New Zealand Paediatric Surveillance Unit

The 3rd Annual Report of the New Zealand Paediatric Surveillance Unit for 2000 contains an increasing amount of important information.

Surveillance of acute flaccid paralysis (AFP) has continued for the Ministry of Health's National Certification Committee for the Eradication of Poliomyelitis (NCCEP). Surveillance has also continued for the other conditions introduced in 1998 and 1999.

Some key findings in this report are:

Acute Flaccid Paralysis (AFP)

- 14 cases of AFP were reported in 2000.
  - The system successfully captured the required rate of AFP.
  - Even though WHO believes polio to have been eradicated from the Western Pacific region, it requires New Zealand to continue surveillance of AFP with a phone notification of every case to the NZPSU.

Fetal Alcohol Syndrome (FAS)

- 29 cases of suspected or definite FAS were notified during 2000. Information has been received on 26 (93%).

Haemolytic Uraemic Syndrome (HUS)

- There were 7 cases of HUS in 2000. This included part of a small cluster having atypical HUS following streptococcal pneumoniae infections.

Perinatal HIV Exposure

- 5 infants were born in New Zealand to women known during the pregnancy to be infected with HIV, none of these infants are known to be infected. However one child with HIV was born in New Zealand in 1999 and diagnosed in 2000 to a woman who had not been known to be infected during the pregnancy.

Retinopathy of Prematurity (ROP)

- There were 22 notifications of ROP in 2000; of these 13 were valid reports and information has not been received on 7.

Subdural Haemorrhage

- There were 20 cases of subdural haemorrhage in children under 2 in 2000, completed reports have been received on 14 cases.
  - In the completed reports, subdural haemorrhage was due to birth injury in 4 cases, accidental injury in 2, child abuse in 7 and an arterio-venous malformation in 1 case.

Vitamin K Deficiency Bleeding (VKDB)

- There were two notifications of VKDB received in 2000, although in one case the diagnosis is only "probable."
    - Neither baby received vitamin K at birth because of parental refusal, although in one case there may have been communication problems.

Paediatric Diabetes Mellitus: Final Report

- There were 315 cases over 2 years of which 94.6% were Type 1, and 3.8% Type 2 diabetes. The incidence of Type 1 is 17.9 cases per 100,000 with non-Maori having higher rates than Maori.
- The incidence of Type 2 was 0.72 per 100,000. 92% were obese with a predominance of Maori/Pacific island ethnicity.

The ongoing success of 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.

Barry Taylor Nigel Dickson Melissa Carter

Introduction

Surveillance is important to monitor both the incidence of emerging conditions and the effectiveness of prevention measures. The Paediatric Society of New Zealand (PSNZ) had for some years promoted the establishment of a unit that could regularly request specialist paediatricians to report on a number of conditions. The New Zealand Paediatric Surveillance Unit (NZPSU) was established in October 1997.

The aim of the NZPSU is to facilitate and improve the knowledge of rare 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 Organization (WHO), as part of the global eradication process, requires such surveillance to confirm New Zealand is free of poliomyelitis. Since the NZPSU's establishment, the number of conditions under surveillance has increased and now includes nine rare childhood conditions.

The NZPSU is a member of the International Organisation of Paediatric Surveillance Units (INoPSU). Further information can be viewed on our website at: http://www.paediatrics.org.nz/nzpsu/nzpsu1.html

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 Organisation.

- To facilitate national surveillance and improve the knowledge of uncommon 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.

Specialist paediatricians in New Zealand gave their support to the surveillance system after the concept was discussed at an annual meeting of the Paediatric Society of New Zealand. A database of eligible clinicians, which included specialist 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 in 2000 participants were sent a reply-paid card to report whether in the previous month they had seen any cases of the conditions under surveillance. However, cases of AFP were required to be reported immediately by phone to the NZPSU. When a case of any of the conditions was reported, the reporting clinician was sent a short questionnaire to complete on the case. The case's identity 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 on for a finite period, usually 2 or 3 years.

Regular surveillance reports are made to the Ministry of Health, specifically updating the progress with AFP surveillance.

Inclusion of New Conditions

A Scientific Review Panel (SRP) has been established primarily to consider the inclusion 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 rare childhood condition (or a rare 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.

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.

There were nine conditions under surveillance in 2000, two of which were removed at the end of the year and two others were added.

Table 1: The members of the NZPSU Scientific Review Panel (SRP)

Member	Institution
Professor Barry Taylor	Dunedin School of Medicine
Dr Nigel Dickson	Dunedin School of Medicine
Dr Alison Roberts	Ministry of Health
Dr Elizabeth Elliot	Australian Paediatric Surveillance Unit
Dr Jeff Brown	Palmerston North Hospital
Professor Brian Darlow	Christchurch School of Medicine
Professor Diana Lennon	University of Auckland

Surveillance Activities in 2000

In 2000, 165 clinicians participated in the system. The average response rate to the monthly mail-out of report cards was 94%, with no consistent set of non-responders. Table 2 shows the response rate per area.

Table 2: Response rate per health locality (as defined by the HFA) 1999 & 200

Health Locality	1999 (%)	2000 (%)
Northland, Auckland	93	93
Waikato, Bay of Plenty, Taranaki	98	97
Wellington, Wairarapa, Manawatu, Wanganui, Tairawhiti, Hawkes Bay	97	91
Nelson, Marlbourgh, Canterbury, West Coast	92	94
Otago, Southland	95	97
TOTAL	95	94.4

Respondent workload

Minimising the extra workload that the system imposes on paediatricians is a key factor for its success. The range of conditions under surveillance and their incidence needs to be kept under review. Confining the system to conditions that are rare will limit the demand on clinician's time, but conversely it will be less likely to provide useful information.

Figure 1 shows the percentage of clinicians on the mailing list that reported cases during 1999 and 2000. The figure shows that in 2000 48% of participants did not report any cases, with 39.4% reporting between one and three cases. 12.1% reported 4 or more cases during 2000.

