The Paediatric Society of New Zealand

New Zealand Paediatric Surveillance Unit

ANNUAL REPORT 2020-2021

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

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

The Ministry of Health *Manatū Hauora* funds the NZPSU to undertake surveillance of acute flaccid paralysis for the National Certification Committee for the Eradication of Poliomyelitis (NCCEP), as part of the Global Polio Eradication Initiative led by national governments in association with the World Health Organization and other partners. We acknowledge and appreciate this funding.

This report covers acute flaccid paralysis (AFP) surveillance from 1 July 2020 to 30 June 2021.

The pattern of monthly active surveillance of paediatricians provides an opportunity to study additional rare childhood conditions at a national level. These rare conditions are included alongside AFP on the report card These additional studies are undertaken by paediatricians with a particular clinical research interest, or by NZPSU staff at the request of the Ministry of Health. Unless otherwise stated, reports for these additional studies cover the 2020 calendar year.

New Zealand paediatricians take time each month to respond to the report cards and provide information on the conditions under surveillance. This has been particularly challenging during the COVID-19 pandemic, and we thank all participants for their assistance in this work.

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

Associate Professor Ben Wheeler

Ella Williams

Dr Mavis Duncanson

INTRODUCTION

The New Zealand Paediatric Surveillance Unit (NZPSU) was set up in 1997 to facilitate and improve the knowledge of rare childhood conditions in Aotearoa. These conditions need case ascertainment on a national basis, often over two or more years, to provide enough cases for meaningful analysis. The conditions occur uncommonly, with few cases in the community.

The surveillance method was developed in the United Kingdom by the British Paediatric Surveillance Unit (BPSU) and has been used there since 1986. Other countries, including Australia and Canada, use a similar process.

All paediatricians practising in Aotearoa are eligible to participate in the surveillance programme. The NZPSU maintains contact with the Royal Australasian College of Physicians Division of Paediatrics and Child Health

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). This surveillance contributes to the global polio eradication initiative, overseen by the World Health Organization, and confirms ongoing absence of polio in Aotearoa. There were nine additional conditions under surveillance in the 2020/21 financial year.

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 eligible clinicians, including all 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 cases of the conditions under surveillance. Cases of AFP are required to be reported immediately by phone to the NZPSU.

When a case of any of the conditions is reported, the reporting clinician is sent a short questionnaire to complete on the case. The identity of the cases remains anonymous. The child's NHI is used only to identify duplicate notifications but not linked to other health data.

Study protocols, which include definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number are all available on the NZPSU website www.otago.ac.nz/nzpsu

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	Ministry of Health
Professor Elizabeth Elliott	University of Sydney
Dr Emma Best	University of Auckland

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

SURVEILLANCE ACTIVITIES FROM JULY 2020 to JUNE 2021

In 2020/21 there were around 260 clinicians participating in the surveillance programme, with an average monthly response rate of 70% (Table 2).

Table 2. Conditions under surveillance 1 July 2020 - 30 June 2021, NZ Paediatric Surveillance Unit

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

REPORTS ON ONGOING STUDIES

Acute Flaccid Paralysis

Dr Mavis Duncanson
Ongoing study started January 1998

Introduction

Acute flaccid paralysis (AFP) is a clinical description of sudden onset of muscle weakness without any spasticity or rigidity. The most common medical conditions resulting in AFP are Guillain-Barré syndrome and Transverse Myelitis. Active surveillance Polio presents with acute limb weakness and surveillance rm for a number of different conditions characterised by paralysis, including Guillain-Barré syndrome and polio. Acute flaccid paralysis is characterised clinically by the acute onset of flaccid limb weakness.

