually presents with lymphadenopathy in healthy children aged < 5 yrs. *Mycobacterium avium intracellulare* and *mycobacterium fortuitum* most commonly isolated. Surgery is the most common therapy. Relapse occurs in about 20% of cases regardless of the medical therapy used.
Identifying and quantifying safety hazards	
Adverse effects from complementary and alternative medicine Jan 2001 – Jun 2004	Sentinel adverse effects documented in infants and children range from mild to fatal. Dietary restrictions, use of complementary and alternative medicine in pregnancy, and use in place of conventional medications pose significant risks.
Near drowning May 1993 – Dec 1996	Neurological outcomes poor; age determines near drowning site; most commonly home pool; significant proportion in rural areas – informed rural water safety policy. (19)
Serious seatbelt injuries Jan 2006 - Dec 2007	In 2006, 30 cases of injuries related to inappropriate seatbelt use were identified with 70% of injured children in the 4 to 9 year age group. Most injured children were restrained by adult seatbelts rather than child restraints or booster seats. Serious injuries including abdominal, spinal and head injuries resulted in lengthy hospitalisation or admission to ICU. Results from this study informed the current review of child restraint laws by the Australian Transport Commission. (20)
Other APSU studies	
Acute rheumatic fever Oct 2007 - ongoing	This APSU study aims to provide national data of acute rheumatic fever (ARF) in children and to determine where and in whom ARF is currently occurring, as well as document recurring episodes of ARF and the use of secondary prophylaxis. Information will be used to make recommendations on where ARF and rheumatic heart disease programs should be established.
Anaphylaxis following food ingestion Jul 2002-Dec 2003	Peanut most common cause; also other nuts, soy and shellfish implicated.
Arthrogryposis multiplex congenita Jan 1996 – Dec 1998	Arthrogryposis multiplex congenita (AMC) is a heterogenous group of conditions with an incidence of 6.2/100,000 among live born infants. This rate underestimates the overall incidence because cases resulting in termination of pregnancy or stillbirths are not included. This study will assist in the further development of classification of AMC and causal pathways. (21)

Conditions Under Surveillance	Key findings, implications and publications
Congenital idiopathic nephrotic syndrome Jul 1998 – Jun 2001	Study identified non-adherence to evidence based management guidelines. (22)
Extrahepatic billiary artresia May 1993 – Dec 1996	APSU study identified late diagnosis and the need for education. Preliminary analysis of follow-up data shows increased rates of end stage liver failure in children diagnosed late and signifies the importance of early diagnosis. (23)
Hirschsprung disease Jan 1997 – Dec 2000	APSU study has provided valuable information on the clinical features of this disease in Australia and its current management. The most often used surgical procedure is the Soave technique.
Haemoglobinopathies Jan 2004 – Mar 2006	APSU study aims to establish an incidence rate, types of haemoglobinopathies and the distribution amongst ethnic groups.
Kawasaki disease Apr 1993 – Jun 1995	Surveillance identified that young children may not fulfil the international diagnostic criteria. (24)
Neuromuscular disorder Jan 2007 – ongoing	Incidence data in children are often outdated and incomplete. This study will aim to provide epidemiologic data to secure adequate funding of clinical, diagnostic and research services.
Prader-Willi syndrome Jan 1998 – Dec 2000	First DNA confirmed estimate of birth prevalence. Prader-Willi syndrome is often missed clinically in infants, requiring education of health professionals.(25)
Primary immunodeficiency syndrome Jan 1997 – Dec 1999	Documented numbers affected, need for immunotherapy and bone marrow transplant. (26)
Severe combined immunodeficiency May 1995 – Dec 2001	Confirmed good outcome of bone marrow transplant. (27)

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Study 1: Fetal Alcohol Syndrome

Investigators: Carol Bower, Ingrid Bucens Elizabeth Elliott, Eric Haan, Alison Leversha, Anne Morris, Greta Ridley

Background: Fetal alcohol syndrome (FAS) represents the severe end of the spectrum of structural, behavioural and neurodevelopmental abnormalities caused by exposure to alcohol in utero. FAS is a chronic disorder with a poor prognosis. Many adolescents and adults with FAS have had disrupted education (60%), problems with the law (60%), drug and alcohol abuse (30%), mental health disorders (90%) and high rates of unemployment (90%). Early diagnosis and upbringing in an appropriate environment decreases these risks up to four fold. Before the APSU FAS study, there were no national Australian data documenting FAS rates, societal groups at risk; co-morbidities; health and educational requirements. Such data are crucial to inform prevention and development, and funding of specialised diagnostic and intervention services.
APSU surveillance for FAS, conducted from January 2001 to December 2004 inclusive, provided the first national data about FAS, as highlighted below[1].

Demographics

1. In children aged <15 years at diagnosis (total population) the reported incidence per 10^5 per annum was 0.58 (95% CI 0.46 to 0.71).
   - Non-indigenous population 0.18 (95% CI 0.12 to 0.27).
   - Indigenous population (p<0.0001) 8.11 (95% CI 6.19 to 10.44).
2. In children aged <5 years at diagnosis (total population) the reported incidence per 10^5 per annum was 1.14 (95% CI 0.87 to 1.47)
   - Non-indigenous population 0.37 (95% CI 0.22 to 0.59).
   - Indigenous population (p<0.0001) 14.60 (95% CI 10.22 to 20.22).

Rates were significantly higher in Indigenous children. Birth prevalence was 0.06/1000 live births.

Of the 92 children identified, 65% were Indigenous and 51% had a sibling with FAS, indicating missed opportunities for prevention. Only 40.2% lived with a biological parent: 20.7% lived with relatives, and 38.0% were in foster care.

Service usage: A wide range of medical, educational, psychological and community services are used by children with FAS, including specialist paediatrics 80.4%; general paediatrics 66%; child development 51%; genetic 18.5%; psychological medicine 13%; neonatal 5.4%; and community child health 2.2%. Other services used are the Department of Community Services (including child protection) 67.4%; remedial education 33.7%; respite care 8.7% and other services 6.5%.

Child's place of residence: 40.2% were with biological parents, 20.7% lived with relatives, and 38.0% were in foster care.

Catalyst for future research: This study has prompted additional research including two surveys of health professionals' knowledge and attitudes regarding alcohol use in pregnancy; evaluation of education materials for health professionals; a national survey of women's attitudes, knowledge and practice regarding alcohol use and the effects on the fetus; exploration of Indigenous women's knowledge and practice; a systematic review of interventions for FAS; an international audit of services for FAS; and a review of international policy for alcohol use in pregnancy. (Refer page 45 for a list of FAS publications)

1 Elliott EJ, Payne JM, Morris A, Haan E, Bower CA. Fetal alcohol syndrome: a prospective national surveillance study. *Archives of Disease in Childhood* 2007. (In press)

Study 1: Fetal Alcohol Syndrome

Impact on future policy

The study has also resulted in APSU investigators' appointment to committees that will inform about alcohol and pregnancy including the:

- NHMRC Alcohol Guidelines Review Committee.
- Committee to develop Alcohol Policy: Using Evidence for better outcomes, a joint publication by the RACP and the Royal Australasian and New Zealand College of Psychiatrists.
- Intergovernmental Committee on Drugs Working Party on FASD, reporting to the Ministerial Council on Drug Strategy.
- Planning committee for a National Workshop on FASD in 2008.
- Committee to develop GP Life Scripts relating to alcohol and pregnancy.

Educational activities

- Development, distribution and evaluation in Western Australia of educational materials for health professionals.
- APSU workshop on FAS in Sydney 2005 for parents and health care professionals, with keynote speaker Prof Ken Jones.
- Rural Education Network Broadcast, DVDs and SBS program screened in 2007-8.
- Workshop convenors, 2nd International FASD conference, Victoria, Canada, March 2007.
- Presentations at scientific meetings including the International Society Biological Research in Alcohol.
- Speakers at numerous conferences including a rural forum on FAS, Ballina, September 2006.
- Western Australia Workshop on Alcohol and Pregnancy Health Professionals Making a Difference, August 2007 and telecast to rural services.

Discussion: This study affirms that FAS is a complex, chronic disorder impacting significantly on children, families, health professionals and the community, and requires a multidisciplinary approach to care. No such services exist in Australia. Early intervention decreases long term adverse effects but requires an early diagnosis. In Australia no national data on FAS had previously existed. This study highlights the strong over-representation of Indigenous children, the complexity of this condition, the need for community education, prevention programs and specialised diagnostic services.

Study 2: Rett Syndrome

Investigators

Gordon Baikie, Carol Bower, John Christodoulou, Nick de Klerk, Martin Delatycki, Carolyn Ellaway, Susan Fyfe, Walter Kaufmann, Helen Leonard, Jim McGill, Michael Msall , Lakshmi Nagarajan, Alan Percy, David Ravine, Sheena Reilly, Jon Silberstein, Sven Silburn, Elizabeth Thompson, MK Thong, Helen Woodhead

Background

Classical Rett syndrome is characterised by seemingly normal development for 6-18 months, followed by a period of regression. This severe neurodevelopmental disorder is caused, in most cases, by mutations in the X-linked methyl-CpG-binding protein 2 gene (MECP2). Because presentations may be similar to that of other disorders Rett syndrome may be difficult to diagnose on clinical criteria alone. Rett syndrome has been on the APSU card on two occasions – before and after identification of the above mutations. This study has facilitated research in molecular epidemiology and enabled genotype-phenotype studies. Genetic testing allows early confirmation of the diagnosis in subgroups of children and, in turn, facilitates early access to specialised multidisciplinary care.