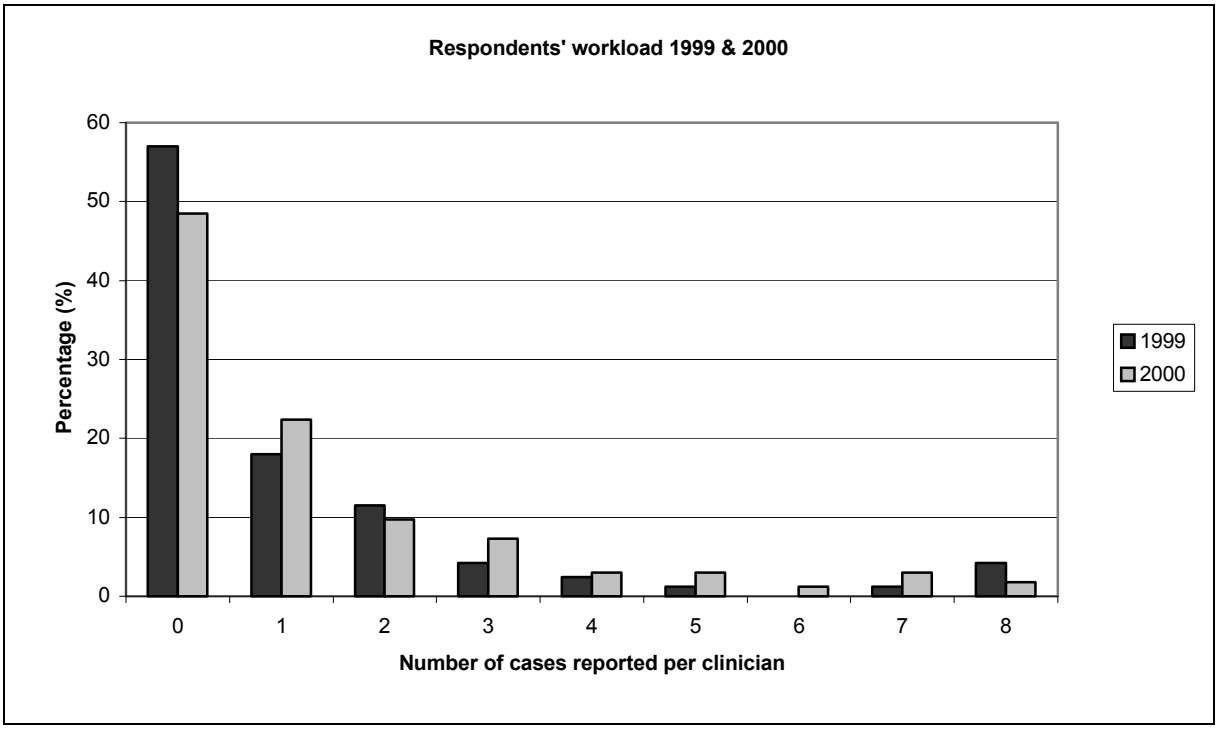

Figure 1: The percentage of clinicians that reported cases during 1999 and 2000

In 2000, NZPSU monitored 9 uncommon childhood conditions (Table 3). Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit.

Table 3: Conditions under surveillance in 2000

Condition (age range included)	Surveillance started	Principal Investigator(s)
Acute flaccid paralysis (<15 years)	October 1997	Dr Nigel Dickson, Dr Paul Shillito
Haemolytic uraemic syndrome (<15 years)	January 1998	Dr William Wong
Congenital rubella syndrome (<15 years)	January 1998	Professor Diana Lennon
Perinatal HIV exposure (<15 years)	January 1998	Dr Nigel Dickson, Dr Lesley Voss
Vitamin K deficiency bleeding (<15 years)	January 1998	Professor Brian Darlow
Subdural haemorrhage (<2 years)	January 1999	Dr Patrick Kelly
Retinopathy of Prematurity (<15 years)	January 1999	Professor Brian Darlow
Diabetes Mellitus (<15 years)	January 1999	Dr Priscilla Campbell-Stokes Professor Barry Taylor
Fetal Alcohol Syndrome (<15 years)	July 1999	Dr Alison Leversha

Classification of Case reports

A valid report is one confirmed by the investigator as satisfying the diagnostic criteria set out in the case definition.

Invalid reports can be either:

- Duplicate reports of cases already reported to the NZPSU, or
- Reporting errors arising from cases that have been reported but which:
    - Do not satisfy the diagnostic criteria, or
    - Are a result of misdiagnosis, or
    - The wrong box on the yellow card was ticked

An unknown report is one where insufficient follow-up information is available to the investigator or information has not been received by the NZPSU.

Table 4 shows the number of total and valid cases reported to the NZPSU for conditions under surveillance in 2000.

Table 4: Total and valid reports for each condition under surveillance in 2000

Conditions under surveillance	Total reports	Valid Reports	
	n	n	%
Acute Flaccid Paralysis	14	14	100
Congenital Rubella Syndrome	1	0	0
Perinatal HIV exposure	10	8	80
Haemolytic Uraemic Syndrome	10	7	70
Vitamin K Deficiency Bleeding	2	2	100
Subdural Haemorrhage	21	20	95
Retinopathy of Prematurity	22	20	91
Diabetes Mellitus	202	163	81
Fetal Alcohol Syndrome	29	26	90

Brief Reports on Selected Conditions

There is no report for Congenital Rubella as there were no valid cases reported in 2000. Herpes Simplex Virus (HSV) was initially included on the card for 2000, but because of the few reports and low response rate, a report has not been included.

Acute Flaccid Paralysis

Dr Nigel Dickson

Ongoing study started in October 1997

Introduction

To confirm the absence of poliomyelitis the World Health Organization (WHO) requires a surveillance system to be in place:

1. That captures an annual incidence of Acute Flaccid Paralysis (AFP), not due to polio, of at least 1/100,000 children <15 years.
2. In which 80% of cases of AFP have 2 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 2000

In 2000, 14 children were notified with confirmed Acute Flaccid Paralysis. Information has been obtained on all these children including follow up information two months after diagnosis.

