New Zealand Paediatric Surveillance Unit

ANNUAL REPORT 2019-2020

A unit within the Department of Womens and Children's Health, Otago Medical School Dunedin Campus, University of Otago

UNIVERSITY of OTAGO
Te Whare Wānanga o Otāgo
NEW ZEALAND
SAPERE AUDE

Department of Women's and Children's Health
Te Tari Hauora Wāhine me te Tamariki

New Zealand Paediatric Surveillance Unit
Te Hunga Aroturuki Mate Tamariki

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PREFACE: NEW ZEALAND PAEDIATRIC SURVEILLANCE UNIT

Welcome to the 2020 Annual Report of the New Zealand Paediatric Surveillance Unit *Te Hunga Aroturuki Mate Tamariki* (NZPSU).

The NZPSU was established with funding from the Ministry of Health *Manatū Hauora* 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).

This report covers acute flaccid paralysis surveillance from 1 July 2019 to 30 June 2020.

Regular surveillance of paediatricians provides an opportunity for the study of additional rare conditions in childhood that have high impact at individual or health services levels. Such conditions are included alongside AFP on the report card. These additional studies are undertaken by paediatricians with a particular clinical research interest, or by NZPSU staff at the request of the Ministry of Health. Unless otherwise stated, reports for these additional studies cover the 2019 calendar year.

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 acknowledge the ongoing funding from the Ministry of Health *Manatū Hauora.*

Associate Professor Ben Wheeler

Amanda Phillips

Sarah-Jane Robertson

Dr Mavis Duncanson

INTRODUCTION

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 Canada.

Paediatricians in New Zealand gave their support to the surveillance programme after the concept was discussed at several annual meetings of the Paediatric Society of New Zealand. All paediatricians practising in Aotearoa are eligible to participate in the surveillance programme.

The core activities of the NZPSU are funded through a contract with the Ministry of Health *Manatū Hauora* 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. There were nine additional conditions under surveillance in 2019 and 2020.

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

Aims

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 the World Health Organization.
- To facilitate national surveillance and improve the knowledge of uncommon high-impact childhood conditions in New Zealand.

Surveillance method

An initial database of eligible clinicians, which sought to include all paediatricians, was developed using the specialist register and the membership list of the Paediatric Society. The database is maintained by regular audit against specialist registration in paediatrics with the Medical Council of New Zealand (publicly available data) and by word of mouth encouraging participants to invite colleagues to join. Study protocols, which include definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number are all available on the NZPSU website www.otago.ac.nz/nzpsu

Every month participants are sent an email with linked REDCap survey to report whether in the previous month they have seen any cases of the conditions under surveillance. 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 of the cases remains anonymous. The child's NHI is used only to identify duplicate notifications but not linked to other health data.

Study selection

The NZPSU seeks assurance that studies conducted through the surveillance programme are well designed and worthwhile. A Scientific Review Panel (SRP) considers applications for new conditions to be added into the programme. The SRP considers 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. 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.

A new SRP was convened in late 2019. The members are listed below:

Table 1: Members of the New Zealand Scientific Review Panel

Name:	***Institution:***
Dr Mavis Duncanson	University of Otago
Associate Professor Ben Wheeler	University of Otago
Associate Professor Tony Walls	University of Otago
Dr Anne Morris	University of Sydney
Dr Geoffrey Roche	Ministry of Health
Professor Elizabeth Elliott	University of Sydney
Dr Emma Best	University of Auckland

After review by the SRP, additions to the surveillance programme are subject to approval by the Southern Health and Disability Ethics Committee and must be agreed to by the Ministry of Health.

SURVEILLANCE ACTIVITIES FROM JULY 2019 to JUNE 2020

In 2019–2020, there were 247 clinicians participating in the surveillance programme. Each month, the average response rate was 80%.

For the success of the surveillance programme, the workload of respondents needs to be kept to a minimum. From 1 July 2019–30 June 2020, most of the 247 respondents (90%) had not seen any relevant cases; 7.5% reported one case and only 11 clinicians reported more than one case (Table 2). Because the conditions under surveillance are uncommon, the process is unlikely to impose an undue workload on clinicians, with only around 10% needing to complete full questionnaires.

From 1 July 2019–30 June 2020 the NZPSU monitored ten uncommon childhood conditions (Table 3). Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit or other INOPSU members.

