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Preface

Welcome to the 2002 Annual Report of the New Zealand Paediatric Surveillance Unit. This is the 5th of its kind since the Unit was established in 1997.

Surveillance of acute flaccid paralysis (AFP) has been undertaken since October 1997 for the Ministry of Health's National Certification Committee for the Eradication of Poliomyelitis (NCCEP). It has also been undertaken for other conditions introduced since that time, most of which have been for paediatricians with a particular research interest.

Some key findings in this report are:

Ongoing studies

Acute Flaccid Paralysis (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.
    - There were 11 true cases of AFP in New Zealand in 2002, giving an incidence of 1.29 per 100,000 children <15 years.
    - All cases were excluded as Poliomyelitis.
    - All cases were from the North Island.

Bronchiectasis

- There were 52 true cases of Bronchiectasis notified over an 18 month period to the end of June 2002.

Haemolytic Uraemic Syndrome (HUS)

- There were 11 confirmed cases of HUS in 2002. The annual incidence in 2002 was almost double that of 2001.

Idiopathic Nephrotic Syndrome (INS)

- There were 23 confirmed cases of INS reported during the first 22 months of the study, male to female ratio 2.3:1.

Inflammatory Bowel Disease (IBD)

- There were 26 cases of IBD notified in 2002, information has been received on 17.
- Of the 17 confirmed cases, 11 were diagnosed with Chron's disease, 2 with ulcerative colitis and 4 with indeterminate colitis.
- M:F ratio 1:1.4

Perinatal HIV Exposure

- There were 10 notifications of Perinatal HIV Exposure in 2002, 2 of which were infected children born overseas and 2 were late reports of babies born in 2001.
- All 6 babies born in NZ were born to mothers whose HIV had been diagnosed before the pregnancy and none of the babies have been found to be infected with HIV.

Vitamin K Deficiency Bleeding (VKDB)

- There were 5 true cases of Vitamin K Deficiency Bleeding reported to NZPSU in 2002.
    - Two were of classic type and three were late onset.

Completed studies

Kawasaki Disease

- There were 48 confirmed cases of Kawasaki Disease (KD) notified to NZPSU over the two year study period which gives a rate of 2.8 per 100,000 children under 15 years of age in NZ.
- M:F 1.9:1
- Age range 2 months to 11 years.
- 70.2% North Island, 29.8% South Island.
- KD was diagnosed at a mean of 7.2 days from the onset of illness (range 0-39 days).

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 and this led to the establishment of the New Zealand Paediatric Surveillance Unit (NZPSU) 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 ten rare childhood conditions.

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 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.

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 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 are reported, the reporting clinician is 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 ten conditions under surveillance in 2002.

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
Professor 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 2002

In 2002, 189 clinicians (including 11 Neurosurgeons) participated in the system. The average response rate to the monthly report card/email was 95%, 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 DHB) 2001 & 2002

Health Locality	**2001**	**2002**
	%	**%**
Northland, Auckland, Waitemata, Counties Manukau	91	94
Waikato, Bay of Plenty, Taranaki, Lakes	94	93
Capital and Coast, Hutt, Wairarapa, Whanganui, Tairawhiti, Hawkes Bay, MidCentral	94	97
Nelson Marlbourgh, Canterbury, South Canterbury, West Coast	95	97
Otago, Southland	99	95
TOTAL	94.8	95.2

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.

Figure 1 shows the percentage of clinicians on the mailing list that reported cases during 2001 and 2002. The figure shows that in 2002 fifty-one percent of the participants did not report any cases, with 38% reporting between one and three cases.