(i) The overall incidence was 1.7 per 100,000 children <15 years.

The Ministry of Health is currently undertaking a search of children discharged from all New Zealand hospitals in 2000 with an ICD code that could relate to AFP. This will be used to audit notifications.

(ii) A diagnosis of Guillain-Barre syndrome was made in 7 (50%) and transverse myelitis in 3 (21%), of these children. One child had weakness due to an identified non-polio echo 33 virus (and Guillain-Barre syndrome was not specifically diagnosed). Of the remainder, one each was diagnosed as having paralysis due to trauma, a tumour, and a respiratory chain disorder.

(iii) Analysis of stool samples satisfying the WHO criteria was only complete for 8 of the 14 (57%) children (see Table 5).

Table 5: Percentage of AFP cases with adequate stool samples (or otherwise)

Category	Stool samples	
	n	%
2 stool samples within 14 days of onset of paralysis	8	57
2 stool samples, but one or both not within 14 days of onset of paralysis	2	14
1 stool sample	1	7
No stool sample*	3	21

* These were the children with paralysis due to trauma, tumour and GBS

(iv) The Polio Eradication Committee was satisfied that there was no evidence of polio causing the paralysis in any of these children.

Comment

The system successfully captured the required rate of AFP. An audit is also currently underway to detect under-notification.

The rate of stool testing (57%), while not yet meeting the WHO criteria (80%), was markedly better than in 1999 when this was only 20%. The NZPSU continue to remind clinicians of the need to make telephone notifications of AFP to ensure that timely stool specimens are sent to ESR for appropriate testing.

Ongoing surveillance of AFP, even though WHO believes Polio to have been eradicated from the Western Pacific region, is likely to be required for some years. This will necessitate 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, 'acute flaccid paralysis', that has been designed for surveillance in developing countries in a health system where a more definitive diagnosis for such children is likely to be made.

Fetal Alcohol Syndrome (FAS)

Dr Alison Leversha

Year 2 of a 2½ year study started in July 1999

29 cases of suspected or definite FAS were notified during 2000. Information has been received on 26 (93%) of these.

- 14 definite cases of FAS were reported.
- The remainder were suspected FAS but were awaiting further investigations or assessments over time.
- 13 paediatricians reported the 29 cases; 4 reporting 3 or more cases.

- The diagnosis was usually suspected by the notifying Paediatrician, however, other agencies also suspected the diagnosis and facilitated referral (3 by Special Education Services, 4 by CYPFA, 3 by mental health professionals and one by the child's parents).
- Reasons for referral to the Paediatrician were most commonly behaviour and learning problems.
- In contrast to the previous year, only one child was born outside of New Zealand. 14 were of Maori and 10 of European ethnicity. 1 Pacific child was reported.
- Only 4 of the 26 were living with their biological parents, 10 lived with family and the remainder were adopted or in foster care.

Comment
The reported New Zealand incidence of FAS is low compared to other countries. A small number of New Zealand Paediatricians are diagnosing children with FAS. The majority of affected children are in extended family/foster/adopted care and are referred to paediatricians for assessment of learning or behavioural difficulties.

Haemolytic Uraemic Syndrome

Dr William Wong

Ongoing study started in January 1998

The annual incidence of haemolytic uraemic syndrome (HUS) has diminished significantly since the commencement of the study in 1998 (Fig 2). There were 7 cases of HUS in both 1999 and 2000. There was a small cluster of 3 children having atypical HUS following streptococcal pneumoniae infections at the end of 1999 and the beginning of 2000. This small outbreak is reminder to paediatricians about clinical presentation and management of this type of HUS particularly in relation to the use of blood products which are generally contraindicated in pneumococcal induced HUS.

Overall 2 of the 28 (7.1%) children reported between 1998 and 2000 died. In 2000 one child died from severe pneumococcal meningitis and acute renal failure. The child who died in 1998 did so as a result of a massive intra cerebral haemorrhage.

The majority of cases continue to occur in children less than 5 years of age in the North Island only. The median interval from onset of symptoms to diagnosis was 7 days compared with a median of 4.5 days in 1998 and 6 days in 1999.

In most cases, neither the bacterial organism nor the source of the infection were identified. This is not surprising as by the time the syndrome is recognised, *E coli*, the most frequently identified organism is usually no longer detectable in the stools. The incidence of reported shiga toxin producing *E coli* infections continue to increase each year (Fig 3), however, the number of HUS cases has remained stable over the past 2 years. Possibly, public health education measures have been in part successful in containing outbreaks of this disease.

