

New Zealand Paediatric Surveillance Unit  
c/- Department of Women's & Children's Health  
Dunedin School of Medicine

p: + 64 3 470 9688  
e: [nzpsu@otago.ac.nz](mailto:nzpsu@otago.ac.nz)  
w: [www.otago.ac.nz/nzpsu](http://www.otago.ac.nz/nzpsu)

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## **PREFACE: NEW ZEALAND PAEDIATRIC SURVEILLANCE UNIT**

Welcome to the 2015 Annual Report of the New Zealand Paediatric Surveillance Unit (NZPSU).

The NZPSU was established with funding from the Ministry of Health in order to undertake surveillance of acute flaccid paralysis (AFP) for the Ministry of Health's National Certification Committee for the Eradication of Poliomyelitis (NCCEP).

The opportunity was taken for the study of other uncommon high impact conditions, most of which has been undertaken by paediatricians with a particular research interest.

The ongoing success of the NZPSU is largely due to the high level of support from New Zealand paediatricians who have taken the time to provide information on the conditions under surveillance.

We would like to acknowledge the ongoing funding from the Ministry of Health.

## **CHANGE OF PERSONNEL**

During 2016 the two Co-directors of the NZPSU are stepping down from their roles.

Associate Professor Nigel Dickson has been involved since the beginning of the NZPSU in 1997 and been instrumental in the day to day running of the Unit. He is retiring in December 2016 and his role will be taken by Dr Mavis Duncanson.

Professor Barry Taylor was influential in establishing the Unit and is currently the Dean of the Dunedin School of Medicine. The clinical input provided by Professor Taylor will be taken by Dr Ben Wheeler.

The NZPSU welcomes Dr Mavis Duncanson and Dr Ben Wheeler into their roles.



*Nigel A. Dickson*



*Mavis Duncanson*



*Barry Taylor*

## INTRODUCTION

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The NZPSU was established in 1997 to facilitate and improve the knowledge of uncommon high-impact childhood conditions in New Zealand. These are conditions of sufficiently low incidence or prevalence that case ascertainment on a national scale is needed to generate adequate numbers for meaningful study. The method was developed in the United Kingdom by the British Paediatric Surveillance Unit (BPSU) and has been used there since 1986. Subsequently, it has been introduced into several other countries, including Australia, and is used by some other specialist groups.

The core activities of the NZPSU are funded through a contract with the Ministry of Health to provide active surveillance of acute flaccid paralysis (AFP). The World Health Organization (WHO), as part of the global eradication process, requires such surveillance to confirm New Zealand is free of poliomyelitis. Since the establishment of the NZPSU, the number of conditions under surveillance has increased and in 2015 included nine.

The NZPSU is a member of the International Organisation of Paediatric Surveillance Units (INoPSU).

## Aims

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The aims of the NZPSU are:

- To operate a system for monitoring acute flaccid paralysis, as part of the global certification of eradication of poliomyelitis, required by WHO.
- To facilitate national surveillance and improve the knowledge of uncommon high-impact childhood conditions in New Zealand.

Paediatricians in New Zealand gave their support to the surveillance system after the concept was discussed at several annual meetings of the Paediatric Society of New Zealand. A database of eligible clinicians, which included all paediatricians and other specialists working predominantly with children, was developed using the specialist register and the membership list of the Paediatric Society. All eligible clinicians were contacted and invited to participate. Those who agreed were provided with study protocols, which included definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number. Efforts are made to keep up-to-date with the paediatric specialist work force using information received from the Medical Council of New Zealand.

Every month participants are sent either a reply-paid card or an email (depending on their preferred method of reporting) to report whether in the previous month they have seen any cases of the conditions under surveillance. However, cases of AFP are also required to be reported immediately by phone to the NZPSU. When a case of any of the conditions is reported, the reporting clinician is sent a short questionnaire to complete on the case. The identity in most cases remains anonymous. Duplicate notification is recognised by a code derived from the child's initials and date of birth.

A Scientific Review Panel (SRP) considers the applications of new conditions into the scheme (see Table 1 for details on members of the SRP) A study is eligible for consideration in the scheme if the condition in the scheme if the condition of interest is:

- A relatively uncommon high-impact childhood condition (or an uncommon complication of a more common disease)
- Of such a low incidence or prevalence as to require ascertainment of cases on a national scale in order to generate sufficient numbers for the study

The SRP may also consider inclusion of short-term or geographically limited studies of more common conditions.

It is important for the success of the scheme that the work-load of the respondents is kept to a minimum. Accordingly, the SRP must be certain that studies conducted through the NZPSU are well designed and worthwhile. The SRP will take into consideration the scientific interest and public health importance of the proposed study, its methodology, and the suitability of the condition for ascertainment through the NZPSU scheme. Studies depending on immediate reporting and/or sample collection, or requiring the participation of other specialties, are less likely to be suitable.

