The Paediatric Society of New Zealand

New Zealand Paediatric Surveillance Unit

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

University of Otago
Te Whare Wānanga o Otāgo
New Zealand

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

New Zealand Paediatric Surveillance Unit Annual report 2022

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Te Hunga Aroturuki Mate Tamariki
Department of Women's & Children's Health
Te Tari Hauora Wāhine me te Tamariki
Otago Medical School
Te Kura Hauora o Ōtākou

p: (+64) 021 279 1728
e: nzpsu@otago.ac.nz
w: www.otago.ac.nz/nzpsu

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PREFACE: NEW ZEALAND PAEDIATRIC SURVEILLANCE UNIT

The New Zealand Paediatric Surveillance Unit, Te Hunga Aroturuki Mate Tamariki, (NZPSU) is pleased to present this annual report.

The NZPSU undertakes surveillance of acute flaccid paralysis (AFP) for Manatū Hauora (Ministry of Health) as part of a national programme to certify elimination of poliomyelitis. The data collected are reviewed by the National Certification Committee for the Eradication of Poliomyelitis (NCCEP), and contribute to the Global Polio Eradication Initiative in association with the World Health Organization and other partners.

This report covers acute flaccid paralysis surveillance from 1 July 2021 to 30 June 2022.

Regular surveillance of paediatricians provides an opportunity to investigate of other rare conditions in childhood that have high impact for individuals or health service delivery. These additional studies are undertaken by paediatricians with a clinical research interest, or by NZPSU staff at the request of Manatū Hauora, and the conditions are included alongside AFP on the monthly report card. Unless otherwise stated, reports for these additional studies cover the 2021 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 and appreciate ongoing funding from Manatū Hauora.

Dr Mavis Duncanson, Co-director
Associate Professor Benjamin Wheeler, Co-director
Ms Rachel Bates, Administrator

INTRODUCTION

The NZPSU was established in 1997 to facilitate and improve knowledge of rare 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 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 2021 and 2022.

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 rare childhood conditions in New Zealand.

Surveillance method

The NZPSU maintains a database of active paediatricians in Aotearoa, and audits it against specialist registration in paediatrics with the Medical Council of New Zealand (publicly available data). Clinicians in each hospital are encouraged to invite colleagues to join.

Every month participants are sent an email with linked REDCap survey to report whether in the previous month they have seen any children with the conditions under surveillance. Cases of AFP are required to be reported immediately by phone to the NZPSU.

When a case is reported to NZPSU, the Principal Investigator is advised and sends the reporting clinician a 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 protocols, which include definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number are available on the NZPSU website www.otago.ac.nz/nzpsu

Study selection

A Scientific Review Panel (SRP) considers applications for new conditions to be added into the programme, considering the scientific interest and public health importance of the proposed study, methodology, and suitability of the condition for ascertainment through NZPSU.

A study is eligible for consideration in the scheme if the condition in the scheme if the condition of interest is:

- A rare childhood disease or condition with high impact at personal or population level (or an uncommon complication of a more common disease)
- Of such a low incidence or prevalence that ascertainment of cases is needed on a national scale to generate adequate numbers for the study

The SRP may also consider inclusion of short-term or geographically limited studies of more common conditions. The SRP members are listed in Table 1:

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
Professor Peter McIntyre	University of Otago
Associate Professor Tony Walls	University of Otago
Dr Anne Morris	University of Sydney
Dr Geoffrey Roche	Manatū Hauora
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 Manatū Hauora.

Manatū Hauora may request surveillance of emerging diseases or health conditions deemed to be of national or international significance.

SURVEILLANCE ACTIVITIES FROM JULY 2021 to JUNE 2022

In 2021–2022, there were around 260 clinicians participating in the surveillance programme with an average monthly response rate of 70%.

From 1 July 2021–30 June 2022 the NZPSU monitored nine uncommon childhood conditions (Table 2). Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit or other INOPSU members.