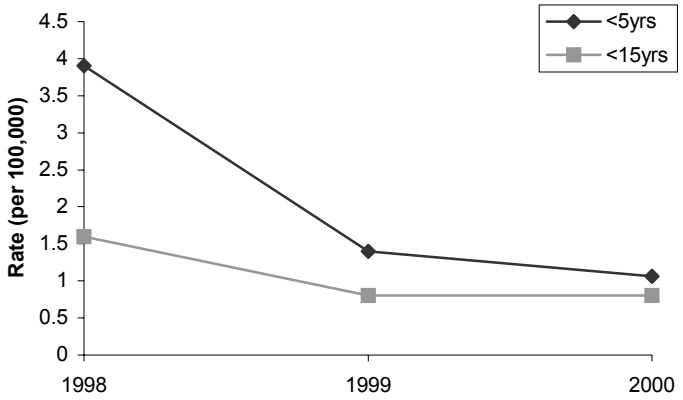

Figure 2: Annual age related incidence of childhood HUS

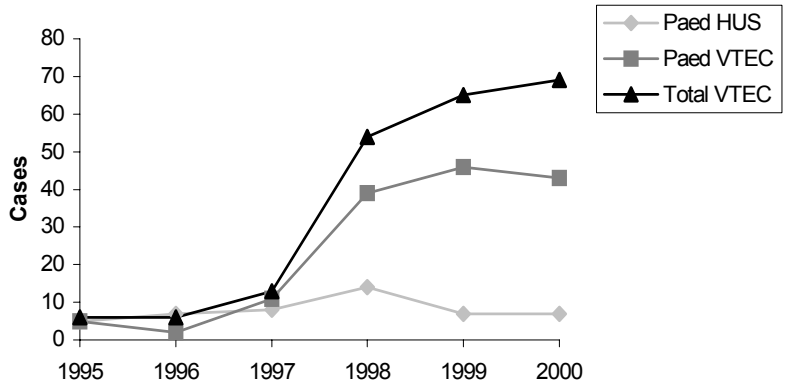

Figure 3: The Number of Cases of HUS and VTEC infections

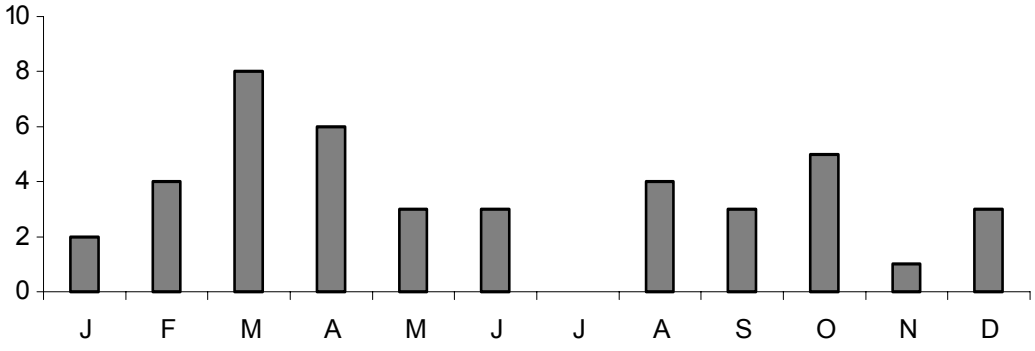

Figure 4: Seasonal incidence of HUS, 1998-2000

No clear seasonal pattern of occurrence of childhood HUS in New Zealand has been apparent between 1998 and 2000 (Fig 4). This is in contrast to the more seasonal pattern observed in Western Europe and North America where most cases are reported in the spring and summer months. A more definite seasonal pattern may become apparent with time.

Overall there have been 23 children potentially available for follow up analysis at 12 months. One child has been lost to follow up. Of the 22 children available for reassessment at one year, only one has chronic renal failure with a glomerular filtration rate (GFR) of 20ml/min/1.73m^2. The remainder have normal GFR as determined by plasma creatinine. Five children have minor urinary abnormalities with low grade proteinuria and or haematuria. Further and more prolonged follow up of this group is required to determine their long term outcome.

Perinatal exposure to HIV

Dr Nigel Dickson

Ongoing study started in January 1998

In 2000 there were a total of 8 notifications of infants/children born to women infected with HIV.

5 infants were born in New Zealand to women known during the pregnancy to be infected:

- 4 mothers were diagnosed with HIV before and one during the pregnancy.
- 2 mothers were African, and one each Asian, European and of mixed Maori/Pacific island ethnicity.
- All but one (who refused) were treated with antiretroviral drugs in pregnancy, 4 were delivered by Caesarian section, and none were breast fed.
- None are known to be infected.

One child with HIV infection was born in New Zealand in 1999 and diagnosed in 2000. The mother was not known to be infected during the pregnancy.

2 were children infected with HIV who had been born overseas (one in 1998 and one in 2000) and were diagnosed in New Zealand in 2000.

It is important to appreciate that a number of studies have found a low rate of enquiring about HIV risk, and also of HIV testing, during pregnancy in New Zealand. There are therefore most likely to be HIV infected women who gave birth in 2000 whose infections are undiagnosed and this possibility should be considered when treating children with a wide variety of problems.

Retinopathy of Prematurity (Stage III and over)

Professor Brian Darlow

Final year of a 2-year study started in January 1999

There were 22 notifications in 2000; of these, 13 were valid reports, there was one error, one duplicate and, to date, information has not been received on 7.

Of the 13 infants for whom information has been received:

- The mean gestation was 25.2 weeks (range 23-28weeks).
- The mean birthweight was 707g (range 440-1020g) with just one infant having birthweight more than 1000g.
- Five infants had "no plus" disease and 6 infants had "pre-threshold" staging of disease.
- Eight infants were treated; 1 infant had cryotherapy to 1 eye only; 7 infants had bilateral treatment – 3 with laser therapy, 1 with cryotherapy, and 3 with a combination of laser and cryotherapy.
- The outcome for most infants is not known at this time but 1 infant is bilaterally blind and 2 have cicatricial disease.

This is the second year of a two year study. A full report on both years combined will appear in the 2001 report.

Subdural Haemorrhage in Children Under 2 Years of Age

Dr Patrick Kelly

Ongoing study started in January 1999

There were 20 cases of subdural haemorrhage in children under 2 years of age in 2000, the first full year of ascertainment in this study. Completed reports have only been received on 14 cases.

- The cases come from throughout New Zealand, ranging from Invercargill to Auckland, but 17 of the 20 notified cases were from the North Island.
- The age range for the 2000 cohort of patients was birth to 2 years. Most infants were under the age of 6 months.
- In the completed reports, subdural haemorrhage was due to birth injury in 4 cases, accidental injury in 2, child abuse in 7 and an arterio-venous malformation in 1 case
- Two of the 14 cases died, 5 were neurologically normal at time of discharge, and 6 were neurologically abnormal.

Comments

The number of cases being reported is close to what was predicted from our experience of the Auckland area. At present, the percentage of completed questionnaires is not good enough to

draw any inferences from the data. We propose to extend the study for a further year and include the neurosurgeons in ascertainment.

Vitamin K Deficiency Bleeding (VKDB)

Professor Brian Darlow

Ongoing study started in January 1998

There were two notifications of VKDB received in 2000, both were valid reports although in one case the diagnosis is only "probable."

