

New Zealand Addison's Network

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NZAN Newsletter, March-April 2004 (No 21)

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From Professor Ian Holdaway, NZAN's Medical Advisor:

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Second Northern Regional Meeting in
Auckland, May 2003: pages 9-13

NZAN Regional Meeting

Lower Hutt, Sunday 2 May, 1-4pm.

organised by Gary Roselli, Central Region
Co-Ordinator, - Phone 04 565 1783,

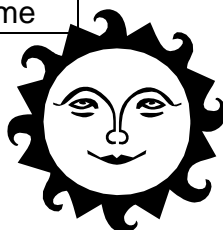
email pamandgary@xtra.co.nz

or contact Jeanette

All Addisonians, family and friends welcome

**Wishing you all good health,
Jeanette and the team**

Disclaimer: The content of NZAN Newsletters is intended as information and sharing of experience, and not as personal medical advice. We advise readers to consult their own doctor before making changes to their Addison's disease management programme



The 3 M's...members' stories, medical advisor contributions, and meetings...matter most!

Jeanette's comment

One day recently when I was feeling rather overwhelmed by the NZAN load I seem to have created, a beautiful card came in the post from Margaret Morison, with this letter inside:

Dear Jeanette

Felt I would like to share with you again, the celebration of 45 years with diagnosed Addison's. It really is a cause for celebration, especially when I remember the rather dour future they [gave] - the specialists I went before - with instructions on how to take your tablets, the illnesses that would send me back to them, and the possible side effects!! But I have done so many things - long trips overseas, a great deal of travel, went back teaching, worked for the Hospice, Red Cross, Save the Children, the Old Folk's Lunch each month. I brought up three children, watched my grandchildren grow up, attended the 'capping' of my oldest grand daughter in Dunedin and plan to be at the next two. I garden still, though on a much smaller scale, attend as many concerts as I can get to, and am in touch with many friends from my Grammar days. Life has been so good for me, I do wish everyone could be so fortunate. I thank you Jeanette for introducing me to NZAN. It has been a precious experience. My wish is it may continue to help people. Sorry about the writing - the eyes don't work very well. With all good wishes for you and NZAN.

Margaret Morison

Thank you, Margaret. So timely! You reminded me where NZAN's strength lies - in the human connections. Members have said over the years that they especially like (not necessarily in this order), members' personal stories, medical advisor contributions, and meetings.

Progress is continuing on all these fronts!

Members' stories...

In other members' stories, we find a lot of common ground. Realising we are not alone in our pesky experiences, we can get some aspects of our lives into better perspective. Newly diagnosed Addisonians can find some encouraging role models. The 22 stories to date now have their own direct access button on our website, and are also available to members as a printed A4 booklet.

Member's Stories – new compilation available

All the personal stories in our newsletters over the years have been crafted with care, and attention to detail and accuracy.

This newsletter contains number 22, Rosemaree's story.

We've copied the stories from the newsletters they originally appeared in, and they now also have their own direct button access on the newsletters page of our Web site.

This set of personal stories is also available printed on A4 and wire-bound – tick the box on your subscription invoice, and add \$10 if you'd like a copy posted to you.



Medical advisor contributions...

We are very fortunate to be able to tap into the extensive knowledge and experience of our medical advisor, Professor Holdaway. In the newsletters he answers members' questions, and gives medical comment on their experiences. He was keynote speaker at the Northern Regional Meeting in Auckland in 2001 and 2003. Topics on the tapes of his addresses, and his overhead transparencies, have been used at meetings in other centres. In this newsletter, we include some topics from the Open Forum at the Northern Regional Meeting in Auckland last May see pages 9-12.

**Medical Advisor
Resource Material available:**

All the material contributed to our newsletters by NZAN's medical advisors is accessible on the Newsletters page of our website – both within individual newsletters, and also as three separate compilations, downloadable from the section "Medical Advisor Q&A and Topics".

If you'd like a copy, and don't have access to a computer, contact Jeanette. We currently include printed copies of these files in our information packs.

AUDIO TAPES of Professor Holdaway's talk and the Q&A Forum at the Northern Regional Meeting in May03 are still available. These are a great resource, for people newly diagnosed, and for all Addisonians . Prof Holdaway's style is practical, and easy to listen to and understand.

Cost: \$15 for the 2 tapes of Prof Holdaway's address, including a photocopy of the overheads. \$5 for the Open Forum tape. [This is the price we paid for copying – no add-on]

Contact: Jeanette (address on front page)

Some tapes of Professor Holdaway's address at the 2001 Northern Regional Meeting are also still available – Contact Jeanette.



Meetings...

For many participants, an NZAN meeting has been their first encounter with other Addisonians. Some were cautious, doubtful, at first – but have quickly become enthusiastic about the value they've got from attending. Meetings provide updates and reminders on medical matters, practical tips, and an opportunity to compare notes with others. Time doesn't drag!

*Reprinted from Newsletter No. 16, July02:
Ngaire's comment to Jeanette after the first
Central Region Meeting in May 2002:*

"I've been diagnosed nearly 40 years, but it brought some things back to me that I've let slip – having the [Solu-Cortef] injection available, having a list of meds on the fridge. It reminded me to take care of myself. I do well, but I realise I could do better. I took a lady from nearby with us. She said as we headed in to the meeting 'I am so excited'." Kaye is one of our new members from the meeting.

A reasonable goal seems to be at least one NZAN meeting in each region, each year. See the box below for 2004 plans so far – in Lower Hutt, Bay of Plenty, Northland and Manawatu/Hawkes Bay.



Meetings planned for 2004 include:

* **Lower Hutt, Sunday 2 May, 1-4pm.** organised by Gary Roselli, Central Region Co-Ordinator,.

