The Paediatric Society of New Zealand
Te Kāhui Mātai Arotamariki o Aotearoa

Annual report

2025

Ōtākou
Whakaihu Waka
UNIVERSITY OF OTAGO

Te Hunga Aroturuki Mate Tamariki
New Zealand Paediatric Surveillance Unit

New Zealand Paediatric Surveillance Unit

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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 The Ministry of Health - Manatū Hauora 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. The 2025 NCCEP report covers acute flaccid paralysis surveillance from 1 July 2024 to 30 June 2025.

In addition to AFP surveillance, the NZPSU undertakes important complementary surveillance of other communicable diseases (congenital rubella, exposure to maternal HIV infection, exposure to maternal syphilis infection, acute hepatitis ,HUS associated with either Shiga-toxin producing *E coli* or invasive pneumococcal disease) not fully captured by laboratory or public health surveillance. This provides valuable additional support to the 2025-2030 national public health surveillance strategy[1]. Conditions may be included at the request of The Ministry of Health - Manatū Hauora or approved by the Scientific Review Panel (SRP) following a request from paediatricians. Unless otherwise stated, this report is for the 2024 calendar year.

The ongoing success of the NZPSU relies on the voluntary participation of busy paediatricians who have taken the time to notify relevant cases and provide the additional information requested. We acknowledge and appreciate ongoing funding from The Ministry of Health – Manatū Hauora.

Professor Peter McIntyre, Co-director

Professor Benjamin Wheeler, Co-director

[1.] New Zealand Public Health Surveillance Strategy 2025-2030
https://www.health.govt.nz/publications/public-health-surveillance-strategy-2025-2030

NZPSU SURVEILLANCE ACTIVITIES IN 2024

In 2024, there were between 262–289 clinicians participating in the surveillance programme with an average monthly response rate of 73% (Figure 1). The NZPSU has ensured that there is at least one participating paediatrician in each district of Health New Zealand - Te Whatu Ora and encourages participation through regular communication with paediatricians and presentations at relevant conferences and scientific meetings.

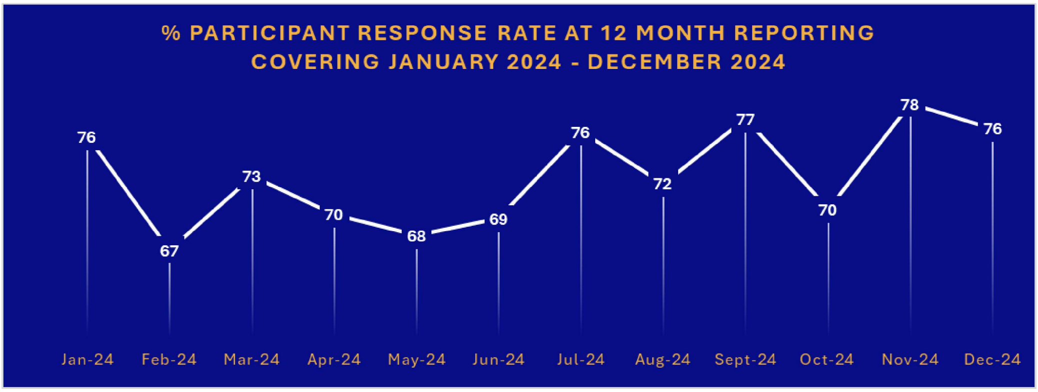

Figure 1: Monthly survey response rate from active Paediatricians on NZPSU mailing list 2024.