- Both reports were late onset with bleeding in the second/third week of life (incidence approximately 1 in 28,500).
- Neither baby received vitamin K at birth because of parental refusal, although in one case there may have been communication problems.
- Both cases presented with rectal haemorrhage, in one case there was also umbilical haemorrhage and bruising, and in one case also vaginal haemorrhage.
- One case was confirmed by coagulation studies and was treated with vitamin K. This child also had evidence of neonatal hepatitis, although a liver biopsy at one year of age was normal.
- One case was not confirmed by coagulation studies and it is uncertain whether this child was treated with vitamin K.
- Both children apparently have no ongoing morbidity.

Final Reports for Completed Studies

Childhood Diabetes Mellitus

Dr Priscilla Campbell-Stokes, Research Fellow
Professor Barry Taylor, Principal Investigator

Final year of a 2-year study started in January 1999

Background
Childhood diabetes mellitus (DM) is a chronic illness with serious ongoing consequences for the child and family. Due to its' chronicity and complications it also places a significant burden on health care resources.

There have been two previous national incidence studies concerning DM in New Zealand children (Crossley and Upsdell, 1980, Smith, 1987). The first reviewed hospital admission data for the five years 1968-1972. During this period the average annual incidence for all under 20 years was 10.4 /100,000. The incidence was 6.1 and 8.9 per 100,000 respectively for those under 11 and under 16 years. The rate in the South Island was 1.4 higher than that of the North Island.

The other national survey sought to establish the incidence of DM in those under 20 years using voluntary reporting by paediatricians and physicians over the 4-year period 1978-1982. The average annual incidence during that period was 5.4/100,000 for those under 20 years and 6.2/100,000 for those under 16 years. The difference between the North and South Islands was smaller and inverse to that previously described, but there was a significant degree of under-reporting in that study.

Since then only regional data, from regional registers, have been available. In the years 1977-1984, Auckland incidence showed no change, with an average annual incidence of 9.3/100,000, comparable to the overall North Island rate (1968-1972) of 8.1/100,000 for children under 16 years. Canterbury data however showed an average annual incidence of 19/100,000 over the 1990-1991 period for under 20 years.

The international literature suggests the incidence of childhood DM is increasing in some populations especially in the younger age groups.

This study was undertaken to determine the current national incidence, and geographic and ethnic differences. Such information might reveal clues to the possible environmental influences on the development and onset of childhood DM. The knowledge of current incidence rates and trends will also be useful for health resourcing purposes.

Objectives

- Determine the national incidence of diabetes mellitus in children less than fifteen years of age over a two-year period.
- Determine the effect of gender, ethnicity, region, season and family history on incidence.
- Compare national and regional results with those from the 1968-1972 study, and with international figures.
- Describe the clinical presentation and initial management of new cases.
- Estimate current and future demands on health resources.

Case Definition

Any child under 15 years old with either a random blood glucose measurement >11 mmol/l and presence of classical symptoms (polyuria, polydipsia, polyphagia, weight loss, weakness, blurred vision), or a fasting blood glucose > 7 mmol/l or a blood glucose >11 mmol/l at 2 hours during an oral glucose tolerance test or 2 hours after a high carbohydrate breakfast.

The hyperglycaemia should not be secondary to drugs or stress (e.g. sepsis).

Results and discussion

There were 372 notifications of diabetes mellitus to the NZPSU between January 1999 and December 2000. Information was received on all 372 notifications, 315 were valid cases, and 57 were invalid (47 duplicates and 10 reporting errors either through not fulfilling the case definition criteria because of diagnosis, outside the study period, or being an overseas resident on holiday to New Zealand).

Incident cases of Diabetes Mellitus

Of the 315 valid cases, 298 (94.6%) have Type 1 diabetes and 12 (3.8%) Type 2 diabetes. In addition there were five cases with other specific types (two of probable maturity onset diabetes of the young (MODY), one of cystic fibrosis, one of Prader-Willi, and one of a mitochondrial disorder). For Type 1 Diabetes Mellitus, the average annual incidence of in those under 15 years of age was 17.9 per 100,000 (95% CI 15.9-20.0 per 100,000). The incidence varied by region within and between the North and South Islands (Figure 5). The incidence in the South Island was 1.4 times higher than the North Island. The least populated region of each island had no cases during the 2-year period. The average annual incidence of Type 2 diabetes was 0.72 per 100,000 (95% CI 0.37-1.26 per 100,000). Estimation of case ascertainment is being undertaken using hospital admission data.

Type 1 Diabetes Mellitus

There were 142 males and 156 females, a male to female ratio of 0.91:1. 21% were less than 5 years old, 37% 5 to 9 years old and 42% 10 to 14 years old. The ethnic distribution was 85.4% European, 7.1% Maori, 4% Pacific Island and 3.4% other ethnic group. Tables 6 and 7 show the incidence rates according to age, gender and ethnicity. Nine percent (25) of children and adolescents have at least one first-degree relative with Type 1 diabetes, while another two percent (7) have a first-degree relative with Type 2 diabetes.

A significant seasonal variation in incidence was seen with presentation being more common during the late-autumn and winter months. The mean blood glucose at hospital presentation was

26.9 ± 0.64 mmol/l (range 4.5 - 73 mmol/l). The majority of children and adolescents were not acidotic at diagnosis, although 29% had a pH less than 7.3 and 5% a pH below 7.1. There were no deaths during the period from diagnosis to first follow-up visit.

At first outpatient follow-up (median 32, range 3 to 395 days) 87% were on twice daily insulin regimes, 10% once daily and the remainder three or four times daily. Fifteen percent were using intermediate or long acting insulins only. Seven percent had regimes that included the newer rapid-acting insulins, 60% of whom were younger than five years. Only three percent were using pre-mixed insulins, the average age of this group was 13 years.