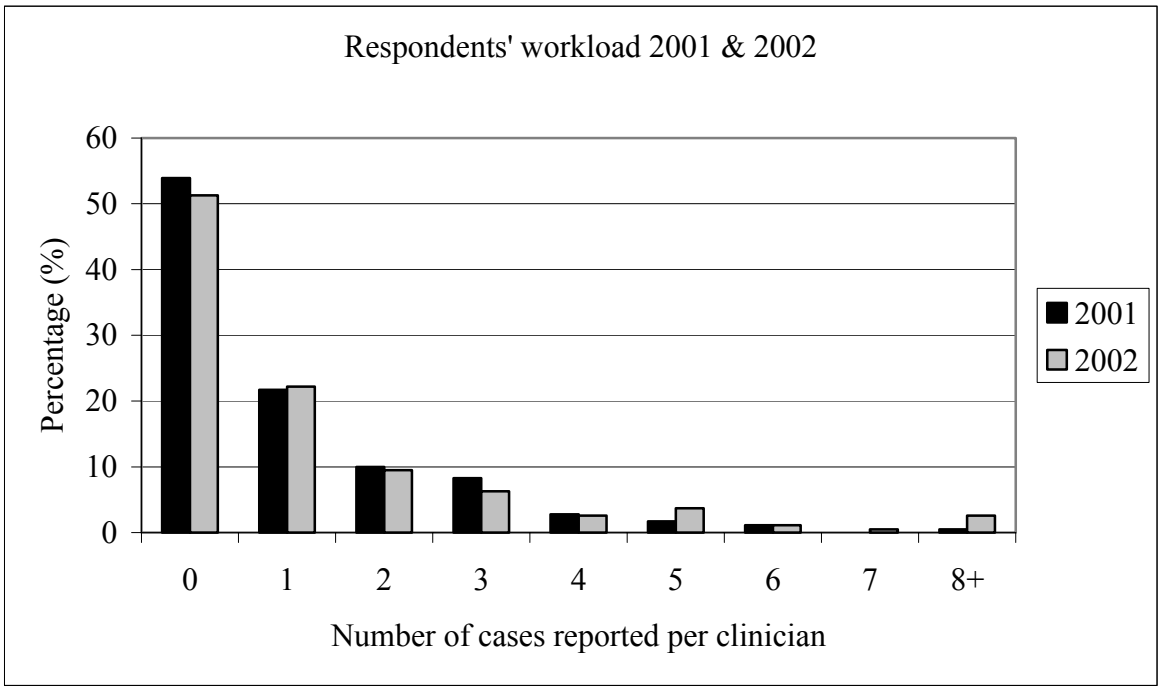

Figure 1: The percentage of clinicians that reported cases during 2001 and 2002

In 2002, NZPSU monitored 10 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 2002

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
Kawasaki disease (< 15 years)	January 2001	Dr Paul Heaton
Bronchiectasis (<15 years)	January 2001	Dr Cass Byrnes
Idiopathic nephrotic syndrome (<15 years)	July 2001	Dr William Wong
Inflammatory bowel disease (<15 years)	January 2002	Dr Alison Wesley

Brief Reports on Selected Conditions

We have not provided a report for Congenital Rubella as there were no cases reported in 2002.

Acute Flaccid Paralysis

Dr Nigel Dickson, Melissa Carter

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 poliomyelitis, of at least 1 per 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 2002

- There were 14 cases notified to the NZPSU in 2002, of which 3 cases did not fit the criteria for AFP.
- Information has been obtained on all of these children including follow up information two months after diagnosis.
- All 11 true AFP cases were from the North Island.
- 4 males, 7 females (Ratio 1:1.75 M:F).
- Age range 8 months to 11 years, median age 4.5 years.
- No seasonal variation.
- The overall incidence was 1.29 per 100,000 children <15 years.
- A diagnosis of Gullain-Barre syndrome (GBS) has been made in 7 of these cases, transverse myelitis in 2, and acute demylinating encephalomyelitis (ADEM) in the remaining 2 cases.
- All 11 cases have been discounted as Polio by the National Certification Committee for the Eradication of Polio (NCCEP).
- Analysis of stool samples satisfying the WHO criteria was only complete for 6 of the 11 children (see Table 4).

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

Category	Stool samples	
	n	%
2 stool samples within 14 days of onset of paralysis	6	55
2 stool samples, but one or both not within 14 days of onset of paralysis	2	18
1 stool sample	0	0
No stool samples	3	27

Comment

The system successfully captured the required rate of AFP, however, the rate of stool testing (55%) is not yet meeting the WHO criteria (80%). 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 the WHO believes Polio to have been eradicated from the Western Pacific region, 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.

Bronchiectasis

Dr Cass Byrnes, Dr Jacob Twiss

Final year of a two-year study
Report for period 01/01/2001 – 01/07/2002

There were 62 bronchiectasis notifications (this excludes children with cystic fibrosis) for this report period (18 months). Ten of these were later excluded (4 because diagnosis was outside study period, 2 because the radiologist did not confirm bronchiectasis, 1 was notified in error and 3 were duplicate notifications) leaving 52 true notifications. Information is awaited on 2 cases.

The following data are from the information provided by questionnaires one year after diagnosis, and figure 2 (below) includes the remainder of 2002 for perspective.

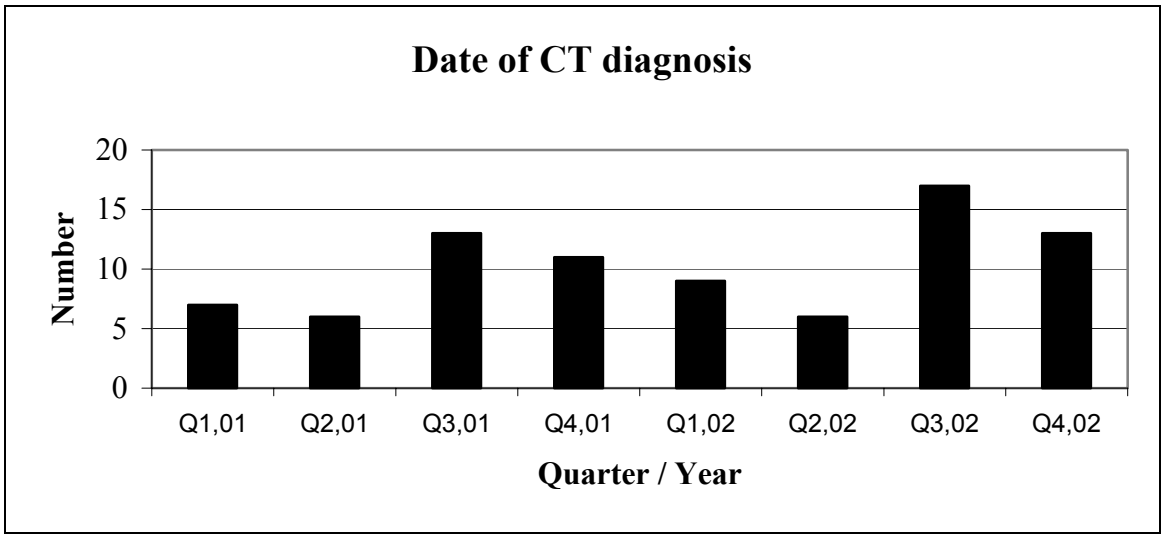

Figure 2: The number of CT scans performed per quarter

Not surprisingly, more bronchiectasis was diagnosed during and after winter, often following hospital admission or presentation with respiratory infection (see figure 2 above).