Table 2: Conditions under surveillance in 1 July 2021 - 30 June 2022

Condition	Surveillance Started	Surveillance Ending	Principal Investigators
Acute flaccid paralysis	October 1997	Ongoing	Dr Mavis Duncanson
Congenital rubella syndrome	January 1998	Ongoing	Dr Mavis Duncanson
Perinatal HIV exposure	January 1998	Ongoing	Dr Sue McAllister Dr Lesley Voss
Serious paediatric adverse drug reactions	May 2008	Ongoing	Dr Michael Tatley
Potential prenatal exposure to syphilis (positive maternal serology)	April 2018	Ongoing	Associate Professor Tony Walls Dr Leeyan Gilmour
Confirmed or probable SARS-CoV-2 infection (COVID-19)	May 2020	Ongoing	Dr Mavis Duncanson Prof Stuart Dalziell
Congenital cytomegalovirus (confirmed or probable)	April 2020	April 2022	Dr Elizabeth Wilson Dr Michelle SAm
Self-harm seen by Paediatrician	June 2020	June 2024	Dr Sarah Fortune Dr Gabrielle McDonald
Severe acute hepatitis	April 2022	Ongoing	Dr Helen Evans Professor Andrew Day

REPORTS ON ONGOING STUDIES

Acute Flaccid Paralysis

Dr Mavis Duncanson
Ongoing study started October 1997

Introduction

Acute flaccid paralysis (AFP) is a clinical description of sudden onset of muscle weakness without any spasticity or rigidity. These symptoms are similar to those observed clinically in polio. In the context of polio elimination, as in Aotearoa, the most common medical conditions resulting in AFP are Guillain-Barré syndrome and Transverse Myelitis.

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 2021- June 2022

There were 13 cases notified to the NZPSU from July 2021 until June 2022. The NCCEP determined that one case was non-AFP (a chronic rather than acute presentation). Information has been obtained on the remaining 12 AFP cases, including follow-up information two months after diagnosis. Of these 13 cases:

- 10 were from the North Island
- 7 females, 6 males.
- Age range 1 year to 11 years
- The AFP incidence was 1.2 cases per 100,000 children aged under 15 years.
- All 12 cases were discarded as non-polio by the NCCEP.
- Stool sample collection was complete for 9 of the 12 children (75 %) and timely for 7 (58%).

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 AFP 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 2021/22. The rate of complete and timely stool testing (58%) was below the WHO target of 80%. Timeliness of stool testing was affected by delayed presentations with symptoms present for up to three weeks before presentation to health services.

At the request of Manatū Hauora the NZPSU has continued 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 (021 279 1728) of all cases of AFP, including those with a definitive diagnosis such as Guillain Barré syndrome (GBS) or Transverse Myelitis.

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 2021

In 2021 there were 13 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 13 infants:

- Nine were born in Auckland, and four in other parts of New Zealand.
- Eleven were born to mothers whose HIV had been diagnosed before their pregnancy, and two were diagnosed during their pregnancy.
- The mothers were identified as of European, Māori, African, Asian, and Pacific ethnicities
- Thirteen of the mothers were given antiretroviral treatment during pregnancy; 5 gave birth by caesarean section and 8 gave birth vaginally; two of the babies were breastfed.

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

Serious Paediatric Adverse Drug Reactions (ADR)

Assoc. Prof. David Reith, Prof. Michael Tatley, Prof. Keith Grimwood, Dr. Desirée Kunac
Ongoing study started August 2007.

Objectives:

1. To gain a greater understanding of serious paediatric adverse drug reactions (ADR's) in children below the age of 16 years.
2. To determine the level to which the NZPSU active surveillance method captures information about serious paediatric ADR's not currently captured by an existing passive spontaneous reporting system (Centre for Reactions Monitoring, CARM) operated by the New Zealand Pharmacovigilance Centre (NZPhvC).

Key Results for 2021

There were 21 notifications made during the 2021 year. Two did not meet the study definition (one was a dispensing error), 2 were duplicates, and for 6 notifications there was no follow up report received.

At NZPSU's request suspected COVID vaccine related reports of pericarditis/myocarditis were added to the notification card on September 2021. For those reported for the COVID vaccine only 1 has been included in the study (as seen in table 1.). The other 2 have been added to the COVID adverse reaction reporting system (CIR).

There are no further details for one of the cases that was outside the study definition.