Table 2: **Respondents' Workload 1 July 2019 – 30 June 2020**

Number of Notifications per respondent	1-Jul-2019 -31-Dec-2019		1-Jan-2020 – 30-Jun-2020	
	Number	%	Number	%
None	222	90	222	90
One	18	7	21	8
2-4	7	3	4	2
5 or more	0	0	0	0
TOTAL	247	100	247	100

Table 3: **Conditions under surveillance in 1 July 2019 - 30 June 2020**

Condition	Surveillance Started	Surveillance Ending	Principal Investigators
Acute flaccid paralysis	October 1997	Ongoing	Dr Mavis Duncanson
Haemolytic Uraemic Syndrome	January 1998	December 2020	Dr William Wong
Congenital rubella syndrome	January 1998	Ongoing	Dr Mavis Duncanson
Perinatal HIV exposure	January 1998	Ongoing	Dr Sue McAllister Dr Lesley Voss
Adverse Drug Reactions	May 2008	Ongoing	Dr Desiree Kunac
Potential prenatal exposure to syphilis (positive maternal serology)	April 2018	Ongoing	Associate Professor Tony Walls
Confirmed or Probable SARS-CoV-2 infection (COVID-19)	May 2020	Ongoing	Dr Mavis Duncanson
Delay in paediatric care due to COVID-19 pandemic	May 2020	June 2020	Dr Mavis Duncanson
Congenital Cytomegalovirus (confirmed or probable)	April 2020	April 2022	Dr Elizabeth Wilson
Self-harm seen by Paediatrician	June 2020	June 2022	Dr Sarah Fortune

REPORTS ON ONGOING STUDIES

Acute Flaccid Paralysis

Dr Mavis Duncanson
Ongoing study started January 1998

Introduction

Acute flaccid paralysis is used as a term for a number of different conditions characterised by paralysis, including Guillain-Barré syndrome and polio. Acute flaccid paralysis is characterised clinically by the acute onset of flaccid limb weakness.

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

Key Results July 2019- June 2020

There were 9 cases notified to the NZPSU from July 2019 until June 2020.
Information has been obtained on all of these children including follow-up information two months after diagnosis.

- 9 were from the North Island
- 4 females, 5 males.
- Age range 1 year to 16 years
- No seasonal variation.
- The overall incidence was 0.94 cases per 100,000 children aged under 15 years.
- All 9 cases have been classified as Non-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 less than 14 days after onset of paralysis, was complete for 5 of the 9 children (56 %) and partially complete for 1 child (11%) (see Table 4)

***Table 4*: AFP cases with adequate (or otherwise) stool samples: July 2019–June 2020**

Category	Stool samples	
	No.	%
2 stool samples within 14 days of onset of paralysis	5	56
2 stool samples, but one or both not within 14 days of onset of paralysis	0	0
1 stool sample	1	11
No stool samples	3	33

The NZPSU has notified the World Health Organization of these findings, as part of New Zealand's obligation to contribute to the certification of the eradication of polio through regular reports on polio-free status.

The rate expected by WHO in a country without endemic polio (1 case of acute flaccid paralysis per 100,000 age-specific person-years) was reached in 2019, but not in the first six months of 2020. The rate of stool testing (56%) was below the WHO target of 80%.

Most cases of acute flaccid paralysis in Aotearoa are treated at Starship Children's Hospital in Auckland (Starship). Through clinical relationships with Neurology Nurse Specialists at Starship, Barbara Woods and Erin Skidmore, the NZPSU has been able to improve both notification rate and stool reporting rate for these cases. The leadership shown by these staff is greatly appreciated. Throughout Aotearoa the NZPSU appreciates the vigilance and commitment shown by paediatricians in reporting cases and obtaining timely stool testing.

Stool specimens may not be clinically indicated in cases of acute flaccid paralysis. These children may often require transfer from a regional to a tertiary level centre with some urgency. Stool samples are not always taken when the focus is on the urgent health needs of children who are often seriously unwell. The nature of the health conditions affecting these children can mean that passage of stool is infrequent, a further barrier to stool sample collection.

At the request of the Ministry of Health *Manatū Hauora*, we continue to send regular reminders to paediatricians and other clinicians about the importance of stool samples from children with acute flaccid paralysis, for surveillance purposes. Paediatricians and other child health clinicians are reminded that the NZPSU requires immediate telephone notification (03) 470 9541 of all cases of AFP, including those with a definitive diagnosis such as Guillain Barré syndrome (GBS).