From 1 January 2024–31 December 2024 the NZPSU monitored eight rare childhood conditions (Table 1). Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit or other INOPSU members

Table 1: Conditions under surveillance in 2024

Condition	Surveillance Started	Surveillance Ending	Principal Investigator(s)
Acute flaccid paralysis	October 1997	Ongoing	Dr Mavis Duncanson Professor Peter McIntyre Professor Ben Wheeler
Congenital rubella syndrome	January 1998	Ongoing	Dr Mavis Duncanson Professor Peter McIntyre Professor Ben Wheeler
Perinatal HIV exposure	January 1998	Ongoing	Dr Sue McAllister Ashleigh de Gouw
Serious paediatric adverse drug reactions	May 2008	Ongoing	Prof Michael Tatley Ass Prof David Reith Prof Keith Grimwood
Potential prenatal exposure to syphilis	April 2018	Ongoing	Prof Tony Walls Dr Leeyan Gilmour
Acute self-harm seen by Paediatrician	June 2020	June 30 2025	Dr Sarah Fortune Dr Gabrielle McDonald
Severe acute hepatitis	April 2022	Ongoing	Dr Helen Evans Prof Andrew Day
Vitamin D Deficient Rickets	September 2024	Ongoing	Prof. Ben Wheeler Dr. Emma McNamara

REPORTS ON ONGOING STUDIES

Acute Flaccid Paralysis

Dr Mavis Duncanson
(until March 2024)

Professor Peter McIntyre
(from March 2024)

Professor Ben Wheeler
(from December 2016)

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 consistent with those observed clinically in polio. The most common medical conditions resulting in AFP in Aotearoa are Guillain-Barré syndrome and Transverse Myelitis.

As part of the global initiative to eradicate polio, countries in the Western Pacific region of the World Health Organization (WHO) confirm the absence of poliomyelitis through active surveillance that captures an annual incidence of acute flaccid paralysis (AFP), not due to poliomyelitis, of at least one case per 100,000 children aged under 15 years. It is also a WHO expectation that at least 80% of cases of AFP have two stool samples at least 24 hours apart, within 14 days of onset, negative for wild polio virus in a WHO-accredited laboratory.

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

Key Results for 2024

There were 10 cases notified to the NZPSU with onset of AFP from 1 Jan 2024 until 30 December 2024, 2 of whom were identified only on an audit of ICD codes for transverse myelitis and Guillain Barre syndrome.

- 8 were from the North Island
- All were older than one year of age
- All but one was fully vaccinated for age against polio
- Adequate stool samples were obtained for all 8 non-audit cases (100%)
- All cases were judged to be non-polio AFP by the National Certification Committee for the Eradication of Polio (NCCEP)

The AFP rate expected by WHO in a country without endemic polio is one case of acute flaccid paralysis per 100,000 age-specific person-years, which was met for 2024. The stool sample collection is high but relies on timely notification of cases in order to arrange special testing at Public Health Forensic Science (PHF-S, formerly ESR).

Congenital Rubella Syndrome (CRS)

Dr Mavis Duncanson
(until March 2024)

Professor Peter McIntyre
(from March 2024)

Professor Ben Wheeler
(from March 2024)

Ongoing study started January 1998

There have been no cases of congenital rubella reported in newborn infants throughout the surveillance period. A notification of an historical case aged 5–9 years in 1998 remains the only case that has been reported to the NZPSU. This is consistent with elimination of congenital rubella in New Zealand.

Perinatal HIV Exposure

Dr Sue McAllister

Ashleigh de Gouw

Ongoing Study started January 1998

Study Objectives

To determine the extent and outcome of recognised perinatal exposure to HIV infection in Aotearoa.

Key Results for 2024

In 2024 there were 7 infants reported to have been born in New Zealand to women living with HIV who were diagnosed prior to or during their pregnancy. Information has been received on all of these patients.

Of these 7:

- 2 were born in Auckland, 2 in Northland, 1 in Bay of Plenty, 1 in Wellington, and 1 in Canterbury.
- All were born to mothers whose HIV had been diagnosed before their pregnancy.
- 3 of the mothers were of European ethnicity, 1 Māori, 1 African and 2 Asian
- All the mothers were given antiretroviral treatment during pregnancy; 4 gave birth by caesarean and 3 gave birth vaginally; 3 of the babies were breastfed.

None of the children are believed to have acquired HIV, although most are still awaiting confirmation.