Gender
There was a male to female ratio of 1:1.3.

Geography
85% of individuals were NZ born; 62% (32) were currently living in Auckland.

Age at diagnosis
About one third (34%) of the children were below the age of 5 years at diagnosis, half (54%) between 5 and 12 yrs, and the remaining 12% 13 yrs or greater.

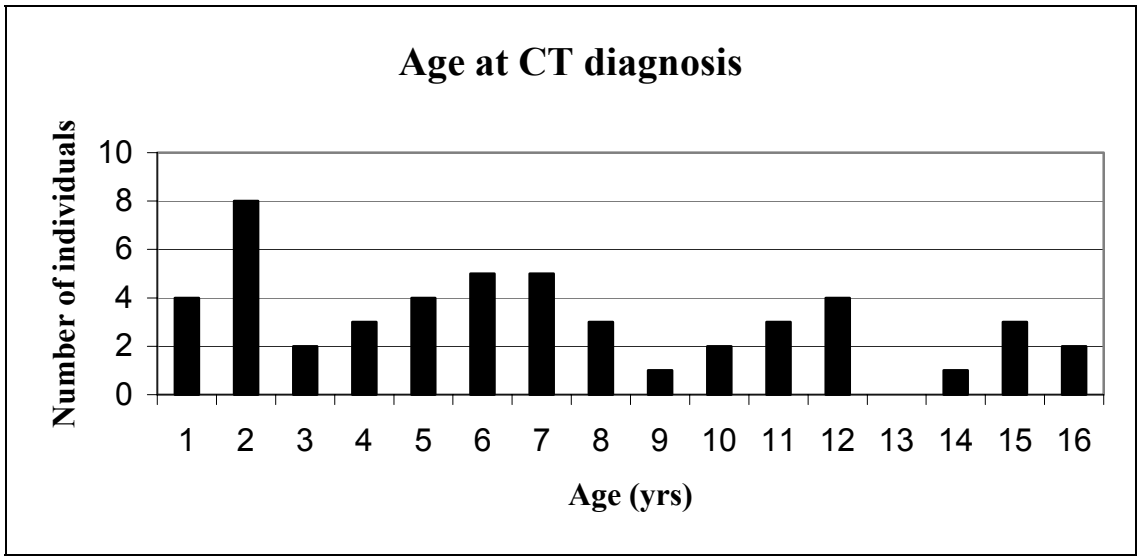

Figure 3: Age at CT diagnosis

Cough and hospitilization

22% had had a persistent cough for more than 5 years at the time of diagnosis, 52% of individuals for less than 2 years, and nearly 30% less than 6 months. 37% had been hospitalized in their first 2 years of life with respiratory infection while 17% had never been.

Ethnicity

Nearly half of the children diagnosed were Pacific, and of these, half were Samoan and the remainder Cook Island Maori, Tongan, and Fijian. Just under a third were Maori and a fifth of European ethnicity.