Haemolytic Uraemic Syndrome (HUS)

Dr William Wong
Ongoing study started January 1998

Key Results for 2019

- 15 cases of childhood HUS reported, 12 had a diarrhoeal prodrome (D+), 8 had *E coli* O157H7 or Shiga toxin identified and 4 had *E coli* O26:H11
- 3 children had no diarrhoea prodrome, (1 had a CFH autoantibody, 2 streptococcus pneumoniae)
- Median/mean age at presentation of D(+) HUS was 2.7 (3.2)years (range 2.1-6.7)
- 5/12 diarrhoeal cases had been in contact or lives on a farm within the past 2 weeks before presentation, 1 from contaminated tank water
- Median/mean time to diagnosis of HUS was 5 days (range 1-11)
- 8/15 of the whole group received acute dialysis and all recover renal function to discontinue dialysis.
- One fatality occurred as a result of massive intracerebral injury from diarrhoea related HUS

Congenital Rubella Syndrome (CRS)

Dr Mavis Duncanson
Ongoing study started January 1998

There have been no cases of congenital rubella reported in newborn infants throughout the surveillance period. There was one notification of a child aged 5–9 years in 1998.

Perinatal HIV Exposure

Dr Sue McAllister and Dr Lesley Voss
Ongoing Study started January 1998

Key Results for 2019

In 2019 there were 15 infants reported to have been born in New Zealand to women infected with HIV who were diagnosed prior to or during their pregnancy. Information has been received on all of these infants.

Of these 15:

- Four were born in Auckland, 4 in Hamilton, 3 in Wellington, 2 in Christchurch, and 2 in other parts of New Zealand.
- Thirteen were born to mothers whose HIV had been diagnosed before their pregnancy, and two were diagnosed during their pregnancy.
- Six of the mothers were of European ethnicity, 3 African, 2 Asian, 1 Māori, and 3 Middle Eastern/Latin American.
- Fourteen of the mothers were given antiretroviral treatment during pregnancy; 9 gave birth by caesarean section and 6 gave birth vaginally; one of the babies was breastfed.

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

Congenital cytomegalovirus

Dr Michelle Sam, Dr Elizabeth Wilson
Ongoing Study

Data collection commenced in May 2020. There will be a brief report on this study in the NZPSU annual report in 2021.

Acute self-harm seen by paediatrician

Dr Sarah Fortune
Ongoing Study

Data collection commenced in June 2020. There will be a brief report on this study in the NZPSU annual report in 2021.

Serious Paediatric Adverse Drug Reactions (ADR)

Dr Desiree Kunac, Dr Michael Tatley, Associate Professor David Reith, Professor Keith Grimwood
Ongoing study started August 2007.

Key Results for 2019

There were 14 notifications made during 2019; one was made in error, one case was reported by two paediatricians (duplicate report) and for 5 no further details were provided. A further report was excluded as it related to a wound dressing with limited information, leaving a total of 6 reports which are summarised below in Table 1.

Of the 6 reports, two are new reports that were not previously notified to the Centre for Adverse Reactions Monitoring (CARM). Four of the 6 cases resulted in a medical warning or danger being entered for the child in the national Medical Warning System. All 6 reports are included in the CARM database to further enhance our understanding of serious ADRs in children.

Table 5: Information on the five reports of Serious Adverse Drug Reactions (ADR) notified through NZPSU in 2019. The column titled" Medical Warning" indicates those added to the National Medial Warning System, and that titled CARM indicates whether the adverse reaction has also been notified to the Centre for Adverse Reactions (CARM)

Suspect Medicine	Reaction(s)	Age (Years)	Sex	Seriousness/Outcome	Medical Warning	CARM
Cefazolin IV then oral cephalexin for 4-5 weeks	Severe neutropenia	18 months	M	Hospitalised/recovered	Warning	No
Fleet® enema	Hyperphosphataemia agitation	7 years	M	Hospitalised / recovered	Warning	Yes
Bonjela® (higher than recommended dose)	Respiratory distress Tachypnoea Metabolic acidosis Salicylate toxicity	7 months	F	Life-threatening / recovered	Nil	Yes
Carbamazepine	DRESS syndrome face oedema	13 years	F	Hospitalised/recovered	Danger	Yes
Desmopressin	Hyponatraemia convulsions	8 years	M	Hospitalised/recovered	Danger	Yes

This annual report summary will be considered by the Medicines Adverse Reactions Committee (MARC) which is a technical advisory committee to the Minister of Health.

