

# New Zealand Addison's Network

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## Update Newsletter, March 2002 (No 15)

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### In this issue we feature

- More meetings happening:  
**NZAN meeting in Petone, 5 May**
- Northern Region plans
- Membership - and subscriptions due
- It's worth being firm! Ngaire's experience.
- Kathryn's story, continued - DHEA benefits
- Karen's weight loss success
- Ideas for avoiding confusion of different round white pills – Part 2
- Our hydrocortisone tablets – NZ made
- Leaflet about Addison's disease - on the way!
- Emergencies in the home – identifying your medications
- Reminder - foreign language emergency information
- Margaret's story – reflections of a cortisone pioneer:

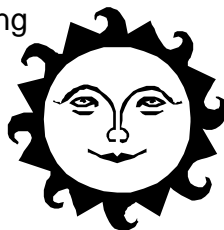
From our medical advisor, Prof Ian Holdaway:

- Do people with Addison's disease ever need adrenaline in emergencies?
- What can I do about muscle cramps?
- Some challenges with cortisol replacement and its monitoring
- Optimising fludrocortisone (Florinef)
- Addison's and bone density

Index of topics, Updates 1-15

Members' Survey

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



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

## MORE REGIONAL AND LOCAL MEETINGS HAPPENING IN 2002.

The first Central Region meeting is being organized by pharmacist member Gary Roselli, in **Petone, on Sunday 5 May** – or Saturday 4 May if that suits more people. Hopefully an outcome will be a nucleus of people locally, who'll plan future get-togethers for the region.

### ANNOUNCING: NZAN MEETING IN PETONE

**Date: Sunday 5 May (or Saturday 4 May, if that suits more people)**

**Time: 11am – 3pm.**

**Place:** Zuellig Pharma, 7-19 Fitzherbert St, Petone. (2 doors from the Esplanade, and directly behind Valentines. There'll be someone at the door.)

**Programme** – After the welcome, participants introduce themselves to the group. Then, after lunch, there's discussion and sharing on topics of interest to the group, using the whiteboard. These sessions are usually lively, and very informative for all attendees. Resource materials are available.

**Cost** \$10 per attendee – covers finger food lunch, and beverages.

**Meeting Co-ordinator** - Gary Roselli, a pharmacist, and NZAN's central region co-ordinator, will chair the meeting, and keep it on track! He can be contacted by phone 04 565 1783 (evenings), 04 567 7514 (business), fax 04 565 3982, but will be overseas between 6 and 21 April

**Registration:** Ngaire, phone 04 298 4515, or by post, PO Box 1527 Paraparaumu Beach.

Gary's story was featured in the July 2000 Update (number 10). A recent experience of Ngaire's is shared on page 4 of this issue.

All Addisonians and their family and friends are welcome to attend.

We hope doctors will tell their Addison's patients about the meeting. We are enclosing separate flyers for them to give their patients.

Pharmaceutical wholesaler Zuellig-Pharma, who currently sponsor the postage and envelopes for our newsletters, have kindly offered the use of their Petone board room for this and future NZAN meetings. With comfortable seats, facilities such as a white board, and overhead projector, and a little kitchen area, it's ideal for our purpose. Thank you!



### Personal meetings bring a further dimension

Newsletters, personal letters, phone-calls, and emails, can connect us easily with other Addisonians. But there's nothing quite like meeting in person!

Several Addisonians have told us they vividly remember their first meeting with others 'in the same boat'. Reassured by how "normal" we all look, people soon find plenty of common ground, sharing experiences, and talking about the many issues we all face, but may handle in slightly different ways.

Some are reticent... perhaps it will be a bit punishing, a few hours focussed on listening and talking about Addison's? I just want to get on with life, they may glibly say. But have you really got all the tools and tips, contacts

and confidence to get the most out of your life?

Successful meetings need not have a formal speaker. Enough structure can come from a 5-minute personal introduction by each attendee, and then a discussion forum – with a facilitator gathering input onto a whiteboard, or at least someone taking notes. Topics might include "Do you ever run low on cortisol, what circumstances precipitate it, and how smart are you at nipping it in the bud, what are your tips"; "How does living with Addison's impact your life"... A likely outcome of a forum is questions to put to the medical advisor for clarification.

If you are willing to help organize a meeting in your city or region, or are interested in participating in one – please put pen to paper in Survey Question 5 – or contact Jeanette.

\* Jeanette hopes to spend a week's holiday with friends in Christchurch late May or June (dates uncertain at this stage) and would enjoy a lingering lunch or similar to meet local members. Perhaps we could expand it into a mini-meeting? Please contact Jeanette directly if you are interested.



