Table of Contents

Preface	**2**
Introduction	**3**
Key Events in 2009	**3**
Aims	**4**
How the surveillance system works	**4**
Inclusion of new conditions	**5**
Surveillance activities in 2009	**6**
Brief reports on ongoing studies	**8**
List of all conditions ever monitored by NZPSU	**17**
Publications	**18**
Some other uses of NZPSU study findings	**19**
International Network of Paediatric Surveillance Units	**20**
List of clinicians with 100% return rate and Prizewinner	**24**

Preface

Welcome to the 2009 Annual Report of the New Zealand Paediatric Surveillance Unit (NZPSU).

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

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.

New Zealand Paediatric Surveillance Unit
c/- Department of Women's & Children's Health
Dunedin School of Medicine
PO Box 913
Dunedin 9054

phone: +64 3 474 7825
e-mail: nzpsu@otago.ac.nz
website: www.otago.ac.nz/nzpsu

Barry Taylor

Nigel Dickson

Amanda Phillips

Introduction

The aim of the NZPSU is to facilitate and improve the knowledge of uncommon high-impact childhood conditions in New Zealand. These conditions are 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 to provide active surveillance of acute flaccid paralysis (AFP). The World Health Organisation (WHO), as part of the global eradication process, requires such surveillance to confirm New Zealand is free of poliomyelitis. Since the establishment of the NZPSU, the number of conditions under surveillance has increased and in 2009 includes eight high-impact childhood conditions.

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

Key Event in 2009
National Poliomyelitis Response Plan for New Zealand

NZPSU staff were involved in the development of a National Poliomyelitis Response Plan produced by the National Certification Committee for the Eradication of Poliomyelitis, the committee that reviews all AFP notifications.

The recent importation of wild poliovirus into Europe and outbreaks in Tajikstan and the Russian Federation serve as a reminder that such a plan is required here. In addition, maintaining high immunisation rates and surveillance are needed to minimise the risk of ongoing spread if a case occurs in New Zealand.

http://www.moh.govt.nz/moh.nsf/indexmh/national-poliomyelitis-response-nz-may09

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

How the Surveillance System Works

The method of surveillance is based on that developed in the United Kingdom in 1986 by the British Paediatric Surveillance Unit (BPSU).

It has subsequently been used for the monitoring of rare childhood conditions in several other countries, including Australia, and also by other specialist groups.

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. Those who agreed were provided with study protocols, which included definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number. Efforts are made to keep up-to-date with the paediatric specialist work force.

Every month participants are sent either a reply-paid card or an email (depending on their preferred method of reporting) to report whether in the previous month they have seen any cases of the conditions under surveillance. However, 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. Duplicate notification is recognised by a code derived from the child's initials and date of birth.

Where possible, cases are regularly compared with other data sources such as hospital discharge data, notifications to the local Medical Officer of Health, and the New Zealand AIDS Epidemiology Group.

It is envisaged that some of the conditions under surveillance will be ongoing, while others will be for a finite period, usually two or three years.

Inclusion of New Conditions

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 of interest is:

- a relatively uncommon high-impact childhood condition (or an uncommon complication of a more common disease); and

- of such a low incidence or prevalence as to require ascertainment of cases on a national scale in order to generate sufficient numbers for study; and

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

It is important for the success of the scheme that the workload of the mailing list 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.

***Table 1*: The Members of the NZPSU Scientific Review Panel (SRP) 2009**

Member	Institution
Professor Barry Taylor	NZPSU, University of Otago, Dunedin
Associate Professor Nigel Dickson	NZPSU University of Otago, Dunedin
Dr Pat Tuohy	Ministry of Health
Professor Elizabeth Elliott	Australian Paediatric Surveillance Unit
Dr Jeff Brown	Palmerston North Hospital
Professor Brian Darlow	University of Otago, Christchurch
Professor Diana Lennon	University of Auckland

Surveillance Activities in 2009

In 2009, 215 clinicians participated in the system. The average response rate to the monthly report card/email was 93%. We are very pleased with the ongoing high response rate from the whole of the country.

