

New Zealand Addison's Network

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NZAN Newsletter, August 2004 (No 22)

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From NZAN's Medical Advisor, Professor Ian Holdaway:

15

Q&A:

1. Does Addison's contribute to anaemia?
2. Under what circumstances should people with Addison's disease also have their blood glucose checked?

Reminder: monitoring thyroid function

Guidelines for Intra-Muscular Injection of Solu-Cortef are included with this Newsletter, as a separate booklet.

Extra copies are available on request, or can be downloaded from our website.

**** See correction about cost at the bottom of page 4 →**

**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



Meetings and Momentum

Jeanette wonders – what next?

Over recent months there have been enthusiastic regional meetings in Wellington and Christchurch, and a mini-meeting in Auckland, involving all-up 47 Addisonians. Reports and some topics discussed are in this newsletter.

Beverley's comments after the inaugural Southern Region event included most of the points made by other attendees too: "A big thank you for a great informative and friendly day on Sunday. All those present both 'old' and new Addisonians I am sure enjoyed meeting together. Great atmosphere and humour. The knowledge of knowing they were no longer alone with Addison's. I am equally certain everyone gained some answers to questions they asked. We sincerely hope this meeting will be the first of many."

Hearing the diversity of stories relating to the initial diagnosis of Addison's disease helped some get their own situation into a new perspective. Being severely unwell for a long time (sometimes years) before Addison's diagnosis has been the experience of several NZAN members. In hindsight, a few were lucky to survive. But quite a few have been diagnosed relatively quickly by doctors who recognised the main signs and symptoms of Addison's - in particular the super-tanned skin, salt-craving, and low blood pressure especially on standing, as well as the weight loss and severe fatigue.

In hindsight, some GPs were probably falsely reassured by blood sodium and potassium results being in the normal range. Normal sodium and potassium results by themselves don't exclude the diagnosis of Addison's disease. As a few members experienced, that apparent "normality" can be the net result of a lot of physiological and dietary compensation, and also severe dehydration.

Once the probable connection with Addison's is made, a short synacthen test ["the gold

standard"] usually confirms diagnosis. Treatment with hydrocortisone can be started before the test results come back. Many Addisonians, and their doctors, have experienced the miracle of within a day "getting their life back".

The medical schools in New Zealand constantly ensure that students are exposed to real people with Addison's disease. Some of our members in the main centres are involved each year in presentations to medical students. [See Ngari's story, page 16]. Hopefully imprints are left, that will be reactivated when needed in the future!

With NZAN we are doing our best to increase awareness of Addison's as a possible diagnosis. We are pleased that our canary yellow pamphlets are now widely distributed in hospitals and doctors' waiting rooms around New Zealand. They are clearly being found by people who value them [p3] - our warm thanks to the franchise holders of Medi-Board.

One of our new members was whisked into hospital when a locum GP measured her blood pressure as 80/0, a few months ago. A few days later she was given an NZAN pamphlet by the consultant at the same time as he told her the diagnosis was confirmed.

We hope the letter and pamphlets sent to almost all GPs a year ago, sponsored by a generous member family of this network, will enable quicker diagnoses for some.

We are including with this newsletter, a booklet with comprehensive guidelines for Solu-Cortef self-injection. The next publication milestone is nearing completion: "Reminders for living with Addison's Disease" is a booklet with a practical checklist, backed up by the wealth of information that's in our newsletters, in an easy access format.

How can we best sustain and evolve NZAN through the next few years? I'll be sharing my ideas soon, and I look forward to hearing yours.

Membership Update

We welcome the following 15 new members since the March/April newsletter:

Andrew, Christine, Colinda, Don, Glen, James, Jo, KarenM, Murray, PaulineB, PaulineD, Phillipa, Tony, Robert, GraemeB,

and we welcome back Dorothy.

How did our new members find us?

Endocrinologist, or nurse specialist:	8
Found pamphlet or poster at the hospital:	4
Found pamphlet at GP surgery:	2
Another NZAN member:	1

Thanks for donations from Beverley, Beryl, Christine, Colleen, Don, Graeme, James, Jill, KarenM, Kaye, Marianne, Maureen, Ngaire, Joanne, Sheryn, Margie, Patsy, PaulineD

We now have almost 130 members. The majority have paid their subscription for the current year. A reminder is enclosed for those who haven't. If you'd like to remain a member, please respond promptly, and help minimize extra work for us all! *If the fee is a hardship for you, please talk to us about it – a few members have donated extra for this very situation.*

Explaining our admin systems

We keep methodical receipt books, but don't send the receipts out unless requested. With our larger membership now, administration has become very time-consuming, and so strategies are being reviewed. It is becoming more challenging to keep a finger on the pulse, so please don't take it personally if Jeanette makes the occasional administrative slip-up!

In case newer members are wondering, we are continuing the same financial policies as when NZAN started. NZAN cheques are written only against invoices, and co-signed by Jeanette Crossley and Hugh Douglas, a member who is the local optometrist in Havelock North, where Jeanette also lives.

WARM THANKS to Annette Church who keeps the membership database for us, prints and sends out the newsletters, and is always willing, helpful, efficient, and kind in her interactions with Jeanette.



Information about medications changes

1. DHEA Capsule Change:

The DHEA capsules made by Pharmaceutical Compounding NZ have changed in size (they are now smaller), and also in the composition of the non-active component (filler). For at least some people, they are proving more potent than the former capsules.