**Table 1: The Members of the NZPSU Scientific Review Panel (SRP) 2015**

<b>Member</b>	<b>Institution</b>
Associate Professor Nigel Dickson (Chair)	NZPSU, University of Otago, Dunedin
Professor Barry Taylor	NZPSU University of Otago, Dunedin
Dr Pat Tuohy	Ministry of Health
Professor Elizabeth Elliott	Australian Paediatric Surveillance Unit
Dr Jeff Brown	Palmerston North Hospital
Professor Brian Darlow	University of Otago, Christchurch
Professor Diana Lennon	University of Auckland

## SURVEILLANCE ACTIVITIES IN 2015

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In 2015, 242 clinicians participated in the system. The average response rate to the monthly report card/email was 91%. The ongoing high response rate from the whole of the country is very pleasing. Minimising the extra workload that the system imposes on paediatricians is a key factor for its success. Table 2 shows the percentage of clinicians on the mailing list that reported between 2014 and 2015; in 2015, 165 did not report any cases at all, with 7 reporting 5 or more.

In 2015, the NZPSU monitored nine uncommon childhood conditions (*Table 3*). Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit.

**Table 2: Respondents' Workload 2014 and 2015**

Notifications	2014		2015	
			No.	%
None	157	66.5	165	68.1
One	53	22.0	41	16.9
2-4	19	9.4	29	11.9
5 or more	6	2.1	7	2.8

**Table 3: Conditions under surveillance in 2015**

<b>Condition</b>	<b>Surveillance Started</b>	<b>Surveillance Ending</b>	<b>Principal Investigators</b>
Acute Flaccid Paralysis	October 1997	Ongoing	A/Prof Nigel Dickson
Haemolytic Uraemic Syndrome	January 1998	Ongoing	Dr William Wong
Congenital Rubella Syndrome	January 1998	Ongoing	Professor Diana Lennon
Perinatal HIV Exposure	January 1998	Ongoing	A/Prof Nigel Dickson Dr Lesley Voss
Adverse Drug Reactions	May 2008	Ongoing	Dr Desiree Kunac
Eosinophilic Oesophagitis	January 2014	Dec 2016	Dr Helen Evans
Supratherapeutic Paracetamol	January 2014	Dec 2015	Dr Jon Bishop
Pleural empyema	June 2014	May 2016	Dr Emma Best
Alcohol Ingestion	July 2014	June 2016	Dr Stuart Dalziel

## BRIEF REPORTS ON ONGOING STUDIES

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### Acute Flaccid Paralysis

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Associate Professor Nigel Dickson

*Ongoing study started in January 1998*

#### *Introduction*

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To confirm the absence of poliomyelitis WHO requires a surveillance system to be in place:

1. That captures an annual incidence of acute flaccid paralysis (AFP), not due to poliomyelitis, of at least one per 100,000 children < 15 years.
2. In which 80% of cases of AFP have two stool samples taken at least 24 hours apart within 14 days of onset, tested negative for wild polio virus in a WHO-accredited laboratory.

Telephone notification of all cases of AFP is required by the NZPSU to ensure that the necessary stool containers are dispatched in time to the notifying paediatrician.

#### *Key Results for 2015*

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- There were six cases notified to the NZPSU in 2015.
- Information has been obtained on all of these children including follow-up information two months after diagnosis.
- Five were from the North Island, one was from the South Island.
- Three females, three males.
- Age range 9 months to 13 years
- No seasonal variation.
- The overall incidence was 0.67 per 100,000 children < 15 years.
- A diagnosis of Guillaine-Barré syndrome (GBS) has been made in five of these cases, and transverse myelitis in one.
- All six cases have been discounted as Polio by the National Certification Committee for the Eradication of Polio (NCCEP).
- Complete and timely collection of stool samples, satisfying the WHO criteria of 2 samples at least 24 hours apart <14 days after onset paralysis, was complete for three of the six children (50.0%).

These findings have been notified to the World Health Organization to fulfill New Zealand's obligation to report on its polio-free status.



**Table 4: Percentage of AFP cases with adequate (or otherwise) stool samples: 2015**

Category	Stool samples	
	No.	%
2 stool samples within 14 days of onset of paralysis	3	50.0
2 stool samples, but one or both not within 14 days of onset of paralysis	1	16.6
1 stool sample	0	0.0
No stool samples	2	33.3

The required rate (of 1.0 per 100,000) expected by WHO in a country without endemic polio was not reached in 2015, and the rate of stool testing was 50.0%, less than the WHO target which is 80%.

We appreciate that this surveillance requirement is a challenge, in the absence of endemic polio. We wish to thank the paediatricians for vigilance in obtaining timely testing in most instances.

Even though the WHO believes polio to have been eradicated from the Western Pacific region, ongoing surveillance of AFP is likely to be required for some years. This will require the continued telephone notification of all cases of AFP, including those with a definitive diagnosis such as Guillaine-Barré syndrome (GBS).