Minimising the extra workload that the system imposes on paediatricians is a key factor for its success.

Table 2 shows the percentage of clinicians on the mailing list that reported cases during 2008 and 2009. The table shows that in 2009, 163 of the participants did not report any cases, with none reporting five or more.

In 2009 the NZPSU monitored eight uncommon childhood conditions *(Table 3).* Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit.

***Table 2*: Respondents' Workload 2008 & 2009**

Notifications	2008		2009	
	No.	%	No.	%
None	155	73.8	163	75.8
One	21	10	34	15.8
2-4	32	15.2	18	8.3
5 or more	2	0.9	0	0

Table 3: **Conditions Under Surveillance in 2009**

Condition	Surveillance Started	Surveillance Ended	Principal Investigators
Acute flaccid paralysis	October 1997	Ongoing	A/Prof Nigel Dickson
Haemolytic uraemic syndrome	January 1998	Ongoing	Dr William Wong
Congenital rubella syndrome	January 1998	Ongoing	Professor Diana Lennon
Perinatal HIV exposure	January 1998	Ongoing	A/Prof Nigel Dickson Dr Lesley Voss
Inborn errors of metabolism	January 2004	Ended December 2009	Dr Nikki Kerruish Dr Callum Wilson
Adverse drug reactions	May 2008	Ongoing	Dr Desiree Kunac
Acute Post Streptococcal Glomerulonephritis	October 2007	Ended September 2009	Dr William Wong

Brief Reports on Ongoing Studies

ACUTE FLACCID PARALYSIS (AFP)

A/Prof Nigel Dickson

Ongoing study started in October 1997

INTRODUCTION

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

KEY RESULTS FOR 2009

- There were nine cases notified to the NZPSU in 2009.
- Information has been obtained on all of these children including follow-up information two months after diagnosis.
- Eight were from the North Island, one from the South Island.
- Five females, four males.
- Age range 2 years to 13 years, median age 6 years.
- No seasonal variation.
- The overall incidence was 1.0 per 100,000 children < 15 years.
- A diagnosis of Guillain Barré Syndrome (GBS) has been made in six of these cases, hereditary neuropathy in one, encephalopathy in one and transverse myelitis in the remaining case.
- All nine cases have been discounted as Polio by the National Certification Committee for the Eradication of Polio (NCCEP).
- Timely analysis (< 14 days after onset paralysis) of stool samples satisfying the WHO criteria was complete for four of the seven children, (44%).

***Table 4*: Percentage of AFP cases with adequate stool samples (or otherwise)**

Category	Stool samples	
	No.	%
2 stool samples within 14 days of onset of paralysis	4	44.4
2 stool samples, but one or both not within 14 days of onset of paralysis	1	11.1
1 stool sample	0	0
No stool samples	4	44.4

COMMENT

The system did successfully capture the required rate of AFP in 2009 as would be expected in a country in the absence of endemic polio. The rate of stool testing however was only 44%, less that the WHO criteria is 80%. We appreciate that this surveillance requirement is a challenge in the absence of endemic polio but still request paediatricians to try to achieve a high rate of timely testing.

Even though the WHO believes polio to have been eradicated from the Western Pacific region, ongoing surveillance of AFP is likely to be required for some years. This will require the continued telephone notification of all cases of AFP, including those with a definitive diagnosis such as Guillain Barre syndrome etc.

A challenge has always been to utilise a non-specific case definition – such as 'acute flaccid paralysis' – in a health system where a more definitive diagnosed for children with such symptoms is likely to be made.