## Northern Region plans

The Auckland team who organized the successful meeting in July 2001, Kathryn, Karen, Andrea and Lyn, intend another meeting later this year - a bit more informal. We'll let you know more in the next Update, and post details on the Website when available.

If you're in the Northern Region, and keen to meet up with a few fellow Addisonians, you can register that interest in the Survey.

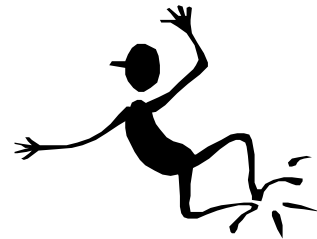
You are also welcome to convey your interest directly to Kathryn, phone 09 445 6427 (evenings), or fax 09 445 6428, or PO Box 101-631 North Shore Mail Centre, Auckland!

## MEMBERSHIP

NZAN's membership remains steady at 77.

As we have previously noted, more than half our members hear about NZAN from their specialists or their hospital clinic.

The flyer we are developing (see later in this newsletter) will help give NZAN a higher profile.



A couple of people have contacted us from our Website – but so far haven't joined.

NZAN newsletters are available on the Website. The visitor statistics show that they are being downloaded around the world.

*But the impetus for creating the newsletters, comes from our New Zealand based membership of "real people", sharing ideas, experiences and questions. Your membership is important for the evolution and future of NZAN. Your ideas are welcomed.*

### Some benefits of NZAN membership:

- Three newsletters per year, plus copies of overseas newsletters. These are also sent to all endocrinologists and endocrine clinics in New Zealand.
- Contact with other members through the phone and email list;
- Regional and local meetings;
- Opportunities for questions to the medical advisor;
- Opportunities to participate in members' surveys



## SUBSCRIPTIONS DUE

Subscriptions for the year from 1 April 2002 are now due. Invoices are enclosed.

Lola Copy in Havelock North gives us good rates and service, but our photocopying bill is quite hefty. You receive more than 50 pages of information, local and overseas, in each mailout. The same package goes to the endocrinologists and endocrine clinics in New Zealand, as well as to some specialist physicians and other health professionals with an interest in Addison's disease. We also send starter packs of information, about NZAN and about Addison's disease, to anyone who asks.

Sponsorship from Zuellig Pharma, and members' donations help us to maintain the subscription at \$20 – thank you.

***Please pay your subscription promptly. Follow-up is extra work we can do without!***

*If paying is a hardship for you, please talk to us about it.*

## COMPILATION OF NZAN UPDATES:

### ISSUES 1-11 (July'97- Nov'00)

Fill out the section on the Subscription Invoice if you are interested - \$4 per copy.

## TOPIC INDEX FOR NZAN UPDATES now available

We've prepared an index of the main topics from our newsletters. A copy is included in this package, and is also available on the NZAN website.

## IT'S WORTH BEING FIRM! Ngaire's experience:

"I've had Addison's since the early 1960's and about seven years ago was diagnosed with diabetes, now being insulin dependent. Early in December I drove my car at 11.30am, and was obviously low in sugar as I had a bad "hypo", became unconscious, and finished up in an ambulance and was taken to my local doctor [in Paraparaumu].

After I had been treated for my diabetes, I recalled what I had read [in the November 2001 NZAN Update] that Professor Holdaway had said about being firm in asking for treatment. So I told my doctor that as I was under stress, I needed extra hydrocortisone. My doctor said that he didn't know sufficient about Addison's but would talk with another doctor – and together they said I could have an injection of hydrocortisone. If I hadn't read the article just the day before, I may have asked if they thought extra cortisone was necessary, but that article made me adamant to ask for cortisone to be administered. The outcome is that I was quickly fit and well with no side effects."



## KATHRYN'S STORY, continued - DHEA benefits

A positive mindset, and a supportive family, help one to suppress the frustration – but for many Addisonians, fatigue and tiredness are more out of control and more frequent than before diagnosis. Referencing against one's peers shows it's not just a case of getting older!

Kathryn's up-beat story was printed in the November 01 Update. "Having Addison's has not changed my life a lot", she said in that story. "I do get tired but manage to work

around that as I have too many things that I want to do.”

In September, Kathryn decided to try adding 25mg DHEA daily to her daily meds. The benefit has been clear to her, with no adverse side-effects.

“By Christmas I felt really good for the first time in the 18 months since diagnosis. I am more evenly well throughout the day now, and don’t get so tired. It has helped my heat problem, especially in summer - I haven’t got wiped out so quickly this summer, compared with my first summer after diagnosis.”