Key study findings

- In 2005:
  - The cumulative incidence was 1.20 per 10,000 females by 15 years of age.
  - Mean age at diagnosis was 5.3 years (SD 3.9).
  - Survival was 77.8% at 25 years with pneumonia the most common reported cause of death.
- Enrolment of new cases of Rett syndrome continues, the cohort now consisting of 312 cases.
- In contrast to the original diagnostic criteria, abnormal early development is not uncommon in Rett syndrome and is associated with specific mutations.
- Relationships have also been demonstrated between a number of mutations and the clinical phenotype.
- By combining Australian population-based data with UK data and using laboratory expertise from the University of Cardiff, a quantitative relationship between the degree and direction of X inactivation and clinical severity was demonstrated for two common mutations in Rett syndrome.
- Median age at scoliosis onset was 9.8 years and 75% had developed scoliosis by 13 years of age.
- Children with abnormal early development (< six months), those who were less mobile at ten months, and those who never walked, had earlier onset of scoliosis.
- The onset and course of epilepsy are related to the genotype and that likely time of onset of seizures can be predicted at the time of diagnosis from the child's early development and genotype. These findings have relevance to understanding the biological consequences of MECP2 mutations and allow us to provide parents with practical clinical information.
- Mean weight, height and BMI z-scores in Rett syndrome were below that of their age group and decreased steadily with age.
- The fracture rate in Rett syndrome is nearly four times that of the general population (as estimated from Tasmanian females <20 years) with the femur the most common bone to fracture.

Service usage

Socio-demographic, phenotypic and genetic characteristics all affect health service use in Rett syndrome. For example, younger children,

Study 2: Rett Syndrome

those with a severe phenotype and those with random X-inactivation are the highest users of health services. Therefore a team approach, where many kinds of health care providers like physical therapists, occupational therapists and speech-language therapists play a role is optimal. Regular monitoring of trends in incidence and prevalence are important for predicting present and future use of medical and disability services and resource needs.

Impacts of the study

This has been an extremely productive project, resulting in numerous publications (refer page 47-49 for a list of Rett publications) and scientific presentations. The major impacts of this study have been:

- The biennial collection of information on a cohort of children with Rett syndrome (as an extension of the APSU study) increasing our understanding of the progression and prognosis of the disorder – this will be useful for clinicians diagnosing and managing the disorder and health service planners.
- APSU Rett cohort has participated in longitudinal studies, case control and randomised controlled trials.
- Establishment of a consumer reference group which meets intermittently by teleconference, ensures family representation and input to the study.
- Regular Australian Rett Syndrome study reports utilising data collected from family questionnaires.
- Identification of a number of Australian males with a neonatal encephalopathic picture and the presence of a MECP2 mutation.
- The award of a National Institutes of Health grant to fund the Australian Rett Syndrome study from 2003 to 2008.
- Informed development of specialised Rett clinics in Sydney, Melbourne and Perth.

Historical Development of the Network

In the 1990s, several active national paediatric surveillance units were developed, based on adaptations of the model created by the British Paediatric Surveillance Unit (BPSU) in 1986. The establishment of the International Network of Paediatric Surveillance Units (INoPSU) was a natural extension to formally link existing units (Table 3).

Table 3: INoPSU summary

Country	Date Established	Child Population (0-15 years)	Average Number of Reporting Clinicians	Response Rate of Returned Cards (%)	Response Rate of Returned Question-naires (%)
Australia (APSU)	1993	4,100,000	1277	96	86
Britain (BPSU)	1986	12,700,000	2550	91	92
Canada* (CPSP)	1996	7,600,000*	2500	82	96
Cyprus/Greece (CGPSU)	2003	1,280,000	110	100	100
Germany (ESPED)	1992	12,000,000	462	98**	60-95**
Ireland (IPSU)	1996	1,500,000	150	80	80
Latvia (LPSU)	1998	348,960	8	70	85
Malaysia† (MPSU)	1994	7,700,000	395	75%	n/a
Netherlands (NSCK)	1992	3,000,000	692	0	70
New Zealand (NZPSU)	1997	800,000	208	94	n/a
Papua New Guinea† (PNGPSU)	1996	2,000,000	40	79%	n/a
Portugal (PPSU)	2001	1,400,000	1,800	33	66
Switzerland (SPSU)	1994	1,300,000	38	100	98
Wales (WPSU)	1994	577,800	158	100	n/a

* Canadian Paediatric Surveillance Program paediatric population is aged 0-17.9 years

** 2004 Annual Results

† Malaysian and Papua New Guinea units have ceased surveillance

Key protagonists in Britain for forging links between international units were the late David Baum, past President of the Royal College of Paediatrics and Child Health, and Professors Euan Ross and Chris Verity, former Chairs of the BPSU. The late Victor Marchessault, Vice President of the Canadian Paediatric Society, played a major role in the development of the CPSP and forged close links between Canada, Britain, Australia and elsewhere. A proposal for INoPSU was drawn up in 1996 and ratified at the 22nd International Congress of Paediatrics in Amsterdam in August 1998. Establishment of the network was documented in the Amsterdam-Ottawa Note[2], which outlines the principles behind the development of the network and formalised links among units.

Dr Angus Nicoll was elected as the first convenor of INoPSU from 1998 to 2000, and the first INoPSU conference was held in Canada in June 2000. At the end of his tenure Elizabeth Elliott from the APSU took on the role of Convenor from 2000-2004 and provided strong drive and support. Under her direction, the network continued to thrive. The second INoPSU conference was held in York, England in 2002 and the third in Lisbon, Portugal in 2004. There, Professor Rudi von Kries (Germany) and Dr. Rob Pereira (Netherlands) were elected Co-Convenors. The fourth meeting in London in 2006, coincided with 20 years of surveillance by the BPSU. The next INoPSU meeting will be held in September 2008 in Munich, Germany in association with the German Paediatric Society Meeting.

At a scientific and business meeting held every two years, members meet to present research findings, discuss research methodology, funding and ethical issues, and to plan the activities of the network. Key to the success of INoPSU is Richard Lynn, Scientific Coordinator of the BPSU and Secretariat for the network. Richard serves as the 'engine room', coordinating activities, disseminating information and facilitating study collaboration between different units. Recently, individual units have contributed to the costs of administrative support for INoPSU.

The mission and aims of INoPSU are listed in Table 4. A key facet of the network is its ability to facilitate joint studies through sharing of study protocols, case definitions and questionnaires, and to link investigators with one another. Examples of studies in which epidemiological and clinical data have been collected simultaneously include vitamin K deficiency bleeding, *haemophilus b influenzae*, childhood diabetes, early onset eating disorder and haemolytic uraemic syndrome. There have been several key papers documenting INoPSU activities, including a seminal paper led by the APSU (Elliott et al)[3] and a subsequent publication highlighting the public health impacts of INoPSU studies (Grenier et al)[4]. In order to highlight the activities of the network the first INoPSU report (edited by the British unit) was published in 2003. Subsequent regular reports are available on the INoPSU website (www.inopsu.com).

2The International Network of Paediatric Surveillance Units (The Amsterdan-Ottawa Note 2000) http://www.inopsu.com

3 Elliott EJ, Nicoll A, Lynn R, Marchessault V, Hirasing R, Ridley G. Rare disease surveillance an international perspective. *Paediatrics Child Health* 2001; 6: 251-60 http://www.inopsu.com/downloads/rare_disease_surveillance.pdf

4 Grenier D, Elliott EJ, Zurynski Y, Rodrigues Pereira R, Preece M, Lynn R, von Kries R. Beyond counting cases: public health impacts of national Paediatric Surveillance Units. *Archives of Disease in Childhood* 2007; 92(6):527-533

Table 4: Mission and Aims of INoPSU

Mission

The advancement of knowledge about rare and uncommon childhood infections and disorders through the participation of paediatricians in surveillance on a national and international basis.

Aims

To encourage and facilitate:

- Communication and co-operation between existing national paediatric surveillance units.
- Development of new and existing units.
- Information sharing about the surveillance process and methods such as study selection, data validation, statistical techniques, surveillance methodology and evaluation, including development of an INoPSU website.
- Peer review and evaluation of ethics and confidentiality issues.
- Simultaneous or sequential collection of comparable epidemiological and clinical data in two or more nations.
- National comparisons of incidence estimates for selected rare disorders of childhood.
- Dissemination of information to national and international health authorities in order to raise awareness, encourage early diagnosis and management of rare conditions.
- Identification of emerging disorders.
- Establishment of international cohorts which could potentially support future research.
- Development and clarification of internationally recognised diagnostic criteria.
- Dissemination of new knowledge to the general public and others, e.g. parents support group.
- Prompt response to international emergencies relating to emerging rare childhood conditions.

International delegates at the 4th INoPSU Conference, London, May 2006

Impacts of Paediatric Surveillance Unit Studies

With access to over 50 million children and monthly contributions by over 10,000 reporting clinicians, INoPSU has, in a short time, developed into a potent system for investigating rare paediatric conditions. Public health outcomes of INoPSU studies are summarised in Table 5 (Grenier et al)[5]. Study outcomes have been categorised into seven main areas:

- monitoring public health interventions;
- informing the development of new screening policy;
- highlighting international differences that impact on local public health policy;
- describing the epidemiology and features of child mental health disorders;
- facilitating molecular epidemiological studies;
- guiding paediatric clinical practice policy;
- identifying and quantifying product safety hazards.

National surveillance is essential for low-frequency conditions, and through high quality evidence, INoPSU members contribute to improve the health of children and youth.