The change occurred when PCNZ opened new premises a few months ago, not far from their previous location on Auckland's North Shore. Changing the filler from calcium lactate to lactose was planned as an improvement, enabling improved quality control. No change in the bioactivity of the capsules was expected.

However, the experience of five NZAN members seems to indicate that the new capsules are better absorbed than the previous preparation, leading to side effects such as acne at low doses, with blood levels of DHEAS that are about twice what was measured taking the same milligram dose of the previous formulation.

This is additional to the higher potency for the NZ product that Professor Holdaway mentioned in NZAN Newsletter July02:; *"Whereas the overseas studies used doses of 25-50mg DHEA daily, the NZ preparation seems to be better absorbed, and doses of around 10mg daily may be all that is needed. I generally start people on 10mg, and then measure the blood DHEAS level (the sulphated form of DHEA), 2-4 hours after a dose, to check that it is not too high."*

Therefore, an appropriate starting dose of the new formulation of DHEA capsules is likely to be 5-10mg.

Supply of DHEA requires a prescription from your doctor. We understand that PCNZ is pointing out the change of potency to prescribers, before dispensing. PCNZ is investigating the puzzle, and we'll keep you posted.

Contact details for PCNZ:
62c Diana Drive, Glenfield
PO Box 101 142, NSMC, Auckland.
Phone 09 442 5850, fax 09 442 5851

2. White Florinef delayed until 2005

We've been told by the distributors in New Zealand that white Florinef is unlikely to be dispensed here before 2005. We'll keep you posted.

Meeting Report: Central Region, 2 May, 1-4pm



Jeanette's overview: When Gary Roselli told me that a record attendance was likely, I decided to make a personal visit south, and be part of the action! Sixteen Addisonians participated, some with family members also. Several had already attended Central Region meetings in 2002 and 2003. There was plenty of interaction and ready sharing of ideas and information - quite a warm sense of belonging. We were again fortunate to use pharmaceutical wholesaler Zuelig-Pharma's meeting room in Petone.

Gary chaired the meeting, which started with self-introductions "around the circle", with some questions and discussion along the way, and a refreshment break in the middle with taste temptations master-minded by Pam Roselli and some of the other participants. Gary had planned a reminder of the basics of Addison's and its management, with some of Prof Holdaway's overheads from the

Auckland meetings, but time ran out and that was left for another time.

Topics discussed included sleep issues, the differences between prednisone and hydrocortisone, the warning signs of adrenal crisis, calcium, coping in hot climates, the use of Solu-Cortef, difficulties making decisions when unwell, and adjusting medications to cope with illness, activities and work pressures – and mountain biking. [see also "Mike's Strategy" in the box below] Thanks to Grant for note-taking.

Among the participants was NZAN's most recent new member. Don was diagnosed 18 years ago in Hong Kong, where he was living and his career was based. Over 6-9 months he'd noticed getting dizzy climbing steps, weight loss, fatigue – and hiccups (see previous newsletter!). He'd struggled a bit with the heat over the years since diagnosis, and acknowledged he now felt he had a better understanding of Addison's having heard from others at the meeting.

Gary and his wife Pam are overseas on a six week adventure from early August. Gary's knowledge of Addison's from his profession as a pharmacist, and from forty years of personal experience, make him a valuable resource for NZAN. Sporting and other interests take him around New Zealand a bit, and he's willing to catalyse mini-meetings in other places where there are clusters of members, including Nelson and Manawatu. We'll keep you posted!

There is an error in Section 3b of the Solu-Cortef Injection Guidelines (V2 August 04) enclosed with this newsletter.

SOLU-CORTEF PRESCRIBED FOR AN INDIVIDUAL'S ADDISON'S EMERGENCY INJECTION KIT IS NOT SUBSIDISED BY PHARMAC. The cost per vial is about \$13 (varies between pharmacies). It's a bit confusing, because Solu-Cortef obtained by a GP on a PSO (Prescription Supply Order), is fully subsidised.

Vicki (Glen's mum), Glen, and Nicole at the Wellington meeting:



Glen, one of our youngest members, later contributed his photo caption by email:

"My name is Glen and I am 10. I have had Addison's since I was 4. I went to my first Addison's meeting two weeks ago with my Mum and Dad. I thought it was really neat and I liked talking to other people with Addison's. I now know that lots of other people also have Addison's like me".

Future meetings:

Midland Region: Mt Maunganui, September 25, contact Diane Goldsack, , phone 07 572 1430 diane.goldsack@actrix.co.nz

Northern Region (informal): Auckland, During October, contact Karen Carson, Phone 09 4837043, kcarson@xtra.co.nz

**Others are also being planned.
Contact your regional co-ordinator, or
Jeanette, if you'd like to organise a
meeting, or attend one!**

To Sleep or Not To Sleep Well

Waking in the early hours of the morning, and then having difficulty getting back to sleep, was a problem that struck a chord with several participants at both the Wellington

and the Christchurch meetings, and experiences were shared.

After the meetings several went away keen to explore (with their doctor's support), whether changes in the timing and maybe the actual amount of the afternoon/evening dose could help them achieve both appropriate evening energy levels, and better sleep.

**** If you try some changes, and find that they work for you, please send your feedback to Jeanette to share in the newsletter!**



There are general guidelines. If the overall daily dose is too high, in particular if the late afternoon or evening dose of steroid is a bit too high, or else taken a bit close to 'lights out' time, falling asleep can be difficult - and probably staying asleep is more difficult too.