Serious Paediatric Adverse Drug Reactions (ADR)

Professor David Reith

Professor Michael Tatley

Professor Keith Grimwood

Ongoing study started August 2007.

Study Objectives:

1. To understand serious paediatric adverse drug reactions (ADRs) in children below the age of 16 years.
2. To determine to what extent NZPSU active surveillance captures information about serious paediatric ADR's not captured by passive spontaneous reporting.

Key Results for 2024

Over the one-year period January 2024 to December 2024 there were six reports of serious ADR to the NZPSU. Since 2023, the ADR reporting previously undertaken by CARM has been taken over by Medsafe and paediatricians notifying NZPSU referred to Medsafe for further reporting details.

In the first half of 2024, the most common events were allergic reactions reported to Medsafe for children were allergic (urticaria in 24 (15.1%), anaphylactic reaction in 15 (9.4%) and angioedema in 9 (5.7%).

Potential Prenatal Exposure to Syphilis

Professor Tony Walls

Dr Leeyan Gilmour

Ongoing study commenced April 2018

Investigators:

NZPSU – Dr Leeyan Gilmore, Dr Tony Walls, Dr Emma Best

ESR/PHF-S – Putu Duff, Callum Thirkell, Dr. Julia Scott

Study Objectives:

To measure incidence of confirmed congenital syphilis and outcomes of infants exposed antenatally to syphilis.

During the 2024, worked closely with PHF-S to streamline data collection systems. Our previously separate systems combined into a single questionnaire, enabling greater collaboration between NZPSU and PHF-S

Key results for 2024:

29 infants born in 2024 met the criteria - 19 (66%) identified through NZPSU. The response rate following notification was 100% - five had findings consistent with congenital syphilis (3 microbiologically confirmed). 24 cases had antenatal exposure to syphilis but did not develop congenital syphilis on follow-up.

27/29 (93%) of cases from the North Island. Infants born to Māori women disproportionately affected.

Of the five infants with confirmed or probable congenital syphilis:

- Two had prominent clinical signs, such as hepatosplenomegaly, anaemia, jaundice/hepatitis, CNS/eye signs, pneumonitis, and skin rash. One infant died at 15 days of age.
- 1/5 had long bone changes on X-ray, and 1/5 had Treponema identified in cerebrospinal fluid (CSF), 1 had CSF changes and 2 had normal CSF; one not tested
- None of the mothers whose infants had probable or confirmed syphilis received adequate treatment.
    - One no antenatal care; two syphilis not diagnosed until delivery (1 not tested, one negative on antenatal screening prior to 3rd trimester, serology positive at delivery.
    - Two diagnosed with syphilis during pregnancy but did not receive adequate treatment.
- All probable and confirmed cases of congenital syphilis were treated appropriately.

Acute Self-Harm seen by Paediatrician


Dr Sarah Fortune


Dr Gabrielle McDonald


Linda Hobbs

Ongoing Study started June 2020

Study Objectives:

Surveillance by NZPSU contributes to 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
2) To establish and test robust data collection methods for sentinel surveillance of self-harm
3) Characterise presentations for SH or suicidal ideation by age, gender, ethnicity, methods of SH, alcohol misuse, prior history of SH, exposure to suicide, mental health assessments and discharge outcome
4) Identify patterns of repetition of non-fatal SH

Key Results for 2024

This ongoing four-year study is collecting sensitive data that will be reported on completion of the study in 2025. In 2024 there were 29 reports of self-harm seen by a paediatrician in under-15-year-olds. 27 of these were cases that were reported to the NZPSU, with the additional two reported directly to the research team. Two cases were excluded. Clinical data was not completed by the reporter for 10 cases.

Severe Acute Hepatitis

Dr Helen Evans

Professor Andrew Day

Ongoing Study started April 2022

Study 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 2024

There were 26 cases of severe acute hepatitis reported to the NZPSU in 2024. Since surveillance commenced there have been 71 cases of severe acute hepatitis notified to NZPSU. Study report not received in time for the Annual report.