HAEMOLYTIC URAEMIC SYNDROME (HUS)

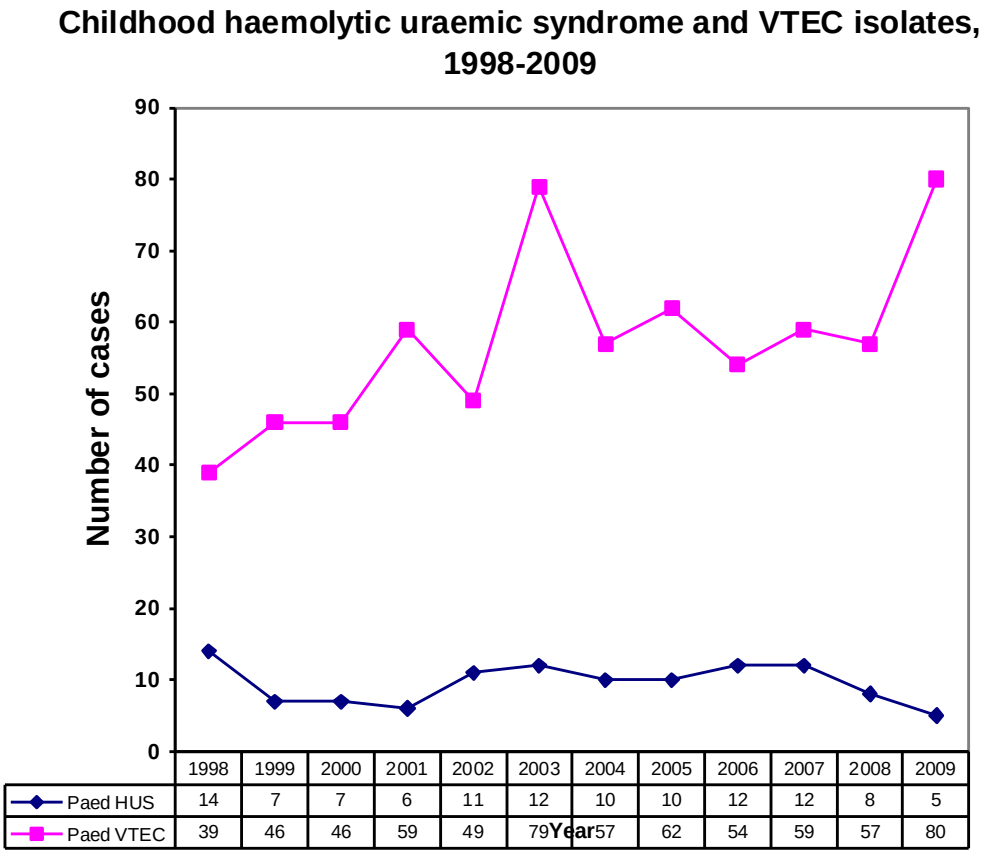
Dr William Wong

Ongoing study started in January 1998

KEY RESULTS FOR 2009

Key results for 2009 cohort

- 5 cases of HUS reported, all of which had a diarrhoeal prodrome (D+)
- Geographic distribution of D(+) HUS – scattered throughout central North Island
- Median age at presentation of D(+) HUS was 3.6 years, range 1.7 to 9.4 years
- 4/5 of the diarrhoeal group had E coli 0157H7 isolated from their stools
- 3/5 patients needed acute peritoneal dialysis for 5-24 days
- All patients regained renal function to come off dialysis.



INBORN ERRORS OF METABOLISM (IEM)

Urea cycle, amino acid, organic acid disorder or fatty acid oxidation defect

Dr Nikki Kerruish, Dr Dianne Webster, Dr Callum Wilson, Dr Esko Wiltshire, Dr Liza Edmonds

Study completed December 2009

Table 5: Key Results of Infants/Children notified in 2009

Disorder	Number of cases	Age at diagnosis	Reason for diagnosis
3 Methylcrotonyl CoA carboxylase deficiency (3-MCC)	1	< 1 month	Newborn Screening
Benign citrullinemia	3	< 1 month	Newborn Screening
Galactosaemia	1	< 1 month	Newborn Screening + Poor feeding, vomiting, jaundice
Hyperphenylalaninemia	2	< 1 month	Newborn Screening
Isovaleric acidaemia	1	< 1 month	Newborn Screening
	1	19 months	Asymptomatic brother of above
Medium chain acyl dehydrogenase deficiency (MCAD)	4	< 1 month	Newborn Screening
	1	62 months	Fasting hypoglycaemia and lethargy with vomiting illness
Multiple acyl-CoA dehydrogenase Deficiency (MADD)	1	< 1 month	Newborn Screening
Non-ketotic hyperglycinaemia	1	< 1 month	Neonatal encephalopathy Died age 5 days
Phenyketonuria (PKU)	2	< 1 month	Newborn Screening
Very long chain acyl-CoA dehydrogenase deficiency (VLCAD)	1	< 1 month	Newborn Screening