Table 5: Impacts of paediatric surveillance unit studies[5]

Study	Impact	Participating PSU
Acute flaccid paralysis	Confirms absence of wild poliovirus; Contributes to WHO eradication program.	APSU, BPSU CPSP, NZPSU, SPSU
Haemophilus influenzae type B infection	Documented success of Hib vaccination programs including combined pentavalent vaccine.	APSU, ESPED, NSCK
Pertussis infection in infants	Informed changes to vaccination schedules; Identified need to review age of first vaccination and for targeted adult/adolescent vaccination.	APSU, BPSU CGPSU, NSCK
Pneumococcal infection	Documented disease burden and supported universal vaccination programs.	ESPED, NZPSU
Congenital rubella syndrome (CRS)	Document persistence of CRS despite good vaccine coverage, and identify need for targeted vaccination for susceptible women including immigrants, non-immune, pre-conception and postpartum.	APSU, BPSU, CPSP, NZPSU, SPSU, NSCK
Subacute sclerosing panencephalitis	Confirms disease is rare in countries with well implemented measles vaccination programs and is associated with wild measles virus infection.	APSU, BPSU CPSP, ESPED

5 Grenier D, Elliott EJ, Zurynski Y, Rodrigues Pereira R, Preece M, Lynn R, von Kries R. Beyond counting cases: public health impacts of national Paediatric Surveillance Units. *Archives of Disease in Childhood* 2007; 92(6):527-533.

Study	Impact	Participating PSU
Congenital varicella; neonatal varicella; complications.	Confirms need for universal vaccination, and education for community and health professionals regarding infection in pregnancy.	APSU, BPSU, CPSP, ESPED, SPSU
Neonatal herpes simplex virus infection	Confirms HSV-1 most prevalent in Australia and Canada; incidence is lower than in USA; disease is often severe. Identifies need for effective screening, vaccine against HSV-1 & 2.	APSU, BPSU, CPSP, SPSU
HIV/AIDS, perinatal exposure to HIV	Support recommendation for anti-retroviral agents, caesarian section, bottle feeding in infected mothers; supported recommendation for universal prenatal screening in some countries.	APSU, BPSU, LPSU, NSCK, NZPSU
Invasive group B streptococcal disease	National prevention guidelines recommended, either based on risk factors or through universal screening in late pregnancy.	BPSU, CPSP, ESPED, NSCK, PPSU
Progressive intellectual and neurological deterioration (PIND) and Childhood dementia.	Identified variant CJD in Britain but not Canada but no trend to increased rate. Identified PIND has many aetiologies; many cases idiopathic; all highly demanding of health services.	APSU, BPSU, CPSP
Early onset eating disorder (<13y)	Confirms need for pre-adolescent diagnostic criteria; substantial proportion of boys age ≤ 9y.	APSU, BPSU CPSP, NSCK
Conversion disorder	Describes clinical features, disease burden, co-morbidity and risk of recurrence.	APSU, CPSP, BPSU
Munchausen syndrome by proxy	Identified large disease burden; feelings of isolation in clinicians and need for multidisciplinary support.	APSU, BPSU
Rett Syndrome; Prader -Willi Syndrome; SLOS	Describe molecular epidemiology and genotype-phenotype correlations, establish research cohorts for longitudinal and other studies.	APSU, BPSU, CPSP

Study	Impact	Participating PSU
CHARGE association	Identified the complexity of CHARGE; overlap with other syndromes; need for future health resources plan; facilitated genetic studies.	APSU, CPSP
Medium chain acyl CoA dehydrogenase deficiency	Confirmed the value of neonatal tandem mass spectrometry screening for early identification of disease.	BPSU, NSCK
Vitamin K deficiency bleeding	Confirms most cases are late onset and related to underlying liver disease; high proportion of cases receive none or incomplete prophylaxis.	APSU, BPSU, CPSP, ESPED, NZPSU, SPSU, NSCK
Fetal alcohol syndrome	Identified need for educational preventative measures for the community and health professionals.	APSU
Haemolytic uraemic syndrome	Described geographic variation in aetiology, highlighting the need for new diagnostic tests. Supported preventative measures eg education; hygiene recommendations for kindy farms; legislation regarding food production.	APSU, BPSU, CPSP, LPSU, NZPSU, PPSU, SPSU
Chemistry set poisoning	Resulted in amended legislation in Britain regarding packaging and information provided.	BPSU
Reye syndrome	Ban of aspirin in paediatric/youth populations.	BPSU, ESPED
Baby walkers	Ban on sale, re-sale, advertisement and importation of baby walkers in Canada.	CPSP
Lap-belt syndrome	Call for age and size-appropriate use of restraints for children in motor vehicles.	CPSP

International study collaboration

International study collaboration is an ideal way to utilise the INoPSU mechanism. It encourages the simultaneous collection of comparable epidemiological and clinical data in two or more countries. The following studies – early onset eating disorder (EOED), haemolytic uremic syndrome (HUS) and vitamin K deficiency bleeding (VKDB) are examples of how this mechanism has been used to compare study results from different countries.

Early onset eating disorder

The study from Australia and Canada showed that children aged 5-13 years of age with eating disorders present with significant weight loss (5-6kg respectively), or failure to gain weight, psychosocial problems and medical complications such as bradycardia (42%, 29%), hypothermia (32%,13%) and hypotension (21%). Symptoms include food avoidance (100%, 98%), preoccupation with food (93%, 83%), fear of weight gain or fat (77%, 74%), preoccupation with weight (75%, 72%), depression and anxiety, excessive exercise (57%, 51%) and self-induced vomiting (12%, 11%). Many children do not meet the DSM-IV diagnostic criteria for anorexia nervosa indicating the need for establishing pre-adolescent diagnostic criteria.

Haemolytic uremic syndrome

Haemolytic uraemic syndrome (HUS) is the most common cause of acute renal failure in children but no contemporary international data comparisons are published. Data were compared from six members of INoPSU. In total, 887 incident HUS cases were identified. Most (91.8%) followed a diarrhoeal illness and occurred during summer. The reported rate was higher in Switzerland (3.5 per 10^5 children aged <5y per annum) than other countries (Australia 1.11, Britain 1.54, Canada 2.12, NZ 1.72, Portugal 0.43). The median age at presentation ranged from 23 to 44 months; 57.8% children were aged <5years at diagnosis; 43.9% were male. Early mortality was 3.4%. Outbreaks contributed 5.7% cases and occurred in UK, Australia (20 cases) and Canada (15 cases) and were associated with contaminated mettwurst, well water, animal contact or the environment. E.coli O157 accounted for most Shiga toxin-producing E.coli isolates in the UK, 94% in Canada, 46% in NZ, 24% in Switzerland and 10% in Australia, where E.coli O111 predominated (56% isolates). Non-O157 atypical HUS accounted for 7.9% cases and was commonly associated with Strep. Pneumoniae infection.

Vitamin K Deficiency Bleeding

Publication of claims linking the use of intramuscular vitamin K administration in newborns and later childhood cancer, resulted in several countries re-evaluating their prevention policy consequently recommending an oral vitamin K as an alternative for the prevention of VKDB. Publicity stemming from this allegation led some parents to refuse consent for vitamin K. Data were compared from seven countries and confirmed an increased number of patients, some with intracranial bleeding and severe neurological sequelae[6,7]. International comparison showed that the lowest incidence rates of such complications occur in countries predominantly using intramuscular vitamin K, confirming the safest route of administration. This led to the revision of practice guidelines.

6 Cornelissen M, Von Kries R, Loughnan P et al. Prevention of vitamin K deficiency bleeding: efficacy of different multiple dose schedules of vitamin K. *European Journal of Paediatrics* 1997;156:126-30

7 McMillan DD, Grenier D, Medaglia A. Canadian Paediatric Surveillance Program confirms low incidence of haemorrhagic disease of the newborn in Canada. *Paediatrics and Child Health* 2004; 9:235-238

Funding and Sponsorship 1993 to 2007

Major funders:

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- The Children's Hospital at Westmead
- The Financial Markets Foundation for Children
- The Royal College Australasian College of Physicians – Paediatrics and Child Health Division
- The University of Sydney, Faculty of Medicine

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- Davies Collison Cave Attorneys
- Glaxo Smith Kline
- Healthway, WA
- Mount Majura Wines
- National Centre in HIV Epidemiology and Clinical Research
- NSW Department of Health
- Nutricia Australasia
- Orlando Wines
- Paediatric Research Society of Australia and New Zealand
- Rett Syndrome Association of Australia
- Roche Products Pty Ltd
- Telethon Institute for Child Health Research
- The Royal Women's Hospital and the Royal Children's Hospital, Melbourne
- USA National Institutes of Health

Institutions and Organisations Collaborating with the APSU 1993 to 2007

National Organisations

- Australia and New Zealand Paediatric Nephrology Association
- Australian CHARGE Association
- Australian Enteric Pathogens Surveillance Scheme
- Australian Maternity Outcomes Surveillance System
- Australian Polio Expert Committee
- Australasian Paediatric Endocrine Group
- Australian Institute of Health and Welfare
- Australian Society of Clinical Immunology and Allergy
- Commonwealth Department of Health and Ageing
- Intergovernmental Committee on Drugs
- 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
- Rett Syndrome Association of Australia & AussieRett
- Women's and Children's Hospitals Australasia

New South Wales

- Bankstown Hospital
- CAMSHNET
- Centre for Kidney Research
- Centre for Mental Health, NSW Health
- Children's Hospital at Westmead
- Gastroenterology & Liver Unit, Prince of Wales Hospital
- Institute for Neuromuscular Research
- Hunter Genetics
- Liverpool Health Service
- Macleay Hastings Health Service
- Millennium Institute of Health Research
- NSW Birth Defects Register
- NSW Centre for Perinatal Health Services Research
- NSW Health
- Paediatric HIV Services Unit, Sydney Children's Hospital
- Prince of Wales Medical Research Institute
- Royal Prince Alfred Hospital
- Royal North Shore Hospital
- Sydney Children's Hospital
- University of NSW
- University of Sydney
- South Eastern Sydney & Illawarra Area Health Service
- South Eastern Area Laboratory Services
- South Western Sydney Area Health Service