(Better heat tolerance in summer was the main benefit Jeanette had noticed when she started taking DHEA more than 3 years ago.)

Kathryn takes 0.1mg Florinef, thyroxine for hypothyroidism, and calcium supplement. It’s 12 years since she stopped Depovera contraceptive injections at 48 – she’s had no periods since she was 35, and hasn’t taken any form of HRT.

Her specialist had told her, that if she was worried about putting on a bit much weight, she could try cutting down from 25mg to 20mg hydrocortisone. ‘I tried reducing my dose of hydrocortisone for about three weeks early last year, but was waking up tired,’ she said. The boost DHEA had given her, made her more confident to try reducing her hydrocortisone again. Since changing to 20mg hydrocortisone early February, Kathryn has had no reduction in wellness... her weight hasn’t dropped yet, either, but she is still hoping!



## KAREN’S WEIGHT LOSS SUCCESS

Congratulations, Karen (in Auckland), on achieving 15kg weight loss since joining the Weight-Watchers programme last July. In September she had the setback of having her gall-bladder removed. “In the end it was just a glitch on the radar, and now I am better than ever! I have been really working on my health - body and soul!” Karen shares some lessons learned, in the next issue of NZAN Update.



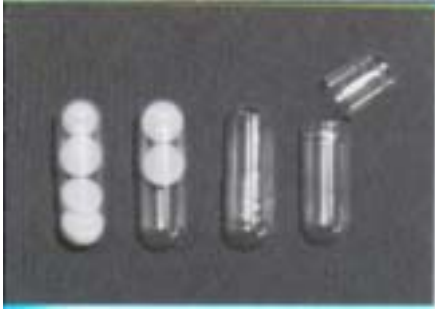
## IDEAS FOR AVOIDING CONFUSION OF DIFFERENT ROUND WHITE PILLS – PART 2

The Medicines Act says that medications should be kept in the container in which they were dispensed, with the original pharmacy labeling. That is straightforward for the bulk supplies, at home, or when traveling overseas.

But what about storing doses one needs to take ‘on the run’, away from home base? Having several vials isn’t always practical. In the previous Update newsletter, we presented some options – and said we’d find out more about capsules for storing mixed pills. Jeanette thinks she’s struck the jackpot!

She has a generous sample pack from Pfizer, of Size 0 clear gelatin capsules, 20mm long by 7mm diameter, that can be easily opened and reassembled. One or more tablets of 1mg or 5mg prednisone, or 5mg hydrocortisone, or half a 20mg hydrocortisone tablet, or one or more Florinef, fit inside easily. The filled capsules can be carried in one’s

pocket container (appropriately labeled), then pulled apart and the pills tipped into one's hand, and the capsule re-used, or discarded. That's Jeanette's current strategy for meds taken away from home.



Size 0 capsules – shown actual size.

*The capsule on the left contains, top to bottom: 1mg prednisone (P), 5mg P, 0.1mg Florinef, and 5mg hydrocortisone (HC). The second capsule contains, top to bottom, 5mg HC and 0.1mg Florinef*

The capsules can also be swallowed whole, with the pills inside. How might that affect the absorption of the medications? "We know that capsules take about 7-10 minutes to dissolve", says Margaret Sorensen, customer service representative for Pfizer.

When there is food present it can introduce many variables which might prolong dissolution slightly., she said. However, a study has shown no significant difference in capsule opening times between the fed and fasted state:

"Results from a gamma scintigraphy study on hard gelatin capsules filled with amoxicillin show the following average opening times in the GI tract:

10 volunteers, each dosed with two capsules  
Fasted: Mean = 7 min +/- 5 min Range = 2 min to 26 min

Fed: Mean = 11 min +/- 7 min Range = 5 min to 23 min"

"Capsules will last several years as long as they are stored according to our recommendations," says Margaret. "Ideal

storage conditions are a relative humidity of 50% and a temperature of 20 degrees C. If, however, Capsugel hard gelatin capsules are stored in closed containers, they can safely be kept in areas where the ambient temperature is 15 to 25 degrees C and the relative humidity 35-65%. Prolonged storage in areas outside these conditions may cause capsules to soften and lose their shape or to become difficult to separate. They should also be stored away from radiators and direct sunlight." Age of the capsules should have no effect on dissolvability at all, she says.