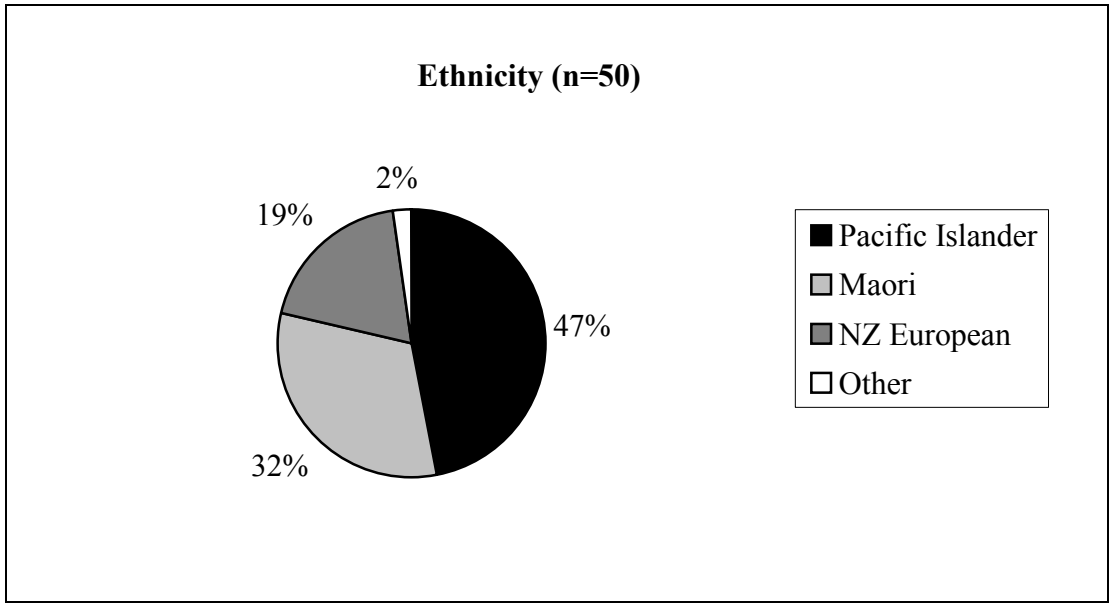

Figure 4: Ethnicity of children diagnosed with bronchiectasis

Extent

High resolution CT scoring is incomplete and yet to be analysed. However based on the questionnaires returned, 73% had bilateral disease, 80% had multilobular involvement with both lower lobes, and the right middle lobe was most commonly affected.

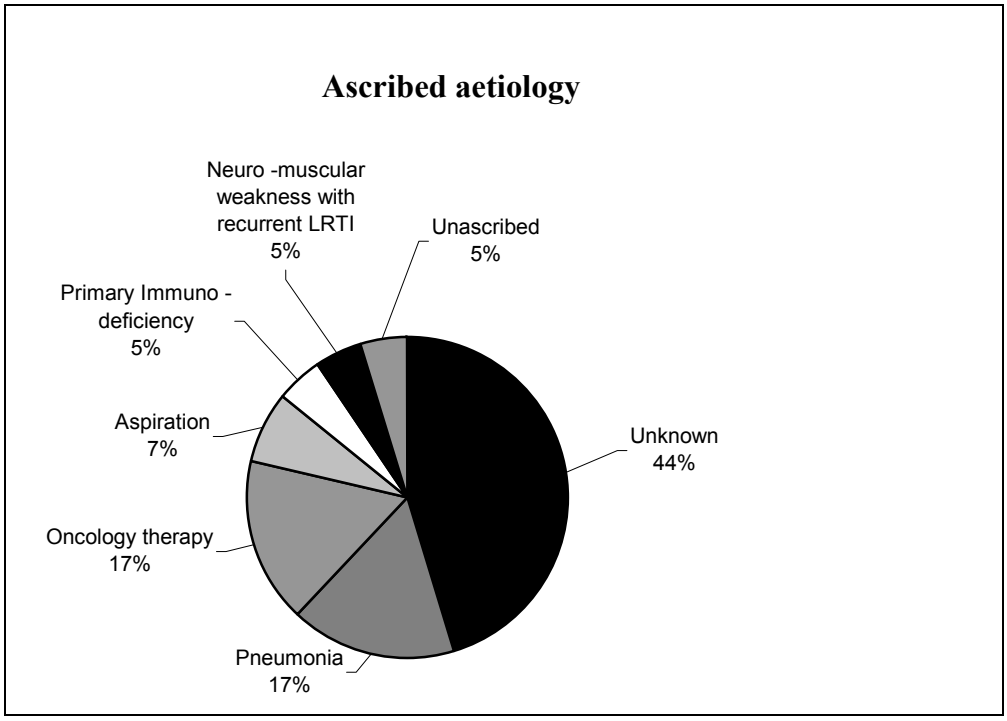

Figure 5: Ascribed aetiology

Aetiology

Aetiologies ascribed by the paediatrician completing the questionnaire are summarized here:

'Pneumonia' was the largest 'known' group, and was considered to be the cause for seven children. This was due to adenovirus in four children, pertussis in two, and tuberculosis in one.

Data yet to be analysed (study period incomplete) includes microbiology and immunology data, the results of HRCT scoring, lung function and growth. We will provide further analysis, including relating diagnosis rates with population size, at that time.

Summary of interim analysis

Over the 18 month period reported here, 52 verified notifications were received. Diagnosis was most common in early childhood and in those of Maori or Pacific Island ethnicity. Duration of cough was not always easily determined, however while some had prolonged cough, many had persistent cough for a year or less. Nearly ¾ had bilateral multilobular disease, more extensive than reported in the international literature. Notifications were received from throughout the country but the majority (61%) were from greater Auckland. In most, the aetiology remained unknown a year

after diagnosis. Interestingly, oncology therapy was an association in a significant number (17%) of those notified. We look forward to completing the follow up, radiological review and presenting the full results.

Thanks to all paediatricians participating in the surveillance programme for their support of this study.

Haemolytic Uraemic Syndrome

Dr William Wong

Ongoing study started in January 1998

In 2002, eighteen notifications of haemolytic uraemic syndrome (HUS) were made to the NZPSU of which 11 were confirmed cases. The annual incidence of HUS during 2002 increased by almost 200% when compared with 2001 when there were 6 confirmed cases. The geographic features of the cases remain unchanged with the majority reported from the North Island. There was one patient from the Southland region. There continues to be no seasonal pattern to the cases. The mean age at presentation is 7 years. The median interval from onset of symptoms to diagnosis was 7 days (range 7-25). One patient whose diagnosis was delayed for more than 3 weeks, skewed the time to diagnosis.