Vitamin D Deficiency Rickets (VDDR)

Dr Emily McNamara

Professor Ben Wheeler
(from March 2024)

Associate Professor Craig Jefferies

Ongoing Study started September 2024

Study Objectives

1. To ascertain the incidence of vitamin D deficiency in NZ in children aged under 16 years
2. To obtain information of the demographics and clinical characteristics of Vitamin D deficiency
    a. Risk factors for development of the disease in Aotearoa
    b. Implementation of recently updated preventive strategies (i.e did cases and/or their mothers receive Vitamin D supplementation as per national guidelines)
3. To inform public health policies to prevent vitamin D deficiency rickets in Aotearoa

Key Results for 2024

- Since study commenced, 39 notifications, of which 5 were duplicates, 3 questionnaires outstanding
- Of the remaining 30, 24 are confirmed cases (1 did not meet biochemical diagnostic criteria for VDDR and the remainder diagnosed prior to study commencement).
- Of the 24 confirmed cases
    - Slightly skewed male:female distribution (14 and 10 cases respectively)
    - Mean age at diagnosis was 15 months, with range 3 months to 14 years
    - One case was born prematurely, remainder born at term.
    - Median birthweight 3.2 kg (range 1.63 – 4.39 kg)
    - Most cases from Auckland, other reporting regions Southern, Waikato and Hawkes Bay
    - All cases were born in NZ, whereas only 3 mothers of cases were born in NZ.
    - Indian ethnicity most common (33%), with other ethnicities reported including Samoan, Māori, NZ European, Chinese, Bangladeshi, Tongan, Sri Lankan, Zimbabwean and Iranian.
    - All but one had intermediate or dark skin colouring
    - Only one child was reported to have received any Vitamin D supplementation prior to diagnosis. 2 mothers Vitamin D during pregnancy, none postnatally.
    - Most common presenting symptom was limb deformity, closely followed by growth and motor delays. Other presenting symptoms included seizures, bone pain, fracture, hypotonia, respiratory illness and eczema.
    - Over two-thirds of cases had radiological signs, most both ulna and femoral epiphysis.
    - 19 inpatients, with VDDR primary reason for admission in 10. 6 required IV calcium).
    - No cases were diagnosed as a result of screening of affected siblings
    - Most cases notified in Spring months (typical pattern)

Key results

- There are still a number of at-risk children and their mothers not receiving Vitamin D supplementation as per the latest national guidelines
- Data supports existing literature with risk factors such as darker skin and migrant status of mother.

Acknowledgements

Dr Mavis Duncanson, Co-Director of NZPSU until early 2024 continues to be an Honorary Senior Research Fellow with the Department of Paediatrics and Child Health and to provide expert input into AFP surveillance. Mavis was a member of the consultation group for the NZ Public Health Surveillance Strategy 2025 in her continuing role with the College of Public Health Medicine

Ms Melanie O'Brien was Research Administrator in the Department of Paediatrics and Child Health, Dunedin School of Medicine, University of Otago from March 2023 to July 2025. In this role, Melanie took a lead role in updating the format of the Annual Report and was responsible for most of the drafting of the 2024 report before she moved to another position in the University. Her work and expertise is gratefully acknowledged.

In September 2025 **Dr Kate Sneddon** was appointed to a new position of Research Coordinator for NZPSU. Kate brings a background in Microbiology and Public Health to this role and has been responsible for finalising this year's Annual Report.

Reporting Period NZPSU Surveillance Publications

Sandy JL, Nunez C, Wheeler BJ, et al. Prevalence and characteristics of paediatric X-linked hypophosphataemia in Australia and New Zealand: Results from the Australian and the New Zealand Paediatric Surveillance Units survey. *Bone* 2024; 173:116791. https://doi.org/10.1016/j.bone.2024.116791

Taylor A, Duncanson M, Mitchelson B, Nuthall G, Voss L, Walls T, et al. Multisystem Inflammatory Syndrome in New Zealand Children. The Pediatric Infectious Disease Journal 42: e232–e234.2024. http://dx.doi.org/10.1097/INF.0000000000003933

Duncanson M, Wheeler B, McIntyre P, et al. Paediatricians in Aotearoa contribute to rare disease surveillance. Presentation at Paediatric Society of New Zealand Te Kāhui Mātai Arotamariki o Aotearoa 74th Annual Meeting; November 2024, Rotorua.