Members from the Wellington area and further afield are warmly welcome. The format will be similar to last year – a round of self-introductions, then facilitated discussion of topics participants raise, which may focus into questions to pass on to the medical advisor.

For more information, contact Gary, phone 04 565 1783. [or contact Jeanette]

You'll get more information about these meetings, later on:

Mt Maunganui, June, organised by Diane Goldsack, Midland Region Co-Ordinator,

Hawkes Bay/Manawatu.

Northland, organised by Maureen Bourgaize

Regional Co-Ordinators

We have been trying to get a handle on the way endocrinology services flow around the country, through the 21 district health board areas, especially outside the main cities. It's not an easy puzzle to try and put together!

We have learned that for some purposes the Ministry of Health uses four regions, based on the territories of the former regional health boards. It seems sensible for NZAN to follow the same 4 regions, each with a co-ordinator who'll work with Jeanette.

Jeanette is letting them know of enquiries and new members in their patch, and welcomes their proactive input:

Karen Carson (Auckland) for Northern Region,

Diane Goldsack (Mt Maunganui) for Midland Region,

Gary Roselli (Lower Hutt) for Central Region

We don't yet have a co-ordinator for the Southern Region. If you are interested, please contact Jeanette. Meanwhile, Gary and Jeanette will fill the gap.

Each region is composed of several districts, and so covers quite a large territory. We hope that some members will be interested and willing to have a co-ordinating role in their own district. Please contact your regional co-ordinator, or Jeanette.

Karen Carson



This photo was also published in the previous issue - Karen is self-injecting "Solu-Cortef" at the Northern Region meeting in May, under the watchful eye of Karen Unwin, endocrine nurse specialist. Karen was diagnosed with Addison's six years ago. Her story in Newsletter 11, November 2000, in particular discusses her third pregnancy, which was after her diagnosis of Addison's.

Diane Goldsack



Diane has had secondary adrenal failure (hypopituitarism) for nearly 25 years. Last year she took over from Colleen Follett as Bay of Plenty Co-ordinator. Colleen organised the first Bay of Plenty meeting in 2001, and they've been held annually since. Jeanette took this photo while visiting Tauranga and catching up with a few members just before Christmas. Diane's story for the newsletter is yet to come!

Gary Roselli



Gary has had Addison's for more than 40 years. He has been a member of NZAN almost since the beginning, and his story featured in Newsletter No.10, July 2000. As a retired pharmacist, Gary is a valuable resource person for NZAN. He has arranged successful NZAN meetings in Lower Hutt, in 2002 and 2003. He is still a keen tennis player, and that takes him to various places around New Zealand



Membership Update

Since the November 03 newsletter, we welcome as new members Barbara, Jo, Krishna, Robyn, Robert, Ron, and Vicky on behalf of her 8-year old son Benjamin. We now have 114 members, two of whom have a New Zealand connection, but live overseas.

It's subscription time again. An invoice is enclosed with this newsletter. We're keeping the amount at \$20, with the option for members to add a bit extra if they so choose.



This is your Network and your Newsletter. Please share your stories, news, and tips for healthy living with Addison's disease. Please share your ideas and your concerns too.

If you have a topic for discussion, or a question that you'd like passed on to NZAN's medical advisor, please send it to Jeanette.



The members' contact list is enclosed with this newsletter. If you see any details that need changing, please let Jeanette know.

International Addison's Survey – Update

We had a good response rate. We got back 92 completed forms from individuals with adrenal insufficiency, 67% of the total sent out.

Survey forms for the Addisonian and friend had been sent to 137 addresses – 106 NZAN members, and 31 others with Addison's and other causes of adrenal insufficiency who were not members of NZAN, but for whom we had a valid address.

The Survey Team in the UK is now busy analyzing the results. Preliminary results, primarily from the UK, are accessible on their website www.adshg.org.uk We'll keep you posted.

White Florinef – Update

We understand that BMS plans to introduce white Florinef in Australia about mid-June, and it is on track to be introduced into NZ mid- to late this year.



INVESTIGATION: How do our members find out about NZAN?

The question was included in the Nov00 survey, and has been included on our membership form since then: “how did you find out about NZAN”. As the table shows, the majority of members have heard about us from their doctors – their endocrinologist, hospital clinic or GP.

Table 1: How members heard about NZAN

	Nov00 survey (55) respondents	after Mar02 (46)
Endocrinologist/ hospital clinic:	32)	18)
GP	2) 67%	6) 54%
Internet	4	8
Contact info in women’s mags	7	3
Foundation member	2	
Work/personal contact	2	
Other NZAN members		5
Pharmacist friend	1	
Referred by NADF	1	
From meeting ad		2
Former member rejoined		1
<i>[Omit these from %ages:</i>		
Unclear response	4	
We don’t know		2]

Where are our members located?

We last looked at this topic in Newsletter 11, November 00, prompted by an astute member who had suggested from the addresses on the members’ contact list, that Auckland was under-represented. Total membership then was 65. Compared with figures from the 1996 national population census, the percentage of members in Northland and Auckland combined was about as expected, although Auckland’s alone was a bit lower. Wellington’s representation was a bit higher, Canterbury’s a bit lower than expected. Membership in the South Island overall was lower than expected. [See Box 1 below].

Since then our membership has increased to 112. Interestingly the geographical distribution of members has changed quite a bit (see Box 2). Canterbury’s percentage of total membership has doubled, from 8% to 16%. Auckland’s has fallen from 24% to 20% (yet it has 30% of the total population). Wellington’s has fallen from 17% to 13% – there has been only one new member in the wider Wellington area in the past year!