Confirmed or Probable SARS-CoV-2 infection (COVID-19)

Dr Mavis Duncanson, Prof. Peter McIntyre
Ongoing study started May 2020

There have been no cases of SARS-CoV-2 infection reported by paediatricians in Aotearoa. This surveillance refers only to children who were hospitalised or who died with the infection.

Ministry of Health data[1] show that there were 39 confirmed and 45 probable community cases of SARS-CoV-2 infection detected in under-15 year olds in Aotearoa up to 30 June 2020. Five confirmed cases had a history of recent overseas travel, the remainder of confirmed and probable cases had no such history.

[1] Data accessed from https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-current-situation/covid-19-current-cases/covid-19-current-cases-details

FINAL REPORTS

Potential Prenatal Exposure to Syphilis

Associate Professor Tony Walls
Initial study started April 2018 and completed June 2020

Aims

To collect incidence data and identify cases of possible mother to child transmission of syphilis. In addition to identifying confirmed or probable cases of congenital syphilis (as defined by the 2018 Ministry of Health Congenital Syphilis case definition), we also captured data relating to cases of "potential" transmission of syphilis; that is, cases where maternal syphilis serology tested positive, but infection of the infant may not have occurred.

Key Results

- 30 cases were notified during the 26 month study period, all of which were of newborn infants.
- Of these 30 cases, 10 infants had findings consistent with congenital syphilis, with 5 confirmed cases and 5 probable cases.
- 1 infant was born in 2017, 12 in 2018, 9 in 2019, and 8 in 2020.
- All of the cases arose from the North Island of New Zealand, with 10 cases notified from Counties Manukau DHB, 4 cases from Bay of Plenty DHB, 3 cases from Waikato DHB and 1-2 cases from each of the other District Health Boards.
- 13 of the mothers were of Māori descent, 9 of Pacific Peoples (4 Samoan, 3 Tongan, 1 Niuean, 1 Fijian Indian), 6 NZ European, and 2 of Asian ethnicity.
- Of the 10 infants with confirmed or probable congenital syphilis:
    - 8 had clinical signs, which included syphilis skin rash, jaundice/hepatitis, CNS/eye signs, hepatosplenomegaly, anaemia, thrombocytopaenia, pseudoparalysis, and nephrotic syndrome/malnutrition. 1 infant was severely affected with hydrops fetalis, ascites and oedema, and died at 2 days of age. 1 infant was extremely premature (born at 24 weeks gestation), and also died at 2 days of age.
    - 6 had long bone changes visible on x-ray
    - 6 had CSF findings (elevated WCC, protein, and/or reactive VDRL)
    - 3 had infant:maternal (at delivery) non-treponemal titres of 4x or greater
    - 3 had positive tissue samples
    - 6 were born to mothers who were not treated for syphilis during pregnancy, 3 were born to mothers who were treated but were not tested or who had inadequate serological response to treatment, and 1 was born to a mother where it was unknown if she received treatment during pregnancy.

Note: The initial two-year surveillance study is completed. At the request of the Ministry of Health, a new study with ongoing surveillance for potential prenatal exposure to syphilis commenced in July 2020 and will be included in future NZPSU annual reports.

Delay in paediatric care during COVID-19 response

Dr Mavis Duncanson
Study undertaken May-June 2020

Aim

To provide a qualitative snapshot of paediatricians' perceptions of delays that were longer than they would normally expect in a child's presentation, admission, clinical review, investigation, treatment or discharge due to the COVID-19 pandemic and national response

Key Results

Over the six-week period there were 34 reports of delay in care.
1 report was for "all outpatients"
3 reports were for multiple similar cases
30 reports were of individual cases

12 reports were of minor impact (inconvenience, patient or family dissatisfaction)
16 reports of moderate harm (short-term morbidity, increased length of stay, higher level of care)
4 reports of severe harm (life-threatening event, permanent disability, death)

17 reports (including 2 reports of multiple cases) were of infants aged up to 1 year
12 of these reports were about infants aged up to 6 weeks

The most common factors associated with delay in care were hospital avoidance due to concern re potential COVID-19 infection and lack of access to primary care, including postnatal visits. This information will be used to inform policies and practice around paediatric care in pandemic planning.