A challenge has always been to utilise a non-specific case definition- such as “acute flaccid paralysis” – in a health system where a more definitive diagnosis for children with such symptoms is likely to be made

## Haemolytic Uraemic Syndrome (HUS)

Dr William Wong

Ongoing study started in January 1998

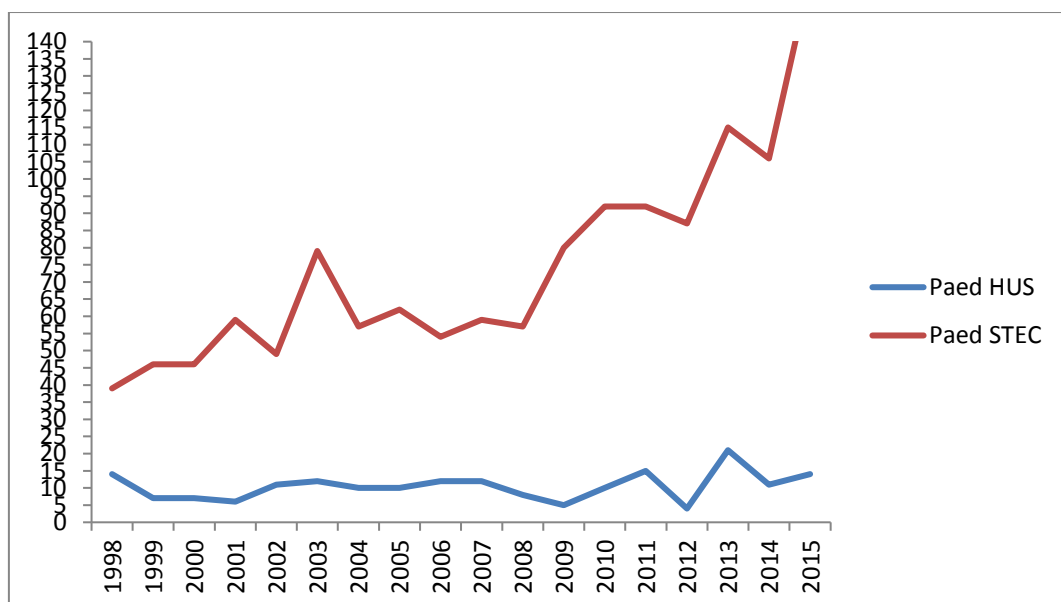
### Key Results for 2015

- 14 cases of childhood HUS reported, in which 12 had a diarrhoeal prodrome (D+)
- The two children with no diarrhoea prodrome were both found to genetic mutations in complement protein regulators
- Geographic distribution of D(+) HUS – 10/12 (83%) from North Island
- Median age at presentation of D(+) HUS was 1.8 years, range 0.7 to 7.4 years
- 7/14 (50%) patients either lived on a farm or had visited a farm in the past 2 weeks, or come into contact with animals (including an Easter show)
- 11/12 (92%) of the diarrhoeal group had E coli 0157H7 isolated from their stools
- 9/12 (75%) of the diarrhoeal group needed acute peritoneal dialysis, mean of 8 days, range 0-18

### Summary

The 2015 cohort showed the importance of close contact with farms and animals. Hygiene measures should be emphasised to the general public. There continues to be significant morbidity related to these cases with prolonged periods of hospitalisation required in some.

The disease rate from infection with Shiga-toxin E coli was 8.8% compared with 10% in 2014 and 18% in 2013. Detection of Shiga-toxin producing strains of E coli by stool culture detected only around 50% of cases, however, the detection rate was improved by PCR for stool Shiga-toxin recently introduced.



**Figure 2:** Annual number of children reported with haemolytic uraemic syndrome (Paed HUS) to the NZPSU and of Shiga toxin associated E coli in children (Paed STEC) reported the ESR enteric laboratory

## Perinatal HIV Exposure

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Associate Professor Nigel Dickson and Dr Lesley Voss  
*Ongoing Study*

### *Key Results for 2015*

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In 2015, there were six reports to the NZPSU of infants/children born in New Zealand to women infected with HIV who were diagnosed prior to or during their pregnancy.

Of these six:

- 4 were born in Auckland, 2 in Dunedin.
- All 6 were born to mothers whose HIV had been diagnosed before their pregnancy.
- 3 of the mothers were Africans, 1 Asian, 1 European and 1 Pacific.
- All of the mothers were given antiretroviral treatment during pregnancy; 3 gave birth by caesarean section and 3 gave birth vaginally; none of the babies were breastfed.

None of the children are believed to be infected with HIV (although most are still awaiting confirmation).

## Congenital Rubella Syndrome (CRS)

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Professor Diana Lennon  
*Ongoing study started January 1998*

There were no reported cases in 2015.

## Serious Paediatric Adverse Drug Reactions (ADR)

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Dr Desiree Kunac, Dr Michael Tatley, Associate Professor David Reith, Professor Keith Grimwood

*Study commenced August 2007.*

### *Key Results for 2015*

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There were 11 notifications made during 2015; however for 8 of these, no further details were provided. Therefore 3 reports were received which are summarised below.