Victoria

- Australian Mycobacterium Reference Laboratory Network
- Centre for Adolescent Health
- Victorian Infectious Diseases Reference Laboratory
- Monash Medical Centre
- Murdoch Children's Research Institute
- Public Health Group, Royal Women's Hospital, Melbourne
- Royal Children's Hospital, Melbourne
- University of Melbourne

Queensland

- Mater Children's Hospital
- Princess Alexandra Hospital
- Queensland University of Technology
- Royal Children's Hospital, Brisbane
- Royal Children's Hospital, Herston, QLD
- Tropical Public Health Unit
- University of Queensland

Institutions and Organisations Collaborating with the APSU 1993 to 2007

South Australia

- Drug and Alcohol Service, 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

Western Australian

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

Tasmania

- Royal Hobart Hospital

Northern Territory

- Alice Springs Hospital
- Royal Darwin Hospital
- The Menzies School of Public Health, Darwin

International Organisations

- Great Ormond St Hospital, London, UK
- Hospital for Sick Children, Toronto, Canada
- Oakland Children's Hospital, USA
- Westkids, Auckland, NZ

INoPSU

- British Paediatric Surveillance Unit
- Canadian Paediatric Surveillance Program
- German Paediatric Surveillance Unit
- Greece & Cyprus Paediatric Surveillance Unit
- Latvian Paediatric Association
- Malaysian Paediatric Surveillance Unit
- Netherlands Paediatric Surveillance Unit
- New Zealand Paediatric Surveillance Unit
- Papua New Guinea Paediatric Surveillance Unit
- Portuguese Paediatric Surveillance Unit
- Swiss Paediatric Surveillance Unit
- Trinidad and Tobago Paediatric Surveillance Unit
- Republic of Ireland Paediatric Surveillance Unit
- Welsh Paediatric Surveillance Unit

APSU Staff 1993 to 2007

DIRECTOR
Elizabeth Elliott 1993 - ongoing

ASSISTANT DIRECTOR
Katrina Williams 1995 - May 2001
Anne Morris (Medical Director) 1999 – 2001
Greta Ridley (Scientific Director) 2001 - 2004
Yvonne Zurynski 2005 – ongoing

STATISTICIAN
Rogan McNeil 1993 – 1994
Jennifer Peat 1995 -2005

STAFF AND FELLOWS
Kerry Chant 1993 – 1994
Diane Redmond 1993 - 2003
Greta Ridley 1998
Emily Fremantle 2005 - February 2007
Louise Tofts 2007 - ongoing
Katie Frith 2006 and 2008
Elizabeth Peadon 2007 - ongoing
Hua Chang 2007 - 2008
Deepika Mahajan 2007 - ongoing
David Lester-Smith 2007 - 2008
Nicola Benwell 2007 - ongoing

DATABASE ADMINISTRATOR/MANAGER*
Jenny Fowler 1999 – 2004
Nicole McKay 2006 - ongoing*

SECRETARY
Diane Hanlon 1993
Lee Proctor 1994 - 1995

ADMINISTRATIVE ASSISTANT/OFFICER/ SENIOR ADMINISTRATOR*
Susan Mildenhall 1995 - 1997
Gabrielle Williams 1997 - 2001 December*
Jenny Fowler 1998
Karen Pattinson 2002 - 2003
Rosemary Robertson 2005 – 2006
Ingrid Charters 2004 - ongoing

OFFICE CO-ORDINATOR
Karen Pattinson 2006 - ongoing

SCIENTIFIC OFFICER/COORDINATOR/ ASSISTANT SCIENTIFIC OFFICER*
Greta Ridley 1999 - 2000, 2001*
Donna Rose 2002 - 2004

RESEARCH/PUBLICATIONS PROJECT OFFICER
Paula Cronin 2004 - 2006
Sarah Srikanthan 2007 - ongoing

SPECIAL PROJECTS
APSU First Evaluation,
Project Coordinator Madlen Gazarian 1998
APSU Second Evaluation,
Project Coordinator Suwen He 2007
PAEDS Trial Coordinator, Margy Pym 2006 - ongoing

APSU Board and Scientific Review Panel 1993 to 2007

Participant	Committee and Tenure
Bower, Carol	APSU Board/Scientific Review Panel, 1997-ongoing; APSU Board Chairman Jan 2003-ongoing
Burgess, Margaret	APSU Board, 1993-2000
Caeser, Claire	Scientific Review Panel, 1998
Carmichael, Alan	APSU Board, 1993-1998
Chant, Kerry	APSU Board/Scientific Review Panel, 1993-1999
Dickson, Nigel	ASPU Board/ Scientific Review Panel, 1997-ongoing
Elliott, Elizabeth	ASPU Board/ Scientific Review Panel, 1993-ongoing
Frommer, Michael	APSU Board, 1993-1996
Hall, Robert	APSU Board/Scientific Review Panel, 1993
Hall, Susan	APSU Board, 1993
Hallam, Elizabeth	APSU Board, 1999-2004
Harvey, Bronwen	APSU Board, 1997
Herceg, Ana	APSU Board, 1996
Isaacs, David	APSU Board, 1993-2006
Jalaludin, Bin	APSU Board/Scientific Review Panel, 2000-ongoing
Laandau, Lou	APSU Board, 1994 – 1999
Lancaster Paul	APSU Board/Scientific Review Panel, 2000; APSU Board, 2001-2004
Longbottom, Helen	APSU Board/Scientific Review Panel, 1994-2002
McIntyre, Peter	APSU Board, 2001-ongoing
Mellis, Craig	APSU Board/Scientific Review Panel, 1993, 1996-1999.
Morris, Anne	APSU Board/Scientific Review Panel, 1999-2001
Murphy, Elisabeth	APSU Board, 1993-ongoing
Nissen, Michael	APSU Board, 2000-ongoing; Scientific Review Panel, 2005-ongoing
Nolan, Terry	APSU Board/Scientific Review Panel, 1993-1999
Oates, Kim	APSU Board/Scientific Review Panel, 1993-1997
Pearne, John	APSU Board, 1993-2000
Peat, Jennifer	Scientific Review Panel, 1996-2000; APSU Board, 1998-2000
Phelan, Peter	APSU Board Chairman, May 1995-1996
Pitt, Robert	APSU Board, 1994-1997
Podesta, Lesley	APSU Board, 2002-ongoing
Procopis, Peter	APSU Board Chairman, 1993-May 1995

APSU Board and Scientific Review Panel 1993 to 2007

Redmond, Diane	APSU Board/Scientific Review Panel, 1994-1998
Ridley, Greta	APSU Board/Scientific Review Panel, 2000-2001
Roberton, Don	APSU Board, 1993-2002; APSU Board Chairman, 1996-2002
Rose, Donna	APSU Board/Scientific Review Panel, 2002-2004
Ruben, Alan	APSU Board/Scientific Review Panel, 1994-1997
Sam, Greg	APSU Board, 1999-2003
Skull, Susan	APSU Board/Scientific Review Panel, 2000-2005
Spencer, Jenean	APSU Board, 2003-2004
Stanley, Fiona	APSU Board 1993; APSU Patron, 2002-ongoing
Sullivan, Elizabeth	APSU Board, 2005-ongoing
Taylor, Barry	APSU Board, 1993-ongoing
Vimpani, Graham	APSU Board/Scientific Review Panel, 1993- May 1994
Wake, Melissa	APSU Board/Scientific Review Panel, 2005-ongoing
Walker, Alan	APSU Board, 1993-1995
Wigg, Neil	APSU Board, 1997; APSU Board/ Scientific Review Panel, 1998-ongoing
Williams, Katrina	APSU Board/Scientific Review Panel, 1995-2000
Ziegler, John	APSU Board, 1993-ongoing
Zurynski, Yvonne	APSU Board/Scientific Review Panel, 2005-ongoing

Study	Investigator
Acute flaccid paralysis	Bruce Thorley* (VIC), Heath Kelly (VIC), Kerri Anne Brussen (VIC), Jayne Antony (NSW), Elizabeth Elliott (NSW), Ana Herceg (ACT), Margery Kennett (VIC), Helen Longbottom (ACT), Monique Ryan (VIC)
Acute rheumatic fever	Jonathan Carapetis* (NT), Sara Noonan (SA), Elizabeth Elliott (NSW), Yvonne Zurynski (NSW), Bart Currie (NT), Malcolm McDonald (NT), Gavin Wheaton (SA), David Isaacs (NSW), James Ramsay (WA), Peter Richmond (WA), Nigel Curtis (VIC), Michael Nissen (QLD)
Adverse effects from Complementary and alternative medicine	Mike South* (VIC), Alissa Lim (VIC), Noel Cranswick (VIC), Susan Skull (VIC)
Anaphylaxis	Ana Dosen* (NSW), John Ziegler (NSW), Alyson Kakakios (NSW), Andrew Kemp (NSW), Mike Gold (SA), Richard Loh (WA), Jane Peake (QLD)
Arthrogryposis multiplex congenita	Lee Taylor* (NSW), Graeme Morgan (NSW), Meredith Wilson (NSW)
CHARGE association	George Williams* (NSW), Meredith Wilson (NSW), Donna Rose (NSW), Paul Lancaster (NSW), P Carter (NSW), Jonathan Craig (NSW), Edward Beckenham (NSW), Eric Haan (SA), Paul Hutchins (SA), Patricia Mutton (SA), Neville Howard (SA), Robert Ouvier (SA), Gary Sholler (SA), J Smith (SA), J Sigafoos (NSW), Matthew Edwards (NSW), Tors Clothier (NT), David Mowat (NSW), J Goldblatt (WA), Christine Oley (QLD)
Childhood conversion disorder	Kasia Kozlowska* (NSW), Kenneth Nunn (NSW), Anne Morris (NSW), Paddy Grattan-Smith (NSW), Robert Ouvier (NSW), John Varghese (QLD), Donna Rose (NSW)
Childhood dementia	Kenneth Nunn*, (NSW), Robert Ouvrier (NSW)
Congenital and neonatal varicella	Margaret Burgess* (NSW), Kerry Chant (NSW), Jill Forrest (NSW), Elizabeth Sullivan (NSW), Mark Ferson (NSW)
Congenital varicella (study reactivated)	Robert Booy* (NSW), David Burgner (WA), Michael Nissen (QLD), Jim Buttery (VIC), Yvonne Zurynski (NSW), Elizabeth Elliott (NSW), Michael Gold (SA), Elizabeth Peadon (NSW)
Neonatal varicella (study reactivated)	Robert Booy* (NSW), David Burgner (WA), Michael Nissen (QLD), Jim Buttery (VIC), Yvonne Zurynski (NSW), Elizabeth Elliott (NSW), Michael Gold (SA), Elizabeth Peadon (NSW)
Congenital adrenal hyperplasia	Geoffrey Ambler* (NSW), Christopher Cowell (NSW), Bridget Wilcken (NSW), Veronica Wiley (NSW), Michael Thomsett (QLD), Geoff Byrne (WA)