Idiopathic Nephrotic Syndrome

Dr William Wong

First full year of a two year study started in July 2001

The surveillance study for childhood idiopathic nephrotic syndrome commenced in July 2001. In the first 22 months of the study, there have been 29 notifications to the NZPSU, of which 23 cases (16 males and 7 females) have been confirmed with nephrotic syndrome. Sixteen of the 23 parents consider themselves to be New Zealand European. None of the children had a family history of nephrotic syndrome. A wide variety of occupations were reported for each parent. The mean age at presentation is 6.8±4.1 years. All had normal renal function at time of presentation and only 2 were hypertensive. There was no family history in any of the patients. Microscopic haematuria was initially detected in 18 of 22 patients. All patients except for one were treated with 1.5-2.0mg.kg/day of prednisone, with the most common regimen being 2mg/kg/day given once daily until remission. The majority (14/22) were given antibiotic prophylaxis with only a minority administering or planning to administer pneumococcal vaccine.

Inflammatory Bowel Disease

Dr Alison Wesley, Dr Stephen Mouat, Dr Jason Yap

First year of a two-year study

In 2002, there were 26 notifications of inflammatory bowel disease from paediatricians. To date questionnaires have been received for 17 children meeting the criteria for this condition. Adult gastroenterologists have been approached to notify cases of children for whom they have cared.

Table 5: Number of notified cases of Inflammatory Bowel Disease

Total notified	26
Complete	17
Error	1
Duplicate	3
Diagnosed out of study time frame	2
No reply/awaited	4

Of the 17 children notified:

- 11 were diagnosed with Crohn's disease, 2 with ulcerative colitis and 4 with indeterminate colitis.
- 10 were female and 7 were male.
- 14 were European, 1 was Indian, 1 Maori, and for one child the ethnicity was not stated.
- The mean age at diagnosis was 10.1 years. The youngest patient was 2.8 years and oldest 14.4 years.
- The average time between onset of symptoms and diagnosis was 1 year. The average delay from time of first presentation to diagnosis was 7 months.

Comments

One year follow-up questionnaires are being sent out to the reporting doctors. The study will be completed in December 2003 with final analysis of data undertaken thereafter. This study will provide useful information on this group of conditions among children and young people in New Zealand.

Perinatal exposure to HIV

Dr Nigel Dickson

Ongoing study started in January 1998

In 2002, there were 10 notifications of infants/children born to women infected with HIV, of whom 2 were of infected children born overseas, and 2 were late reports of babies born in 2001.

Of the 6 babies born in New Zealand in 2002:

- All were born to mothers whose HIV had been diagnosed before the pregnancy.
- Three of the mothers were from parts of the world where HIV is particularly prevalent.
- All of the mothers were given antiretroviral treatment during pregnancy, 5/6 were delivered by Caesarian section and none were breast feed.
- None of these 6 children have been found to be infected with HIV.

How these reports, and the data on children with later diagnosed perinatal HIV born in New Zealand, can give an indication of the proportion of HIV among pregnant women currently being diagnosed has been published in the New Zealand Public Health Reports. Part of the abstract is reproduced below.

> "On the basis of reports of known births to HIV infected women during 1998-2001, and the number of infected children born in New Zealand who have developed AIDS, we have estimated an overall prevalence of HIV among women giving birth. This estimate is 1.5 to 4.0 per 10,000, with 45% to 80% not diagnosed before giving birth. Based on these figures, if all these were detected, an additional 4 to 18 pregnant women would be diagnosed with HIV annually and could be offered effective antenatal care. If interventions to prevent perinatal transmission were taken up by all of these women it is estimated that on average 5 perinatal infection could be prevented every 3 years."
>
> *Dickson N, Paul C, Wilkinson L, Voss L, Rowley S. Estimates of HIV prevalence among pregnant women in New Zealand. New Zealand Public Health Reports, 2002;9:17-19*

Currently the National Health Committee is reviewing whether more widespread testing of HIV among pregnant women should be advocated.

Vitamin K Deficiency Bleeding

Professor Brian Darlow

Ongoing study started in January 1998

There were eight notifications of Vitamin K deficiency bleeding (VKDB) received in 2002; one report was not valid and two cases were each reported twice, hence there were five valid cases.

- Two cases were of classic type with neither infant receiving any vitamin K prophylaxis and both infants being fed only breast milk. In both infants bleeding resolved after i.m. vitamin K and there were no further complications.
    - One infant was born at term, consent for vitamin K was withheld and bleeding occurred on day 3 from heelprick sites following capillary glucose monitoring.
    - One infant was born at 32 weeks gestation, vitamin K was omitted although consent was not withheld and gastrointestinal bleeding occurred at 20 hours of age.

- Three cases were late onset, presenting between 21 days and 3 months; all three infants were exclusively breast fed, two had significant liver disease and two presented with intracranial bleeding and have ongoing morbidity.
    - One infant received i.m. vitamin K at birth and presented with nose bleeding at 3 months. This infant had significant liver disease of unknown cause and required repeat doses of vitamin K.
    - Two infants received no vitamin K, in one case following professional advice but in the other case clearly against such advice. Both infants suffered intracranial bleeding, at 21 and 30 days, and have subsequently had hydrocephalus. One infant had obstructive liver disease.

Editorial note: Over the four year period 1999 to 2002 there have now been 7 infants reported with probable or definite early onset/classical VKDB and 5 with late onset VKDB.

Final Reports for Completed Studies

We have not provided a final report for Subdural Haemorrhage (<2 years) here as a final report is not yet available. A final report will be published in the 2003 Annual Report.