But "too much" doesn't seem to be the whole story with regard to sleep issues. Indeed, in a previous newsletter [No.20 p10] we noted the reference to some research that seems to indicate that too little cortisol in the blood also interferes with sleep patterns.

A newly diagnosed member, taking only 15mg hydrocortisone per day (as the result of a misunderstanding), was flopping into bed rather early (8-9pm), and then waking in the early hours of the morning. Increasing her daily dose to the 20mg originally intended helped to sort that out, so that she was less wiped out in the evenings.

If you are lying there in the early hours feeling slightly nauseous and/or achy, rather than hanging on until it's time to take your morning dose, and perhaps being tempted to take it a bit early, an option is to take an extra 2.5mg (perhaps 5mg) then and there. Under those circumstances that action will probably help you get back to sleep.

For some people, especially if they have all the energy they need in the evenings, a satisfactory solution is to take their last hydrocortisone dose of the day no later than about 3pm. Some do better splitting the afternoon dose into half at lunchtime, and half about 4-5pm or even with dinner if they typically eat reasonably early.

One participant shared that on odd occasions when she felt 'crashed' at bedtime (rather than 'healthy tired'), she took an extra 2.5mg at lights-out to help a good night's sleep, and wake up feeling well. Swapping the end of day 5mg hydrocortisone for 1mg prednisone is another option that works well for some – especially if they were typically quite wiped out on awakening.

There are sound general principles for Addison's management, but we know that with regard to the detail, fine tuning can make a big difference for some people. We don't all metabolise hydrocortisone at the same rate.

A few Addisonians take sleeping tablets (eg Imovane) on an occasional or more frequent basis.

Some members find it hard remembering the afternoon doses on time. That depends on motivation! And perhaps technology! A few have watches with digital alarms.



Mike's Medications Strategy

We are not suggesting that Mike's strategy would suit everyone! However it works well for him.

Substituting just 1mg of longer-acting prednisone for 5mg of his daily hydrocortisone in the evening fixed his regular waking up at 3-4am, and difficulty getting back to sleep. Having the longer-acting steroid to last through the night, then

helped him "cut the fat" out of his overall daily steroid dose.

He lives a full and busy work and family life, and keeps good health.

Jeanette enjoyed catching up with him again at the Wellington meeting, and followed up afterwards: Please would you give more detail about your strategy for wellness – and for good nights sleep! And did you enjoy the meeting?

Mike: Happy to do so. It was a good meeting - I imagine you always get new insights into managing Addison's at each meeting you go to. As somebody at the meeting said "I hardly ever think about my Addison's", but it is good to be reminded again that crises can and do occur and that you need to be prepared at all times. I don't carry tablets everywhere with me (although I do have tablets in my work satchel). But then again, I don't go mountain biking [as does one of the meeting attendees]! I used to windsurf - now that would be a challenge - I imagine that I would be able to put a container of pills under the wetsuit. I have actually been hurt badly while windsurfing, and also had my shoulder dislocated - I would have needed cortisol [Solu-Cortef] on both occasions - fortunately that was before I acquired Addison's disease!

Jeanette: I think you were the one on the lowest dose of adrenal steroid replacement, at least on a body weight basis?

Mike: Yes, that's probably right!... I weigh ~102Kg and I have remained around this weight (+/- 3Kg) from about six months after diagnosis with Addison's disease in 1998. I was less than 80Kg at the point of diagnosis.

I initially started off on 25mg hydrocortisone and 0.1mg fludrocortisone. However, after a few weeks of feeling great I felt that some of my illness seemed to have crept back. Cramps had returned on almost a nightly basis. I was putting on weight like crazy, and I even started getting night sweats again,

although the sweat was now stinky whereas it had no smell prior to my diagnosis. I first tried increasing my medication, but this made things worse. After reducing medication, things improved.

With a bit of experimentation I found that I functioned best on what was considered by the endocrinologists as "very low doses". Between 1999 and October 2002 I took 7.5mg hydrocortisone in the morning and 1mg prednisone in the evening (around 12 mg equivalent hydrocortisone). This is considered a very low replacement dose and extra care is required on these low levels.

I now take 7.5mg hydrocortisone with breakfast at around 7.30am each morning and 2.5mg hydrocortisone and 1mg prednisone with dinner around 6.30pm. The prednisone means that I do not run out of cortisol in my body during the early morning hours and I tend to sleep better - not perfectly, but better than when I took only hydrocortisone in the evening. Prednisone is longer acting - at around 18-24 hours half-life compared with hydrocortisone at 4-6 hours half-life, so you tend not to "run out of gas" as easily. I normally go to bed around 10pm and wake around 6.45am.

I am very careful to take extra medication if I feel in any way sluggish or unwell. For me, the indicator is often a mild headache, particularly in the late afternoon. I take an extra 2.5mg for this - as soon as I feel like a headache is coming on. If I am feeling quite unlike doing anything at all, I would tend to take an extra 5mg. It is amazing how often taking additional medication will change the way you feel and restore your well-being. I feel that I am merely doing exactly what my body would be doing (i.e. producing extra cortisol) under the same circumstances.

How often do I increase my medication? There is no real pattern here. Sometimes I can go for several weeks without increasing my dose at all. Other weeks (if I have been more active or more stressed perhaps) I will

be reaching for an extra 1/2 pill every day. I know that I can't easily overdose on my replacement levels so I don't have any issue with taking extra medication to feel better.