APSU Study Investigators

Study	Investigator
Congenital cytomegalovirus	William Rawlinson* (NSW), Daniel Trincardo (NSW), Beverley Hall (NSW), Christine Baleriola (NSW), Sian Munro (NSW), Gillian Scott (NSW), Pamela Palasanthiran (NSW), Mark Ferson (NSW), David Smith (WA), Geoff Higgins (SA), Michael Catton (VIC), Alistair McGregor (TAS), Dominic Dwyer (NSW), Alison Kesson (NSW), Jonathan Howard (NSW), Maria Craig (NSW), Cheryl Jones (NSW)
Congenital & idiopathic nephrotic syndrome	Elisabeth Hodson* (NSW), Jonathan Craig (NSW), Narelle Willis (NSW), Sandra Puckeridge (NSW)
Congenital rubella	Cheryl Jones* (NSW), Margaret Burgess (NSW), Jill Forrest (NSW)
Drowning and near drowning	Frank Ross* (NSW), Daniel Cass (NSW), Victor Carey (NSW), Robert Pitt (QLD), Graham Vimpani (NSW)
Early onset eating disorder	Sloane Madden* (NSW), Ken Nunn (NSW), Anne Morris (NSW), Michael Kohn (NSW), Susan Sawyer (VIC), Donna Rose (NSW), Bryan Lask (NSW)
Extrahepatic biliary atresia	Elizabeth Elliott* (NSW), Stuart Dorney (NSW), Diane Redmond (NSW), Ross Shepherd (QLD), Arnold Smith (VIC), Geoff Davidson (SA)
Fetal alcohol syndrome	Carol Bower* (WA), Eric Haan (SA), Jan Payne (WA), Anne Morris (NSW), Greta Ridley (NSW), Ingrid Bucens (NT), Alison Leversha (Auckland, NZ), Elizabeth Elliott (NSW)
Haemoglobinopathies	Philip Emder* (NSW), Elizabeth Argent (NSW), Susan Russell (NSW), Rani Sachdev (NSW), David Mowat (NSW), Paul Monagle (VIC), David Ziegler (NSW), Christine Stone (VIC)
Haemolytic uraemic syndrome	Elizabeth Elliott* (NSW), John Burke (QLD), Paul Henning (SA), Geoffrey Hogg (VIC), Harley Powell (VIC), Roy Robins-Browne (VIC), Vicki Bennett-Wood (VIC), John Knight (NSW), Edward O'Loughlin (NSW), Diane Redmond (NSW)
Hepatitis C virus infection	John Kaldor* (NSW), Cheryl Jones* (NSW), Winita Hardikar (VIC), Alison Kesson (NSW), Suzanne Polis (NSW), Elizabeth Elliott (NSW), Catherine Mews (WA)
Hirschsprung disease	Daniel Cass* (NSW), Patricia Manglick (NSW), Shalinder Singh (NSW), Edi Shi (NSW), Rosslyn Walker (QLD), Robert Yardley (VIC), Tim Cartmill (NSW), David Croaker (NSW), Lawrence Lam (NSW), Frank Ross (NSW)
HIV infection, AIDS and perinatal exposure to HIV	Ann McDonald* (NSW), John Kaldor (NSW), Kidest Nadew (NSW), John Ziegler (NSW), Michelle Good (NSW), Elizabeth Elliott (NSW), Marilyn Cruickshank (NSW), Jenny Studdert (NSW)
Hospitalised pertussis in infancy	Peter McIntyre* (NSW), Anne Morris (NSW), Greta Ridley (NSW), John Massie (WA), Julie McEniery (QLD), Geoff Knight (WA), Elizabeth Elliott* (NSW)

Study	Investigator
Hyperinsulinaemic hypoglycaemia	Ristan Greer* (QLD), Andrew Cotterill (QLD), Rosslyn Walker (QLD), David Cowley (QLD), John Bell (QLD), Michael Thomsett (QLD), Michelle Jack (QLD)
Intussusception	Julie Bines* (VIC), Jim Buttery (VIC), Margie Danchin (VIC), Robert Booy (NSW), Michael Nissen (QLD), Vikki Krause (NT), Peter Richmond (WA), Michael Gold (SA), Sean Beggs (TAS), Catherine Lloyd-Johnsen (VIC)
Invasive *haemophilus influenzae* infection	Peter McIntyre* (NSW), David Isaacs (NSW), Angela Merianos (ACT), Lyn Gilbert (NSW), Don Roberton (SA), Geoff Hogg (VIC), Jenny Thomson (ACT), Edward O'Brien (ACT)
Kawasaki disease	David Isaacs* (NSW), Jennifer Royle (NSW), Elizabeth Elliott (NSW), Gary Sholler (NSW), Terry Nolan (VIC), Roger Allen (VIC), Susan Hall (London, UK)
Munchausen by proxy syndrome	Paul Tait* (NSW), Michael Ryan (NSW), Terry Donald (SA), Jon Jureidini (SA), Kasia Kozlowska (NSW), Keiran Moran (NSW), Donna Rose (NSW), Herbert Schreier (California USA), Marie Pinter (NSW)
Neonatal group B streptococcus sepsis	Lyn Gilbert* NSW), Suzanne Garland (VIC), Heather Gidding (NSW), David Isaacs (NSW), Andrew Daley (VIC), David Burgner (WA), Anthony Keil (WA), Joan Faoagali (QLD), Celia Cooper (SA)
Neonatal herpes simplex virus	Cheryl Jones* (NSW), David Isaacs (NSW), Peter McIntyre (NSW), Tony Cunningham (NSW), Suzanne Garland (VIC)
Neuromuscular disorders	Monique Ryan* (VIC), Andrew Kornberg (VIC), Phillipa Lamont (WA), Kathryn North (NSW), Peter Rowe (WA), Kate Sinclair (QLD)
Non-tuberculous mycobacterial infection	Pamela Palasanthiran* (NSW), Christopher Blyth (NSW), Emma Best (NSW), Cheryl Jones (NSW), Andrew Daley (VIC), Guy Henry (NSW), David Burgner (WA), Clare Nourse (QLD), Paul Goldwater (SA)
Prader-Willi syndrome	Arabella Smith* (NSW), Jonathan Egan (NSW), Greta Ridley (NSW), Elizabeth Elliott (NSW), Katrina Williams (NSW), Garry Warne (VIC), Eric Haan (SA), Philip Montgomery (WA), John McMillan (QLD)
Primary immunodeficiency diseases	Miriam Codarini* (NSW), Alyson Kakakios (NSW), David Isaacs (NSW), Karl Baumgart (NSW), Warwick Britton (NSW), Martyn French (WA), Michael Gold (SA), Don Roberton (SA), Pat Hogan (QLD), Kevin Forsyth (SA), Elizabeth Benson (NSW), Andrew Kemp (VIC), Richard Loh (WA), John Ziegler (NSW)
Rett syndrome	Helen Leonard* (WA), Lakshmi Nagarajan (WA), Sue Fyfe (WA), John Christodoulou (NSW), Carolyn Ellaway (NSW), Elizabeth Thompson (SA), Martin Delatycki (VIC), Carol Bower (WA), Jon Silberstein (WA), Jim McGill (QLD), MK Thong (VIC)

APSU Study Investigators

Study	Investigator
Serious seatbelt injuries	Yvonne Zurynski* (NSW), Lynne Bilston (NSW), Mary McCaskill (NSW), Anthony Dilley (NSW), Fred Leditschke (QLD), Elizabeth Elliott (NSW)
Severe combined immunodeficiency disorder	John Ziegler* (NSW), Barbara Lehmann-Moser (NSW), Andrew Kemp (VIC), Tony Yee (NSW), Suk See Ting (NSW)
Severe complication of influenza	Yvonne Zurynski (NSW), David Lester-Smith (NSW), Marino Festa (NSW), Alison Kesson (NSW), Robert Booy (NSW), Elizabeth Elliott (NSW)
Simple vitamin D deficiency rickets	Craig Munns* (NSW), Chris Cowell (NSW), Margaret Zacharin (VIC), Christine Rodda (VIC), Elizabeth Davis (WA), Mark Harris (QLD), Mark Pascoe (TAS), Jan Fairchild (SA), Antony Lafferty (ACT), Annie Whybourne (NT), Leanne Ward (Ontario, Canada), Ruth Morley (VIC), Sarah Garnett (NSW), David Burgner (WA), Michelle Williams (TAS), Jennifer Batch (QLD), Janet Geddes (WA), Sarah Cherian (WA)
Subacute sclerosing panencephalitis	Jeffrey Hanna* (QLD), Ron Messer (QLD), Peter Procopis (NSW)
Varicella complications requiring hospitalisation	Robert Booy*, (NSW), Michael Nissen (QLD), David Burgner (WA), Yvonne Zurynski (NSW), Elizabeth Elliott (NSW), Elizabeth Peadon (NSW), Michael Gold (ADE), Jim Buttery (VIC)
Vitamin K deficiency bleeding	Bin Jalaludin* (NSW), Kerry Chant (NSW), Elizabeth Elliott (NSW), David Henderson-Smart (NSW), Peter McDougall (VIC), Peter Loughnan (VIC), Lee Taylor (NSW)