NZPSU SURVEILLANCE STUDIES and PUBLICATIONS[2]

Condition	Report Period	Findings Reported
Acute Flaccid Paralysis	1997 ongoing	Dow N., Dickson N. & Taylor BJ. The New Zealand Paediatric Surveillance Unit: Establishment and first year of operation. New Zealand Public Health Report. 1999;6(6):41-44. Chambers ST & Dickson NP. Global polio eradication: progress, but determination and vigilance still needed. New Zealand Medical Journal. 2012;124(1337):100-104. Desai S, Smith T, Thorley BR, Grenier D, Dickson N, Altpeter E et al. Performance of acute flaccid paralysis surveillance compared with World Health Organization standards. Journal of Paediatrics and Child Health. 2015;51(2):209-214. **Duncanson M & Wheeler B. Don't forget about polio. Update on local surveillance and international trends. Presentation at Paediatric Society of New Zealand 71st Annual Scientific Meeting – In our backyard, Albany, Auckland, November 2019.**
Haemolytic Uraemic Syndrome	1998 ongoing	Prestidge C & Wong W. Ten years of pneumococcal-associated haemolytic uraemic syndrome in New Zealand children. Journal of Paediatrics and Child Health. 2009;45(12):731-735.
Congenital Rubella Syndrome	1998 ongoing	
Perinatal HIV Exposure	1998 ongoing	Dickson N, Paul C, Wilkinson L, Voss L & Rowley S. Estimates of HIV prevalence among pregnant women in New Zealand. New Zealand Public Health Report. 2002;9:17-19.
Neonatal herpes simplex virus (HSV)	1998–2000	
Proven neonatal bacterial or fungal infection in the first week of life	1998–2008	Darlow BA, Voss L, Lennon DR & Grimwood K. Early-onset neonatal group B streptococcus sepsis following national risk-based prevention guidelines. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2017;56(1): 69-74.
Vitamin K deficiency bleeding (VKDB)	1998–2008	Darlow BA. Vitamin K deficiency bleeding (VKDB) in New Zealand infants: results of surveillance over five years (1998 to 2002). Pediatric Research. 2004;56 (3):474 Darlow BA, Phillips AA & Dickson NP. New Zealand surveillance of neonatal vitamin K deficiency

[2] 2019–2020 references in **bold type**

		bleeding (VKDB): 1998-2008. Journal of Paediatrics and Child Health. 2011;47(7):460-4.
Fetal Alcohol Syndrome	1999–2001	Leversha AM & Marks RE. The prevalence of fetal alcohol syndrome in New Zealand. New Zealand Medical Journal. 1995;108(1013):502–505.
Subdural Haemorrhage	1999–2002	Kelly P & Farrant B. Shaken Baby Syndrome in New Zealand, 2000–2002. Journal of Paediatrics and Child Health. 2008;44: 99–107.
Retinopathy of Prematurity (stage III)	1999–2000	
Diabetes Mellitus	1999–2000	Campbell-Stokes P L & Taylor BJ. Prospective incidence study of diabetes mellitus in New Zealand children aged 0 to 14 years. Diabetologia. 2005;48(4):643-648.
Kawasaki Disease	2001–2002	Heaton P, Wilson N, Nicholson R, Doran J, Parsons, A & Aiken, F. Kawasaki Disease in New Zealand. Journal of Paediatrics and Child Health. 2006;42:184–190
Bronchiectasis	2001–2002	Twiss J, Metcalfe R, Edwards E & Byrnes C. New Zealand National Incidence of bronchiectasis "too high" for a developed country. Archives of Disease in Childhood. 2005;90:737–740. Twiss J. Childhood bronchiectasis: national incidence, disease progression and an evaluation of inhaled antibiotic therapy [PhD Thesis]. University of Auckland; 2008. http://hdl.handle.net/2292/5747
Idiopathic Nephrotic Syndrome	2001–2003	Wong W. 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. Paediatrics and Child Health. 2007;43:337–341.
Inflammatory Bowel Disease	2002–2003	Yap J, Wesley A, Mouat S & Chin S. Paediatric inflammatory bowel disease in New Zealand. New Zealand Medical Journal. 2008;121(1283):19-34.
Prolonged Infantile Cholestasis	2004–2005	
Pertussis	2004–2005	Somerville R, Grant C, Grimwood K, Murdoch D, Graham D, Jackson P, Meates-DM, Nicholson R & Purvis D. Infants hospitalised with pertussis: Estimating the true disease burden. Journal of Paediatrics and Child Health. 2008;43:617-622.
Inborn Errors Of Metabolism	2004–2006	Wilson C, Kerruish N, Wilcken B, Wiltshire E & Webster D. The failure to diagnose inborn errors of metabolism in New Zealand: the case for expanded newborn screening. New Zealand Medical Journal 2008;120:U2727 Wilson C, Kerruish NJ, Wilcken B, Wiltshire E, Bendikson K & Webster D. Diagnosis of disorders of intermediary metabolism in New Zealand before and after expanded newborn screening:

