The Paediatric Society of New Zealand

New Zealand Paediatric Surveillance Unit

ANNUAL REPORT 2018-2019

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

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Te Hunga Aroturuki Mate Tamariki

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PREFACE: NEW ZEALAND PAEDIATRIC SURVEILLANCE UNIT

Welcome to the 2018 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 surveillance for acute flaccid paralysis for 18 months from 1 January 2018 to 30 June 2019. Subsequent reports will be for a July to June year.

The opportunity was taken for the study of other uncommon high impact conditions, most of which has been undertaken by paediatricians with a particular research interest. Reports for these studies cover the 2018 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 would like to acknowledge the ongoing funding from the Ministry of Health/*Manatū Hauora.*

Associate Professor Ben Wheeler

Amanda Phillips

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 is used by some other specialist groups.

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 has been six conditions under surveillance in 2018.

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.

Paediatricians in New Zealand gave their support to the surveillance system after the concept was discussed at several annual meetings of the Paediatric Society of New Zealand. A database of eligible clinicians, which included all paediatricians and other specialists working predominantly with children, was developed using the specialist register and the membership list of the Paediatric Society. All eligible clinicians were contacted and invited to participate. Study protocols, which included definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number are all available on the web: www.otago.ac.nz/nzpsu

Efforts are made to keep up-to-date with the paediatric specialist work force using information received from the Medical Council of New Zealand.

Every month participants are sent either an email on RedCap or a reply-paid card (depending on their preferred method of reporting) 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 in most cases remains anonymous. The child's NHI is used only to identify duplicate notifications but not linked to other health data.

How the Surveillance System Works

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

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

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

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

Due to personal changes a new Scientific Review Panel is being established.

SURVEILLANCE ACTIVITIES FROM JANUARY 2018 to JUNE 2019

In 2018/2019, 265 clinicians participated in the system. The average response rate to the monthly report card/email was 84%. The response rate from the whole of the country is pleasing. Minimising the extra workload that the system imposes on paediatricians is a key factor for its success. Table 1 shows the percentage of clinicians on the mailing list that reported between 2017 /2018- June, 2019. The conditions under surveillance are uncommon, and unlikely to impose an undue workload on individual clinicians.

In 2018 – June 2019, the NZPSU monitored seven uncommon childhood conditions (Table 1). Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit.

Table 1: **Respondents' Workload 2017- 2018 - June 2019**

Notifications	2017		2018		2019	
	Number	%	Number	%	Number	%
None	202	84.2	233	88.00	234	88.3
One	30	12.5	25	9.4	24	9.05
2-4	8	3.3	5	1.8	7	2.64
5 or more	0	0	2	0.75	0	0

Table 2: **Conditions under surveillance in 2018- June 2019**

Condition	Surveillance Started	Surveillance Ending	Principal Investigators
Acute flaccid paralysis	October 1997	Ongoing	Dr Mavis Duncanson
Haemolytic uraemic syndrome	January 1998	Ongoing	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
Possible congenital Zika Syndrome and/or severe microcephaly	July 2018	July 2019	Dr Mavis Duncanson
Potential prenatal exposure to syphilis (positive maternal serology)	August 2018	August 2020	Associate Professor Tony Walls

BRIEF REPORTS ON ONGOING STUDIES

Acute Flaccid Paralysis

Dr Mavis Duncanson
Ongoing study started in January 1998

Introduction

Acute flaccid paralysis is used as a term for a number of different conditions characterized by paralysis, including Guillain-Barré syndrome and polio. Acute flaccid paralysis is characterized 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 for 2018- June 2019

- There were 13 cases notified to the NZPSU from January 2018 until June 2019.
- Information has been obtained on all of these children including follow-up information two months after diagnosis.
- Eleven were from the North Island, two were from the South Island.
- Seven females, six males.
- Age range 4 years to 13 years
- No seasonal variation.
- The overall incidence was 0.92 cases per 100,000 children aged < 15 years.
- All thirteen 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 <14 days after onset paralysis, was complete for nine of the 13 children (69.2 %) (see Table 3)

***Table 3*: Percentage of AFP cases with adequate (or otherwise) stool samples: *January* 2018 - June 2019**

Category	Stool samples	
	No.	%
2 stool samples within 14 days of onset of paralysis	9	69.23
2 stool samples, but one or both not within 14 days of onset of paralysis	2	15.4
1 stool sample	0	0
No stool samples	2	15.4

These findings have been notified to the World Health Organization to fulfill New Zealand's obligation to contribute to the certification of the eradication of polio by reporting 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 2018, but not in the first six months of 2019. The rate of stool testing 69 % was below the WHO target of 80%.

To address both notification rate and stool reporting rate, we have developed a clinical relationship with the Starship Children's hospital, the main tertiary centre where the majority of cases are treated in New Zealand. We thank the team at Starship Hospital, and in particular the Neurology Nurse Specialist, Barbara Woods, who provides leadership in ensuring, where possible, all cases are notified. We appreciate that this surveillance requirement is a challenge, in the absence of endemic polio. We wish to thank the paediatricians for vigilance in obtaining timely testing in most instances.

Stool specimens are generally not clinically indicated in cases of acute flaccid paralysis (the collection of stool specimens is primarily for surveillance purposes). Very often these children require transfer from a regional to a tertiary level centre with some urgency and stool samples are not taken. We understand that the collection of stools is not a clinical priority with these children who are often very ill. The nature of the conditions these children have means that passage of stool can be infrequent.

At the request of the Ministry of Health/Manatū Hauora, we will 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.