SERIOUS PAEDIATRIC ADVERSE DRUG REACTIONS (ADRs)

Dr Desiree Kunac, Dr Michael Tatley, A/Professor David Reith, Professor Keith Grimwood

Ongoing study, commenced August 2008

KEY RESULTS FOR 2009

There were 14 notifications made to the NZPSU during 2009 but for 2 notifications, no further details were received. Of the 12 reports received, two reports were excluded as the relationship between the medicine and the reported ADR could not be determined due to incomplete information available at the time of the report.

Eight of the 10 cases are new reports that were not previously notified to CARM, highlighting the value of this active surveillance system. Importantly, seven of these cases resulted in a medical warning being entered for the child in the NZ Health Information Service database.

All eight cases are now entered into the CARM database to further enhance our understanding of serious ADRs in children.

The 10 reports are summarised:

Table 6: Key Results for 2009

Suspect medicine(s)	Adverse drug reaction	Age	Sex	Seriousness / Outcome	Medical Warning	Also Reported to CARM
HPV vaccine	Bells palsy Face oedema	15 years	F	Not yet recovered at the time of report		✓
Methylphenidate	Anxiety Depression Self injury	6 years	F	Hospitalised. Recovered		✓
Cotrimoxazole	Neutropenia Rash Thrombocytopenia	5 years	M	Life threatening. Recovered	✓ Danger	X
Flucloxacillin	Neutropenia	5 years	M	Life threatening. Recovered	✓ Danger	X
Rifampicin	Thrombocytopenia	17 years	M	Life threatening. Recovered	✓ Danger	X
Phenytoin	Agranulocytosis	12 years	M	Hospitalisation. Recovered	✓ Warning	X
Carbamazepine	Rash Thrombocytopenia Leucopenia	14 years	F	Hospitalisation. Recovered	✓ Warning	x
Carbamazepine	Maculo-papular rash	8 years	M	Not serious. Recovered	✓ Warning	X
Cefaclor Ibuprofen	Hallucination Sleep disorder	5 years	M	Hospitalisation. Recovered	✓ Warning	X
Isoniazid Rifampicin	Raised hepatic enzymes. Vitamin D deficiency Hyperparathyroidism	2 months	F	Intervention required. Recovered		X

PERINATAL EXPOSURE TO HIV

Dr Nigel Dickson, Dr Lesley Voss

Ongoing study started January 1998

In 2009, there were 10 reports to the NZPSU of infants/children born to women infected with HIV. Of these:

- 1 was a perinatally infected child born overseas
- 9 were infants born in New Zealand in 2009 to women whose HIV infection had been diagnosed prior to giving birth or during their pregnancy.
- Of the 9 infants born in New Zealand in 2009:
    - 4 were born in Auckland, 1 in Wellington, 2 in Christchurch, 1 in the Waikato and 1 in Hawke's Bay.
    - 7 were born to mothers whose HIV had been diagnosed before their pregnancy and 2 were diagnosed during their pregnancy.
    - 2 of the mothers were Maori, 6 African and 1 of Pacific ethnicity.
    - All of the mothers were given antiretroviral treatment during pregnancy; 5 were born by caesarean section and 4 vaginally; none of the babies were breastfed.
    - None of the children are believed to be infected with HIV.