I will increase my hydrocortisone with a cold - 10mg instead of 7.5mg in the morning and 5mg instead of 2.5mg in the evening. I have not had the flu' in a long time, but I would at least double my normal medication under these circumstances.

A headache and lethargy in the evening is normally a check on whether I had my pills with the evening meal. Forgetting my pills never happens with normal routine, but rather, when we have people over for dinner or we've been out for dinner. This is when I most need the hydrocortisone! I will also increase my medication slightly when I have alcohol. This seems to help the morning after. Not that I ever have more than a couple of drinks.

I will normally increase my dose slightly if I know I am going to be particularly active that day. If it isn't possible in advance, then it is possible after the event.

It is important to get the doctor to prescribe more medication than what you normally take. This way there will always be some medication in reserve during the 90day prescription period. Doctors may not like doing this, but I remind them that it is important to have extra medication if you are unwell.

I take 0.1mg Fludrocortisone daily. I have tried increasing and decreasing this dose. I seem to get by all right on 0.05mg, but this is probably too low for replacement based on the international evidence for my body weight. I do not feel well on a higher dose. I find it hard to describe exactly how I feel with the higher dose, but it is a general unpleasant feeling and minor discomfort around my kidneys. It also tends to increase my blood pressure. Soon after the meeting, Mike was heading overseas for a break to see his sister in Italy:

"I will be spending two days in Bangkok on the way over, and a few days in Chiang Mai on the way back and I will be conscious of the need to increase my fludrocortisone slightly (a day or two in advance) in order to cope with the heat and all the walking you do when exploring a city at the same time as coping with jet lag. I will take an extra half tablet each day. For the short time I am there, there will be no risk of feeling unwell from overdosing on the fludrocortisone."

And how did the trip go?

"The trip to Italy went well with no problems with my Addison's, as I had anticipated. I walked the Cinque Terre! This is an 18Km mountainous pathway through five adorable fishing villages in Liguria, where people live lifestyles not too far removed from the Middle Ages. Apart from increasing my fludrocortisone intake slightly and tending to my blisters, I was fine!

As always, the tropics of Thailand can take their toll on your body ... it is a matter of pacing yourself to avoid the worst of the heat - morning and evenings are the best times to explore - and keeping up the fluid intake! Wizzened old men will sell you small bottles of Coke for 70 cents (15 Baht) but the Coke will be warm - this will keep you going until you can enjoy the cold mango juice back at the hotel, which is probably OK to drink. Unless you have checked the source of any ice, it may be best to avoid the local preference for having the man pour the drink from the bottle into a plastic bag full of ice.

I forgot to increase the fludrocortisone on the way back from Europe, so I only increased my dose on the day I arrived in Chiang Mai. However, I didn't have any problems coping with the elephant ride!"



Meeting Reports: First Southern Region Meeting Sunday 25 July, 2004

Jeanette's overview

The first Southern Region meeting on 25 July was an enthusiastic affair. The staff-room at Shirley Boys' High School was an ideal venue for the 23 Addisonians to meet each other. With family and friends the tally was 39.

I was delighted to put faces to names, after so many years. Sheryn has been a member since the first months of NZAN. At the other end of the timescale, Graeme, who joined NZAN at the meeting, had been diagnosed only a few days.

Whilst most participants were from Canterbury, several were from further afield - Jan from Dunedin, Pauline from Nelson, Karen from Marlborough, Ngari from Oamaru, and Dyan from Timaru.

Lois, however, earned the distance award! She lives in Malaysia, and timed her annual trip home to visit family, so that she could participate in the meeting.

While several people in the room had previously met one or two other Addisonians, few had previously met about two dozen! There was clearly value in seeing and hearing the common ground, and the diversity. It showed in the sea of smiling faces throughout the day.

One of my hopes was to establish improved co-ordination with and within the Southern Region. I realised there can be a problem with the term "co-ordinator", as though that means all the tasks must fall on one back. I hope the solution we've devised will work out well - the Southern Nucleus! Patsy Fogarty is the personal contact with local members, especially by phone, and will be the Southern Region contact on our letterhead. Russell Stocks is the email contact, and a few others will be involved too, as appropriate.

My thanks to those whose input made the day flow so well, especially Patsy, Russell, Deborah, and Russell's partner Jude. I'd have liked to spend more time catching up with individuals. I won't forget the warm welcome, the beautiful (and totally unexpected) flowers, and the kind words on feedback forms and cards afterwards.

Two years ago, when I was last in Christchurch, I was pleased to meet Lois and Dyan over coffee, but the timing was clearly not right then for a bigger meeting. NZAN has now blossomed in the south!



Ngari's notes: "Jeanette greeted us all warmly, suggesting each member speak for 3-5 minutes, of when they were diagnosed, current medications, quality of life, current issues, successes, etc.

I guess, like me, we were all a bit apprehensive about speaking up, but our fears were quickly dispelled. Russell started the ball rolling, and gave us a friendly welcome to Shirley Boys' High School where he is a teacher, and told his story with humour, so the atmosphere of the meeting was set. [Not a lot of humour prior to Addison's diagnosis!]

The stories all had common threads, and we smiled to ourselves as we were reminded of our own symptoms – lack of energy, low blood pressure, browning of skin (almost blackening in places), vomiting.... Some even had gall bladder removed, or hysterectomy, but the symptoms remained. Some wondered if a change of doctor would have led to an earlier diagnosis. The extreme desire for salt pre-diagnosis was mentioned several times (licking it by the palmful, said one member), and drinking pickle juice and vinegar, and eating lemons...