Our bright canary yellow pamphlets (A4 folded in three) are now widely distributed throughout New Zealand, thanks to Medi-Board. Thanks to a member family’s generous sponsorship, all GPs received a letter in July last year about diagnosing Addison’s disease - and some of our folded pamphlets too.

Some of the Christchurch new members since Nov02 have noted that they saw our poster at their endocrinology clinic. None of the 8 people since March 02 who first found us on the Internet, live in Canterbury – it is tempting to deduce that Cantabrians tend to find us first at their clinic!

The current geographical membership pattern suggests that the pamphlets, and particularly our Canary Yellow A4 Posters, may not be displayed in all endocrinology clinics so that people in the waiting room can see them.

Getting together these figures has highlighted the need to check that our poster is “out there” with endocrinologists and endocrinology clinics. We are enclosing two updated posters with this newsletter for all the doctors and clinics on our mailing list. We hope they will be put on display.

Here’s how all members can help raise NZAN’s profile! We are also enclosing a poster with members’ newsletters. Please would you take it with you, when you next visit your endocrinologist. If you don’t see a poster, please hand over yours and ask whether it can be put on display.

Box 1
History: Location of NZAN members (65), November 2000
(From Newsletter No.11, Nov00)

Using the populations in regions as reported in the 1996 Census, we found that NZAN membership follows regional population densities reasonably closely!

- U Auckland has 30% of the population, 24% of current membership, and has received 20% of all starter packs.
- U Taking Northland and Auckland together: 33% of the population, 32% of the members, 25% of the starter packs.
- U Wellington has 11% of the population, 17% of the membership, and has received 13% of the starter packs.
- U The South Island has 25% of New Zealand’s population – and 14% of NZAN’s members, and has received 23 % of the starter packs. Specifically, Canterbury has 13% of NZ’s population, 8% of NZAN’s members, and has received 11% of the starter packs.
- U Two relatively small regions show the sort of clustering that can occur – by chance, and by the operation of an effective local network, where Addisonians tell each other about NZAN. The Manawatu and Wanganui region has 6% of the population, but has 8% of NZAN’s current

membership, and received 10% of the total starter packs. Taranaki region has 3% of the population, 3% of NZAN’s members, but has received 8% of the starter packs.

Box 2
Location of NZAN members March 04 (112), and of people who contacted us for an information pack over the 12 months to March 04 whether or not they subsequently joined (38).

- Using 1996 population census figures:
- * Canterbury has 13% of NZ’s population, 16% of current members, and had 24% of enquiries over the past year (8 of the 9 who enquired *have* joined so far).
 - * The South Island overall has 25% of NZ’s population, 24% of current members, and had 37% of enquiries over the past year.
 - * Auckland has 30% of NZ’s population, but only 20% of current members (half of them on the North Shore). Although it had 24% of enquiries over the past year, 7 of the 9 *haven’t* joined (yet)!
 - * Wellington has 11% of NZ’s population, 13% of current members, but had *only one new enquiry* over the past year.

The figure has stayed rather constant, that 2/3 of the people who request information about NZAN actually become members.

* * * * *

Jeanette’s footnote:
 A key personal goal for 2004 is to become smarter about how I use my time and energy. There are some new things that I want to fit into my life. I wish that the compilation “Reminders for living with Addison’s Disease” was already finished!! But it is not far away. It’s evolving as a handy checklist, backed up by the wealth of information already in our newsletters, in an easy access format.



From NZAN's Medical Advisor Professor Ian Holdaway:

Addison's Disease and Other Medications - interactions.

In Newsletter No.20, Nov 03, we published material on this topic from Professor Holdaway's talk at the Northern Regional Meeting in May03:

Prof Holdaway pointed out that NSAID painkillers such as Voltaren and Brufen can cause fluid retention and act like extra fludrocortisone.

One of our readers has asked whether this applies also to the "second generation NSAIDS", the COX-2 inhibitors, that are available for people with arthritis, etc.

Prof Holdaway's response is: "The COX-2 inhibitors such as Vioxx, Celebrex and Arcoxia all cause the same effects as typical NSAIDS in terms of fluid retention etc, although they are less likely to cause gastric upset. In general, these agents (NSAIDS and COX-2 inhibitors) may be OK in many instances, so it would be wrong to give the impression that they must never be used - just that caution is needed and any swelling of the ankles, general fluid retention, or weight gain should be reported to the GP."

We are reprinting all the painkillers interactions information together in the box on this page:

Take care with any medication that might induce nausea, vomiting or diarrhoea, such as:

- * some antibiotics (keep a note of your own history with these)

- * some painkillers, such as morphine, occasionally codeine, and tramadol which is a newer painkiller - some people are very sensitive to these.

NSAID pain killers such as Voltaren, Brufen, etc can cause fluid retention and act like extra fludrocortisone. The same applies to the COX-2 inhibitors, Vioxx, Celebrex and Arcoxia. Watch blood pressure, and weight.

Preferably, try something else as a painkiller - such as paracetamol (Panadol), aspirin, acupuncture.

We tend to underplay the simple remedies, like **paracetamol**, which is an extremely safe agent, because we don't take enough of it, and too quickly we say it is not effective.

For paracetamol to be effective, you need to take 2 tablets every 4 hours, whether you have the pain or not. People tend to let the pain build up, such as headache or joint pain, saying they don't want to take too much of the painkiller, and by then the pain may have become quite severe. If you take paracetamol regularly, pain or not, when you have a bad migraine, sore joints or a bad back, and take it round the clock for a couple of days (while awake), it suppresses the pain, and you'll likely be able to get off it again.

Paracetamol is useful for keeping the body temperature down when you have flu and the aches.