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

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

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

Key Results July 2020- June 2021

There were 10 cases notified to the NZPSU from July 2020 until June 2021.
Case reports were obtained for all of these children

- Nine were from the North Island
- Five females, five males.
- Age range 2 years to 13 years
- Possible seasonal variation: Seven cases in July–December and three cases January–June .
- The overall incidence was 1.03 cases per 100,000 children aged under 15 years.
- All 10 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 two samples at least 24 hours apart less than 14 days after onset of paralysis, was complete for 7 of the 10 children (70%) (see Table 3)

Table 3. Acute flaccid paralysis cases with adequate (or otherwise) stool samples: July 2020–June 2021

Category	Stool samples	
	No.	%
2 stool samples within 14 days of onset of paralysis	7	70
2 stool samples, but one or both not within 14 days of onset of paralysis		
1 stool sample		
No stool samples	3	30

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

The rate expected by WHO in a country without endemic polio (1 case of acute flaccid paralysis per 100,000 age-specific person-years) was reached in 2020/21. The rate of stool testing (70%) almost met the WHO target of 80%.

Most cases of acute flaccid paralysis in Aotearoa are treated at Starship Children's Hospital in Auckland (Starship). Through clinical relationships with Neurology Nurse Specialist at Starship, Erin Skidmore, the NZPSU has been able to improve both notification rate and stool reporting rate for these cases. Erin's leadership is greatly appreciated.

Throughout Aotearoa the NZPSU appreciates the vigilance and commitment shown by paediatricians in reporting cases and obtaining timely stool testing. The ESR laboratory has advised that where a stool sample cannot be obtained , then a rectal swab can be used for testing.

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 2020

In 2020 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:

- Eight were born in Auckland, 1 in Hamilton, 2 in Wellington, 1 in Christchurch, and 1 in another part of New Zealand.
- Eleven were born to mothers whose HIV had been diagnosed before their pregnancy, and two were diagnosed during their pregnancy.
- Three of the mothers were of European ethnicity, 4 African, 3 Asian, and 3 Pacific Island.
- Thirteen of the mothers were given antiretroviral treatment during pregnancy; 3 gave birth by caesarean section and 10 gave birth vaginally; one of the babies was breastfed.
- None of the children are believed to be infected with HIV (although most are still awaiting confirmation).

Serious Paediatric Adverse Drug Reactions (ADR)

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

Objectives

1) To gain a greater understanding of serious paediatric adverse drug reactions (ADRs) 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 ADRs 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 2020

There were 13 notifications made during 2020; two were made in error and for 7 notifications no follow up report was received. This is likely attributed to the disruption caused by the COVID-19 pandemic. From 2021, the NZPSU has changed its notification procedure to include the child's National Health Index (NHI) number to facilitate tracking of cases which should increase the number of reports received.
Four reports were received during 2020, however, two reports did not meet the case definition (one case aged 17 years and one an accidental ingestion) so were excluded from this study but have been included in the CARM database. The remaining two reports included in the study are summarised below in Table 4.
One was a new report not previously notified to the Centre for Adverse Reactions Monitoring (CARM). Both cases resulted in a medical warning being entered for the child in the national Medical Warning System. These two reports are included in the CARM database to further enhance our understanding of serious ADRs in children.

Table 4. Information on the two reports of Serious Paediatric Adverse Drug Reactions (ADR) notified through NZPSU in 2020. 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(s)	Reaction(s)	Age	Sex	Seriousness/ outcome	Medical warning	CARM
acetylcysteine	unconsciousness hypertension bradycardia stridor anaphylactoid reaction	14 years	F	Hospitalised / recovered	Warning	Yes
lamotrigine	macular rash skin exfoliation	12 years	M	Medically significant / not yet recovered at time of report	Warning	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

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

Introduction

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:

- 50 cases were notified during the 40 month study period. 48 were newborns, one was notified at 17 months of age, and one at 23 months of age.
- Of these 50 cases, 17 infants had findings consistent with congenital syphilis, with 7 confirmed cases and 10 probable cases.
- 1 infant was born in 2017, 13 in 2018, 11 in 2019, 19 in 2020 and 6 in 2021 thus far.
- All but one of the cases arose from the North Island of New Zealand, with 12 cases notified from Counties Manukau DHB, 5 from Waitemata and Tairawhiti DHBs, and 1-3 cases from each of the other District Health Boards.
- 26 of the mothers were of Māori descent, 12 of Pacific Peoples (4 Samoan, 4 Tongan, 1 Niuean, 2 Fijian and 1 Fijian Indian), 10 NZ European, and 2 of Asian ethnicity.
- Of the 17 infants with confirmed or probable congenital syphilis:
    - 6 were born to women who did not receive antenatal care, with the antenatal care status of a further 2 infants being unknown.
    - 4 infants were born to women who had negative first semester serology testing
    - 12 had clinical signs, which included syphilis skin rash, jaundice/hepatitis, CNS/eye signs, hepatosplenomegaly, anaemia, thrombocytopaenia, pseudoparalysis, and nephrotic syndrome/malnutrition. 1 infant was severely affected with hydrops foetalis, ascites and oedema, and died at 2 days of age. 1 infant was extremely premature (born at 24 weeks gestation), and also died at 2 days of age, and 1 infant was stillborn.
    - 11 had long bone changes visible on x-ray
    - 8 had CSF findings (elevated WCC, protein, and/or reactive VDRL)
    - 3 had infant:maternal (at delivery) non-treponemal titres of 4x or greater
    - 3 had positive tissue samples
    - 13 were born to mothers who were not treated for syphilis during pregnancy, 3 were born to mothers who were treated but were not tested or who had inadequate serological response to treatment, and 1 was born to a mother where it was unknown if she received treatment during pregnancy.
    - All of the probable and confirmed cases were treated appropriately with penicillin.

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

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

There was one case of hospitalised SARS-CoV-2 infection in a child aged under 15 years reported by a paediatrician in Aotearoa in 2020.

Congenital cytomegalovirus (cCMV)

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

Introduction

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 2020

- The study received 25 notifications from clinicians in New Zealand from the period of October 2020 to August 2021. Surveys were sent to notifying clinicians via a unique electronic survey link. 19 surveys were initiated and 18 completed.
- Using total response ethnicity methodology, the following ethnicities were recorded:
    - 5 Māori, 2 Pacific Islander, 12 NZ European, 1 Indian, 2 other.
        - *NB: responses allowed for more than one category*
- Gender: 9 male, 9 female

Timing of diagnosis
- 11 cases were diagnosed < 28 days postnatally
- 3 diagnoses of cCMV were made antenatally (range 20-40 weeks gestation)
- 7 cases were diagnosed > 28 days postnatally

Clinical features described

7 small for gestational age, 3 microcephaly, 5 sensorineural deafness (4/5 bilateral), 1 cataract, 2 chorioretinitis, 6 thrombocytopenia, 5 petechiae, 4 hepatitis, 5 jaundice, 1 pneumonitis, 1 developmental delay

Laboratory investigations
- 15 infants had Urine CMV PCR performed (15/15 positive)
    - 3 tests performed beyond first 21 days of life
- 9 infants had CMV PCR on blood (9/9 positive)
- 7 infants had Guthrie blood spot CMV PCR (6/7 positive)

Imaging
- 17/18 cases underwent neuroimaging, one missing imaging dataset
    - 13 MRI brain, 7 reported with changes consistent with cCMV

Treatment
- 7 infants received antiviral treatment (valganciclovir)
- No maternal antiviral treatment was reported.

This study is ongoing, and recruitment is expected to conclude May 2022.

Acute self-harm seen by paediatrician

Dr Sarah Fortune
Ongoing Study started June 2020

This study will be reported in 2022 when the first full year of data is available

FINAL REPORTS

X-Linked Hypophosphataemic Rickets (XLH) –

Assoc. Prof. Ben Wheeler, Dr Craig Jefferies, Dr S. Aum, Dr C. Munns

Study start date: August 2020
Study finished: November 2020

This study was conducted for 4 months from August 2020 – November 2020 inclusive. We are in the process of collecting final reports to begin analysis.