Two of the three cases are new reports that were not previously notified to the Centre for Adverse Reactions Monitoring (CARM). All three cases resulted in a medical danger or warning being entered for the child in the national warning system and are also now included in the CARM database to further enhance our understanding of serious ADRs in children.

**Table 5: Information on the 3 reports of Serious Adverse Drug Reactions (ADR) notified through NZPSU in 2015. The column titled "Medical Warning" indicates those added to the national Medical Warning System, and that titled CARM indicates whether the adverse reaction has also been notified to the Centre for Adverse Reactions Monitoring (CARM).**

<b>Suspect Medicine</b>	<b>Reaction(s)</b>	<b>Age (Years)</b>	<b>Sex</b>	<b>Seriousness/Outcome</b>	<b>Medical Warning</b>	<b>CARM</b>
Loratadine	Anaphylactic reaction	14	F	Life threatening / unknown outcome	Danger	No
Carbamazepine	Maculo-papular rash	11	F	Medically significant / recovered	Warning	No
Suxamethonium chloride	Rhabdomyolysis Hepatic enzymes increased Creatine phosphokinase increased	4		Life threatening / not yet recovered at time of report	Danger	Yes

## Empyema

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Dr Katherine Rix-Trott and Dr Emma Best

*Two year study commenced May 2014*

### *Key Results*

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This study began in May 2014 with the aim of documenting the burden of empyema in New Zealand children including infectious aetiology, demographics and underlying conditions. We also documented the surgical and medical management of cases, complications, and short term outcomes.

There have been 117 notifications between May 2014 and June 2016. Of these notifications there is complete data on 88 cases or 75% (there were some exclusions due to double up on notifications, and cases notified outside the study timeframe).

- The cases came from around the country from 15 different DHB's with most notifications coming from Auckland, Capital and Coast, Counties Manukau, Hawkes Bay, Bay of Plenty, and South Canterbury DHBs.
- The age range was from 2 months to 15 years with a median age of 3 years and with the highest disease burden seen in those 5 years of age and under, with 72% of cases in this age group.
- 33% of children diagnosed with empyema were of Maori ethnicity, with 23% NZ European, 23% Pacific, 11% Asian and 10% a mix of other ethnicities.
- The commonest organisms identified were *S. pneumoniae* and *S. aureus* (both MSSA and MRSA), making up 30% and 26% of cases respectively.
- 82% of cases required some form of surgical intervention (aspiration, drain, drain plus fibrinolytic, VATS, open thoracotomy), while 18% were managed conservatively with antibiotics alone.

Thank you to the study group and to all those who notified cases and provided data for this study.

## CONDITIONS MONITORED BY NZPSU

Condition	Report Period	Findings Reported
Acute Flaccid Paralysis	1997 - ongoing	Chambers, S. T., & Dickson, N. (2011). Global polio eradication: progress, but determination and vigilance still needed. <i>The New Zealand Medical Journal (Online)</i> . 124(1337)  Desai, S., Smith, T., Thorley, B. R., Grenier, D., Dickson, N., Altpeter, E., & Zurynski, Y. (2015). Performance of acute flaccid paralysis surveillance compared with World Health Organization standards. <i>Journal of paediatrics and child health</i> , 51(2), 209-214.
Haemolytic Uraemic Syndrome	1998 - ongoing	Prestidge, C., & Wong, W. (2009). Ten years of pneumococcal-associated haemolytic uraemic syndrome in New Zealand children. <i>Journal of paediatrics and child health</i> , 45(12), 731-735.
Congenital Rubella Syndrome	1998 - ongoing	
Perinatal HIV Exposure	1998 - ongoing	Dickson, N., Paul, C., Wilkinson, L., Voss, L., & Rowley, S. (2002). Estimates of HIV prevalence among pregnant women in New Zealand. <i>New Zealand Public Health Reports</i> , 9, 17-19.
Fetal Alcohol Syndrome	1999 - 2001	Leversha, A. M., & Marks, R. E. (1995). The prevalence of fetal alcohol syndrome in New Zealand. <i>The New Zealand Medical Journal</i> , 108(1013), 502-505.
Subdural Haemorrhage	1999 - 2002	Kelly, P., & Farrant, B. (2008). Shaken baby syndrome in New Zealand, 2000–2002. <i>Journal of paediatrics and child health</i> , 44(3), 99-107.
Retinopathy of Prematurity (stage III)	1999 - 2000	
Diabetes Mellitus	1999 - 2000	Campbell-Stokes, P. L., & Taylor, B. J. (2005). Prospective incidence study of diabetes mellitus in New Zealand children aged 0 to 14 years. <i>Diabetologia</i> , 48(4), 643-648.
Kawasaki Disease	2001 – 2002	Heaton, P., Wilson, N., Nicholson, R., Doran, J., Parsons, A., & Aiken, G. (2006) Kawasaki disease in New Zealand. <i>Journal of paediatrics and child health</i> . 42(4), 184-190.
Bronchiectasis	2001 - 2002	Twiss, J., Metcalfe, R., Edwards, E., & Byrnes, C. (2005). New Zealand national incidence of bronchiectasis “too high” for a developed country. <i>Archives of disease in childhood</i> , 90(7), 737-740.