As topics were raised they were noted on the whiteboard for addressing later.

We easily related to Graeme's distinctive tan, and were pleased that his diagnosis a few days before, had taken only a month after his first symptoms. A man in his 50s with a dry sense of humour, he said his biggest issue before diagnosis was that Speight's didn't taste right, and he hoped that would be soon be fixed now that he was stabilized on medication.

A number of the participants had multiple illness to contend with, making the rest of us grateful to have just Addison's.

We found we had similar medication regimens, but a few of us got ideas for making little changes, that might help us. Several said they find it hard remembering the afternoon dose on time. The mother of an 8-year-old triplet with Addison's shared that it works well for all three to be involved with Ben's daily medications - his sister checks he has taken his medication, and his brother checks that his sister has checked.

Several participants, including me, found it reassuring to find that others also had periods of being not just tired and weary, but "wiped out".

After a delicious finger-food lunch, and friendly chat, Jeanette gave some background about NZAN, and then started the Forum discussion. Jeanette explained ways and means to overcome various problems. It was inevitable that time ran out before the long list of topics could be covered.

Using a time-expired pack, Jeanette demonstrated mixing the compartments of the Solu-Cortef mix-o-vial, filling a syringe with the solution, preparing the injection site, and then did a simulation of the injection itself, with the needle still capped. We passed round the dissolved Solu-Cortef, so that we could see what it is supposed to look like once dissolved. We also got a copy of the guidelines that are being circulated with the newsletter. There was enthusiasm for a real self-inject session at a future meeting.

I believe we all felt more comfortable with "our" Addison's at the end of the day. Thanks for making our first Southern Region Meeting so informative and friendly. A vote of thanks was given by Russell, and flowers from the group."

Medications and Doses Summary (Southern Meeting)

All the Addisonians at the meeting in Christchurch were taking hydrocortisone.

**The commonest dose was 20mg (10/5/5, 10/10 or 15/5) – 14 participants,

**Two were taking 15mg,

**Four were taking 25mg,

**Two (both men) were taking 30mg.

For fludrocortisone

** The commonest dose was 0.1mg - 11 participants.

**Three were taking 0.05mg.

**Six were taking 0.15mg,

**Two were taking 0.2mg,



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.

REGIONAL CO-ORDINATORS

(details on the members' contact list)

Northern: Karen Carson (Auckland)

Midland: Diane Goldsack (Mt Maunganui),

Central: Gary Roselli (Lower Hutt)

Southern: Patsy Fogarty phone, and

Russell Stocks esp. email, (Christchurch)



Mini-Meeting Report: Northern Region news from Karen Carson, Northern Regional Co-Ordinator

Eight Auckland members enjoyed an informal get together at Karen's house on 15 May. The trigger was participation in a survey originating at the Auckland School of Medicine. [More about that, and the results, in the next newsletter!]

Karen is arranging another get-together in Auckland, in October, probably at a café on the North Shore. If you are interested in attending, email or phone Karen: kcarson@xtra.co.nz, phone 09 483 7043.



A Warm Welcome to Charlie:

In her feedback about the Auckland mini-meeting, Karen Carson mentioned that Addisonian participant Cheryl was about seven weeks away from the birth of her second baby.

Cheryl's news is a mixture of happiness and heartache: "Charlie was born on 28 June and Jon and I are thrilled with our young man who is a little brother to our three year old Daisy. However, he is causing us a lot of worry at the moment with serious health problems. Charlie is undergoing treatment principally for a seizure disorder but he also has a hole in the heart, and Down's, so it's very complicated. Charlie is now becoming more used to the seizure medication and doesn't have to be sedated as much, so we are looking forward to getting to know our boy."

If you would like to receive a copy of this newsletter as a PDF file, please contact Jeanette.

Poor memory?

It was a topic that sparked enthusiastic discussion. Several at the Christchurch meeting wished they had a better memory.

A poll showed that some partners and friends in the room also rated themselves as having a poor memory, and Jeanette took a "devil's advocate" position that our memory isn't really worse than others'. But she wasn't allowed to get away with that!

For example, the husband of one member diagnosed in 2003 said there was no doubt to him, that his wife's memory had been better before the start of Addison's. Another wondered if it's just because we tend to have so much to do and remember these days.

Four of the attendees had taken part in the DHEA trial in Christchurch a couple of years ago. Memory tests had been part of that, and they wondered how they had scored, for their age and sex... they felt motivated to try to find out their results.

The topics of mind and memory function have been covered over the years in the NZAN newsletters. Two articles in particular merit re-reading, if people have concerns about poor memory – see below.

Speaking generally, Addisonians don't have to feel doomed to have a poor memory – rather, it alerts us to things that we can change. Explore tweaking your replacement medications so that the timing and overall dose are right for you. Perhaps the simplest useful messages are, identify and modify the stresses in your lifestyle, don't let yourself get regularly exhausted, and get enough physical exercise! [As they say in Tui ad country, Yeah right]

**** If you find a successful strategy for improving your memory, please let Jeanette know, for sharing in a future newsletter!**

** Reminder of past NZAN articles on this topic:

“Brain Workouts for better memory and reasoning ability”:

In NZAN Newsletter No.20, Nov03, page 6. The information was from a special issue of Scientific American magazine. The punch-line from a senior neurophysiology professor is worth pondering, Addisonian or not: “I predict that if more people knew that a proper diet, enough sleep and exercise can increase the number of neural connections in specific regions of the brain, thereby improving memory and reasoning ability, they would take better care of themselves.”