* Principal investigator

Acute flaccid paralysis

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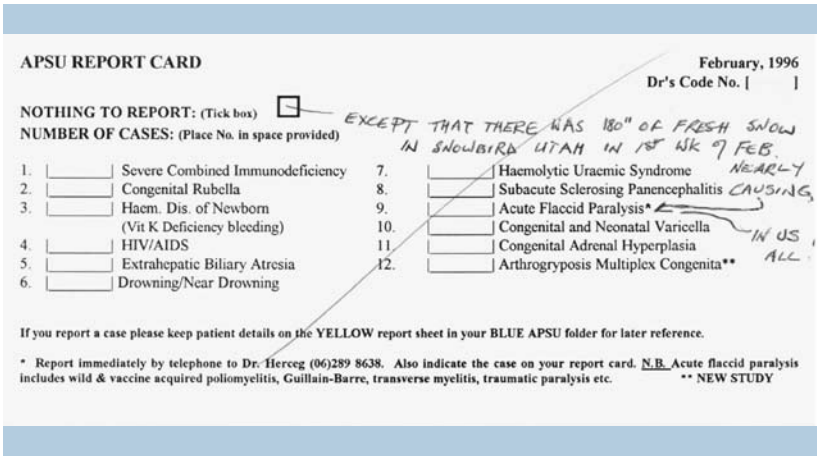


APSU REPORT CARD

February, 1996

Dr's Code No. [ ]

NOTHING TO REPORT: (Tick box) ☐ EXCEPT THAT THERE WAS 180" OF FRESH SNOW IN SNOWBIRD UTAH IN 1ST WK OF FEB.

NUMBER OF CASES: (Place No. in space provided)

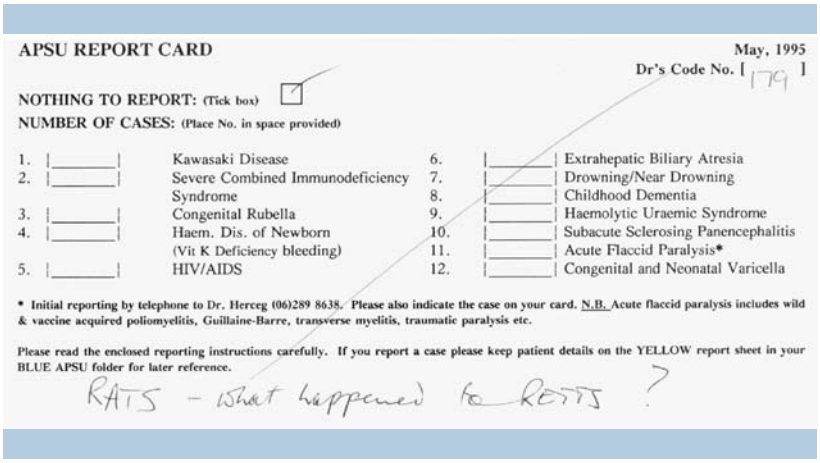
1. [ ] Severe Combined Immunodeficiency
2. [ ] Congenital Rubella
3. [ ] Haem. Dis. of Newborn (Vit K Deficiency bleeding)
4. [ ] HIV/AIDS
5. [ ] Extrahepatic Biliary Atresia
6. [ ] Drowning/Near Drowning
7. [ ] Haemolytic Uraemic Syndrome NEARLY
8. [ ] Subacute Sclerosing Panencephalitis CAUSING
9. [ ] Acute Flaccid Paralysis*
10. [ ] Congenital and Neonatal Varicella IN US
11. [ ] Congenital Adrenal Hyperplasia ALL
12. [ ] Arthrogryposis Multiplex Congenita**

If you report a case please keep patient details on the YELLOW report sheet in your BLUE APSU folder for later reference.

* Report immediately by telephone to Dr. Herceg (06)289 8638. Also indicate the case on your report card. N.B. Acute flaccid paralysis includes wild & vaccine acquired poliomyelitis, Guillain-Barre, transverse myelitis, traumatic paralysis etc. ** NEW STUDY

"The work of the APSU in providing valuable clinical epidemiological information about uncommon conditions in childhood is highly commendable"

Neil Wigg, Associate Professor, Royal Australasian College of Physicians (2004 APSU Annual Report)



APSU REPORT CARD

May, 1995

Dr's Code No. [179]

NOTHING TO REPORT: (Tick box) ☑

NUMBER OF CASES: (Place No. in space provided)

1. [ ] Kawasaki Disease
2. [ ] Severe Combined Immunodeficiency Syndrome
3. [ ] Congenital Rubella
4. [ ] Haem. Dis. of Newborn (Vit K Deficiency bleeding)
5. [ ] HIV/AIDS
6. [ ] Extrahepatic Biliary Atresia
7. [ ] Drowning/Near Drowning
8. [ ] Childhood Dementia
9. [ ] Haemolytic Uraemic Syndrome
10. [ ] Subacute Sclerosing Panencephalitis
11. [ ] Acute Flaccid Paralysis*
12. [ ] Congenital and Neonatal Varicella

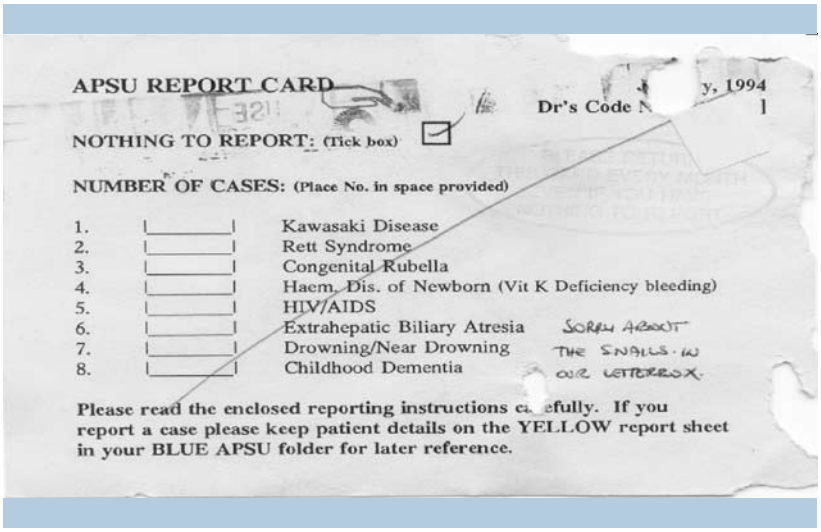
* Initial reporting by telephone to Dr. Herceg (06)289 8638. Please also indicate the case on your card. N.B. Acute flaccid paralysis includes wild & vaccine acquired poliomyelitis, Guillaine-Barre, transverse myelitis, traumatic paralysis etc.

Please read the enclosed reporting instructions carefully. If you report a case please keep patient details on the YELLOW report sheet in your BLUE APSU folder for later reference.

RATS - What happened to RETTS ?

"If a community is to be judged by the way it provides for the health of its children and its most vulnerable members, then the work of the APSU in promoting the health of children is absolutely vital for Australia"

The Honourable Michael Wooldridge, Federal Minister of Health (1997 APSU Annual Report)



APSU REPORT CARD

[illegible]y, 1994

Dr's Code N[illegible]]

NOTHING TO REPORT: (Tick box) ☑

NUMBER OF CASES: (Place No. in space provided)

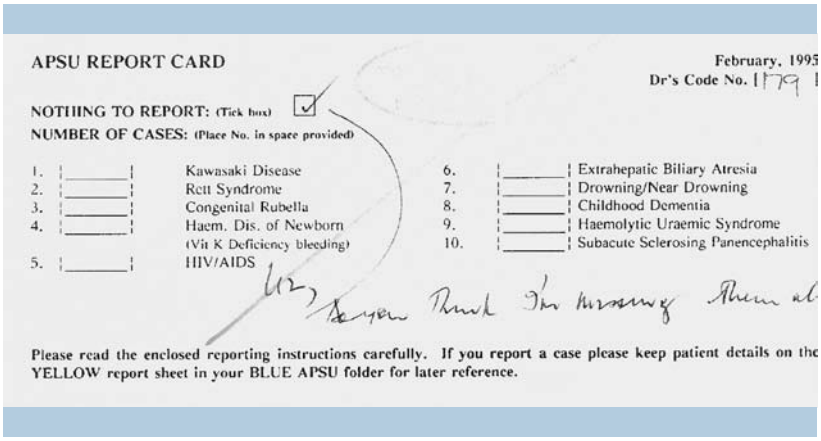
1. [ ] Kawasaki Disease
2. [ ] Rett Syndrome
3. [ ] Congenital Rubella
4. [ ] Haem. Dis. of Newborn (Vit K Deficiency bleeding)
5. [ ] HIV/AIDS
6. [ ] Extrahepatic Biliary Atresia SORRY ABOUT
7. [ ] Drowning/Near Drowning THE SNAILS IN
8. [ ] Childhood Dementia OUR LETTERBOX

Please read the enclosed reporting instructions c[illegible]efully. If you report a case please keep patient details on the YELLOW report sheet in your BLUE APSU folder for later reference.