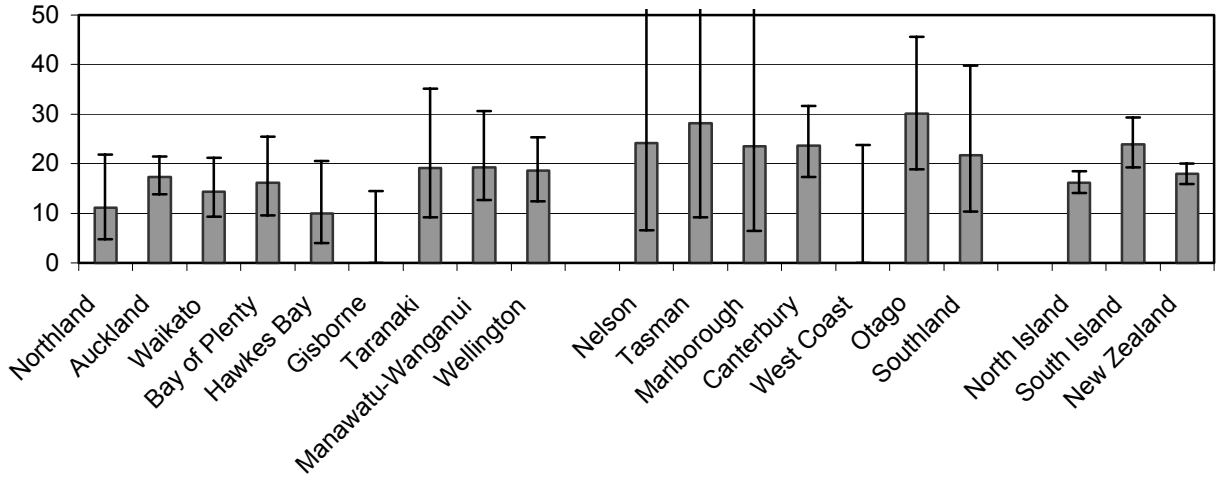

Figure 5: Average annual incidence rates with 95% confidence limits for Type 1 diabetes by region

Table 6: Average annual incidence rate per 100,000 by age and gender

Age (years)	0-4	5-9	10-14	0-14
Male				
Population	144,111	147,720	135,666	427,497
Number cases	34	47	61	142
Incidence	11.79	15.90	22.48	16.60
(95% confidence limits)				(13.9 - 19.5)
Female				
Population	135,492	140,571	128,523	404,586
Number cases	30	64	62	156
Incidence	11.07	22.76	24.12	19.27
(95% confidence limits)				(16.3 - 22.5)

Male and Female				
Population	279,603	288,291	264,189	832,083
Number cases	64	111	123	298
Incidence	11.44	19.25	23.28	17.9
(95% confidence limits)				(15.9 - 20)

Table 7: Average annual incidence rates per 100,000 (95% CI) by ethnicity and island

Ethnicity	North Island	South Island	New Zealand
Maori	5.21 (3.1-8.2)	8.45 (2.3-21.6)	5.60 (3.5-8.5)
Non-Maori	20.16 (17.4-24.4)	26.14 (20.9-32.3)	21.71 (19.2-24.4)

Type 2 Diabetes Mellitus

Of the 12 adolescents, three are female and nine male, the overall female:male ratio being 1: 3. Four are European, six Maori, one Maori/Pacific Island and one European/Fijian Indian. The mean age at diagnosis was 13.7 years (range 12.1 to 14.8 years). Five (42%) have a first-degree relative with Type 2 diabetes. In addition, another adolescent was noted to have seven maternal aunts and both maternal grandparents with Type 2 diabetes. Eight (67%) adolescents were from the Auckland region, two (14%) from the Wellington region and one from each of the Bay of Plenty and Gisborne regions.

Defining obesity as having a BMI $\geq 95^{th}$ percentile for age and sex, 11 (92%) were obese. The mean BMI was 32.1 kg/m^2 (range 21.41 to 40.35 kg/m^2). Acanthosis Nigricans (a cutaneous marker of insulin resistance) was observed in eight (67%). Of the ten for whom pubertal status was reported, nine were pubertal.

At presentation, three (25%) were not admitted to hospital. The mean blood glucose was 22.4 +/- 5.3 mmol/l and of the seven adolescents with blood gas samples, all had pH values greater than 7.3.

At first follow-up (median 43 days, range 0 to 132 days) four were treated with oral hypoglycaemic agents (OHA), five with insulin and three with both an OHA and insulin. In the insulin only group, one had contraindications to OHA use and one was commenced on an OHA at follow-up. In the combined treatment group, one was able to discontinue insulin at follow-up.

Paediatrician workload

Given that diabetes in childhood is not a rare condition, there were initially some concerns regarding the extra workload that this study may create for paediatricians. The workload results are presented in Table 8 and Figure 6. The primary source for the Auckland data was from the diabetes nurse educators (100 case notifications), and their figures are not included in the questionnaire completion data. The majority (70%) of paediatricians completing questionnaires did so with a frequency averaging less than one every four months. Only one paediatrician (Christchurch) averaged a questionnaire completion frequency of greater than one per month.

In the majority of centres the workload was small, however in the larger tertiary centres (which accounted for approximately half the total case load), the workload was more substantial. In some of the larger centres there was input from the local diabetes nurse educators and/or the research fellow for questionnaire completion. When planning similar studies in the future, thought should be given to providing extra support to single paediatricians working in larger centres.

Table 8: Paediatrician workload

Workload for 2-year period	*Case notifications*	*Questionnaire completion*
Total	372	315
Number Paediatricians	52	41
Median number per paediatrician	3	3
Mode	1	1
Range	1 - 100	1 - 38