The emergence of polio in Papua New Guinea from June 2018 marked the end of an 18-year period when polio was thought to be eradicated in the WHO Western Pacific Region. This emergence of new infection highlights the importance of ongoing surveillance of AFP in the wider region. Paediatricians and other child health clinicians are reminded that the NZCYES requires immediate telephone notification 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 in January 1998

Key Results for 2018

- 16 cases of childhood HUS reported, 14 had a diarrhoeal prodrome (D+), 13/16 had E coli 0157H7 identified
- 2 children had no diarrhoea prodrome, (1 had a C3 gene mutation, I streptococcus pneumoniae)
- Median age at presentation of D(+) HUS was 5.2 years (range 1.1-14)
- 4/14 diarrhoeal cases had been in contact or lived on a farm within the past 2 weeks before presentation, this included swimming in a rural river, and possible flood runoff
- 2/14 had consumed unpasteurised milk
- Median time to diagnosis of HUS was 6 days (range 3-14)
- 8/14 in the diarrhoeal group received acute dialysis and all recovered renal function to discontinue dialysis

Potential Prenatal Exposure to Syphilis

Associate Professor Tony Walls
Study started August 2017

Key Results for 2018

In 2018, there were nine reports to the NZPSU of infants born in New Zealand with potential prenatal exposure to syphilis.

- Of the nine infants born in New Zealand in 2018:
    - 3 were born in Auckland, 2 in Hamilton, and 1 each in Rotorua, Tauranga, Whakatane and Wellington
- Further information on eight of the infants was able to be obtained, revealing:
    - 4 of the mothers were of Maori ethnicity, 2 NZ European, 1 Chinese and 1 Pacific Islander
    - 2 were born to mothers with primary syphilis, 2 mothers were in the early latent stage, 1 previously treated, 1 in secondary stage, and 2 had infection of unknown duration
    - 6 of the mothers were treated with penicillin during pregnancy
    - 2 of the infants were symptomatic at birth and diagnosed and treated for congenital syphilis

Congenital Rubella Syndrome (CRS)

Ongoing study started January 1998
There were no reported cases in 2018.

Possible Congenital Zika Syndrome and/or severe microcephaly

Dr Mavis Duncanson
Two year study commenced 2017
There were no reported cases in 2018

Perinatal HIV Exposure

Dr Sue McAllister and Dr Lesley Voss
Ongoing Study

Key Results for 2018

In 2018, there were six infants/children 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 the infants.

Of these six:

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

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

Serious Paediatric Adverse Drug Reactions (ADR)

Dr Desiree Kunac, Dr Michael Tatley, Associate Professor David Reith, Professor Keith Grimwood
Study commenced August 2007.

Key Results for 2018

There were nine notifications made during 2018, but one was made in error and for three notifications, no further details were provided. This resulted in a total of 5 reports received which are summarised in the table below.

Of the five reports, three are new reports that were not previously notified to the Centre for Adverse Reactions Monitoring (CARM) and resulted in a medical danger or warning being entered for the child in the national Medical Warning System. All three new reports are now included in the CARM database to further enhance our understanding of serious ADR's in children.

Suspect Medicine	Reaction(s)	Age (Years)	Sex	Seriousness/Outcome	Medical Warning	CARM
Amoxicillin* greater than 3 months duration	Hepatic enzymes increased	7	M	Medically significant/not yet recovered but improved at time of report	Warning	No
Cephazolin	Anaphylactic reaction	9	F	Life threatening / recovered	Danger	No
Infliximab	Systemic Lupus (TNF inhibitor induced)	15	F	Medically significant/not yet recovered but improved at time of report	Warning	No
Ceftriaxone	Angioedema Erythematous rash Vomiting	2	F	Medically significant/not yet recovered but improved at time of report	Warning	Yes
Adalimumab	Left inflammatory neck mass Lymphadenopathy	12	M	Hospitalised/improved on discontinuation		Yes

Table 4: Information on the 5 reports of Serious Adverse Drug Reactions (ADR) notified through NZPSU in 2018. 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 Monitoring (CARM).

Condition	Report Period	Findings Reported
Acute Flaccid Paralysis	1997 - ongoing	Dow, N., Dickson, N. & Taylor, B. J. 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
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, B. A., Voss, L., Lennon, D. R., & 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, A. M., & Marks, R. E. 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, B. J. (2005). Prospective incidence study of diabetes mellitus in New Zealand children aged 0 to 14 years. Diabetologia, *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. Doctoral dissertation. 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 (Online), 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-Dennis, M., 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, N. J., 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. (2011). 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, D. R., Crone, S., Neutze, J. M., & Reed, P. W. 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, D. R., & 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, B. J., Dickson, N. P., Houghton, L. A., Ward, L. M., & Taylor, B. J. 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, S. C. H., 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): 1078-1083.
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, and Best, E. (2018). Nationwide surveillance of paediatric empyema in New Zealand 2014–2016. Presentation at Australasian Society of Infectious Diseases Annual Scientific Meeting, Leura NSW, March 2018

Grenier, D., Ugnat, A. M., McCourt, C., Scott, J., Thibodeau, M. L., Davis, M., & Dickson, N. Can active surveillance provide a rapid response to an emerging child health issue? The melamine example. Journal of Paediatrics & Child Health, 2009;14(5), 285-286.

Grenier, D., Elliott, E. J., Zurynski, Y., Pereira, R. R., Preece, M., Lynn, R., & Virella, D. Beyond counting cases: public health impacts of national Paediatric Surveillance Units. Archives of Disease in Childhood, 2007; 92(6), 527-533.

Maeusezahl M, Lynn R, Zurynski Y, Moore Hepburn C, Duncanson M & Rudin C (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

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

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.

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	npersianis@cytanet.com.cy	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.