Study aim:

To investigate the prevalence and the characteristics of X-Linked Hypophosphataemic Rickets (XLH) in New Zealand (NZ).

Key Results:

At study conclusion, there were 18 notifications to the NZPSU of infants/children with VDDR. Of these:

- 16 - confirmed cases / 2 – Missing data
- The median age currently and at diagnosis was 8.7 years and 0.4 years, respectively. The majority of cases were female (n=10; 67%) and 57% were NZ European.
- Overall, the estimated prevalence of XLH in children <18 years was 1.6/100,000 (95%CI 0.97 – 2.58).
- Bowing of legs (71%) and short stature (67%) were the most common presenting features
- The most common significant complications related to therapy were hyperparathyroidism (53%) and nephrocalcinosis (33%).
- The use of phosphate supplementation and vitamin D analogs (conventional treatment) were present among all reported cases.
- No cases received burosumab.
- Health professionals involved in the care of XLH included: Paediatrician (86%); paediatric endocrinologist (29%); orthopaedic surgeon (57%); dentist (57%); physiotherapist (29%); occupational therapist (14%); physician (14%); and psychologist (7%).

Conclusions:

XLH is an uncommon childhood disorder with common medical, orthopaedic and dental complications. To ensure optimal management, there is a need to raise awareness of this condition among paediatric teams in NZ (and likely worldwide) with a focus on therapeutic options, potential complications, and the importance of multidisciplinary care.

Haemolytic Uraemic Syndrome (HUS)

Dr William Wong
Study started January 1998, concluded December 2020

Key Results for 2020

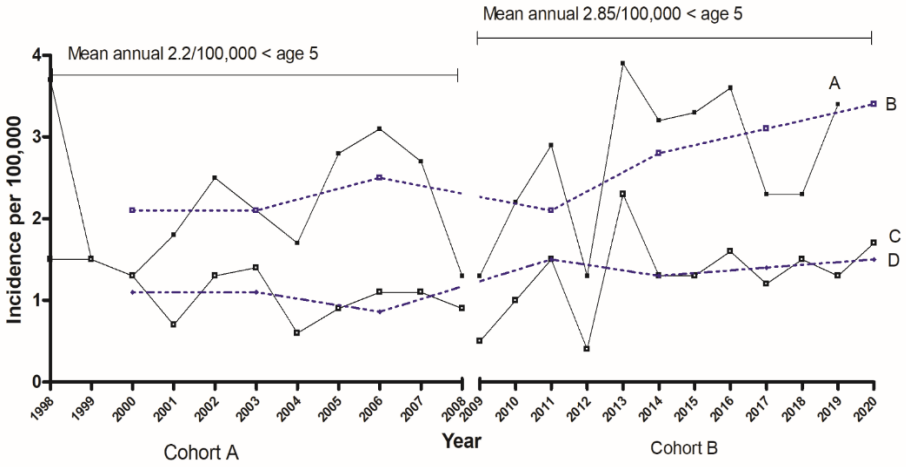
- 17 cases of childhood HUS reported, 16 had a diarrhoeal prodrome (D+), 12 E coli Shiga toxin identified.
- 1 child had no diarrhoea prodrome, had streptococcus pneumoniae associated HUS, dialysed for 17 days.
- Median/mean age at presentation of D(+) HUS was 1.5(3.2)years (range 0.7-10.8)
- 7/16 diarrhoeal cases had been in contact or lives on a farm within the past 2 weeks before presentation
- Median time to diagnosis of HUS was 5 days (range 2-12)
- 3/16 D+ group received acute dialysis and all recover renal function to discontinue dialysis. This is one of the lowest dialysis rates during the entire surveillance period