Aspirin is reasonably safe from the viewpoint of fluid retention, but can cause gut irritation or indigestion or occasional bleeding. Paracetamol is probably the safest overall.

Q&A from the Open Forum session at the Second Northern Regional Meeting in Auckland, May 2003:

There was lively discussion, with Professor Holdaway answering a wide variety of questions from participants. Here are some of them

Question 1:

Does the Solu-Cortef injection have a fludrocortisone component in it?

Prof H: No, it's just hydrocortisone, but as we mentioned hydrocortisone has a little bit of fludrocortisone-like action so you do get a slight double whammy effect. But in the serious illness situations, it's the cortisone lack that's the key thing. So you don't need to worry about the fludrocortisone.



Question 2: What's the best time of the day to have blood taken for renin, sodium, potassium, DHEA?

Prof H: For renin, sodium and potassium timing doesn't matter. For DHEA (the blood test is DHEAS, the sulphated form), if you are not on the capsules and are just having a basal level done, it's better to have the test in the morning between about 8 and 11. That's because there is a slight rhythm through the day with higher levels around that time. If you are on the capsules and you want to know if you are achieving a good level, have the test about 2 to 4 hours after you've taken your capsules.



Question 3: What about the long term prospects for people with Addison's?

Prof H: So long as replacement doses are at a correct level, then your long term health should be as good as anyone else's, and also your longevity. There have been one or two studies of how long people with Addison's disease live, and it doesn't seem to impair life expectancy.

Q...So, other immune disorders that come are because you've got a predisposition to autoimmune problems, not because you've got Addison's?

Prof H: That's quite a good point, it is true that people who have the autoimmune form of Addison's disease can get other sorts of autoimmune conditions as well. They can come on later in life, so it's variable, sometimes the Addison's disease will come first and then someone might develop a thyroid condition five years later, and occasionally some other disorder such as diabetes a few years after that. So, your doctor and yourself do need to be a bit alert to subsequent health problems but as you saw in those percentage figures the percentage chance of getting associated conditions isn't all that high [reference to previous newsletter]. You've got a better chance of not getting any other sort of autoimmune condition than you have of getting an extra one.



Question 4:

Was it an Addison's crisis?

One participant's dialogue with Prof Holdaway was an opportunity for everyone present to learn.

Q...I went to my doctor with a bad run of migraines. My 3-monthly blood tests had been done the week before, but they couldn't find any results from those, so my doctor said, we'll do those again now.

That was on a Wednesday afternoon at 12.30, my husband found me unconscious at 6.00am the next day with what the hospital has told me was an Addison's crisis. But my GP says she cannot see that it was Addison's crisis because the blood test taken less than 24 hours before showed a normal cortisol level. It's made a bit of a barrier between us because I think I have to go by what they told me in the hospital.

Prof H: So you were semi-conscious, and had to be taken to the hospital, and you were

given extra cortisone and you recovered quickly?

Q...Well, I was there for five days, before they got me back to normal.

Prof H: So the key question is whether it was just solely a lack of cortisol or whether it was the very bad migraine or something else. I think it sounds like an Addison's crisis to me, and as we've heard discussed here these things can come on surprisingly quickly in some people. Normally you know if you are unwell, and you have time to get your treatments underway. But just very occasionally cortisol lack can be quite rapid. Do you have much recollection of what led to your ending up on the floor?

Q...None at all. I went to bed the night before feeling groggy because of the migraines, but I had taken all my Addison's medication that day.

Prof H: Yes, and then at six in the morning you were found on the floor ...

Q...In another room, yes.

Prof H: I think you just ran out of cortisol overnight. The fact that your blood measurements were normal 18 hours before doesn't faze me too much. We've mentioned cortisol's short half life, and how quickly the level does decline. Because of the severe migraine, you had the extra demand for cortisol, so it was a true crisis.

Q...Thank you.



Question 5: For the past 14 months I have had low potassium levels despite taking extra potassium chloride. Any ideas?

Prof H: Yes, obviously the first thing one would worry about is the fludrocortisone dosage, whether that's set a little high. Are you on fludrocortisone? Some people taking

average replacement doses will get a potassium losing state that I previously mentioned. It's a natural action of fludrocortisone to make you lose more potassium in the urine. If you are on average doses then that's usually balanced out by your diet and so on, but some people are quite susceptible to a fall in potassium levels.

One would normally measure the amount of potassium in a 24-hour urine collect. If it's high that proves that you are losing it that way and the only real answer is to step up the potassium replacement. You're not on any other tablets that would affect potassium levels?

Q...A calcium channel inhibitor, Cardizem.

Prof H: That shouldn't do it. No diuretics or anything like that? If your blood pressure and general health are good, your doctor could lower the fludrocortisone a little bit in case you are on a wee bit too much and that's making potassium loss worse.

Q...No diuretics. On the three occasions over the years that I have tried to lower my fludrocortisone, I have had severe attacks of vertigo a few days after I've lowered the dose.

Prof H: Right. I think it's sensible to just stay on your present dose then.

Q...I thought that.

Prof H: Nuisance as it is, you just have to crank up the potassium replacement. Do you take Slow K?

Q...Yes

Some people need surprisingly large amounts to get the potassium normal. It is an important thing to do though, so it's good that you are watching it. That's sensible.

Q...Thank you.



Question 6: Hiccups!

Before I was diagnosed with Addison's I used have quite serious periods of hiccups. They would go on during the day. I'd wake up with them during the night. Now I've read in overseas publications this could be a symptom of Addison's. Is this recognised or is it just a coincidence?

Prof H: If you look at the lists of the symptoms people get with Addison's, you are right, I think hiccups are there. But it's rare - it seems 1 to 2% of people may have hiccup problems when they first present with Addison's.