"The importance of the activities of the APSU is clear, both in terms of public health initiatives, clinical management strategies and the furtherance of knowledge. The Australian College of Paediatrics is proud of the activities of the APSU, as are paediatricians in Australia"

Don Roberton, APSU Chairman (1996 APSU Annual Report)

Cards and Quotes



APSU REPORT CARD

February, 1995

Dr's Code No. [179]

NOTHING TO REPORT: (Tick box) ☑

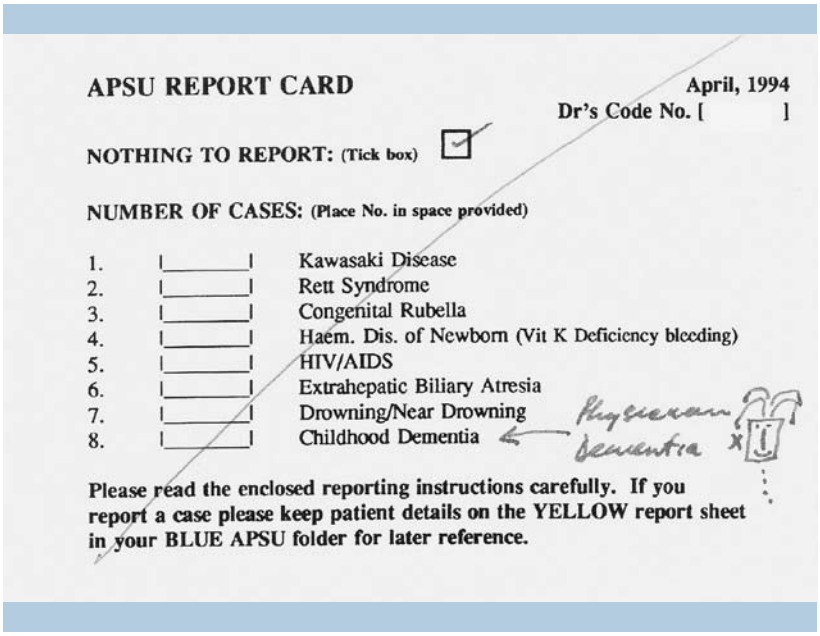
NUMBER OF CASES: (Place No. in space provided)

1.		Kawasaki Disease	6.		Extrahepatic Biliary Atresia
2.		Rett Syndrome	7.		Drowning/Near Drowning
3.		Congenital Rubella	8.		Childhood Dementia
4.		Haem. Dis. of Newborn (Vit K Deficiency bleeding)	9.		Haemolytic Uraemic Syndrome
5.		HIV/AIDS	10.		Subacute Sclerosing Panencephalitis

Please read the enclosed reporting instructions carefully. If you report a case please keep patient details on the YELLOW report sheet in your BLUE APSU folder for later reference.

"Data collected by the Australian Paediatric Surveillance Unit has assisted my Department in providing the evidence to enable Australia to be certified poliomyelitis free. It has also helped my Department in shaping its research agenda and developing appropriately targeted health programs"

Honourable Kay Patterson, Minister for Health and Ageing (2001 APSU Annual Report)



APSU REPORT CARD

April, 1994

Dr's Code No. [ ]

NOTHING TO REPORT: (Tick box) ☑

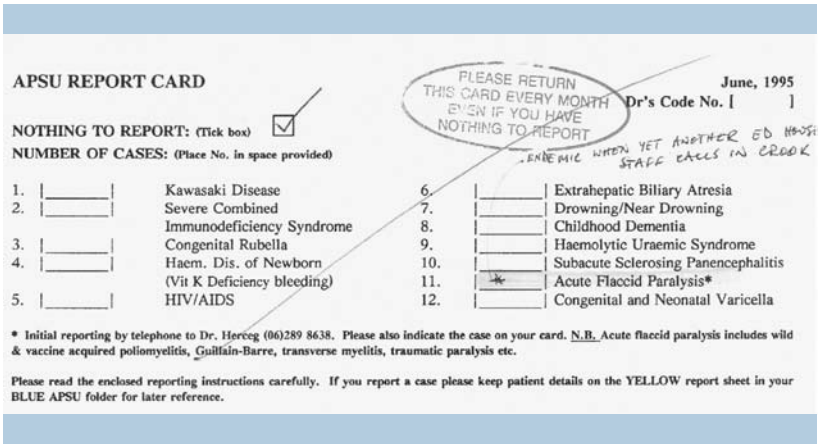
NUMBER OF CASES: (Place No. in space provided)

1.		Kawasaki Disease
2.		Rett Syndrome
3.		Congenital Rubella
4.		Haem. Dis. of Newborn (Vit K Deficiency bleeding)
5.		HIV/AIDS
6.		Extrahepatic Biliary Atresia
7.		Drowning/Near Drowning
8.		Childhood Dementia

Please read the enclosed reporting instructions carefully. If you report a case please keep patient details on the YELLOW report sheet in your BLUE APSU folder for later reference.

"One of the most attractive aspects of the APSU project is that it is such a simple concept. Ideas such as these often prove to be the most effective and achieve the greatest results"

Ian McFarlane, Governor, Reserve Bank of Australia & Chairman, Financial Markets Foundation for Children (1997 APSU Annual Report)



APSU REPORT CARD

PLEASE RETURN THIS CARD EVERY MONTH EVEN IF YOU HAVE NOTHING TO REPORT

June, 1995

Dr's Code No. [ ]

NOTHING TO REPORT: (Tick box) ☑

NUMBER OF CASES: (Place No. in space provided)

1.		Kawasaki Disease	6.		Extrahepatic Biliary Atresia
2.		Severe Combined Immunodeficiency Syndrome	7.		Drowning/Near Drowning
			8.		Childhood Dementia
3.		Congenital Rubella	9.		Haemolytic Uraemic Syndrome
4.		Haem. Dis. of Newborn (Vit K Deficiency bleeding)	10.		Subacute Sclerosing Panencephalitis
			11.		Acute Flaccid Paralysis*
5.		HIV/AIDS	12.		Congenital and Neonatal Varicella

* Initial reporting by telephone to Dr. Hereeg (06)289 8638. Please also indicate the case on your card. N.B. Acute flaccid paralysis includes wild & vaccine acquired poliomyelitis, Guillain-Barre, transverse myelitis, traumatic paralysis etc.

Please read the enclosed reporting instructions carefully. If you report a case please keep patient details on the YELLOW report sheet in your BLUE APSU folder for later reference.

"A 94% response rate from paediatricians participating in the monthly mail-out data collection process is extremely encouraging and indicates that many clinicians also have no doubt in the value of the work of the APSU"

Ian McFarlane, Governor, Reserve Bank of Australia & Chairman, Financial Markets Foundation for Children (1997 APSU Annual Report)

Without the APSU, research of this kind would not be possible. The following pages consist of media highlights resulting from studies conducted through the APSU.

Unit to survey rare child diseases

, UNIT being established to collect nationwide ata on rare childhood diseases should help doc- ors wanting to perform epidemiological studies.

The Australian Paediatric Surveillance Unit is being stablished in Sydney with support from the Federal lealth Department, the University of Sydney and the ustralian College of Paediatrics.

Doctors will be able to submit research proposals to ie Unit for assistance with data collection.

Although the Unit will not become a national regis- r, and will not conduct research of its own, it will rovide a valuable resource to doctors.

The co-ordinator of the Unit, Dr Elizabeth Elliott, aid differences in the collection and storage of data in ach State made it difficult for doctors in Australia to onduct research.

"With rare conditions we really have no idea how many children we are dealing with in Australia and treatment is different in each State," she said.

Initially, data will be collected for congenital rubella, Rett syndrome, extrahepatic biliary atresia, haemorrhagic disease of the newborn, HIV/AIDS, Kawasaki disease, drowning and near-drowning and childhood dementia.

From June, cards will be send to paediatricians on the Unit's mailing list at regular intervals to record any patients with the diseases. The information will be computed in Sydney. Strict diagnostic criteria will be given for each condition, to encourage accurate diagnosis.

Patients will be coded by the first and second letters of their first and last names, and by postcode, to avoid duplication.

Dr Elliott said the cards would be postage-paid encourage doctors to return them even if they had r patients to report. Participating doctors will receiv quarterly updates on response rates and reporting, a the Unit will produce an annual report.

Speaking at the recent conference of the Australi College of Paediatrics in Melbourne, Dr Susan Ha who was involved in the establishment of a similar u in the UK in 1985, explained how the unit there h proved valuable to doctors.

"The only way they could do research into rare di eases was to write to all their colleagues because th only saw one or two cases a year, and now the u does this for them much better," Dr Hall said.

Doctors can contact the Australian Unit on (0 692 6648.

— Susan Va

Australian Doctor – 4 June, 1993

GPs asked to watch for rare illnesses

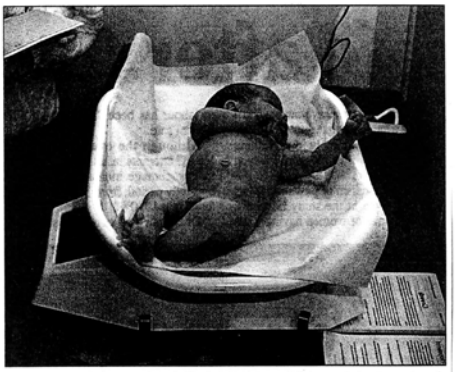
GPs are to be informally enlisted to look out for potential cases of late-onset haemorrhagic disease of the newborn (HDN) as part of a new surveillance scheme for rare childhood illnesses.