“Shall we fly – or walk?”

High cortisol dulls the brain”:

NZAN Newsletter No.13 (July01) pp 9-10: It is about 'ordinary people', not Addisonians... The punch-line is that inappropriate cortisol levels in the blood are linked with woolly thinking and memory problems – and the simplest “correction tool” is exercise.

A&E experience worked out well for Patsy

An unexpected aspect of the Christchurch meeting, was that Patsy, who'd had a special input phoning members and encouraging attendance, and who was going to be "MC", was unwell on the day so couldn't come.

Extra oral hydrocortisone wasn't enough to keep on top of an infection, and she had developed a fever. That night she was admitted to hospital for hydrocortisone, fluids and antibiotics, and was kept in for a few days.

The process worked smoothly - a bouquet to the team at Christchurch Public Hospital A&E!



Patsy's husband called an ambulance, explaining that she had Addison's and they were concerned that she may be going into shock. At A&E her doctor's emergency letter was handed over and heeded, her prior records at the hospital were accessed, and within about half an hour of arrival at A&E she had an IV line in place.

Jeanette was pleased to meet Patsy next day, albeit still in hospital, before heading home to Hawkes Bay.

If you are unlucky enough to need emergency attention at a hospital, please share your experiences!

We would like to identify any obstacles, and hope we can award more "bouquets" !

Did you do your bit?

- * have extra hydrocortisone before going to the hospital (tablets and/or Solu-cortef injection)
- * wear your Medic-Alert ID
- * take a copy of your emergency letter from your doctor, to hand over
- * assertively make sure you got appropriate priority at the hospital

Did the hospital team accept your situation, and give you prompt and appropriate treatment?

Two new members:

Teenagers with Addison's

Among our new members since the April newsletter, are two teenaged boys, Robert and James, diagnosed at a similar age. Both were very relieved when the diagnosis was made –as were their families!

James is 19 now, and was diagnosed with Addison's four years ago. He loves sport - he is a cyclist, has been a soccer rep, for 12 years a highland dancer, and for 10 years a pipe band drummer. He is studying for a B.Sc in earth sciences at Canterbury

University. His mother recently found our yellow brochure in their GP's waiting room.

James has been an insulin-dependent diabetic since he was 6. When he was 15, typical Addison's symptoms developed, including weight loss, dizziness, nausea in the morning, and a tan - which they thought was from skiing. The most frightening development was unexpected low blood sugars, "sudden diabetic lows".

His regular diabetes appointment was scheduled for Christmas Eve. His mother phoned ahead to discuss the above symptoms, and the diagnosis was made at that appointment, just 10 weeks after they first became aware of the symptoms. His diabetes management includes glargine insulin (a new long acting insulin not supported by Pharmac at this time), which James finds makes it easier to balance his Addison's and diabetes.

NZAN now has 8 members with Type 1 diabetes as well as Addison's. It is a very challenging combination.

It seems timely to remind members about Glenn Kardel's Addison's-Diabetes website at <http://addisons-diabetes.gkznet.com>

There is good resource material, and a forum which Glenn manages well. The links page includes several direct connections to Prof Holdaway's articles in our newsletters!

Richard had started to tan more than usual while in his 4th form year. At the Christchurch meeting he shared with a smile: "All the girls liked it, I liked it too, it wasn't a problem."

He wasn't diagnosed with Addison's for another three years (in March 2004, when he was 16), despite increasing lethargy, salt cravings, frequent vomiting and (in hindsight) at least one Addison's crisis in early 2003. That occasion was diagnosed as a stomach bug, says his Mum, because he had vomited then slept a lot and not had a great deal to drink, and became dehydrated. Blood tests

were taken but no abnormalities were obvious.

After he started the treatment for Addison's, his family reports the difference was amazing" However, on the odd occasion when he has forgotten to take medication, the change back to the "other/sick" Richard is reasonably quick and quite distressing for family members.



Richard

For families of teenagers diagnosed with Addison's, memories of the "L" assumption, "Lazy", can be rather haunting. "Richard was often regarded as a lazy lethargic boy with no health issues, even by his parents!" his Mum wrote on his membership form. His two-years younger brother remembers him often sitting on the sofa all day, doing nothing, and would accuse him of lounging around and wasting the day - usually getting the same response: no, I'll just sit here. Hopefully it is helpful and healing for the family members to realise from talking to others, that their assumptions were typical.

The family had wondered if Richard's frequent vomiting was a sign of bulimia. Also, he had a craving for salty snacks (for more than seemed his fair share), and also for vinegar, straight from the bottle. His brother remembers Mum asking "Who's drunk the

vinegar?". Richard still favours salty and vinegary foods, and eating lemons. [Many Addisonians would relate to that, especially the lemons - others select the oysters at the buffet, we grab the lemon garnish to eat, making "ordinary" people squirm!]

Richard is now a 7th former. For many years he's had a passion for flying light aircraft, and often flies at weekends with his father, who is an air traffic controller. He had started training to get his private pilot's licence only a few months before his eventual Addison's diagnosis. He had to put that on hold, while the medical implications were investigated. It was good to hear Richard tell us at the Christchurch meeting that he had recently got his medical clearance back, and is again training in the air.