Elliott EJ, Teutsch S, Nunez C, et al. Improving knowledge of rare disorders since 1993: the Australian Paediatric Surveillance Unit. Archives of Disease in Childhood Published Online First: 13 May 2024. https://doi.org/10.1136/archdischild-2024-326116

McNamara E, Wheeler BJ, Hofman P, Grant C, Jefferies C. An upcoming prospective study on the incidence of vitamin D deficiency rickets (VDDR) in New Zealand children [poster]. Presented at: Paediatric Society of New Zaland Te Kāhui Mātai Arotamariki o Aotearoa 75th Annual Meeting; November 2024, Dunedin

APPENDIX

Introduction to NZPSU

The NZPSU was established in 1997 to facilitate and improve knowledge of rare childhood conditions in Aotearoa. 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 Aotearoa gave their support to the surveillance programme after the concept was discussed at several annual meetings of the Paediatric Society of Aotearoa. 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 certification and surveillance process to document continued elimination of polio from New Zealand the Western Pacific and ultimately global eradication. Another seven conditions were under surveillance in 2024.

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

Aims

The aim of the NZPSU is:

> 'To conduct surveillance for acute flaccid paralysis in children less than 15 years of age and facilitate national surveillance to improve knowledge of other important rare childhood conditions.'

The NZPSU maintains a database of paediatricians in Aotearoa and audits it against publicly available data regarding specialist registration in paediatrics with Te Kaunihera Rata o Aotearoa (the Medical Council of New Zealand). There are participating paediatricians in every district of Te Whatu Ora and 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. This survey is sent out every 8 days to those who have not completed the questionnaire. Cases of AFP are required to be reported immediately by phone or email to the NZPSU.

When a case is reported to NZPSU, the principal investigator for the specific study is advised and seeks further clinical information from the reporting clinician 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. The process used by the

NZPSU, and the conditions under surveillance, have been approved by the Health and Disability Ethics Committee OTA/95/10/113.

Study selection

A Scientific Review Panel (SRP) considers applications for new conditions to be added into the programme. There were no applications for new studies in 2024.

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 more common conditions on a short term or geographically limited basis. The SRP considers the scientific interest and public health importance of the proposed study, methodology, and suitability of the condition for ascertainment through NZPSU. The current SRP members are listed in Table 2.

Table 2. Members of the NZPSU Scientific Review Panel (September 2025).

Name	Institution
Professor Peter McIntyre (Chair)	University of Otago (Dunedin)
Professor Ben Wheeler	University of Otago (Dunedin) / Te Whatu Ora (Southern)
Dr Mavis Duncanson	University of Otago (Dunedin)
Dr Emma Heydon	University of Otago (Dunedin) / Te Whatu Ora (Southern)
Dr Erik Andersen	University of Otago (Wellington) / Te Whatu Ora (Capital and Coast)
Professor Tony Walls	University of Otago (Christchurch)
Bex Joslin	Ministry of Health
Dr Alexandra Wallace	University of Auckland / Te Whatu Ora (Waikato)
Professor Cameron Grant	Starship General Paediatrics and University of Auckland
Dr Danny de Lore	University of Auckland / Te Whatu Ora (Lakes)
Dr Gergely Toldi	Starship Neonatal and University of Auckland
Dr Anne Morris	Australian Paediatric Surveillance Unit
Professor Elizabeth Elliott	Australian Paediatric Surveillance Unit

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.