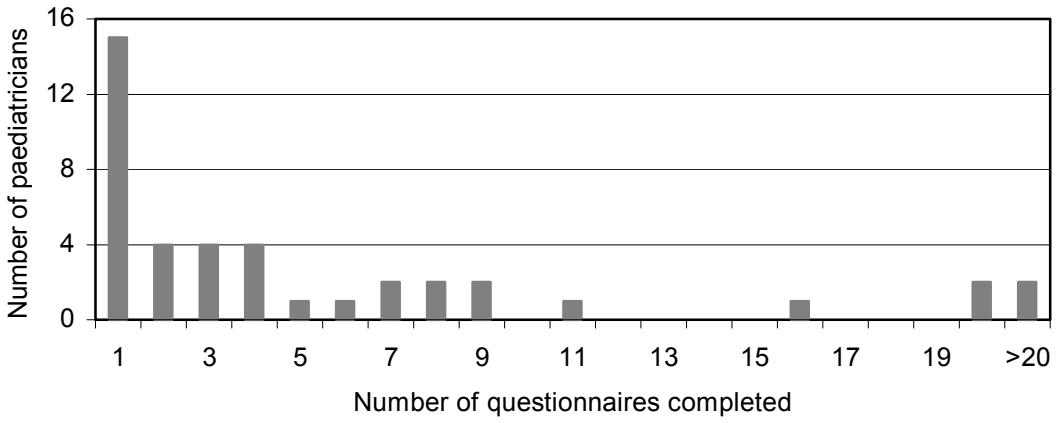

Figure 6: Number of questionnaires completed per paediatrician over the 2-year period

Conclusion

This study has provided current national information on the incidence of diabetes mellitus in the 0 to 14 year age group. The two major findings are a doubling in the incidence of Type 1 diabetes over the last 30 years and the emergence of Type 2 diabetes in this population. Both of these findings are in keeping with international trends. The significant increased risk of Type 1 diabetes for those living in the South Island is largely explained by the differences in ethnic mix between the two islands.

The increase in Type 1 diabetes incidence, both nationally and internationally is currently unexplained. Increases of the magnitude observed here over a period of two to three decades is more consistent with changing environmental influences rather than an increase in the genetically susceptible population. However it is possible that that the penetrance of susceptible genes may be increasing in response to environmental changes without necessarily increasing the pool of those genetically susceptible. The hygiene hypothesis is one current theory put forward to explain the increase in allergic and autoimmune disorders, including Type 1 diabetes in today's society. This hypothesis is based on the concept that living in an increasingly hygiene obsessive world is depriving immune systems of the input required to develop normally. Further research, including prospective longitudinal studies from birth, is required to look at these and other theories in order to identify modifiable risk factors and thus slow the increase in Type 1 diabetes.

It is a major concern that young adolescents are now developing Type 2 diabetes. There is little argument that this international phenomenon is related to diet, sedentary lifestyles and the increasing rates of obesity. Type 2 diabetes is only one of many complications of obesity and therefore these adolescents represent the tip of the iceberg of obesity related health issues. In addition, this study has identified incident cases only, and it is likely this reflects the minimum incidence of Type 2 diabetes in this population, given that up to 50% of adults with Type 2 diabetes are estimated to be undiagnosed.

The findings of this study have major implications for the delivery of health services both now and in the future. Whether or not the increase in incidence of diabetes in this young population represents an increase in total incidence of diabetes or a shift of diabetes development to a younger age, these children and adolescents are likely to develop diabetes complications while still relatively young. The impact of this on their lives and those of their family, and on health resources will be significant.

Acknowledgements

We acknowledge the contribution of paediatricians in reporting cases and providing questionnaire data, and the diabetes nurse educators who supported paediatricians and provided information for case ascertainment.

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International Network of Paediatric Surveillance Units

In August 1998, at the 22nd International Congress of Paediatrics in Amsterdam, ten national paediatric surveillance units met to discuss a proposal that would link pre-existing units and improve international collaboration and discussion. Together, they formed the International Network of Paediatric Surveillance Units (INoPSU) (see Table 9). A secretariat, consisting of representatives from the United Kingdom (UK), Australia, Canada and the Netherlands, was set up to carry out the aims and direct the activities of INoPSU.

Founding members included units from Australia, Canada, Germany, Latvia, Malaysia, Netherlands, New Zealand, Papua New Guinea, Switzerland and the UK. More recently, the Welsh unit, which was formed in 1995, and concentrates on less rare disorders, became the eleventh unit to join INoPSU. Several countries such as Portugal, Belgium and the Czech Republic have also expressed an interest in developing national paediatric surveillance units.

A further meeting was held in Ottawa in 2000 sponsored by the Canadian Government. This meeting was attended by Dr Nigel Dickson and Nicola Dow.

INoPSU is currently chaired by Dr Elizabeth Elliot of the Australian PSU.

Aims of INoPSU

The aims of INoPSU are:

- To facilitate 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.

Table 9: Members of INoPSU

	Email	Website
Australia	apsu@nch.edu.au	www.racp.edu.au/apsu
Britain	richard.lynn@rcpch.ac.uk	http://bpsu.inopsu.com
Canada	joanne_doherty@hc-sc.gc.ca	www.cps.ca/english/proadv/CPSP/CPSP.htm
Germany	heinrich@med.uni-duesseldorf.de	www-public.rz.uni-duesseldorf.de/~esped/rahmen.html
Latvia	aspedlat@com.latnet.lv	
Malaysia	jho@pc.jaring.my	
Netherlands	r.pereira@pg.tno.nl	
New Zealand	nzpsu@stonebow.otago.ac.nz	www.paediatrics.org.nz/nzpsu/nzpsu1.html
Papua New Guinea	hopepng@datec.com.pg	www.hopeww.org/where/png/png5.htm
Switzerland	hans-peter.zimmermann@bag.admin.ch	
Wales	John.Morgan@eglam-tr.wales.nhs.uk	

INoPSU website: www.inopsu.com

Table 10: Characteristics of International Paediatric Surveillance Units as reported in the NZPSU 1999 Annual Report

Country	Population (x106<15years)	Established	Respondents	Response rate
Australia	1.5	1992	934	96%
Britain/Eire	12.8	1986	2005	92%
Canada	6.3	1996	2212	83%
Germany	14	1992	468*	94%
Latvia	0.4	1996	22	90%
Malaysia	7.7	1994	395	65%
Netherlands	2.9	1992	432	91%
Papua New Guinea	1.9	1996	40	79%
New Zealand	0.8	1997	165	94%
Switzerland	1.3	1995	40*	99%
Wales	0.6	1995	121	95%