		Twiss, J. (2008). <i>Childhood bronchiectasis: national incidence, disease progression and an evaluation of inhaled antibiotic therapy</i> (Doctoral dissertation, ResearchSpace@ Auckland).
Idiopathic Nephrotic Syndrome	2001 - 2003	Wong, W. (2007). Idiopathic nephrotic syndrome in New Zealand children, demographic, clinical features, initial management and outcome after twelve-month follow-up: Results of a three-year national surveillance study. <i>Journal of paediatrics and child health, 43</i> (5), 337-341.
Inflammatory Bowel Disease	2002 - 2003	Yap, J., Wesley, A., Mouat, S., & Chin, S. (2008). Paediatric inflammatory bowel disease in New Zealand. <i>The New Zealand Medical Journal (Online), 121</i> (1283).
Prolonged Infantile Cholestasis	2004 - 2005	
Pertussis	2004 - 2005	Somerville, R. L., Grant, C. C., Grimwood, K., Murdoch, D., Graham, D., Jackson, P., & Purvis, D. (2007). Infants hospitalised with pertussis: estimating the true disease burden. <i>Journal of paediatrics and child health, 43</i> (9), 617-622.
Inborn Errors Of Metabolism	2004 - 2006	Wilson, C., Kerruish, N. J., Wilcken, B., Wiltshire, E., & Webster, D. (2007). The failure to diagnose inborn errors of metabolism in New Zealand: the case for expanded newborn screening. <i>The New Zealand Medical Journal (Online), 120</i> (1262).
Pneumococcal meningitis	2005 - 2008	Safar, A., Lennon, D., Stewart, J., Trenholme, A., Drinkovic, D., Peat, B., & Voss, L. (2011). Invasive group A streptococcal infection and vaccine implications, Auckland, New Zealand. <i>Emerg Infect Dis, 17</i> (6), 983-9.
Acute Post Streptococcal Glomerulonephritis	2007 - 2011	Wong, W., Lennon, D. R., Crone, S., Neutze, J. M., & Reed, P. W. (2013). Prospective population-based study on the burden of disease from post-streptococcal glomerulonephritis of hospitalised children in New Zealand: Epidemiology, clinical features and complications. <i>Journal of paediatrics and child health, 49</i> (10), 850-855.
Adverse Drug Reactions (ADR)	2008-ongoing	Kunac, D. L., Kennedy, J., Austin, N., & Reith, D. (2009). Incidence, preventability, and impact of adverse drug events (ADEs) and potential ADEs in hospitalized children in New Zealand. <i>Pediatric drugs, 11</i> (2), 153-160.
Neonatal Bacterial or Fungal Infection	2011-2013	Darlow, B. A., Voss, L., Lennon, D. R., & Grimwood, K. (2016). Early-onset neonatal group B streptococcus sepsis following national risk-based prevention guidelines. <i>Australian and New Zealand Journal of Obstetrics and Gynaecology, 56</i> (1), 69-74.

Pertussis	2004 - 2005	Somerville, R. L., Grant, C. C., Grimwood, K., Murdoch, D., Graham, D., Jackson, P., & Purvis, D. (2007). Infants hospitalised with pertussis: estimating the true disease burden. <i>Journal of paediatrics and child health</i> , 43(9), 617-622.
Acute Post Streptococcal Glomerulonephritis	2007 - 2011	Wong, W., Lennon, D. R., Crone, S., Neutze, J. M., & Reed, P. W. (2013). Prospective population-based study on the burden of disease from post-streptococcal glomerulonephritis of hospitalised children in New Zealand: Epidemiology, clinical features and complications. <i>Journal of paediatrics and child health</i> , 49(10), 850-855.
Adverse Drug Reactions (ADR)	2008-ongoing	Kunac, D. L., Kennedy, J., Austin, N., & Reith, D. (2009). Incidence, preventability, and impact of adverse drug events (ADEs) and potential ADEs in hospitalized children in New Zealand. <i>Pediatric drugs</i> , 11(2), 153-160.
Neonatal Bacterial or Fungal Infection	2011-2013	Darlow, B. A., Voss, L., Lennon, D. R., & Grimwood, K. (2016). Early-onset neonatal group B streptococcus sepsis following national risk-based prevention guidelines. <i>Australian and New Zealand Journal of Obstetrics and Gynaecology</i> , 56(1), 69-74.
Severe Neonatal Hyperbilirubinaemia	2011-2013	
Moderate and Severe Neonatal Encephalopathy	2011-2013	Battin, M., Sadler, L., Masson, V., & Farquhar, C. (2016). Neonatal encephalopathy in New Zealand: Demographics and clinical outcome. <i>Journal of paediatrics and child health</i> .
Vitamin D Deficiency Rickets	2011-2013	Wheeler, B. J., Dickson, N. P., Houghton, L. A., Ward, L. M., & Taylor, B. J. (2015). Incidence and characteristics of vitamin D deficiency rickets in New Zealand children: a New Zealand Paediatric Surveillance Unit study. <i>Australian and New Zealand Journal of Public Health</i> , 39(4), 380-383.
Renal Stones	2011 - retrospective	Dickson, Nigel, Tonya Kara, and Pat Tuohy. "Rapid national survey of renal stones in New Zealand infants." <i>Journal of paediatrics and child health</i> 45.11 (2009): 633-635.
Varicella and post-varicella complications	2011-2013	Wen, S. C. H., Best, E., Walls, T., Dickson, N., McCay, H., & Wilson, E. (2015). Prospective surveillance of hospitalisations associated with varicella in New Zealand children. <i>Journal of paediatrics and child health</i> , 51(11), 1078-1083.