Summary for HUS surveillance 1998-2020

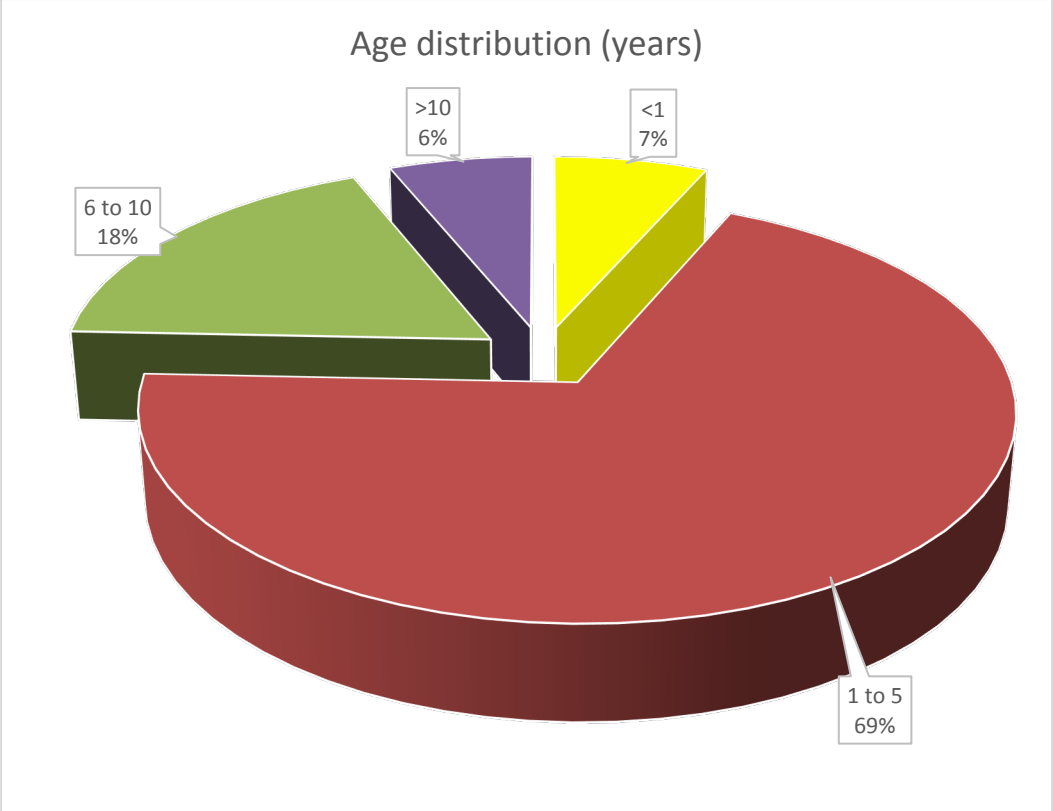
Key points

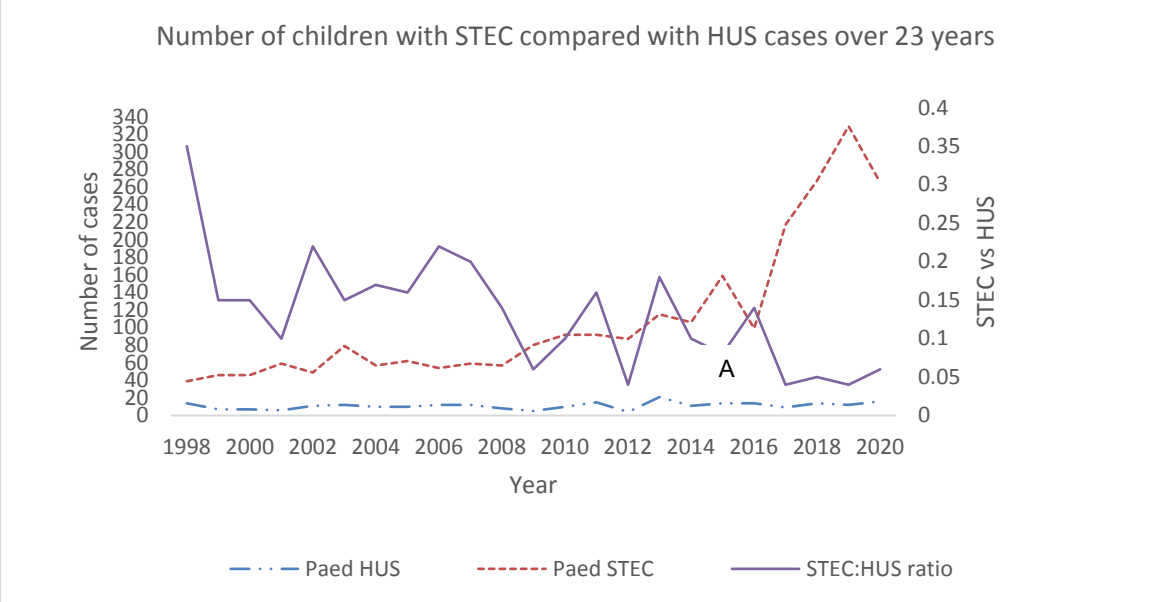
- 274 cases of HUS notified in the 23-year period.
- 226 with diarrhoeal prodrome
- 25 -Streptococcus pneumoniae HUS
- 10 – complement gene mutations/autoantibodies
- 12 – other infections – (Influenza B -1, B. pertussis-1)
- 1 - ADAMTS-13 autoantibody resulting in thrombotic thrombocytopenic purpura