ACUTE POST STREPTOCOCCAL GLOMERULONEPHRITIS (APSGN)

Dr William Wong, Dr Jocelyn Neutze, Professor Diana Lennon

Two year study, commenced September 2007, completed 2009

KEY RESULTS FOR 2009

The study commenced in September 2007. In the first year of the study 65 cases (41 males) were reported. In the second year, a further 92 cases (63 male and 29 female) were notified up to the end of June 2009.

Demographic features of the year 2 group

The age of children ranged from 16 months to 15 years. The mean being 7.5 years, and median 6.8 years and. Of the 87 for whom ethnicity was reported 44 (50.6%) were Maori, 21 (24%) were Samoan, 11 (13%) were European, 4 (5%) were Tongan, and 8 (9%) of other ethnicities.

There was a family history of renal disease for 6 (7%) of the cases.

Clinical history:

There was a history of a sore throat in 48 (51%), and skin infections noted in 30 (32%) of the cases. There was both a history of a sore throat and a skin infection in 10 (11%). 62 patients had the time to onset from infection to APSGN recorded, the mean being 11 days, with a median of 9.5 days. Of the 77 cases for whom information was provided on whether an antibiotic was given for the sore throat or skin infection, one was prescribed for 37 (48%). Only 1 child had another sibling who had APSGN at the same time as the index case.

Gross haematuria was present in 78/92 (85%) of patients with an additional 9 patients having microscopic haematuria only. Oedema was observed in 49/92 (51%), oliguria in 43/88 (49%) and anuria in 2 patients. Hypertension was present in 67/92 (70%). Eight had encephalopathic features, with 1 seizures at presentation.

For 19 (21%) the C3 was not measured, and 17 (18%) did not have streptococcal serology measured, thus rendering their true diagnosis unclear. 46/90 (51%) had significantly raised initial ASOT (>480), 43/90 (48%) had antiDNAase B elevated >680; 31 children had both raised ASOT and antiDNAáse B titres. Of the 92 patients, 47 did not have a throat swab recorded as having been done. Of those who did, 15 patients had Group A streptococcal grown, one each a staphylococcus species and a Group G streptococcus.

Treatment

Of the 92 patients, 79 (85%) were hospitalized for a mean of 5.3 days. Two patients had severe nephritis and received a renal biopsy to exclude other treatable causes of severe acute glomerulonephritis. 42/92 of the children were treated with frusemide because for

hypertension, volume overload, or both. Almost all children were treated with a course of penicillin.

Conclusion

In this second year of the study, the majority of APSGN cases were in Maori and Pacific children. When all the cases of the two years of the study have been scrutinized, it is anticipated that the final number will be about 165-170 cases, with Counties Manukau District Health Board having the single largest case load.

Of concern is that that many of the children failed to attend follow up outpatient clinics to document that their glomerulonephritis has resolved without residual sequelae.

CONGENITAL RUBELLA SYNDROME (CRS)

Professor Diana Lennon

Ongoing study started in January 1998

We have not provided a report for Congenital Rubella as there were no cases reported in 2009.

Conditions Ever Monitored by NZPSU

Table 7: All conditions ever monitored by the NZPSU

Condition	Commenced	Concluded
Acute flaccid paralysis	October 1997	Ongoing
Haemolytic uraemic syndrome	January 1998	Ongoing
Congenital rubella syndrome	January 1998	Ongoing
Perinatal HIV exposure	January 1998	Ongoing
Vitamin K deficiency bleeding	January 1998	Ended Dec 2009
Fetal alcohol syndrome	July 1999	Ended December 2001
Subdural haemorrhage (<2 years)	January 1999	Ended December 2002
Retinopathy of prematurity (stage III)	January 1999	Ended December 2000
Diabetes mellitus	January 1999	Ended December 2000
Kawasaki disease	January 2001	Ended December 2002
Bronchiectasis	January 2001	Ended December 2002
Idiopathic nephrotic syndrome	July 2001	Ended July 2003
Inflammatory bowel disease	January 2002	Ended December 2003
Prolonged infantile cholestasis	January 2004	Ended December 2005
Foregut and hindgut malformations	January 2004	Ended December 2005
Pertussis	July 2004	Ended July 2005
Inborn errors of metabolism	January 2004	Ended Dec 2009
Pneumococcal meningitis	April 2005	Ended May 2008
Acute post streptococcal glomerulnephritis	October 07	Ended Sept 2009
Adverse Drug Reactions (ADR)	May 2008	Ongoing