Figuring out how much extra steroid to take for active sport:

As articles in previous newsletters have addressed, it's a challenge! Two members share their strategies.

* Individuals should involve their doctor in their plans for coping with strenuous sports.

1. Maximising Ski time

Mt Ruapehu is famous for its unpredictable weather in the ski season. Linda was a passionate skier long before her diagnosis with Addison's nearly five years ago, aged 45. She shares her strategy for managing her Addison's medications, to optimize her wellness, and maximize her time on skis.

"If I'm on the mountain and not skiing I take my normal doses. If I am actively skiing, I take increased doses of hydrocortisone – up to 15mg extra.



"I find by taking just 5mg on waking, that I don't have to decide how big a dose to take until I've heard the ski report or looked out the window at the Lodge!! If the field is closed I just take another 10mg, but if it's open I take 20mg. At lunchtime, I take an extra 5mg if I am still skiing, or my usual dose if the weather has packed up.

Skiing has finished by 4pm so I only take my usual 2½ mg at 4.30pm. This plan doesn't seem to affect my sleep."

Linda takes the same dose of fludrocortisone each day, 0.1mg, and she also takes 5mg DHEA in the morning. She carries a Solu-Cortef injection kit on her person, while skiing.

2. Is extra needed, or is it habit, for regular sport?

One participant at the Christchurch meeting was surprised that most of the Addisonians in the room were reasonably slim and trim. She had put on a bit more weight than she was comfortable with, and her face had become a bit puffy.

Her situation was an example of the difficulties that can arise interpreting when to take extra meds. Her daily dose of hydrocortisone was 20mg. She had absorbed in a black-and-white way, the message from her doctors to take an extra 5mg before strenuous exercise.

She walks for an hour 2 mornings a week, plays tennis a morning a week 9.30am - 11.30am (quite strenuous, she says) and then usually plays tennis another night during the week also. She was taking an extra 5mg hydrocortisone before each of the four activities, a regular extra 20mg / week.

She went away from the Christchurch meeting realizing that her sport was an accustomed part of her life, and probably didn't need the extra doses - she'd talk with her doctor, and test some judicious dose pruning.

Feedback a month later: "I have found I don't need to automatically take the extra 5mg!"

She carries hydrocortisone with her, just in case, but she hasn't felt the need for any extra, either at the time, or looking back on the day. "I might when evening tennis starts again in summer. I am not sure if the weight is falling off??? I have always had a round face anyway - but here's hoping!"

REMINDER

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.





**From NZAN's Medical Advisor,
Professor Ian Holdaway:**

Question 1: Three ladies at the Christchurch meeting were having difficulties due to prolonged anaemia. Does Addison's contribute to this?

Answer: Anaemia may occur in untreated Addison's disease, but shouldn't be a problem if treatment has been given. There's a higher incidence of vitamin B12 deficiency and hypothyroidism (underactive thyroid), which can cause anaemia, so these should be excluded. Other unrelated causes of anaemia such as iron deficiency should also be checked. A haematologist may need to be consulted.

Question 2:

Addisonians get the message that osteoporosis is a risk from slightly excessive glucocorticoid replacement, but that not all individuals with Addison's disease are equally at risk. So they are advised to get a bone mineral density test, and then "take it from there."

Steroids like hydrocortisone and prednisone are known insulin antagonists, but the message isn't usually given to people with Addison's disease that impaired glucose intolerance or overt diabetes mellitus is also a risk for them if their dose of steroids is a little bit high.

Under what circumstances should people with Addison's disease also have their blood glucose checked?

Answer: If high dose steroids are needed for long (>4 week) periods then diabetes can occur, especially in those who are genetically

predisposed (positive family history). Individuals with Polyendocrine Autoimmune syndromes (especially Type 2), are also at risk and should be watched with fasting glucose values now and again. Sporadic Addison's individuals shouldn't be at greater risk of diabetes unless they also need routine high dose steroids for other medical conditions.

* * *

NZAN surveys have shown that about 20% of our Addison's members also have another endocrine autoimmune disorder such as an underactive thyroid gland or diabetes. This means they have "Polyendocrine Autoimmune syndrome Type 2".

Professor Holdaway reminds us: "Monitoring thyroid function should also be part of the ongoing management of people with Addison's disease, especially if there are symptoms such as increasing tiredness, intolerance of the cold, weight gain or fluid retention."



At the beginning of September, Professor Holdaway is attending the 12th International Congress of Endocrinology in Lisbon. He is an invited speaker at a symposium about new developments in understanding acromegaly, adult growth hormone deficiency, and traumatic brain injury - the common thread is the growth hormone/IGF axis. Professor Holdaway's paper is about the consequences of IGF-1 deficiency and excess.

ICE congresses are held every four years. The first was in Copenhagen in 1960. The ICE 2004 website makes clear the size and scope of the congress: "Over 55 invited symposia will cover the latest cutting-edge basic and clinical topics delivered by experts in the field from over 25 countries."

We look forward to some feedback about the conference, in a future newsletter.

Beware the drooping head! Jeanette's cautionary tale – try and conserve upper body strength!

In conversations with a few members recently (all of whom would admit we are past the first flush of youth) I found that I'm not the only one whose head feels heavy, and droops forward more often and more easily than I would like.