Vitamin K Deficiency Bleeding	1998-2008	<p>Darlow, B. A. (2004). 60 Vitamin K Deficiency Bleeding (VKDB) in New Zealand Infants: Results of Surveillance Over Five Years (1998 to 2002). <i>Pediatric Research</i>, 56(3), 474-474.</p> <p>Darlow, B. A., Phillips, A. A., &amp; Dickson, N. P. (2011). New Zealand surveillance of neonatal vitamin K deficiency bleeding (VKDB): 1998–2008. <i>Journal of paediatrics and child health</i>, 47(7), 460-464.</p>
General Surveillance publications		<p>Grenier, D., Ugnat, A. M., McCourt, C., Scott, J., Thibodeau, M. L., Davis, M., &amp; Dickson, N. (2009). Can active surveillance provide a rapid response to an emerging child health issue? The melamine example. <i>Paediatrics &amp; child health</i>, 14(5), 285-286.</p> <p>Grenier, D., Elliott, E. J., Zurynski, Y., Pereira, R. R., Preece, M., Lynn, R., &amp; Virella, D. (2007). Beyond counting cases: public health impacts of national Paediatric Surveillance Units. <i>Archives of disease in childhood</i>, 92(6), 527-533.</p>

## **INTERNATIONAL NETWORK OF PAEDIATRIC SURVEILLANCE UNITS**

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### *Establishment of INoPSU*

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The network was formed in August 1998 at a meeting of 10 Pediatric Surveillance Units expressing a desire to link with each other. This took place at the 22<sup>nd</sup> International Congress of Paediatrics in Amsterdam, The Netherlands. The first INoPSU conference was held in 2000 in Canada and was attended by representatives of the existing units. Subsequent meetings have been held in York England, Lisbon, Portugal, Munich Germany and Melbourne. Associate Professor Nigel Dickson has attended the meetings in Canada, England, Portugal and Melbourne.

### *Mission*

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The mission of INoPSU is the advancement of knowledge of uncommon childhood infections and disorders, and the participation of paediatricians in surveillance on national and international basis so as to achieve facilitating communication and co-operation between existing national paediatric surveillance units;

### *Aims*

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- To assist in the development of new units;
- To facilitate sharing information and collaboration between researchers from different nations and scientific disciplines;
- To share information and current, past and anticipated studies and their protocols, and on conditions that have been nominated for surveillance but are not selected;
- To encourage the use of identical protocols to potentially enable simultaneous or sequential collection of data on rare paediatric disorders in two or more countries;
- To share and distribute information of educational benefit to constituent units, notably on study and surveillance methodologies;
- To share techniques and models of evaluation for units;
- To peer review and evaluate existing and proposed units;
- To identify rare disorders of mutual interest and public health importance for co-operative surveys through each national unit;
- To collaborate with, and provide information to, other interest groups interested in rare childhood diseases such as parent support groups; and
- To respond promptly to international emergencies relating to rare childhood conditions where national and international studies where national and international studies can make a contribution to science or public health.

There are currently 12 surveillance units from around the globe that form the INOPSU network.