The 9 reports included in the study are summarized below in Table 3.

There were 6 new reports that had not previously been notified to the Centre for Adverse Reactions Monitoring (CARM). These have now been included in the CARM database to further enhance our understanding of serious ADR's in children.

Table 3: Information on the 9 reports of Serious Paediatric Adverse Drug Reactions (ADR) notified through NZPSU in 2021. The column titled "Medical Warning" indicates those added to the national Medical Warning System, and the column titled CARM indicates whether the adverse reaction had also been notified directly to the Centre for Adverse Reactions Monitoring (CARM).

Suspect Medicine	**Reaction(s)**	**Age**	**Sex**	**Serious/Outcome**	**Medical Warning**	**CARM**
Aminophylline	Tachycardia-supraventricular.	9 years	M	Life threatening/ Recovered at time of reporting	Warning	Yes
Amoxicillin	Urticarial rash/purpuric. Fevers and swollen joints.	3 years	M	Medically significant/ Recovered at the time of reporting	Danger	No
Co-Trimoxazole	Toxic epidermal necrosis.	2 years	M	Life threatening - Required intubation and ventilation/not fully recovered at the time of reporting	Danger	No
Co-Trimoxazole	Rash and irritability.	2 years	F	Required hospitalisation/ Improved at time of reporting	Warning	Yes
Lamotrigine	Stevens-Johnson Syndrome (SJS)	12 years	F	Required hospitalisation/ Recovered at the time of reporting	Danger	Yes
Lamotrigine	Macular rash/skin exfoliation.	12 years	M	Medically significant/ not fully recovered at the time of reporting	Warning	No
Melatonin	Gynaecomastia, chest pain, palpitations, restless leg syndrome and abnormal dreams .	6 years	F	Not serious/ Recovered at the time of reporting	-	No
Tocilizumab	Rash, coronary artery disorder, interstitial lung disease and vomiting.	2 years	M	Required hospitalisation/ Recovered at time of reporting	-	No
COVID vaccine (Pfizer-Paediatric dose)	Myocarditis.	13 years	M	Life threatening/ Recovered at the time of reporting	-	No

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.

Potential Prenatal Exposure to Syphilis - September 2022 update

Dr Leeyan Gilmour, Professor Tony Walls
Ongoing study commenced April 2018

Aim:

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:

- A total of 79 cases were notified during the 53 month study period (69 cases to the NZPSU and 10 cases directly to the investigators).
- Of the 78 cases with complete data, 73 cases were newborns, and five were notified as infants, ranging from 2 weeks to 17 months of age.
- One infant was born in 2017, 13 in 2018, 11 in 2019, 22 in 2020, 15 in 2021, and 16 in 2022 thus far.
- All but nine of the cases arose from the North Island of New Zealand, with 21 cases notified from the Counties Manukau region, eight from the Canterbury region, sever from the Waitemata, Bay of Plenty, and Waikato regions, six from Tairawhiti, and one to four cases from each of the other regions.
- 43 of the women were of Māori descent, 19 NZ European, 16 of Pacific Peoples, and 4 of other ethnicities (some women identified with more than one ethnicity)
- 25 infants had findings consistent with congenital syphilis, with 12 confirmed cases and 13 probable cases. The remaining 54 cases had antenatal exposure to syphilis but were not diagnosed with congenital syphilis.
- Of the 25 infants with confirmed or probable congenital syphilis:
    - 10 were born to women who did not receive antenatal care, with the antenatal care status of a further two infants being unknown.
    - Four infants were born to women who had negative first trimester serology testing
    - 16 had clinical signs, which included syphilis skin rash, jaundice/hepatitis, CNS/eye signs, hepatosplenomegaly, anaemia, thrombocytopaenia, pseudoparalysis, and nephrotic syndrome/malnutrition. One infant was severely affected with hydrops fetalis, ascites and oedema, and died at 2 days of age. One infant was extremely premature (born at 24 weeks gestation), and also died at 2 days of age, and one infant was stillborn.
    - 16 had long bone changes visible on x-ray
    - 12 had CSF findings (elevated WCC, protein, and/or reactive VDRL)
    - Four had infant: maternal (at delivery) non-treponemal titres of 4x or greater
    - Seven had positive tissue samples
    - 18 were born to women who were not treated for syphilis during pregnancy, six were born to mothers who were treated but were not tested or who had inadequate serological response to treatment, and one was born to a mother where it was unknown if she received treatment during pregnancy.
    - All of the probable and confirmed cases were treated appropriately with penicillin.