Kawasaki Disease

Dr Paul Heaton

Final year of a two-year study

There were 58 notifications of Kawasaki Disease in total. Completed questionnaires have been returned in 55 cases, in two cases the clinical notes were untraceable, and one questionnaire has not been returned. In 42 cases the diagnosis of Kawasaki Disease (KD) was considered to be definite, in four probable (not all clinical criteria fulfilled but clinically considered and treated as KD), and in two possible (late presentation but clinically considered and treated as K.D.). There were three duplicate notifications and in four cases K.D. was thought not to be the diagnosis.

Of the 48 new cases:

- 31 were male, 16 female (M:F 1.9:1). Gender was not specified in one case.

- Age range was 2 months to 11 years. 13 cases (27%) were aged less than one year and 41 (85.4%) were less than five years.

- The month of onset of the illness was Dec-Feb in 12 (25%) cases, Mar-May in 18 (37.5%), Jun-Aug in 7 (14.6%) and Sep-Nov in 11 (22.9%).

- When documented the place of residence was North Island in 33 cases (70.2%) and South Island in 14 (29.8%).

- Ethnicity was documented for 44 children (91.6% of all cases). Of these 44, 21 (47.7%) were identified as NZ European, 13 (29.5%) were Maori, 9 (20.4%) were Pacific Islander (4 Samoan, 3 Tongan, 1 Niuean, 1 Fijian) and 5 (11.4%) Oriental (2 Korean, 2 Chinese and 1 Japanese). Four children were of mixed race (3 Maori/European, 1 Maori/Samoan).

- K.D. was diagnosed at a mean of 7.2 days from the onset of the illness (range 0-39 days). In 40 cases (83.3%) the diagnosis was made before the eighth day of illness. The diagnosis was made within two days of admission to hospital in 31 cases (64.6%).

- Only two children had any cardiac symptoms or signs at the time of diagnosis, one with pericarditis and the other (diagnosed post mortem) with cardiac failure.

- Of the 30 cases where ECG was performed and the result documented 29 had no abnormality and one had sinus tachycardia.

- Echocardiography was performed in every case. The first examination was performed at a mean of 21 days from the onset of the illness (range 3-106 days), and was reported as being normal in 30 cases (62.5%). Of the 18 cases with abnormalities, 12 had (usually mild) dilatation of one or more coronary arteries, two had pericardial effusions, one mild aortic regurgitation, one mild mitral regurgitation, one mild left ventricular dilatation and one (fatal case) atrial septal defect and aneurysmal fossa ovale.

- A second echocardiogram was performed in 20 cases at a mean of 37 days from the onset of the illness (range 6-82 days) and was normal in 13 cases. Of the 7 with abnormalities 6 had mild coronary artery dilatation and one had reduced ejection fraction. In two cases the patient failed to attend a second echocardiogram, two cases the investigation had been requested but not yet performed and one patient moved overseas before the test had been performed. In nine cases the first and second scans both showed no abnormality, in six both showed an abnormality, in four the first scan was abnormal but the second was normal. In one case the initial scan on day six of illness was normal but the second on day 29 showed coronary artery dilatation.

- A third echocardiogram had been requested in five cases at a mean of 91 days from the onset of illness (range 51-188 days), three showed no abnormalities, the other two had continued but improving coronary artery dilation.

- 44 cases were treated with IVIG (usually 2g/Kg) and aspirin. In 38 (88% of those who received IVIG) treatment was given within 7 days of the onset of the illness and at a mean of 1.9 days of admission. Of the four not treated with IVIG, three were late presentations on days 20, 38 & 39 of illness and the fourth was an atypical case in whom the diagnosis of K.D. was made post mortem.

- One child died aged 3 months, on day 22 of illness. This was an “atypical” case in which the diagnosis was made post mortem following death from myocardial infarction due to accelerated vaso-occlusive disease affecting coronary and mesenteric arteries. The case-fatality rate was 2%.

Comments

There will be a full report when the analysis has been completed. Current data suggests that approximately 24 new cases of K.D. occur in New Zealand children each year. The disorder affects boys more frequently than girls. Preschool children account for most cases with infants less than 1 year being at greatest risk. It occurs throughout the year though with a vernal preponderance, and shows no geographical predominance. All ethnic groups are affected but children with Pacific Island and Oriental origins are at increased risk. Admission to hospital, diagnosis and appropriate treatment usually occur in a timely manner. Cardiac symptoms and signs, also ECG abnormalities are rare. There is considerable variability in the timing and frequency of echocardiography. Despite timely diagnosis and treatment, coronary artery abnormalities, though usually minor, are commonly seen. The fatal case of accelerated vaso-occlusive disease is of particular concern.