* Heads of Paediatric Centres

Table 11: Conditions under surveillance worldwide 2000

Conditions under surveillance worldwide	Country
Acute flaccid paralysis	Australia, Canada, Netherlands, New Zealand, Papua New Guinea, Switzerland
Acute fulminant liver failure	Malaysia
Aseptic meningitis following MMR vaccination	Germany
Asthma	Malaysia
Asthma deaths	Malaysia
Atresia (stomach, esophagus)	Latvia
Coeliac disease	Netherlands
Cerebral edema in diabetic ketoacidosis	Canada
Children in house fires	Wales
Congenital adrenal hyperplasia	Netherlands
Congenital brachial palsy	Britain
Congenital cytomegalovirus infection	Australia
Congenital heart disease	Malaysia
Congenital hypothyroidism	Papua New Guinea
Congenital nephrosis, Finnish type	Latvia
Congenital rubella	Australia, Britain, Canada, New Zealand, Switzerland
Cystic Fibrosis	Latvia
Diabetes mellitus	Germany, Netherlands, New Zealand, Papua New Guinea, Wales
Duchenne muscular dystrophy	Malaysia
Encephalitis	Britain
Fetal alcohol syndrome	New Zealand
GLUT-1 deficiency	Germany
Group B streptococcal infections	Netherlands
Haemorrhagic disease of the newborn (vitamin K deficiency bleeding)	Australia, Canada, Germany, New Zealand, Switzerland
Haemorrhagic shock encephalopathy syndrome	Germany
Haemophilus influenzae infections	Australia, Britain, Germany
Hemolytic uraemic syndrome	Australia, Britain, New Zealand, Switzerland
Hirschsprung's disease	Australia
Histiocytosis	Latvia
HIV/AIDS	Australia, Britain, Latvia, Malaysia, Netherlands, Papua New Guinea
Idiopathic and congenital nephrotic syndrome	Australia
Inflammatory bowel disease	Netherlands, Britain
Invasive pneumococcal infections	Germany
Ischaemic stroke in infants	Germany
Leukemia	Latvia
Malignant disease	Wales
Marfan syndrome	Wales
Medullary sponge kidney	Latvia
Multiple sclerosis	Germany

Necrotising enteritis	Papua New Guinea
Neurologic endemic cretinism	Papua New Guinea
Neonatal herpes simplex	Australia
Neonatal meningitis	Malaysia
Neural tube defects	Netherlands
Organoaciduria and fatty acid oxidation defects	Germany
Paediatric pulmonologic disease	Latvia
Perinatal exposure to HIV	Australia, New Zealand
Pertussis	Netherlands
Polycystic kidney disease	Latvia
Prader-Willi syndrome	Australia
Progressive intellectual and neurological deterioration/CJD	Britain, Canada
Renal tubular acidosis	Papua New Guinea
Retinopathy of prematurity	New Zealand
Reye syndrome	Britain
Severe/fatal allergic reactions to food ingestion	Britain
Severe visual impairment and blindness	Britain
Subdural haematoma and effusion <2 years	Britain
SSPE	Britain, Canada, Papua New Guinea
Subdural haemorrhage	New Zealand, Wales
Tuberculosis	Latvia, Wales
Transient myeloproliferative syndrome	Germany

List of (possibly obsessive) Clinicians with 100% Return Rate 2000 (& 1999)

Thank you to those clinicians who returned all their cards in 2000

George	Abbott
Richard	Aicken
Geoff	Aiken
Elizabeth	Allen
Mohammad	Ansarian
Jeremy	Armishaw
Nicola	Austin
Nick	Baker
David	Barry
John	Barry
Giles	Bates
Malcolm	Battin
Spencer	Beasley
Nick	Birchall
David	Bourchier
Stephen	Bradley
Roland	Broadbent
Jeff	Brown
Leo	Buchanan
Cass	Byrnes
Louise	Calder
Eleanor	Carmichael
Terry	Caseley
Simon	Chin
John	Clarkson
Jenny	Corban
Robin	Corbett
Joan	Corrie
Tony	De Sylva
Joanne	Dixon
John	Doran
Alan	Drage
Dawn	Elder
Robin	Fancourt
Alan	Farrell
Rodney	Ford
Stephanie	Gapes
Raewyn	Gavin
Tom	Gentles
John	Gillies
John	Goldsmith
Keith	Grimwood
Alistair	Gunn
Jane	Harding
Ian	Hassall
Paul	Heaton
Peter	Heron
Warwick	Hunter
Peter	Jankowitz
Andrew	Kelly
Archie	Kerr
David	Knight
Anne	Kolbe
Carl	Kuschel
Graeme	Lear
Hugh	Lees
Diana	Lennon
Alison	Leversha
Allen	Liang
Roelof	Lourens
Scott	Macfarlane
Neil	MacKenzie
John	Malcolm
Stuart	Malcolm
Fraser	Maxwell
John	McArthur
Peter	McIlroy
Jill	McKie
Lindsay	Mildenhall
Ed	Mitchell
Philip	Moore
Johan	Morreau
Philip	Morrison
Chris	Moyes
Fred	Nagel
David	Newman
John	Newman
Peter	Nobbs
Penny	Palmer
Alan	Parsons
Philip	Pattemore
Ralph	Pinnock
Kevin	Pringle
Ram	Ramadas
Simon	Rowley
Susan	Rudge
Bernadette	Salmon
Elizabeth	Segedin
Roslyn	Selby
Ian	Shaw
Robyn	Shaw
Jan	Sinclair
Jane	Skeen
Jon	Skinner
Oliver	Smales
Thorsten	Stanley
Michael	Sullivan
Barry	Taylor
Prakash	Thiagarajan
Paul	Tomlinson
Bobby	Tsang
Vicki	Tyrrell
Lesley	Voss
Wendy	Walker
Alison	Wesley
Phillip	Weston
Elizabeth	Wilson
Ross	Wilson
Maisie	Wong
William	Wong

Congratulations to Giles Bates who was selected at random to win a $50 book token to be presented at the AGM of the Paediatric Society of New Zealand.