

# New Zealand Addison's Network

## RESULTS OF THE NOVEMBER 2000 SURVEY (page 1)

Thank you all for a tremendous 80% return rate. There were eight questions.

**Question 1:** Since your diagnosis, have you ever had an Addison's Crisis that required emergency medical treatment or emergency hospitalisation?

**Question 2:** Other than the situation(s) you may have recorded in answer to Question 1, have there been any occasions when you have self-administered Solu-cortef (injectable hydrocortisone), or had it administered into a muscle (IM) or vein (IV) by a health professional (other than before a planned medical or dental procedure)?

The intention was not to include the situation surrounding diagnosis. These questions overlapped a bit, and we knew summarising the responses would be difficult. However, several members provided clear information about their experiences, that will be helpful for others.

62% (34/55) have not experienced crises or had IM/IV Solu-cortef other than as part of planned procedures.

Eight respondents had Solu-cortef injected at home, and three of these followed up with admission to hospital on at least one occasion.

- *Danielle says "I was very sick in bed and my doctor came round and injected it into a muscle. I became well again later that day."*
- *In the 14 years since diagnosis in her mid-40s, another member has had IM Solu-cortef injected 3 times at home by her GP or a district nurse, because severe diarrhoea and vomiting meant she couldn't keep down oral HC.*
- *Marjorie has had injections given at home by her doctor on 4 occasions over her long duration of Addison's – the most recent just 2 weeks before filling out her survey form.*
- *Dyan had IM/IV injections a few times in hospital during her childhood, and as an adult, given by her GP.*

Twelve were admitted to hospital in crisis, or for illnesses that could provoke crisis:

- *Caroline was "given a jab at home" – moving house was very busy and stressful. "I was staying with my brother, and it started with a bad headache,*

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- *then I lost my appetite, then I got very hot and very cold and felt bad all day. By midnight they had called the doctor... he knew what to do.”*
- *Ngari was admitted to hospital a couple of years ago because of vomiting and diarrhoea, presumably because of a tummy bug. She couldn't keep down a double dose of oral HC, and didn't have injectable at home. The 7 hour delay before she was given any HC at the hospital worried her. “The health care professional read my medic-alert, but still procrastinated.” Now she carries a letter from her specialist.*
- *Catherine had vomiting and diarrhoea due to food poisoning, and was admitted to hospital in 1998. Despite her medic alert ID, she was distressed by delays before she received hydrocortisone.*
- *Michael W was ill with flu, hadn't increased his oral HC – his GP involved his specialist, and he was promptly in hospital on a drip – and recovered quickly.*
- *Danielle was holidaying in Australia, not long after her diagnosis, and became dehydrated and exhausted. “The hospital staff were extremely helpful and seemed to know what Addison's was, and dealt with me very efficiently.”*
- *Lidy has a complex medical situation to deal with and frequent injections are part of her routine, unfortunately.*

Perhaps one record for Solu-cortef consumption goes to a member, who was diagnosed aged 35, and this February “celebrated 43 very active Addisonian years”. She experienced one or two crises most years. “*Christmas, New Year or Easter were regular. No education – instructed never to change dosage. I had wonderful doctors – they travelled 30 miles to our farm. Always I went to Auckland hospital... [But] I have never met a fellow Addisonian. One day I will pluck up courage. It is a different world for Addisonians today. I wish I knew then what I know now.*” Filling out her survey form was a struggle, as she had broken 2 bones in her wrist, due to a fall late November. “*Joke, when a recent bone density gave me 103%! I wish you well.*”

### **Question 3: Requests for team help**

Thank you to the several members who offered to help with the NZAN load. If we haven't been in touch yet, your name is on a special list.

### **Question 4: a) In principle, would you like to participate in a national conference in 2001?**

53% (29/55) reported interest in a national conference – but not all would be able to go to the same city for it.

### **b) Would you like to participate in a regional meeting for members and their family and friends, during 2001?**

75% (41/55) reported interest in regional meetings – a small number would not be able to make it to Auckland, Wellington or Christchurch. See the separate section above, for more information about planned regional meetings.

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### **Question 5: Are you willing for more detail to appear on the members' phone list published in the Update newsletters?**

- a) How many have used the phone list? 24% (13/55)
- b) Would you find the list more useful if it includes year of birth, age at diagnosis, and email address? Only 62% (34/55) responded clearly that they would – but it was a majority!
- c) If currently on the list, are you willing to have your year of birth and age at diagnosis included?

96% (46/48) of the respondents who are willing to be on the list, are happy for the extra details; 2 didn't want their extra information added, and we respect that.

- d) If you are currently on the list, and have an email address, are you willing to have that listed in the Updates too?

56% (27/48) said Yes. (We have 'unlisted' email addresses for another 8 members, so more than half NZAN's membership is on email at present!

- e) There were no responses here that hadn't been clarified in the earlier parts of the question.

### **Question 6: How did you first find out about NZAN?**

Endocrinologist/hospital clinic:	32	58%
Woman's day note (Dec 99)	7	13%
Internet	4	
GP	2	
Foundation member	2	
Work/personal connection	2	
Pharmacist friend	1	
Referred by NADF	1	
Unclear response	4	

### **Question 7: Has your pharmacist mentioned NZAN to you over the past 4 months?**

Only two people said yes – one being our pharmacist member Gary! But, as we've covered in the membership section, two pharmacists mentioned NZAN to friends, leading to 3 new members.

### **Question 8: Is there anything that you would like NZAN to do for Addisonians, that it is not currently doing?**

Food for thought! Thanks for positive feedback – and some good ideas.