Severe ongoing hiccups is a very rare problem, but can be very difficult to treat. Interestingly, one of the treatments that sometimes works for intractable hiccups (in studies where people didn't have Addison's disease) is a big shot of intravenous hydrocortisone! So there is something 'unusual' about steroids and hiccups, but it's pretty rare. Do you get them nowadays?

Q...No.

Prof H: So it was only before the diagnosis? When you started your replacement treatment they resolved, they went away?

Q...I can't remember back that far. It's going back nearly 40 years. I had never mentioned it to anybody because it wasn't a concern.

Another participant: Yes, definitely hiccups was a symptom for me too! And it was before diagnosis, while I was having a period of feeling really low and maybe being in bed or off work because I was so sick - and always the hiccups. In fact it was almost an indicator that I was getting to be low. As soon as I started taking hydrocortisone I haven't had the hiccups at all since.

And another participant: I was a hiccuper too!

**Question 7: Is thirst a side affect of Addison's or is it a slant towards some other problem?**

Prof H: I think only if your steroids are quite under-replaced. If you are quite short of cortisol, and if because of that your blood volume is a bit contracted, then you may get a thirst switch on to try and build up your fluids. It's a bit of a rare one - you wouldn't normally expect to have an accelerated thirst if you're on standard replacement.

Thirst is usually not a medical problem. Folk who are big drinkers of fluid can get into a sort of vicious circle when they drop their fluid intake a bit - then they feel thirsty and want to keep drinking. Severe thirst, of course, has to raise a suspicion of something like diabetes, but mild thirst is probably just an innocent bystander.

Thirsty constantly? Well there are rare problems that make you very thirsty. There's a condition called diabetes insipidus (quite different from diabetes mellitus) which occurs when hormones that are involved in concentrating the urine don't get produced. But that's not a part of the syndromes associated with Addison's disease, so it would be a real bad luck scenario to have two different conditions going on at the same time. But it is possible, and what we do for people who have major thirst, and it's a real problem, is do a test called an overnight water deprivation test. They don't have any water overnight (it's pretty tough for them), and none in the morning, then they come to the clinic and have their urine tested to see how concentrated it is. If they can concentrate the urine normally then there's no background problem it's just a switch on of thirst of an innocent type. But if they can't concentrate the urine properly then there's a problem. They've got either pituitary or kidney disease. So it may be worth checking it out if constant thirst is a nuisance problem.



Question 8: I have Addison's and I am concerned about my child's risk.

My question relates to the inheritance, the genetics of Addison's, which you have already spoken about. I've got Addison's and three young children. One child in particular I have just a mother's gut feeling about. He is very slow to recover from sickness, and he has got some pigmentation in places, like elbows, where I still have it. Are there tests that can be done to relatively easily detect whether there is a proneness to Addison's, or whether he may develop it.

Prof H: The key test, the important test, is an adrenal stimulation test, which you probably know about, the "short synacthen test". For that we use a form of ACTH called synacthen which is very quick acting. So although kiddies aren't terribly keen on tests, this one is not too big a deal. It's a baseline blood cortisol, then a little injection can be given through the same vein that the blood's taken from, of this ACTH which will stimulate the adrenal and then 30 minutes later you take another blood for cortisol, and should get a normal increase in the blood cortisol in response to the ACTH. It's very sensitive, very reliable, it's how we diagnose the condition.

There's no point in doing it once you've got an established diagnosis because you'll just have a flat response. But if there is concern about a child or a relative you think could have Addison's, that's the test to do. If you ever said to your doctor how about a short synacthen test, he or she would know what you are talking about. GP's can order the test through the private laboratory. However, the private laboratories tend to do a high dose test which takes 60 minutes – they are not quite as used to dealing with kids. The major hospitals do the test, and there's our service at Auckland Hospital, you can have it done as an outpatient, it's very simple. Karen [endocrine nurse specialist, also at the meeting demonstrating self injection with Solu-Cortef] as you can see is fantastic with children, and so its probably better to just get

your GP to send us a note at Auckland Hospital to do a test on a child.



Question 9: About the speed of development of Adrenal Crisis, and the likely relationship with one's usual blood pressure levels...

Karen: You said that some people are prone to crisis much more quickly than others. I was diagnosed in a crisis and then just a couple of months ago I had another crisis. And it was very quick - within a period of three hours I was practically semiconscious on the floor, at home with three young children. So is that something that does happen to others, or is it more peculiar to me, that when I go, I go?

Prof H: It is unusual to have it hit you with such speed, although it's been mentioned several times here today how some people have gone into a crisis situation very quickly. But it is unusual and raises the issue of whether there's some other factor, it might be the dosing of your tablets needing to be adjusted, particularly the fludrocortisone. I imagine since this has all happened to you, people have taken a lot of interest in your replacement and whether it's adequate etc? What sort of schedule are you taking?

Karen: I'm taking 15mg of hydrocortisone in the morning and splitting the afternoon dose, so 5mg at about 12.30 and 5mg at 4.30, and half a Florinef.

Prof H: And if you go higher in the Florinef you're not so good?

Karen: [hadn't tried higher Florinef - see below**]. For about a year I've been having quite dizzy light-headedness. My blood pressure is on the low side, but OK.

Prof H: Because of that, I think you're a bit under-replaced with the fludrocortisone, and we've pointed out [e.g. NZAN Newsletter No.15, pp 15-18] there's been a bit of a tendency for doctors to not quite give enough, then it makes you susceptible to get the

cortisol crisis effects because you start with a somewhat lowered blood pressure and electrolytes that perhaps aren't quite right. So it may be worth going up to a slightly higher dose of fludrocortisone, and then if you still have more crises, possibly consider going over to prednisone instead of hydrocortisone, because of its longer half life in the body.