Conditions ever monitored by NZPSU

Table 6: All conditions ever monitored by NZPSU

Condition	Abb.	Commenced	Concluded
Acute flaccid paralysis	AFP	October 1997	Ongoing
Haemolytic uraemic syndrome	HUS	January 1998	Ongoing
Congenital rubella syndrome	CRS	January 1998	Ongoing
Perinatal HIV exposure	HIV	January 1998	Ongoing
Vitamin K deficiency bleeding	Vit K	January 1998	Ongoing
Neonatal herpes simplex infection	HSV	January 1998	December 2000
Subdural haemorrhage (<2 years)	SDH	January 1999	December 2002
Retinopathy of prematurity (stage III)	ROP	January 1999	December 2000
Diabetes mellitus	DM	January 1999	December 2000
Fetal alcohol syndrome	FAS	July 1999	December 2001
Kawasaki disease	KD	January 2001	December 2002
Bronchiectasis		January 2001	December 2002
Idiopathic nephrotic syndrome	INS	July 2001	Ongoing
Inflammatory bowel disease	IBD	January 2002	Ongoing

Note: all conditions monitored for children <15years unless otherwise stated.

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 7). 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 meeting was held in Ottawa in 2000 sponsored by the Canadian Government and attended by Dr Nigel Dickson and Nicola Dow. A further meeting was held in York in 2002 and attended by Dr Nigel Dickson.

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 7: Members of INoPSU

Country	Unit	Email	Website
Australia	APSU	apsu@chw.edu.au	http://apsu.inopsu.com
Britain	BPSU	enquires@rcpch.ac.uk	http://bpsu.inopsu.com
Canada	CPSP	jo-anne_doherty@hc-sc.gc.ca	www.cps.ca/english/proadv/CPSP/CPSP.htm
Germany	ESPED	ag.epi@lrz.uni-muenchen.de	www.esped.uni-duesseldorf.de/
Ireland	IPSU	gilld@iol.ie	
Latvia	LPSU	aspedlat@com.latnet.lv	
Malaysia	MPSU	jho@pc.jaring.my	
Netherlands	NSCK	r.pereira@pg.tno.nl	
New Zealand	NZPSU	nzpsu@stonebow.otago.ac.nz	www.paediatrics.org.nz
Papua New Guinea	PNGPSU	hopepng@datec.com.pg	www.hopeww.org/where/png/png5.htm
Portugal	PPSU	ana.moreira@sb.com	
Switzerland	SPSU	hans-peter.zimmermann@bag.admin.ch	
Wales	WPSU	John.Morgan@eglam-tr.wales.nhs.uk	

INoPSU website: www.inopsu.com

Table 8: Characteristics of the Paediatric Surveillance Units

Country	Population ($x10^6$<15years)	Established	Approx. no respondents
Australia	3.9	1992	1040
Britain/Eire	12.8	1986	2200
Canada	6.3	1996	2350
Germany	12.0	1992	450*
Ireland	1.3	1996	150
Latvia	0.4	1996	22
Malaysia	7.7	1994	400
Netherlands	2.9	1992	410
Papua New Guinea	2.0	1996	40
Portugal	1.8	2000	2000
New Zealand	0.9	1997	179
Switzerland	1.3	1995	40*
Wales	0.6	1995	135*

* Heads of Paediatric Centres

Table 9: Conditions under surveillance worldwide 2002

Conditions under surveillance	Country
Acute flaccid paralysis	Australia, Canada, Netherlands, New Zealand, Papua New Guinea, Switzerland
Acute rheumatic fever	Switzerland
Adverse effects from complementary or alternative medicine	Australia
Aplastic anaemia	Latvia
Anaphylaxis	Canada
Anaphylaxis following food injestion	Australia
Atypical mycobacterial infections	Netherlands
Bronchiectasis	New Zealand
Cerebral edema in diabetic ketoacidosis	Canada
Cerebral vascular disease/stroke and like illness	Britain
CHARGE association/syndrome	Australia, Canada
Childhood conversion disorder	Australia
Childhood tuberculosis	Wales
Childhood inflammatory bowel disease	New Zealand
Children hospitalized for early onset eating disorder	Australia
Coelic disease	Ireland
Congenital cytomegalovirus infection	Australia, Britain
Congenital hypothyroidism	Papua New Guinea
Congenital rubella	Australia, Britain, Canada, New Zealand, Switzerland
Congenital syphilis	Latvia
Congenital toxoplasmosis	Britain
Diabetes mellitus/insulin-dependent/<5 years	Germany, Latvia, Papua New Guinea, Portugal, Wales
Diaphragmatic hernia	Ireland
Facial palsy	Wales
Fetal alcohol syndrome	Australia
GLUT-1 deficiency/de vivo disease	Germany
Group B streptococcal infections (neonatal)	Portugal, Germany
Haemolytic Uraemic Syndrome	Canada, Latvia, New Zealand, Portugal, Switzerland
Haemorrhagic disease of the newborn (vitamin K deficiency Bleeding)	Australia, Britain, Germany, New Zealand
Hepatitis C virus infection	Canada
Histiocytosis X	Latvia
HIV/AIDS +/- perinatal exposure to HIV	Australia, Britain, Malaysia, Netherlands, New Zealand, Papua New Guinea
Hodgkin's disease	Latvia
Hospitalized pertusis	Netherlands
Idiopathic juvenile osteoporosis	Germany
Idiopathic nephrotic syndrome	New Zealand
Imported tropical diseases: malaria, schistosomiasis, leishmaniasis	Germany
Ingestion of lamp oil (intoxications)	Germany