**Table 6: Members of INoPSU**

Country	Unit	Email	Website
Australia	APSU	<a href="mailto:apsu@chw.edu.au">apsu@chw.edu.au</a>	<a href="http://www.apsu.org.au">www.apsu.org.au</a>
Belgium	BSU	<i>under development</i>	<i>under development</i>
Britain	BPSU	<a href="mailto:enquiries@rcpch.ac.uk">enquiries@rcpch.ac.uk</a>	<a href="http://www.bpsu.inopsu.com">www.bpsu.inopsu.com</a>
Canada	CPSP	<a href="mailto:melaniel@cps.ca">melaniel@cps.ca</a>	<a href="http://www.cps.ca/cpsp">www.cps.ca/cpsp</a>
Germany	ESPED	<a href="mailto:Prof.von.kries@gmx.de">Prof.von.kries@gmx.de</a>	<a href="http://www.esped.uni-duesseldorf.de">www.esped.uni-duesseldorf.de</a>
Greece and Cyprus	GCPSU	<a href="mailto:xhatzi@med.uth.gr">xhatzi@med.uth.gr</a>	
Ireland	IPSU	<a href="mailto:robert.cunney@malix.hse.ie">robert.cunney@malix.hse.ie</a>	
Netherlands	NSCK	<a href="mailto:nsck@nvk.nl">nsck@nvk.nl</a>	<a href="http://www.nvk.pediane.nl">www.nvk.pediane.nl</a>
New Zealand	NZPSU	<a href="mailto:nzpsu@otago.ac.nz">nzpsu@otago.ac.nz</a>	<a href="http://www.otago.ac.nz/nzpsu">www.otago.ac.nz/nzpsu</a>
Portugal	PPSU	<a href="mailto:uvp-spp@ptnetbiz.pt">uvp-spp@ptnetbiz.pt</a>	<a href="http://www.spp.pt/ingl/index_17.html">www.spp.pt/ingl/index_17.html</a>
Switzerland	SPSU	<a href="mailto:mirjam.maeusezahl@bag.admin.ch">mirjam.maeusezahl@bag.admin.ch</a>	<a href="http://www.bag.admin.ch/infekt/melde/spsu/d/index/.htm">www.bag.admin.ch/infekt/melde/spsu/d/index/.htm</a> (German)
Wales	WPSU	<a href="mailto:heather.oconnell@cardiffandvale.wales.nhs.uk">heather.oconnell@cardiffandvale.wales.nhs.uk</a>	<a href="http://www.welsh-paediatrics.org">www.welsh-paediatrics.org</a>

**Table 7: Characteristics of the Paediatric Surveillance Units**

<b>Country</b>	<b>Population (x10<sup>6</sup>&lt;15 years)</b>	<b>Established</b>	<b>Approximate number of respondents</b>
Australia	4.1	1992	1360
Belgium			
Britain	12.8	1986	3300
Canada	7.5	1996	2500
Germany	12.0	1992	460*
Greece and Cyprus	1.6	2001	
Ireland	1.3	1996	150
Netherlands	3.0	1992	780
Portugal	1.67	2000	1506
New Zealand	0.86	1997	250
Switzerland	1.3	1995	250
Wales	0.56	1994	135*