Lyn: Is there a possibility that having normal or low blood pressure could be a trigger for quicker crisis, because Karen and I share that in common. I take my hydrocortisone 30mg all at once in the morning, and 0.2mg Florinef daily. [Lyn is a keen bike rider, who does everything at "ninety miles an hour"!]]

Prof H: Yes, I think that's probably quite a good point, isn't it? Some individuals who don't have Addison's, particularly women, do run quite low blood pressures. People often get worried about it, but normally low blood pressure's a great thing! It means you're probably going to have an excellent life expectancy, compared with the effects of having high blood pressure! So I always reassure people whose blood pressure is naturally around 90/60, even though, true, in hot weather they might get a bit faint and dizzy. I haven't heard it addressed scientifically but it is quite possible that if you've got this natural low blood pressure then you are sailing a bit closer to the wind if you have cortisol deficiency. You haven't got the reserves of someone who's normally got a blood pressure of 130/80 - they can tolerate dropping their blood pressures by 20 millimetres of mercury a lot better than you can, because if you drop from 90 systolic you're only 70 systolic and that's when you're definitely beginning to feel pretty weak. So that is an interesting point. All the more reason to pay attention to the fludrocortisone dose



**** Follow-up to Question 9:**

After the meeting Karen doubled her daily dose of fludrocortisone, to 0.1mg, and reports she's had a lot fewer dizzy spells and much less salt craving. She is off to Brisbane in May with her family, and is alerted to having a bit extra salt, especially if the weather's hot.



**Jeanette's
"belt and braces"
IV saline kit**


When Rosemaree joined NZAN in 2001 (her story follows), she mentioned on her membership form that she'd put in her own IV fluids line when unwell in Thailand. That stuck in my mind.

When planning my holiday in Tahiti last year, I was mindful of my possible increased risk of dehydration because I have intermittent problems with severe diarrhoea unrelated to Addison's or tummy bugs, and I was going to a hot climate, which would be a challenge for Addison's management. I was also travelling on my own, and I know only too well that Addisonians low on cortisol are not good advocates for themselves. Although I could be sure "tourist English" would be spoken, when it came to medical issues, I felt I might strike communication problems on the French and Tahitian speaking island of Moorea, where I'd be staying most of the time.

My blood calcium needs monitoring, especially when 'things go haywire'. I feel that enough of my energy is consumed on health issues, without extra bureaucracy adding its frustrations. I have found that arriving at the lab with the already collected microsample, correctly labelled and with my GP's form, takes me straight past "square one", and minimises hassle.

So I figured that if I had my own 'ready to go' IV saline pack with me in Tahiti, then if I did

get into difficulties, I could use the fact that I had it, as evidence that I did need it. I had a mental picture of waving it under someone's nose, if necessary, saying "I need this". The local specialist, whom I was seeing at that time for a non-Addison's reason, was at first a bit taken aback at my request, describing it as like having a belt *and* braces, but accepted my logic, and got me access to the goods. When I checked into the resort on the island of Moorea, I got the mobile phone number of the local doctor, to keep in my purse. I put the saline kit, and one of my Solu-Cortef kits, in a place in my room that I could easily direct someone to. Then I put medical matters out of my mind, and got on with my holiday.

I didn't need to activate the plan – but the peace of mind it gave me was great. A real case of 'set and forget'. I'd do it again if faced with similar risk factors. The cost of the IV kit is less than \$30. The fact that I had it with me (in my suitcase) was included in the letter I carried from my GP 

Rosemaree's Story

Rosemaree didn't let diagnosis of Addison's disease and Graves' disease stop her from going to live in Thailand the following year, and work there as a teacher and paramedic for four years.

She weathered several adrenal crises, sometimes administering her own IV fluids. She's keen to go back, but she says she wouldn't live there alone again, and would make sure she had a means of transport and a phone.

These days, she has a busy life in Hamilton, with her husband and two stepsons. What drives her? To quote the final paragraph of her story: "My parents both died with significant unfulfilled goals, when I was in my mid-twenties. I decided then that if anything was really important to me I would do my best to do it now, rather than wait for some time in the

future. I regularly reassess my lifestyle & adjust it where necessary to help achieve the things that are the most important to me"

Her story...

DIAGNOSIS:

I first became sick while living in Perth as a student in Bible College for two years. I was working part-time and studying full time. Towards the end of my first year away (1994), my mother died after a long battle with leukaemia. During the second half of the following year I started losing weight & was constantly tired. Despite comments from my workmates, I brushed their concerns off, putting these symptoms down to stress from Mum's death & my long working hours.

After graduating from Bible College at the beginning of December, I followed it immediately with an intensive 12-week block missions training course in Sydney. I planned to return to New Zealand for one year to work in my church to gain ministry experience then to move to Thailand long term as a missionary. Two weeks before I was due to return home, my father died suddenly & unexpectedly. I returned to New Zealand for his funeral, & completed the last two weeks of my course the following year.

After my return to Auckland in January 96, many friends commented on my wonderful "tan". Since I had always had a naturally dark skin which tanned easily, & had just returned from 2 years in Aussie where my main mode of transport was a bicycle - again I thought nothing of it. I continued to feel very lethargic, forcing myself to work each day. I lost weight steadily (about 15kg over 7-8 months) despite eating huge meals & starting to "snack" as well to try to maintain my weight.