Professor David Henderson-Smart, head of the department of perinatal medicine at Sydney's King George V Hospital, said he is liaising with the RACGP on the role the College and GPs can play in the surveillance and reporting of HDN cases via paediatricians.

HDN is just one of eight conditions included on a reporting card sent to all Australian paediatricians by the Australian Paediatric Surveillance Unit (*Australian Doctor*, 4 June).

There is concern that there may be a resurgence of HDN as a result of confusion in the wake of the publication last year of a retrospective UK study asserting that intramuscular vitamin K was associated with a doubling of the risk of childhood cancer.

Australian authorities moved to discourage the use of a single dose of parenteral vitamin K at birth in favour of three oral doses over the first four weeks of life, releasing new recommendations early this year.



New recommendations on vitamin K administration to infants are being inconsistently implemented.

Australian Doctor – 16 July, 1993

Rare childhood diseases monitored

by Joanna Johnson

A NATIONAL surveillance unit for rare diseases and complications in Australian children was launched last month at the Australian College of Paediatrics annual conference in Melbourne.

The Australian Paediatric Surveillance Unit (APSU) will operate an active case-reporting scheme whereby all paediatricians tick a notification card mailed to them monthly.

The unit is modelled on one which has operated in the UK since 1985.

Dr Elizabeth Elliott, a Sydney paediatrician who has studied the highly successful British unit, said the response rate there of paediatricians to the monthly card is at least 93 per cent. More than 40 conditions are now on the waiting list to be considered for inclusion on the British card.

As well as providing specific case definitions for rare conditions and monitoring their incidence and prevalence, such schemes provide invaluable data for researchers.

One early benefit to come from the British unit was confirmation of the suggested relationship between the use of aspirin in children under 12 and Reye's syndrome, a rare condition with a high mortality rate.

More recently, the reporting of deaths from chemistry set poisoning in schoolchildren alerted the unit to recommend that warnings be placed on the sets.

There are eight conditions currently being considered for inclusion on the APSU card (the British card has 13). These are congenital rubella, extra-hepatic biliary atresia, haemorrhagic disease of the newborn, near-drowning, HIV-AIDS, Kawasaki disease, Rett's syndrome and childhood dementia.

"By monitoring the incidence of rubella, for example, we will be able to look at such factors as whether the mother was vaccinated and, if so, whether the vaccine failed," Dr Elliott said.

"Extra-hepatic biliary atresia accounts for most liver transplants in children, so looking at its frequency will help us evaluate the potential requirements for liver transplants. And monitoring haemorrhagic disease of the newborn should help us understand the relative efficacies of oral and intramuscular vitamin K as a preventive treatment."

The scheme will involve mainly paediatricians, as the conditions monitored will be sufficiently unusual to require investigation and management by a specialist paediatrician or paediatric medical service.

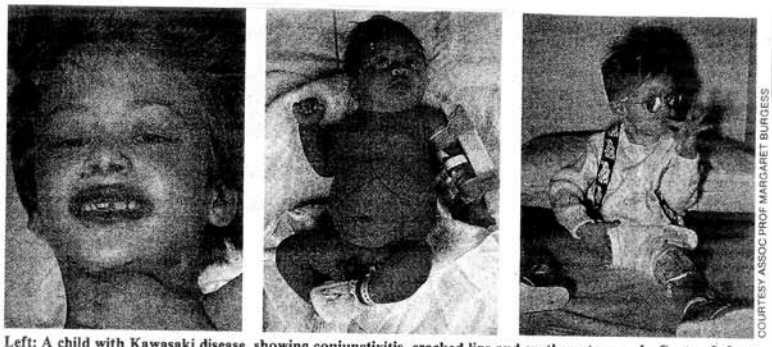
Dr Elliott believes that GPs too may find it useful.

"Many GPs will see these conditions at some stage and refer them on to a paediatrician. If they are interested in, say, a case definition, they can get it by ringing the unit."

Dr Elliott, who will co-ordinate the Australian scheme, believes a national reporting system is of particular importance here because both distance and separate state health systems have resulted in insular, self-contained units in paediatric teaching hospitals and little in the way of national registers for diseases.

The APSU will be a joint venture of the Communicable Disease Section of the federal Department of Health, the department of paediatrics and child health at the University of Sydney and the Australian College of Paediatrics.

Similar units are currently being set up in the US and in Europe. M(



COURTESY ASSOC PROF MARGARET BURGESS

Left: A child with Kawasaki disease, showing conjunctivitis, cracked lips and erythematous rash. Centre: Infant with extra-hepatic biliary atresia, showing jaundice and hepatosplenomegaly. Right: Boy with congenital rubella who has visual, intellectual and hearing impairments. He is using sign language.

Medical Observer – 1993

Rubella claims newborn babies

SYDNEY — Two babies have died after being exposed to rubella infection in the womb, prompting a call for new immigrants to be vaccinated against the preventable disease.

The Australian Paediatric Surveillance Unit found the mothers of 12 babies had rubella in pregnancy, at least six of them because they had not been vaccinated against the disease, also known as german measles.

As a result, two babies died, seven developed severe birth defects and three escaped with no defects, associate professor in paediatric and child health Margaret Burgess said yesterday.

Medical Observer

Bloody diarrhoea may point to HUS

■ HAEMOLYTIC uraemic syndrome (HUS) needs to be excluded if a child presents with atypical gastroenteritis and bloody diarrhoea.

The syndrome had to be considered "particularly if the child is unwell, not passing urine and looks pale", Dr Elizabeth Elliott, senior lecturer in paediatrics at the University of Sydney, told the meeting.

Dr Elliott said the Australian Paediatric Surveillance Unit's study had shown that cases of HUS continued to occur around Australia.

In the period July 1994 to June 1997, 83 new cases were noted – including 22 in the South Australian Garibaldi salami epidemic.

Medical Observer – 30 April, 1999

Vitamin K jab is best

■ INTRAMUSCULAR injection of vitamin K provides the best protection against haemorrhagic disease in newborns, Dr Kerry Chant, director of public health for the South Western Sydney Area Health Service, told delegates.

Dr Chant said an early 1990s study had associated intramuscular vitamin K with childhood malignancy and procedures in administering the vitamin had then been changed but further research had not substantiated the link.

"We went from intramuscular administration to oral administration and then back to intramuscular," she said.

Dr Chant has been studying surveillance results from 1993 and has found that intramuscular vitamin K offers the best protection for infants. This is followed by vitamin K provided orally.

"The risk of haemorrhagic disease in newborns is greatest if they have no vitamin K [at all]," she said.

After intramuscular vitamin K, the incidence of haemorrhagic disease was extremely low. **MO**

Deaths, birth defects blamed on lack of rubella vaccination

TWO infants have died after being exposed to rubella infection in the womb, prompting a call for new immigrants to be vaccinated against the preventable disease.

The Australian Paediatric Surveillance Unit found the mothers of 12 babies had had rubella in pregnancy, at least six of them because they had not been vaccinated against the disease, also known as german measles.

As a result, two babies died, seven developed severe birth defects and three escaped with no defects, associate professor in paediatric and child health Margaret Burgess said yesterday in Sydney. Two of the mothers had recently arrived from overseas, Professor Burgess of the Royal Alexandra Hospital for Children, said.

The results from the unit also indicate that more babies were being affected by rubella per head of population in Australia than in the US or Britain.

"We do seem to be getting more than they are reporting so that means that we have to upgrade our rubella vaccination program," Professor Burgess said.

"We have to pay particular attention to recent immigrants, especially immigrants from south-east Asia who tend to be susceptible to rubella and who need to be vaccinated before they become pregnant."

About 3000 people a year in Australia were infected with rubella in the past three years.

Warrnambool Standard
9 February, 1995

Seatbelt kids still injured

NEARLY 70 per cent of children who were restrained with a seatbelt, but without a booster seat, received serious injuries when in vehicle accidents, a study has found.

The details were revealed after the National Transport Commission announced a plan for children under the age of seven to be required to be strapped into special restraints.

The Australian Paediatric Surveillance Unit found, despite the fact that more than 92 per cent of children surveyed were restrained by seatbelts, they continued to be severely injured in car crashes. The study identified 27 cases of children over the past year who were restrained but injured.

The Daily Telegraph - 15 May, 2007

Consider herpes in newborns

■ IF a baby has a vesicular rash in the first few days after birth, herpes simplex virus has to be considered and ruled out, according to Dr Peter McIntyre, deputy director of the National Centre for Immunisation Research and Surveillance and specialist in infectious diseases at the New Children's Hospital, Westmead, NSW.

Dr McIntyre said that although the incidence of the virus was rare, if it was not picked up at the skin rash stage, there was a high chance the baby would go on to develop more severe herpes disease.

He said Australia had roughly the same incidence frequency – about two cases per 100,000 deliveries – as the UK. In the US, where STD rates were much higher, the incidence was 10 times higher. **MO**

Medical Observer – 30 April, 1999

RESEARCH OPPORTUNITIES: CALL FOR NEW STUDIES

Do you have a good idea for an APSU surveillance study?

Willing to convene a group of investigators?

If so, please contact Yvonne Zurynski to discuss possibilities.
Phone: +61 2 9845 1202 or Email: yvonnez@chw.edu.au

"*The Australian Paediatric Surveillance Unit plays a crucial role in developing rigorous scientific approaches to obtain accurate national information which informs programs aimed at the prevention and management of disease in Australian children*"

The Honourable Michael Wooldridge, Minister for Health and Ageing, 1998

Notes Section

Australian Paediatric Surveillance Unit
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Locked Bag 4001 • WESTMEAD NSW 2145
Tel: 02 9845 3005 • Fax: 02 9845 3082
Email: apsu@chw.edu.au • Website: apsu.org.au

The University of Sydney

The Royal Australasian College of Physicians
Paediatrics & Child Health Division