Annual and mean incidence of HUS in two age groups over the study period 1998 to 2008 and 2009 to 2020



Solid lines shows annual incidence, broken lines three yearly averaged incidence in age group <5 years-lines A,B; < 15 years- lines C,D





A = Introduction of molecular testing for Shiga toxin. Paed=paediatric, HUS=haemolytic uraemic syndrome, STEC=Shiga toxin producing Escherichia coli
Source: Institute of Environmental Scientific Research New Zealand
https://surv.esr.cri.nz/episurv/index.php (used with permission)

Clinical features of children with diarrhoea related haemolytic uraemic syndrome 1998-2020

Number of children 226

- Mean age presentation (years) (±SEM) 3.8±0.3
- E coli 0157:H7 detected 130
- Mean prodrome duration(days) 6.4

- Bloody diarrhoea 168 (74.3%)

- Seizures 27 (11.9%)

- Jaundice 34(15%)
- Acute hypertension 71 (31.4%)
- Number anuric 108 (47.7%)
    - Mean anuria duration (days) 6.1
- Number dialysed 128 (56.6%)
    - Mean duration of dialysis 10.2

Outcomes

1) 3 deaths, all secondary to severe intra-cerebral injury/haemorrhage
2) 1 end stage renal failure at age 16
3) Chronic kidney disease following STEC-HUS (hypertension, reduced glomerular filtration rate, proteinuria or combinations thereof – approximately 15-20% of entire cohort – this is an on-going study
4) 3 patients developed severe colonic necrosis with subsequent bowel obstruction requiring bowel resection
5) Increasing numbers of STEC infections in the community over the past 20 years due in part to better detection methods and increased exposure
6) Emergence of E coli non O157 serotypes over the past 10 years

NZPSU SURVEILLANCE STUDIES and PUBLICATIONS

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	1998–2020	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.
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.
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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, et al. Paediatric eosinophilic oesophagitis in New Zealand: A 3-year prospective study. Journal of Paediatrics and Child Health. 2021;57(2):234-8.
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

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) was established in 1998 as a collaborative organisation, bringing together members from several countries around the world. More than 10,000 clinicians contribute and over 300 conditions have been studied so far.

In 2011, INOPSU was accepted for membership of the International Paediatric Association (IPA).

INoPSU has held ten scientific meetings since 2000 and members communicate regularly with each other. 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 12 surveillance units that form the INoPSU network (Table 5).

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	No information	
Greece and Cyprus	GCPSU	xhatzi@med.uth.gr	
Irish	IPSU	robert.cunney@hse.ie	
Netherlands	NSCK	nsck@nvk.nl	www.nvk.nl/onderzoek/nsck
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.