The problem for me gradually worsened, without my noticing. Upper body strength, and arm strength above horizontal have been a problem for several years. I had a slow recovery from a lung abscess last year, and for various reasons have probably not regained my former (albeit still modest) level of fitness. I had a particularly stressful few months of work. Long spells at a desk and keyboard weren't helping. In April I stayed a few days with an elderly friend, who had my best interests at heart when she pointed out how chronic my stooping posture had become – I was closing our apparent age gap!

An X-ray showed slight wedging of cervical vertebrae, and my GP recommended that help from a physiotherapist might at least stop the situation worsening.

The physiotherapist explained that muscle weakness affects the biomechanics of the joints. It alters the spinal position and causes the spine to jam up, with wedging of the joints. He started with gentle mobilisation to improve the "joint play" for the thoracic spine. I found I could turn my head far further to the left and right.

He said the best exercise for me is lying horizontal (on the floor) for 10-15 minutes 2-3 times a day, with arms at 90 degrees, and elbows also at 90 degrees, so that my hands are up in the air a bit, but pointing behind me. I find that hard to build frequently enough into my day. The other exercise is, when sitting at the computer for example, to frequently stretch the chest muscles and straighten the

top of the spine, by putting the arms behind and over the back of the chair, and then holding hands.

I can't go for more than 2-3 weeks yet, without another "freeing up" session with the physiotherapist

Ngari's story:

Ngari was 65 when she was finally diagnosed with Addison's disease. She is now 73.

For several years she has been invited by Dr Patrick Manning [consultant endocrinologist at Dunedin Hospital] to speak of her symptoms prior to diagnosis to fourth year medical students in Otago – every term for an hour, to four groups of three to four students each time.

This is the story she tells:

I was diagnosed October 1996 at A&E, Dunedin Hospital. But at the end of 1989 my twin sister had died. I was grief stricken to the extent of feeling physically sick. I didn't really recover, this sickness kept recurring, and I just seemed unable to come to grips with it all, although I have faced other crises in my life and got through. But looking back, I feel my illness 'kicked in' (I don't name it at this point in the talk). I visited my GP (rather, two GPs) during this time, explaining the nausea, some vomiting and diarrhoea, feeling very lethargic etc, nasty cramps during the night (I placed magazines beside the bed – the coldness gave relief!).

My increasing desire for salt was so intense that I frequently filled my hand with it and licked it all – feeling guilty for some reason! This made me very thirsty, so I drank lots of water which seemed to go straight through me. It was embarrassing to be invited out for a meal, because I ate so little. My weight was dropping quite dramatically, my blood pressure varied but was lowish. Gradually my skin colour darkened, less so my trunk. All this time I had numerous tests/scans/X-rays

etc. The 2-3 years before diagnosis were particularly difficult. The last holiday we were camping. I lived on 3-minute noodles. I don't want to see them again!

A daughter who lived out of town, visited one day, and was horrified at my extreme weakness. That night I couldn't sleep, so I got up with difficulty to make some hot milk, but couldn't lift the jug to pour the milk in. I didn't want to wake my husband, so I just crawled back to bed. Next morning I rang the GP as my daughter had insisted, and she first suggested I come on in. I explained that I wasn't able to. So she called in at 5.30pm, got a blood pressure of 90/40, became very concerned and called an ambulance.

On admittance at A&E I was examined by a young New Zealand-trained doctor, whose name I have never forgotten, who listened to my story, turned my hands over noting black lines on palm creases, and said "You've got [I pause for the students to give the right answer at this point – some do!] - but it has to be confirmed".

As soon as they had taken the bloods for a synacthen test, first steps were to rehydrate me, followed by hydrocortisone, and I was sent to Chest X-ray. What a gratifying diagnosis to make. I felt completely better next day, before the blood test results even came back.

I can feel quite angry now, that it took so long for diagnosis, and my quality of life suffered all those years. Also, because the dark pigmentation of my skin was so gradual, my husband did not notice, but he was supportive of my unwellness.

That is the story I give. My second GP told me more than once that she knew nothing about Addison's. Hopefully the students I talk to will file it away in their memories. I appreciate 'life' now – even though I have the odd 'wiped out' days.

There is another twist to Ngari's story, which she sometimes adds.

Her twin sister had some autoimmune conditions - thyrotoxicosis, vitiligo and pernicious anaemia. Ovarian cancer was unfortunately diagnosed late, and that had been the cause of her death.

Eighteen months before Ngari's diagnosis with Addison's, her gynaecologist found an abnormality that raised alarm bells of cancer, and merited a hysterectomy. Fortunately, the problem turned out not to be serious, just a polyp.

After the operation, staff were concerned because her blood pressure was down a bit – but that had happened before, including after the births of her children, so Ngari wasn't worried, and said it wasn't unusual, it would come right. The staff also commented on her tan. She asked her husband to bring in the salt shaker, because she wasn't given enough salt with the hospital food. But the diagnosis of Addison's, "putting two and two together" had to wait a further 18 months.

Ngari doesn't have other diagnosed autoimmune conditions herself, but believes her grandmother had Addison's – "She had vitiligo and low blood pressure, and was given regular injections of what I believe was liver extract. She became very thin and loved salt and pickles and vinegar...!"

Ngari takes 15mg hydrocortisone in the morning, 5mg in the afternoon, and 0.1mg fludrocortisone. Earlier this year, she and her husband moved to Oamaru. She will continue with the talks – it's only an hour and a half's drive, and she enjoys catching up with friends too, she says.

Reminder: The members' stories from our newsletters can be downloaded from our website, or are available printed on A4 paper and wire-bound for \$10, contact Jeanette .