Publications

Dickson N, Kara T, Tuohy P, Rapid National Survey of Renal Stones in New Zealand Infants, *Journal of Paediatrics and Child Health*; 2009 45, 633-635

Kelly P, Farrant, B, Shaken Baby Syndrome in New Zealand, *Journal of Paediatrics and Child Health*, 2008; 44: 99–107

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, *Journal of Paediatrics and Child Health* 2008; 43: 337–341

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

R 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

Heaton P, Wilson N, Nicholson R, Doran J, Parsons A, Aiken, G, Kawasaki disease in New Zealand, *Journal of Paediatrics and Child Health* 2008; 42: 184–190

Grenier D, Elliott EJ, Zurynski Y, Rodrigues PR, Preece M, R Lynn, von Kries R, Zimmermann H, Dickson N, Virella, D, Beyond Counting cases: public health impacts of national Paediatric Surveillance Units *Archives of Disease in Childhood* 2008; 92:527-533

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

Campbell-Stokes P, Taylor B, on behalf of The New Zealand Children's Diabetes Working Group Prospective incidence study of diabetes mellitus in New Zealand children aged 0 to 14 years, *Diabetologia* 2005; 48: 643–648

Darlow BA. Vitamin K deficiency bleeding (VKDB) in New Zealand infants: results of surveillance over five years (1998 to 2002). *Pediatric Research* 56; 474, 2004

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

Dow N, Dickson N, Taylor B, The New Zealand Paediatric Surveillance Unit: Establishment and First Year of Operation *New Zealand Public Health Report*, 1999; 6: 41-44

Some other uses of NZPSU study findings

ACUTE FLACCID PARALYSIS (AFP)

Information collected on Acute Flaccid Paralysis is used regularly to report to World Health Organization on the national situation regarding polio eradication in New Zealand.

PERINATAL EXPOSURE TO HIV

The information collected on infants born to women with diagnosed HIV has been used to develop a policy on the testing of pregnant women for HIV during pregnancy.

PERTUSSIS

Information on pertussis in children under one year of age has been used to inform the revision of the Immunisation Handbook, and has contributed to policy through the Ministry of Health's immunization technical working forum.

SELECTED PRESENTATIONS

- Darlow BA, on behalf of the New Zealand Paediatric Surveillance Unit. Vitamin K deficiency bleeding (VKDB)in New Zealand infants; results of surveillance over five years(1998-2002). *Proceedings of the 8th Annual Congress of the Perinatal Society of Australia and New Zealand,* Sydney, March 2004

- Darlow BA. VKDB in New Zealand after the vitamin K-cancer controversy: an 11 year surveillance study. *Neonatal Society, 2009 Spring Meeting, Darlington, UK* http://www.neonatalsociety.ac.uk/abstracts/abstracts_2009.shtml

International Network of Paediatric Surveillance Units (INoPSU)

Establishment of INoPSU

The network was formed in August 1998 at a meeting of 10 Paediatric Surveillance Units expressing a desire to link with each other. This took place at the 22nd International Congress of Paediatrics in Amsterdam, The Netherlands. The first INoPSU conference was held in 2000 in Canada and was attended by representatives of the existing units. Subsequent meetings have been held in York, England in 2002, Lisbon, Portugal in 2004 and Munich Germany 2008.

Associate Professor Nigel Dickson has attended the meetings in Canada, England and Portugal.

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

- facilitating communication and co-operation 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 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 co-operative surveys through each national unit;
- to collaborate with, and provide information to, other groups interested in rare childhood diseases such as parent support groups; and
- 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.