ALL 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. Wong, W. Shiga Toxin Producing Escherichia coli Infections and Associated Haemolytic Uraemic Syndrome in New Zealand Children: Twenty Three Years of Epidemiology and Clinical Observations. International Journal of Pediatric Research. **https://doi.org/10.23937/2469-5769/1510085** Wong, W., Prestidge, C., Dickens, A. and Ronaldson, J. Diarrhoea-associated haemolytic uraemic syndrome and Shiga toxin-producing Escherichia coli infections in New Zealand children: Clinical features and short-term complications from a 23-year cohort study. Journal of Paediatrics and Child Health. **https://doi.org/10.1111/jpc.16332**
Congenital Rubella Syndrome	1998 ongoing	No cases
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	Discontinued
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.
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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 New Zealand. Presentation at Paediatric Society of New Zealand 72nd Virtual Conference (replacing 72nd Annual Scientific Meeting) November 2021.
Multisystem inflammatory syndrome associated with COVID-19	2021 - 2024	Taylor A, Duncanson M, Mitchelson B, Nuthall G, Voss L, Walls T, et al. Multisystem Inflammatory Syndrome in New Zealand Children. The Pediatric Infectious Disease Journal 42(7): e232–e234.2024. **http://dx.doi.org/10.1097/INF.0000000000003933**
X-linked hypophosphataemic rickets	2020	Sandy JL, Nunez C, Wheeler BJ, et al. Prevalence and characteristics of paediatric X-linked hypophosphataemia in Australia and New Zealand: Results from the Australian and the New Zealand Paediatric Surveillance Units survey. *Bone* 2024;173:116791. https://doi.org/10.1016/j.bone.2024.116791

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.

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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

Duncanson M, Wheeler B, McIntyre P, et al. Paediatricians in Aotearoa contribute to rare disease surveillance. Presentation at Paediatric Society of New Zealand Te Kāhui Mātai Arotamariki o Aotearoa 74th Annual Meeting; November 2024, Rotorua.

Elliott EJ, Teutsch S, Nunez C, et al. Improving knowledge of rare disorders since 1993: the Australian Paediatric Surveillance Unit. Archives of Disease in Childhood Published Online First: 13 May 2024. https://doi.org/10.1136/archdischild-2024-326116

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 eleven 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 regular scientific meetings since 2000. The most recent meeting was held virtually in 2021. Members communicate regularly with each other and in recent years there has been increasing collaboration in developing surveillance studies.

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 10 surveillance units that form the INoPSU network (Table 5). Services of the Netherlands Paediatric Surveillance Unit have been suspended since 1 January 2020.

***Table 4:* Members of the International Network of Paediatric Surveillance Units**

Country	Acronym	Email	Website
Aotearoa	NZPSU	nzpsu@otago.ac.nz	www.otago.ac.nz/nzpsu
Australia	APSU	SCHN-APSU@health.nsw.gov.au	www.apsu.org.au
Belgium	PediSurv	pedisurv@sciensano.be	https://www.sciensano.be/en/projects/network-pediatric-infectious-disease-surveillance
Canada	CPSP	cpsp@cps.ca	https://cpsp.cps.ca/
Germany	ESPED	esped@uni-mainz.de.	https://www.unimedizin-mainz.de/esped/home/
Ireland	IPSU	robert.cunney@hse.ie	https://www.inopsu.com/
Netherlands	NVK	nvk@nvk.nl	www.nvk.nl/onderzoek/nsck
Switzerland	SPSU	spsu@bag.admin.ch	https://www.spsu.ch/en/home
UK	BPSU	bpsu@rcpch.ac.uk	https://www.rcpch.ac.uk/work-we-do/british-paediatric-surveillance-unit
Wales	WPSU	enquiries@welshpaediatrics.org.uk	https://www.welshpaediatrics.org.uk/

Special thanks to all the paediatricians who contribute every month to Aotearoa New Zealand's Paediatric Surveillance Unit.

Your contribution is valued and appreciated.

Ngā mihi nui ki a koutou!