		2004–2009. New Zealand Medical Journal. 2012;125(1348):42-50.
Pneumococcal meningitis	2005–2008	Safar A, Lennon D, Stewart J, Trenholme A, Drinkovic D, Peat B & Voss L. Invasive group A streptococcal infection and vaccine implications, Auckland, New Zealand. Emerging Infectious Diseases. 2011;17(6):983-9.
Acute Post Streptococcal Glomerulonephritis	2007–2011	Wong W, Lennon DR, Crone S, Neutze JM & Reed PW. Prospective population-based study on the burden of disease from post-streptococcal glomerulonephritis of hospitalised children in New Zealand: Epidemiology, clinical features and complications. Journal of Paediatrics and Child Health. 2013;49(10):850-855.
Renal stones	2008	Dickson N, Kara T & Tuohy P. Rapid national survey of renal stones in New Zealand infants. Journal of Paediatrics and Child Health. 2009;45(11): 633-635.
Adverse Drug Reactions (ADR)	2008 ongoing	Kunac D, Tatley M, Grimwood K & Reith D. Active surveillance of serious drug adverse reactions in New Zealand children. Archives of Disease in Childhood. 2012;97(8):761-762.
Neonatal Bacterial or Fungal Infection	2011–2013	Darlow B A, Voss L, Lennon DR & Grimwood K. Early-onset neonatal group B streptococcus sepsis following national risk-based prevention guidelines. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2017;56(1):69-74.
Severe Neonatal Hyperbilirubinaemia	2011–2013	
Moderate and Severe Neonatal Encephalopathy	2011–2013	Battin M, Sadler L, Masson V & Farquhar C. Neonatal encephalopathy in New Zealand: Demographics and clinical outcome. Journal of Paediatrics and Child Health. 2017; 52(6):632-636
Vitamin D Deficiency Rickets	2011–2013	Wheeler BJ, Dickson NP, Houghton LA, Ward LM & Taylor BJ. Incidence and characteristics of vitamin D deficiency rickets in New Zealand children: a New Zealand Paediatric Surveillance Unit study. Australian and New Zealand Journal of Public Health. 2015;39(4):380-383.
Varicella and post-varicella complications	2011–2013	Wen SCH, Best E, Walls T, Dickson N, McCay H & Wilson E. Prospective surveillance of hospitalisations associated with varicella in New Zealand children. Journal of Paediatrics and Child Health. 2015;51(11): 078-1083.
Supratherapeutic Paracetamol Ingestion	2014–2015	
Eosinophilic Oesophagitis	2014–2016	
Empyema	2014–2018	Rix-Trott K, Byrnes C, Twiss J, Matsas R, Hamill J, Evans S, Mahon C, Williamson D, Dickson N, Walls T, Voss L. & Best E. Nationwide surveillance of paediatric empyema in New Zealand 2014–2016. Presentation at Australasian Society of

		Infectious Diseases Annual Scientific Meeting, Leura NSW, March 2018
Acute Post-Streptococcal Glomerulonephritis	2007–2015	**Vogel AM, Lennon DR, van der Werf B, Diack M, Neutze JM, Horsfall M, Emery D, & Wong W. Post-streptococcal glomerulonephritis: Some reduction in a disease of disparities. Journal of Paediatrics and Child Health. 2019; 5,652-658.**
Tongue-Tie	2016–2018	**Hale M, Mills N, Edmonds L, Dawes P, Dickson N, Barker D & Wheeler BJ. Complications following frenotomy for ankyloglossia: A 24-month prospective New Zealand Paediatric Surveillance Unit study. Journal of Paediatrics and Child Health. 2020;56,557-562.**

GENERAL SURVEILLANCE PUBLICATIONS

Elliott EJ, Nicoll A, Lynn R et al. Rare disease surveillance: An international perspective. Paediatrics and Child Health. 2001 (5):251-60.