Inherited hypocalemic salt-losing tubulopathies/Bartter-like syndromes and narcolepsy	Germany
Internal abdominal injuries in children under 14 years	Britain
Intersexuality and severe genital malformations	Germany
Invasive *Haemophilus influenzae* infection	Germany
Ischaemic stroke in infants (neonatal sinus venous thrombosis)	Germany
Kawasaki Disease	New Zealand, Portugal
Kernicterus	Germany
Leukaemia: ALL, AML	Latvia
Marfan syndrome	Wales
Munchausen by proxy syndrome	Australia
Necrotizing enterocolitis	Papua New Guinea
Necrotizing fascitis	Canada
Neonatal herpes simplex virus infection	Australia, Canada, Switzerland
Neonatal liver failure/perinatal hemochromatosis	Canada
Nephrocalcinosis	Ireland
Neural tube defects	Netherlands, Switzerland, Ireland
Neurological endemic cretinism	Papua New Guinea
Newly diagnosed malignant disease	Wales
Non-Hodgkin's lymphoma	Latvia
Phenylketonuria	Latvia
Pneumococcal sepsis/meningitis	Germany
Progressive intellectual and neurological deterioration/CJD	Britain, Canada
Renal tubular acidosis	Papua New Guinea
Rett syndrome	Australia
Reye syndrome	Latvia
RSV disease requiring intubation and artificial ventilation; severe	Germany, Switzerland
Severe complications of medical therapy	Netherlands
Smith-Lemli-Opitz syndrome	Canada
Status epilepticus	Ireland
Steroid resistant nephrotic syndrome	Germany
Subacute sclerosing panencephalitis	Papua New Guinea
Subdural haemorrhage	New Zealand, Wales
Suspected fatal adverse drug reactions	Britain
Thrombosis in childhood	Britain
Tick-borne encephalitis	Switzerland
Transient myeloproliferative syndrome in newborns with Down syndrome	Germany
Tuberculous meningitis	Ireland
Varicella/zoster infection/complications	Switzerland, Britain

List of Clinicians with 100% Return Rate 2002 (& 2001)

Thank you to those clinicians who returned all of their cards in 2002

Aftimos	Salim	Gunn	Alistair	Nicolls	Wayne
Aho	George	Heron	Peter	Nutthall	Gabrielle
Aiken	Geoff	Hewson	Michael	Palmer	Penny
Ansarian	Mohammad	Hofman	Paul	Parsons	Alan
Austin	Russell	Hunter	Warwick	Pattemore	Philip
Baker	Nick	Jackson	Pam	Pitcher	Lydia
Barry	David	Jackson	Suzanne	Pringle	Kevin
Barry	John	Jamison	David	Radcliffe	Marlon
Bates	Giles	Jankowitz	Peter	Ramadas	Ram
Battin	Malcolm	Kelly	Andrew	Richardson	Vaughan
Beasley	Spencer	Kelly	Patrick	Rowley	Simon
Bok	A.	Kerr	Archie	Sadleir	Lynette
Bourchier	David	Klimek	Jan	Sadowsky	Joel
Breen	Felicity	Kolbe	Anne	Segedin	Elizabeth
Broadbent	Roland	Kuschel	Karl	Selby	Roslyn
Brown	Jeff	Langdana	Anu	Shaw	Robyn
Buchanan	Leo	Leadbitter	Philip	Shillito	Paul
Buckley	David	Lear	Graeme	Simpson	A. K.
Byrnes	Cass	Lennon	Diana	Sinclair	Jan
Calder	Louise	Leversha	Alison	Skeen	Jane
Campanella	Silvana	Liang	Allen	Skinner	Jon
Campbell-Stokes	Priscilla	MacFarlane	M.	Smales	Oliver
Caseley	Terry	MacFarlane	Scott	Smith	D. Warwick
Charles	Keith	Maikoo	Rejesh	St John	Martyn
Chin	Simon	Malcolm	Stuart	Stanley	Thorsten
Clark	Phillipa	Manikkam	Noel	Sullivan	Michael
Clarkson	John	Mao	M.	Teague	Lochie
Coleman	David	Marks	Rosemary	Thiagarajan	Prakash
Corbett	Robin	Maxwell	Fraser	Tomlinson	Paul
Coulter	Belinda	McArthur	John	Tsang	Bobby
Dalton	Marguerite	McKie	Jill	Tuck	Roger
Darlow	Brian	Mee	E.	Tyrrell	Vicki
De Sylva	Tony	Meyer	Michael	Vogel	Alison
Dixon	Joanne	Mildenhall	Lindsay	Voss	Lesley
Doran	John	Miles	Fiona	Watson	Peter
Farrell	Alan	Mitchell	Ed	Watt	Mike
Finnis	N.	Montgomery	David	Webster	Diane
Ford	Rodney	Moore	Philip	Wesley	Alison
Gavin	Raewyn	Morris	Max	Weston	Phillip
Gentles	Tom	Morrison	Philip	Wickremesekera	A.

Gillies	John	Nagel	Fred	Wills	Russell
Goldsmith	John	Neutze	Jocelyn	Wilson	Callum
Graham	David	Newman	David	Wilson	Nigel
Grimwood	Keith	Nicholson	Ross	Wilson	Ross
				Wong	Maisie

Congratulations to Keith Charles who was selected at random to win a $50 book token to be presented at the ASM of the Paediatric Society of New Zealand.