\*Heads of Paediatric Centres

## LIST OF CLINICIANS WITH 100% RETURN RATE 2015

Clinicians who had 100% return rate in 2014 and 2015 are underlined

<u>Aikin, Richard</u>	<u>Asher, Innes</u>	<u>Ayers, Rosemary</u>	Bach, Kitty
<u>Bates, Giles</u>	<u>Battin, Malcolm</u>	<u>Best, Emma</u>	Bishop, Jon
<u>Baker, Nic</u>	Bell, Anthony	<u>Binfield, Alex</u>	<u>Blair, Nikki</u>
<u>Bloomfield, Guy</u>	<u>Bond, David</u>	<u>Bradley, Stephen</u>	<u>Breen, Felicity</u>
Bremner, Catherine	<u>Broadbent, Roland</u>	<u>Brooks, Jeanine</u>	<u>Brown, Jeff</u>
<u>Brynes, Cass</u>	<u>Buckley, David</u>	<u>Buskh, Mariam</u>	<u>Campanella, Silvana</u>
<u>Campbell, Moira</u>	<u>Campbell-Stokes, P</u>	<u>Carter, Philippa</u>	Carmichael, Eleanor
Chang, Emily	<u>Chin, Simon</u>	<u>Clark, Philippa</u>	<u>Clarke, Rachel</u>
<u>Cole, Nyree</u>	<u>Corban, Jenny</u>	<u>Corbett, Rob</u>	<u>Coulter, Belinda</u>
<u>Craig, Angela</u>	<u>Craine, Karina</u>	Crone, Sonya	<u>Cunningham, Vicky</u>
<u>Currie, Sarah</u>	<u>Dalton, Marguerite</u>	<u>Dalziel, Stuart</u>	<u>Daniel, Alison</u>
<u>Darlow, Brian</u>	<u>Day, Andrew</u>	De Lore, Danny	<u>Dickson, Cameron</u>
<u>Dixon, Bronwyn</u>	<u>Dixon, Joanne</u>	<u>Doocey, Clare</u>	<u>Drake, Ross</u>
<u>Edmonds, Liza</u>	<u>Edward, Kathryn</u>	<u>Elder, Dawn</u>	<u>Evans, Helen</u>
Farrant, Bridget	Fischer, Annette	<u>Ferguson, Janet</u>	<u>Fleming, John</u>
<u>Ford, Rodney</u>	<u>Forster, Richard</u>	<u>Gapes, Stephanie</u>	<u>Garrett, John</u>
Gangkhedkar, Arun	<u>Gavin, Raewyn</u>	<u>Gentles, Tom</u>	Geddes, Janet
<u>Goldsmith, John</u>	<u>Goodwin, Mick</u>	<u>Graham, Dave</u>	<u>Grangaard, Erik</u>
<u>Grant, Cameron</u>	<u>Grant, Shaun</u>	<u>Grupp, Oliver</u>	<u>Gunn, Alistair</u>
<u>Hainsworth, Oliver</u>	Hall, Anganette	<u>Harding, Jane</u>	<u>Hewson, Michael</u>
Hector-Taylor, James	Hegarty, Jo	Hoare, Simon	Hou, David
<u>Hobbs, Vivienne</u>	<u>Hofman, Paul</u>	<u>Hornung, Tim</u>	<u>Hunter, Warwick</u>
<u>Hunter, Wendy</u>	Jellyman, Timothy	<u>Jordan, Nicola</u>	Kamphambe, Willie
Johnson, Rachel	<u>Kelly, Andrew</u>	<u>Kelly, Patrick</u>	<u>Laughton, Stephen</u>
Law, Michelle	<u>Leadbitter, Philip</u>	<u>Lear, Graham</u>	<u>Lennon, Diana</u>
<u>Liang, Allen</u>	<u>Lynn, Adrienne</u>	<u>Lyver, Amanda</u>	<u>Maikoo, Rajesh</u>
Maulidi, Halima	<u>Marks, Rosemary</u>	<u>Marshall, Andrew</u>	<u>Maxwell, Fraser</u>
<u>McArthur, John</u>	<u>McCarthy, Karen</u>	<u>McCay, Hamish</u>	<u>McFarlene, Scott</u>
<u>McIllroy, Peter</u>	<u>McKie, Jill</u>	<u>Meyer, Michael</u>	<u>Mildenhall, Lindsay</u>
Miles, Fiona	<u>Momsen, Tracey</u>	Mordaunt, Dylan	<u>Moore, Philip</u>
Morrison, Philip	<u>Moyes, Chris</u>	Munro, Karen	<u>Nair, Arun</u>
<u>Neas, Katherine</u>	<u>Nel, Jaco</u>	<u>Neutze, Jocelyn</u>	<u>Newman, David</u>
Nelson, Nicola	<u>Nicholson, Ross</u>	<u>Nolan, Melinda</u>	<u>Nutthal, Gabrielle</u>
Orr, Nigel	<u>Ostring, Genevieve</u>	<u>Pattemore, Philip</u>	<u>Perira, Nicola</u>
Pinnock, Ralph	Porteous, Louise	<u>Purvis, Diana</u>	Raithatha, Meera
<u>Ramadas, Ram</u>	<u>Reith, David</u>	<u>Robertson, Stephen</u>	Robinson, Stephen
<u>Robertshaw, Kate</u>	<u>Rowley, Simon</u>	<u>Sadlier, Lynette</u>	<u>Selby, Roslyn</u>
Schmidt Uli, Meia	<u>Sharpe, Cia</u>	<u>Shaw, Ian</u>	<u>Shaw, Robyn</u>
<u>Shepherd, Michael</u>	<u>Shillito, Paul</u>	Shirani Vetharaniem	<u>Sinclair, Jan</u>
<u>Siversten, Louise</u>	<u>Skeen, Jane</u>	<u>Skinner, Jon</u>	<u>Smiley, Richard</u>

<u>Smith, David</u>	Sommerville, Rebecca	<u>St John, Martyn</u>	<u>Stanley, Thorsten</u>
Stanley, Clare	<u>Steinmann, Kai</u>	<u>Stonehouse, Mary</u>	<u>Taylor, Barry</u>
Thomson, Janine	Trani, Paul	Trenholme, Adrian	<u>Tomlinson, Paul</u>
<u>Townsend, Tom</u>	<u>Tsang, Bobby</u>	<u>Tuck, Roger</u>	<u>Twiss, Jacob</u>
<u>Van de Boom, Jutta</u>	Vogel, Alison	<u>Voss, Lesley</u>	<u>Wallace, Alex</u>
<u>Walls, Tony</u>	Walker, Wendy	Webster, Diane	<u>Webster, Nicky</u>
<u>West, Clare</u>	<u>Weston, Phil</u>	<u>Wheeler, Ben</u>	<u>Wilde, Justin</u>
Williams, Gregory	Williamson, Kate	Wilson, Callum	<u>Wilson, Elizabeth</u>
<u>Wilson, Nigel</u>	<u>Wilson, Ross</u>	<u>Wilson, Toni</u>	<u>Wiltshire, Esko</u>
Winstanley, Mark	<u>Wong, Sharon</u>	<u>Wong, William</u>	<u>Yan, Jacqui</u>

**Congratulations to  
William Wong  
who was selected to win a \$50 book token to be presented  
at the ASM of the Paediatric Society of New Zealand**