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

Dr Mavis Duncanson, Professor Peter McIntyre, Professor Stuart Dalziel
Ongoing study started May 2020

Aims

To describe the impact of the COVID-19 pandemic on children and young people in Aotearoa through identifying paediatric cases with severe symptoms requiring hospitalisation and describing the clinical course for these children.

Key Results

There were 26 cases of children hospitalised with SARS-CoV-2 infection in 2021 reported to the NZPSU in 2021. Questionnaires were returned for 16 of these cases, with duplicate reports for three cases.

- All 16 cases were hospitalised between October and December 2021
- All cases were domiciled in the Auckland, Counties Manukau or Waikato DHB areas
- Seven cases were aged under one year; remainder aged 1 to 14 years
- There were 12 males and 4 females
- In this cohort the majority (9/16) were hospitalised for social concerns (e.g. hospitalised to provide care for the child due to COVID-19 in household with no suitable caregiver available for the child). The remainder were hospitalised with clinical concerns due to SARS-CoV-2 or COVID-19 like symptoms (5) or clinical concerns for another reason and found to be SARS-CoV-2 positive (2).

In 2022 the case definition was amended to identify only children with SARS-CoV-2 infection who required ICU level care, and cases with a multi-inflammatory syndrome. These cases will be reported in 2023.

Congenital Cytomegalovirus

Dr Michelle Sam, Dr Elizabeth Wilson
Ongoing Study started May 2020

Objectives:

1) To describe the clinical profile and risk factors of children with confirmed and probable cCMV infection reported to the surveillance unit
2) Determine whether there have been missed opportunities for early diagnosis which might have enabled antiviral therapy
3) Describe the implementation and uptake of postnatal antiviral therapies to reduce neurodevelopmental sequelae (SNHL, developmental delay, CP)
4) Determine the feasibility and best practice processes and governance of establishing a register for cCMV in Australia and NZ
5) Provide a sampling frame for future research into cCMV

Case definition: Infants or children up to 12 months of age with confirmed or probable congenital cytomegalovirus infection were eligible for study recruitment.

Key Results for 2021

The study received 18 notifications of cCMV from clinicians in New Zealand in 2021, representing 11 individual children once duplicates were removed.

This study will be completed in 2022 with a final report in the 2023 annual report

Acute Self-Harm seen by Paediatrician

Dr Sarah Fortune, Dr Gabrielle McDonald, Ms Linda Hobbs
Ongoing Study started June 2020

Objectives:

Surveillance by NZPSU is part of a broader research study.
The primary objectives of this study are:

1) To establish multi-centre sentinel surveillance of SH patients at four large public hospitals, as per the recommended WHO practice guidelines on sentinel surveillance for self-harm
2) To establish and test robust data collection methods as per the recommended WHO practice guidelines on sentinel surveillance for self-harm
3) Identify the epidemiology of current presentations for SH or suicidal ideation in terms of age, gender, ethnicity, methods of SH, alcohol misuse, prior history of SH, intention to die, exposure to suicide, mental health assessments and discharge outcome
4) Identify patterns of repetition of non-fatal SH
5) Undertake surveillance of self-harm among children and adolescents under 15 years of age via the NZ Paediatric Surveillance Unit (NZPSU)

Key Results for 2021

This ongoing four-year study is collecting sensitive data that will be reported on completion of the study in 2024. In 2021 there were 61 reports to the NZPSU of self-harm seen by a paediatrician in under-15-year-olds.

Severe Acute Hepatitis

Dr Helen Evans, Professor Andrew Day
Ongoing Study started April 2022

Objectives:

This is a rapid surveillance study in response to an emerging condition. The UK reported more cases than expected of severe acute hepatitis of unknown origin in April 2022, and hundreds of cases have since been reported in multiple countries. A small cluster of up to 15 cases of acute hepatitis was detected in New Zealand children between May and September 2021.