Grenier D, Elliott EJ, Zurynski Y et al. Beyond counting cases: Public health impacts of national Paediatric Surveillance Units. Archives of Disease in Childhood, 2007; 92(6), 527-533.

Grenier D, Ugnat AM, McCourt C et al. Can active surveillance provide a rapid response to an emerging child health issue? The melamine example. Journal of Paediatrics and Child Health, 2009;14(5), 285-286.

Dickson N., Duncanson M & Best, E. Twenty years of the New Zealand Paediatric Surveillance Unit and the future. Presentation at Paediatric Society of New Zealand 69th Annual Scientific Meeting – Strengthening our foundations, 16 November 2017, Christchurch

Maeusezahl M, Lynn R, Zurynski Y et al. (on behalf of the International Network of Paediatric Surveillance Units INoPSU). The power of surveillance data to change Public Health policy and practice in rare paediatric conditions. Poster presentation at European Society of Paediatric Infectious Disease conference 28 May 2018, Malmö, Sweden

INTERNATIONAL NETWORK OF PAEDIATRIC SURVEILLANCE UNITS (INoPSU)

Establishment of INoPSU

The International Network of Paediatric Surveillance Units (INoPSU) is a collaborative organisation. Established in 1998, it currently joins 11 diverse countries which span the globe from Canada to New Zealand. More than 10,000 clinicians contribute and over 300 conditions have been studied so far.

INOPSU was accepted for membership in the International Paediatric Association (IPA) at their September 2011 meeting in Beijing.

INoPSU has held ten scientific meetings since 2000. Associate Professor Nigel Dickson attended meetings in Ottawa, York, Lisbon and Melbourne. Dr Mavis Duncanson attended the 10th Scientific Conference in Glasgow in 2018. Members communicate regularly with each other and in recent years there has been increasing collaboration in developing surveillance studies. The NZPSU has contributed to international discussions in the development of surveillance methods for SARS-CoV-2 infection, delay in paediatric care due to the COVID-19 pandemic, severe microcephaly

Mission

The mission of INoPSU is the advancement of knowledge of uncommon childhood infections and disorders and the participation of paediatricians in surveillance on a national and international basis so as to achieve a series of benefits.

Aims

- To collaborate with and provide information to other groups interested in rare childhood diseases, such as parent support groups and policy-makers
- To respond promptly to international emergencies relating to rare childhood conditions where national and international studies can make a contribution to science or public health
- Facilitating communication and cooperation between existing national paediatric surveillance units
- 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 on 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 school 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 cooperative surveys through each national unit
- To collaborate with and provide information to other groups interested in rare childhood diseases such as parent support groups
- To respond promptly to international emergencies relating to rare childhood conditions where national and international studies can make a contribution to science or public health.

There are currently 11 surveillance units that form the INoPSU network (Table 5). The Netherlands Paediatric Surveillance Unit closed in 2019.

Table 5: **Members of the International Network of Paediatric Surveillance Units**

Unit	Acronym	Email	Website
Australian	APSU	apsu@chw.edu.au	www.apsu.org.au
Belgium	PediSurv	elise.mendes@wiv-isp.be	www.wiv-isp.be/pedisurv
British	BPSU	bpsu@rcpch.ac.uk	www.bpsu.org.uk
Canadian	CPSP	cpsp@cps.ca	www.cpsp.cps.ca
German	ESPED	prof.von.kries@gmx.de	www.esped.uni-duesseldorf.de
Greece and Cyprus	GCPSU	xhatzi@med.uth.gr	
Irish	IPSU	robert.cunney@hse.ie	
New Zealand	NZPSU	nzpsu@otago.ac.nz	www.otago.ac.nz/nzpsu
Portuguese	PPSU	uvp-spp@ptnetbiz.pt	
Swiss	SPSU	spsu@bag.admin.ch	www.spsu.ch
Welsh	WPSU	heather.oconnell@wales.nhs.uk	www.welsh-paediatrics.org.uk/wpsu

Special thanks to all the paediatricians who regularly contribute every month to New Zealand's Paediatric Surveillance Unit. Your contribution is valued and appreciated.