By about March, I was often nauseous, getting heart palpitations daily & often getting dizzy while walking up stairs or hanging out the washing etc. I was also getting a lot of cramp, often waking at night with my back muscles

arched in cramp. After Easter I went to see my GP who ordered a range of blood tests. She rang a few days later to say that I had hyperthyroidism (Graves' disease, an overactive thyroid gland), & that she had spoken with a specialist at the hospital for an urgent appointment in about a month. The specialist told her to order further blood tests, those results pointed to my having Addison's disease as well, so my GP arranged for me to see the specialist in a few days. He confirmed the diagnosis of Addison's disease & Graves' disease after my first visit (at age 27). Then began the process of juggling medications to find the right balance.

STABILISATION:

Initially I took 25mg of hydrocortisone daily, 15mg in the morning, and 10mg with dinner at 6pm. I also took 0.1 mg of fludrocortisone and 15 mg of Carbimazole (to slow my thyroid metabolism). I had regular specialist appointments while we fiddled with drug dosages & I gradually began to feel like a new person. I also had a persistent cough, which caused the specialist to wonder about TB as I had worked in a TB lab previously. He soon realised it was asthma & put me on to Flixonase & Ventolin, which resolved the cough – which I still take. I slowly regained the weight I had lost, to about 65kg (my height is 172cm). But it has continued to fluctuate up and down, depending on my state of health.

My specialist encouraged me to have radiation or surgery to reduce the size of my thyroid gland as he felt that would help stabilize my Addison's. But for various reasons I chose not to do that. I was told that most people with Graves' disease take carbimazole for only about two years, then, if they haven't improved, have other treatment. My dose of carbimazole has been gradually decreased, and I am now (6 years later) taking 5mg daily.

LIVING WITH ADDISONS;

When I spoke to my specialist about my plans to move to Thailand the following year, he was gently encouraging. He had done some of his medical training in Thailand & was confident in the level of healthcare I could be provided there, as long as I was carefully monitored.

I had been an Ambulance Officer. I had also done a short tropical medicine course at the School of Medicine, University of Sydney, before my Addison's diagnosis.

I moved to Thailand as a missionary in March 1997, and was to live there for a total of four years, with a few months home after my third year. I took with me a 3-month supply of tablets, 10 bottles of Solu-Cortef and some needles, and two one-litre bags of fluid replacement with the needles, tubes etc. Getting more medicines in Thailand was easy – I went to the chemist, and bought whatever I needed (hydrocortisone, carbimazole, etc), no prescription was necessary. When I later switched to prednisone I had to buy that from the hospital pharmacy, however. I got replacement needles from a mission hospital, because I knew they were not re-used.

My New Zealand specialist put me in touch with a specialist in Bangkok whom I saw a few times at an outpatient clinic in my first year or so there. The system is that people turn up, and are seen in order of arrival. No appointment is necessary.

I began working for a Thai organisation as a teacher/paramedic. I was supposed to have one day a week off, but in practice that rarely happened. I was "on call" for medical emergencies 24 hours a day, & 7 days a week so often had broken sleep. There were three other westerners working in the same place, but we had very different responsibilities and hours so really only saw each other for a meal once a day. At that stage I spoke no Thai, but with an urgent need to be able to communicate I gradually picked up a few words. After 6 months, there was an opening for me in a language school where I spent 6



months full-time in intensive language study, learning as much as most do part-time in 2 years.

One day during my stay there I developed a fever, and was too weak to get out of bed. I had no telephone & no means to contact anyone for help. I upped my oral hydrocortisone, and by chance a friend who was a nurse dropped in to visit, and stayed to help. She was a great morale boost, got me fluid etc, & I rapidly improved.

On my return to the campus where I worked, I began to teach my classes & prepare class notes in Thai. The cultural, language, climate changes & work conditions all increased the stress on my body. However my doctor was about 12 hours away by public transport so I learned mostly by trial and error how to alter my medication doses as needed. I knew the principles, but was still on a learning curve with regard to applying them. For example, I wasn't really sure how sick I would need to be before having an injection.



At one stage I had an acute Addison's crisis (minor) with nausea, vomiting, fever & diarrhoea. I was too ill to travel to Bangkok by public transport to see my doctor, & the staff at the hospital would not allow me to talk to him by phone. I decided that was no help to me, so once I had improved (after increasing my hydrocortisone orally) I rang friends who worked in a mission hospital in central Thailand (Manorom Christian Hospital) who said they were happy for me to phone them in future. That hospital was harder to get to, but going there worked better for me.

A few months later I contracted a tummy bug with copious diarrhoea, & vomiting. I inserted my own IV & gave 100mg Solu-cortef & 1L of fluid replacement. This was tricky as it was night-time (we had no electricity where I was living), I was too unwell even to sit up & had

to insert the IV one-handed. Some friends kindly drove me to the Manorom Christian Hospital (about 6 hours drive) where I was admitted for a week & received excellent treatment. They also changed me from hydrocortisone to prednisone as it has a longer half life & the doctors felt it would suit my erratic working hours better. Initially I was taking about 20 mg prednisone daily, but this was gradually decreased. They also increased my fludrocortisone to 0.2mg daily. They allowed me to stay with a friend on the hospital compound for a few extra days than I really needed to, to ensure I was strong enough for both the return overnight journey by public transport & a return to full workload as soon as I arrived back on campus.

After about a year in Thailand, I found some breast lumps which were growing steadily. I'd had friends die of breast cancer so was understandably nervous. Due to my isolated living conditions & limited access to medical care I asked the surgeon I saw to remove the lumps prior to a biopsy, which he agreed to. The school where I was teaching was about to go into recess as our Thai director was overseas on sabbatical leave, the temporary acting director had to leave Thailand & no-one else was available to fill the role.

Once this was arranged, I travelled to central Thailand to have the surgery - removal of three breast lumps under general anaesthetic. The doctors followed the Addison's protocol my specialist in New Zealand had given me, for increasing my steroid dose prior to & following surgery. There were no complications (the lumps were benign) and about a week later the acting director drove up to collect me from hospital.