Members of INoPSU

Founding members:

- Australian Paediatric Surv Unit
- British Paediatric Surv Unit
- Canadian Paediatric Surv Programme
- German Paediatric Surv Unit
- Latvian Paediatric Surv Unit
- Malaysian Paediatric Surv Unit
- Netherlands Paediatric Surv Unit
- New Zealand Paediatric Surv Unit
- Papua-New Guinea Paediatric Surv Unit
- Swiss Paediatric Surv Unit

Additional Members:

- Welsh Paediatric Surv Unit (2000)
- Portuguese Paediatric Surv Unit (2001)
- Irish Paediatric Surv Unit (2001)
- Greece and Cyprus Paediatric Surv Unit (2004)

Associate Members:

- Trinidad and Tobago Paediatric Surv Unit (2004)
- British Ophthalmological Surv Unit

Administration of the Association

In order to carry out the aims and direct the activities of INoPSU a secretariat has been set up. From 2004 Professor Rudi von Kries (ESPED) has acted as convenor, Dr R Pereira (NSCK) has acted as deputy convenor and Richard Lynn (BPSU) has acted as communications liaison.

International Collaboration

New Zealand paediatricians who are interested in undertaking international studies, or compare the rates of uncommon disease between countries, are encouraged to consider using INoPSU for this purpose. Please

Table 8: **Members of INoPSU** INoPSU Website: www.inopsu.com

Country	Unit	Email	Website
Australia	APSU	apsu@chw.edu.au	www.apsu.org.au
Britain	BPSU	helen.friend@rcpch.ac.uk	www.bpsu.inopsu.com
Canada	CPSP	cpsp@cps.ca	www.cps.ca/cpsp
Germany	ESPED	Prof.von.kries@gmx.de	www.esped.uni-duesseldorf.de
Ireland	IPSU	robert.cunney@malix.hse.ie	
Latvia	LPSU	aspedlat@com.latnet.lv	
Malaysia	MPSU	jho@pc.jaring.my	
Netherlands	NSCK	rob.rodriguespereira@tno.nl	www.nvk.pedianef.nl
New Zealand	NZPSU	nzpsu@otago.ac.nz	www.otago.ac.nz/nzpsu
Papua New Guinea	PNGPSU	hopepng@datec.com.pg	
Portugal	PPSU	uvp-spp@ptnetbiz.pt	www.spp.pf/ingl/index_17.html
Switzerland	SPSU	hans-peter.zimmermann@bag.admin.ch	www.bag.admin.ch/infekt/melde/spsu/d/index/.htm(German)
Wales	WPSU	John.Morgan@eglam-tr.wales.nhs.uk	www.link-wales.org.uk
Trinidad and Tobago	T &TPSU	Prof MIA Omer	
Greece and Cyprus	GCPSU	xhatzi@med.uth.gr	

Table 9: **Characteristics of the Paediatric Surveillance Units**

Country	Population ($x10^6$<15 years)	Established	Approximate number of respondents
Australia	4.1	1992	1360
Britain	12.8	1986	2500
Canada	7.5	1996	2400
Germany	12.0	1992	460*
Greece and Cyprus	1.6	2001	
Ireland	1.3	1996	150
Latvia	0.4	1996	22
Malaysia	7.6	1994	400
Netherlands	3.0	1992	750
Papua New Guinea	1.92	1996	40
Portugal	1.67	2000	1506
New Zealand	0.83	1997	210
Switzerland	1.3	1995	250
Trinidad & Tobago	0.5	2005	
Wales	0.65	1994	135*

*Heads of Paediatric Centres

List of Clinicians with 100% Return Rate 2009
Clinicians who had a 100% return rate in both 2008 and 2009 are underlined

Thank you to those clinicians who returned all of their cards in 2009.