The study seeks to answer the research question: In New Zealand, what features are associated with acute hepatitis with aspartate transaminase (AST) or alanine transaminase (ALT) over 300 UL in children aged under 17 years, presenting after 1 January 2021?

Case definition:

An acute hepatitis, in a child aged 0–16 years (inclusive), with discrete or acute onset of symptoms (e.g. fever, jaundice, abdominal pain, fatigue, loss of appetite, dark urine, pale coloured stools, itchy skin, muscle or joint pain, nausea or vomiting); AND elevated serum transaminase (ALT) levels (>300U/L).

Key Results for 2021

This study will be reported in 2023 when the first full year of data is available.

NZPSU SURVEILLANCE STUDIES and PUBLICATIONS[1]

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. Wong W, Morris MC, Kara T, Ronaldson JE. Haemolytic uraemic syndrome in New Zealand children. A nationwide surveillance study from 1998-2009. Poster presented at 15th Congress of International Pediatric Nephrology Association, New York, August–September 2010. Wong W, Prestidge CP, Ronaldson J. Shorter prodrome of symptoms is associated with an increased severity of diarrhoea associated HUS (D+HUS). Poster presented at 18th Congress of International Pediatric Nephrology Association, Venice, October 2019 Wong W, Prestidge CP, Ronaldson J, Dickens A. Atypical HUS in New Zealand children; outcomes without Eculizumab. Poster presented at 18th Congress of International Pediatric Nephrology Association, Venice, October 2019.

[1] 2021–2022 references in **bold type**

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 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	Roberts AJ, Day AS, Sinclair J, Dickson N, Porter J, Wellington G & Evans H. Paediatric eosinophilic oesophagitis in New Zealand: A 3-year prospective study. Journal of Paediatrics and Child Health. 2021;57(2):234-38.
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 Rix-Trott K, Byrnes CA, Gilchrist CA, Matsas R, Walls T, Voss L, et al. Surveillance of pediatric parapneumonic effusion/empyema in New Zealand. Pediatric Pulmonology. 2021;56(9):2949-57.
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.
Potential Prenatal Exposure to Syphilis	2018–2020 then ongoing	Gilmour LS, Best EJ, Duncanson MJ, Wheeler BJ, Sherwood J, Thirkell CE, Walls T. High Incidence of congenital syphilis in New Zealand. The Pediatric Infectious Disease Journal, 2021 Online First June 22, 2021
Self-harm seen by paediatrician	2021–2024	**Fortune S, Hetrick S, Sharma V, McDonald G, Scott K, Mulder RT, Hobbs L. Multisite sentinel surveillance of self-harm in New Zealand: protocol for an observational study. BMJ Open 2022;12(5):e054604.**

Delay in paediatric care during COVID-19 response	2020	Duncanson M, Wheeler BJ, Jelleyman T, Dalziel SR, McIntyre P. Delayed access to care and late presentations in children during the COVID-19 pandemic New Zealand-wide lockdown: A New Zealand Paediatric Surveillance Unit study. Journal of Paediatrics and Child Health. 2021;57(10):1600-4. Duncanson M with acknowledgment of Ben Wheeler, Tim Jelleyman, Stuart R Dalziel, Peter McIntyre, Johann de Water Naude and Chris McKinlay. Perceived impact of COVID-19 pandemic response on paediatric hospitalisations in Aotearoa. Presentation at Paediatric Society of New Zealand 72nd Virtual Conference (replacing 72nd Annual Scientific Meeting) November 2021.

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	tine.grammens@sciensano.be	www.sciensano.be
British	BPSU	bpsu@rcpch.ac.uk	www.rcpch.ac.uk/work-we-do/bpsu
Canadian	CPSP	cpsp@cps.ca	www.cpsp.cps.ca
German	ESPED	No further information	No further information
Irish	IPSU	robert.cunney@hse.ie	
New Zealand	NZPSU	nzpsu@otago.ac.nz	www.otago.ac.nz/nzpsu
Netherlands		nsck@nvk.nl	www.nvk.nl/onderzoek/nsck
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.