On the return journey he told me he was leaving the following week, but our director had forbidden us to put the school in recess – so I would be the acting director! My scheduled leave was cancelled - I had not yet been allowed to take any since my arrival in Thailand. I had limited language ability & cultural knowledge & was required to oversee

a mixture of Thai & western staff who were at the time in conflict with each other.

At this point I had another Addison's crisis, with vomiting, diarrhoea & fever. I again inserted my own IV therapy by torchlight, & decided not to travel to hospital as I was too unwell for the journey. A close friend who I thought of as my foster mother had come to visit me in Thailand for my recuperation from the surgery. She went to see the acting director before he left, demanding that I be allowed two weeks leave or insisting that she would return me to New Zealand on a one-way ticket. After two-weeks of sitting on a deck chair at a beach I was much improved & returned north to begin my new role.

A few months later our director returned, & I prepared to return to New Zealand after 3 years in Thailand. I was in New Zealand for about 5 months, working part-time and my health slowly improved. I wanted to go back to Thailand, but wanted to work elsewhere, where I could have a more realistic workload & be closer to medical help when I needed it. During that time I was introduced to a Bible school where I could teach in Chiangmai, which is a large city in northern Thailand (so a cooler climate) and has excellent hospitals. So I went there and worked for a year, teaching.

By this stage my Thai was almost fluent so preparation for classes was much easier. I also had electricity, a telephone and Internet access (a life-line to home for me). During the year I had one minor Addison's crisis, again with vomiting, diarrhoea and fever. This time however I was able to phone friends, who drove me 5 minutes down the road to a hospital where I stayed for only 1 night. Being a westerner, I was treated like a VIP (this was the case at any hospital I went to). My New Zealand specialist's letter made it clear that I had Addison's and what I needed. All the doctors speak English, (but the nurses don't). It was a luxury not having to deal with the injection myself. At the end of this year the school where I was teaching was

restructured. Rather than stay on in a different role, I chose to return home to New Zealand, in March 2001.

Back again in Auckland, I had two part-time jobs, one in administration & one doing evening shifts in a medical laboratory. My health was good & I continued periodically to see the specialist who had initially diagnosed me.

A friendship gradually developed between myself and a man I had met in Thailand who was there short-term at the same place I was working. We decided to marry, so in November 2002 I left my work and moved to Hamilton in time for our wedding. I found part-time work in a medical laboratory (3 days a week) and also began to work one day a week as a volunteer ambulance officer. I was also a new step-mother to 2 boys (then aged 6 and 8), adjusting to family life, so my life was again very full.

During the first few months of 2003, my Addison's again became unstable. I was waking most mornings with nausea &/or vomiting. I was on a waiting list to see a specialist at Waikato hospital for the first time, which I was told would be a wait of several months. My GP did pregnancy tests (negative) & wrote to the specialist asking for an urgent appointment. Nothing changed, so I sent an SOS email to my previous specialist in Auckland saying that I was sick, but unable to get a doctor's appointment. He advised me to double my Prednisone & the following week I was given a specialist appointment in Hamilton. This new specialist is very good, and rapidly rearranged my medications until they were again controlling things well. This included splitting my daily prednisone into three doses, 2-3mg am, 2mg (6pm) & 1mg before bed. This seems to be working well & has eradicated my morning nausea.



CURRENT:

My current medications are prednisone as above, Florinef 0.2mg, Carbimazole 5mg, Flixotide/Ventolin, & Flixonase as needed for hayfever.

I keep busy & active, also playing sport with my family, including swimming, running, tennis & mountain-biking. During active exercise or hot weather I increase my salt intake (usually by adding a little salt to a fruit juice drink) to prevent severe cramp which wakes me up at night when uncontrolled. Having Addison's hasn't affected my choice of sports, but I do take care to watch my energy levels & not push myself too hard on "low" days. If needed I also increase my Fludrocortisone (especially during hot seasons in the tropics). I wear a medic-alert bracelet & keep Solu-Cortef injections & prednisone tablets with me for emergencies.

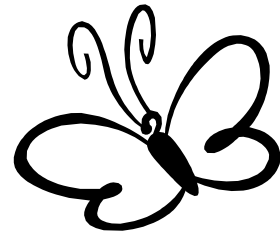
Since being back in New Zealand I have only had one Addison's crisis (Christmas 2001), again with vomiting, diarrhoea & fever. Friends took me to an A&E clinic where I was given Solu-Cortef IM, observed, then sent home to recuperate. My family, some workmates & some close friends know about my Addison's, and my husband is confident to inject Solu-cortef if needed.

Addison's hasn't affected my choice of work, however at the moment I have chosen not to attempt shift work (eg a return to full-time ambulance work) as lack of sleep is an aggravating factor for me. I have chosen to work part-time (20 hours a week) rather than full-time in my lab job. My work performance is only affected if I "crash", otherwise I am well able to do whatever is required.

However Addison's has been a factor in our decision not to have more children at this time, due to concerns about my health during a pregnancy & with the broken sleep required with babies & young children.

When hearing about my health issues, many people are surprised at my active lifestyle,

and that I chose to live and work in Thailand, despite Addison's. My parents both died with significant unfulfilled goals, when I was in my mid-twenties. I decided then that if anything was really important to me I would do my best to do it now, rather than wait for some time in the future. I regularly reassess my lifestyle & adjust it where necessary to help achieve the things that are the most important to me.

**Photo Corner**

(l to r) NZAN members Diane Goldsack, Ray Mapp, Jeanette Crossley and Colleen Follett at Diane's home, Mt Maunganui just before Christmas, 2003.