Aftimos	Salim
Aiken	Richard
Asher	Innes
Baker	Nicholas
Barker	David
Bates	Giles
Battin	Malcolm
Blair	Nikki
Bourchier	David
Bradley	Stephen
Broadbent	Roland
Broomfield	Guy
Broomfield	Frank
Brown	Jeff
Brynes	Cass
Buchanan	Leo
Buckley	David
Campbell-Stokes	Priscilla
Calder	Louise
Campanella	Silvana
Chin	Simon
Clarkson	John
Cole	Nyree
Corban	Jenny
Coulter	Belinda
Cunningham	Vicky
Dalton	Marguerite
Daniel	Alison
Darlow	Brian
De Sylva	Tony
Drage	Alan
Denny	Simon
Dickson	Cameron
Dixon	Joanne
Elder	Dawn
Evans	Juliana
Evans	Helen
Farrell	Alan
Fletcher	Rachel
Fleming	John
Ford	Rodney
Forster	Richard
Gangakhedhar	Arun
Gapes	Stephanie
Gavin	Raewyn
Grangaard	Eric
Gentles	Tom
Goldsmith	John
Grant	Cameron
Graham	Dave
Grangaard	Erik
Gunn	Alistair
Hall	Anganette
Hall	Kate
Hewson	Michael
Harding	Jane
Hoare	Simon
Hofman	Paul
Heron	Peter
Hornung	Tim
Hunter	Warwick
Hunter	Wendy
Hector –Taylor	James
Jackson	Pam
Jankowitz	Peter
Jefferies	Craig
Jellyman	Timothy
Kamphamphe	Willie

Doocey	Claire
Doran	John
Drake	Ross
Laughton	Stephen
Leadbitter	Philip
Lear	Graham
Lees	Hugh
Lynn	Adrienne
Leversha	Alison
Liang	Allen
Longchamp	Daniele
Lourens	Ralph
McArthur	John
Maikoo	Rajesh
Marks	Rosemary
Marshall	Andrew
Matas	Richard
Maxwell	Fraser
McCarthy	Karen
McCay	Hamish
McFarlene	Scott
McIlroy	Peter
Mitic	Schuman
Meyer	Michael
Mildenhall	Lindsay
Miles	Fiona
Milledge	John
Mitchell	Ed
Mitic	Schuman
Moore	Philip
Morreau	Johan
Morris	Max
Morrison	Philip
Moyes	Chris
Nagel	Fred
Nair	Arun
Neas	Katherine
Nelson	Nicola
Nolan	Melinda
Nel	Jaco
Neutze	Jocelyn
Newman	David
Nicholson	Ross
Nobbs	Peter
Kara	Tonya
Kelly	Andrew
Langdana	Anu
Patel	Rakesh
Percival	Teuila
Pereira	Nicola
Pinnock	Ralph
Pringle	Kevin
Ramadas	Ram
Reith	David
Richardson	Vaughan
Robertson	Stephen
Robertshaw	Kate
Rudge	Susan
Russell	Glynn
Rowley	Simon
Sadlier	Lynette
Sadowsky	Joel
Sanders	John
Schmiti-Uli	Meia
Shaw	Robyn
Shillito	Paul
Sinclair	Jan
Singh	Deepika
Siversten	Louise
Skeen	Jane
Skinner	Jon
Stanley	Thorsten
St John	Martyn
Stirling	John
Smith	David
Smith	Warwick
Subraminiam	Prema
Sullivan	Michael
Spooner	Claire
Selby	Robyn
Shaw	Ian
Steinmann	Kai
Stonehouse	Mary
Swan	Catherine
Taylor	Barry
Taylor	Paul
Tomlinson	Paul
Teague	Lochie

Nutthall	Gabrielle
O'Donnell	Clare
Palmer	Penny
Parsons	Alan
Pattemore	Philip
Warner	Todd
Wallace	Alexandra
West	Clare
Weston	Phil
Whale	Janine
Wills	Russell
Wilson	Nigel
Wilson	Ross
Wilson	Callum
Wiltshire	Esko
Wilson	Toni
Wong	Maisie
Wong	William
Wong	Sharon

Trenholme	Adrian
Tsang	Bobby
Tuck	Roger
Twiss	Jacob
Wendy	Walker

Congratulations to JOHN DORAN who was selected to win a $50 book token to be presented at the ASM of the Paediatric Society of New Zealand