***If you'd like some capsules to trial, contact Jeanette.***



## **OUR HYDROCORTISONE TABLETS – MADE IN NZ:**

Addisonians in parts of the US have since December been experiencing supply problems with 5mg and 10mg hydrocortisone tablets. Several have been getting "it's on backorder" messages when they try to fill their prescriptions at their usual pharmacy. At the time of writing this, the reason is not clear, or the extent to which it applies to both the US manufacturers. Some US Addisonians have had to switch to prednisone, at least for the short term.

The US situation won't affect Addisonians in New Zealand. The 5mg and 20mg hydrocortisone tablets we take are manufactured by Douglas Pharmaceuticals in Auckland - and have been for the past 7 years. Prior to this they were manufactured in New Zealand under contract for distribution by Douglas.

Roger Smart (Director, Regulatory Affairs) confirmed there are no plans to change the dosages or availability of hydrocortisone tablets. "We recognise that the tablets are a

product for which there is a serious medical need, with no other supplier."

The company manufactures new batches when there is a three-month supply of tablets on hand. The bulk hydrocortisone is currently imported from the US, from Pharmacia-Upjohn.

Douglas has no intention of changing the source of the active ingredient at this time. However, if supply problems for the active ingredient develop for New Zealand, Douglas has access to a second source of equal quality, so that there will be no disruption to the availability of finished hydrocortisone tablets in New Zealand.

Thanks, Roger, for clearly putting us in the picture, regarding the production of our life-preserving medication.



**MEMBERS' SURVEY  
ENCLOSED  
- PLEASE PARTICIPATE!**

Your responses help to guide NZAN's direction, and to keep the Network relevant to you.

Our previous "annual" surveys have had a high return rate – we hope you'll continue the tradition!

Results will be published in the July Update newsletter.

**LEAFLET ABOUT  
ADDISON'S DISEASE  
- on the way!**

Vicky, an NZAN member in Taranaki, is in the second year of her Bachelor of Nursing degree at the Western Institute of Technology. As part of the requirements for the first year of the course, she had to "prepare a pamphlet, small booklet, or other resource aimed at educating an identified sector of the public on a selected health issue."



"As you can see, I have pretty much free range of what I do, and I want it to look good!" she emailed to Jeanette. "I would really value your opinion on what you think would be good for new and current Addisonians, and what NZAN requires."

We know NZAN needs a pamphlet available in doctors' waiting rooms, pharmacies, etc, alerting the general public to the symptoms and basic facts about Addison's disease.

Vicki took on the challenge, and her booklet earned her a Merit in her course. "The hardest thing was getting the important information across in as few words as possible, - also, coming up with an interesting title page that may attract people to pick it up in the first place."

We are adapting Vicki's booklet to be an NZAN publication, and hope to include copies with the next issue of Update.

Vicky is no stranger to the many symptoms of undiagnosed Addison's disease, whose significance may at first be overlooked. She'd been a receptionist for several health professionals since leaving school, and also a

volunteer ambulance officer. At the age of 27, in February 1998, she headed overseas on her big OE, with a sun tan whose significance she didn't appreciate at the time. For several months she doggedly pushed on with her plans, but her energy levels gradually declined, she lost weight, lost her appetite, craved salt, became nauseous... She came home in November 1998, still "suntanned". By early December, the diagnosis of Addison's disease was established.



## EMERGENCIES IN THE HOME – identifying your medications

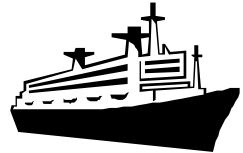
A para-medical speaking at an Addison's meeting in the US, said that the fridge door is one place they often look for information about medications taken, when the person they are attending in their home cannot speak for themselves. What if the ambulance is called to your home, and you are not able to explain your medications?

"We will usually have a scout around looking for medications or lists of medications. This usually starts in the kitchen, so the fridge would be fine for a list," said Dr Tony Smith, chief medical advisor for the Order of St John, Northern Region. "We don't however have a specific policy of looking on the fridge. It is unusual for us to phone Medic-Alert, as the information on the bracelet is usually enough."



## REMINDER: FOREIGN LANGUAGE EMERGENCY INFORMATION

We have on file information in several languages– and many international contacts to help plug the gaps. Travel prepared!



Lois, our member living in Malaysia, enjoyed an 11-day cruise with her husband, around parts of Italy and Spain in February. She took emergency information in Italian and Spanish with her. "It was reassuring to have, and thankfully I did not need it."

Snippets from Lois's newsy report - "This ship can accommodate over 2000 but there were only 1800 people on board. It is usually in the Caribbean, but because Americans are still worried about travelling, there was no business there, so the Cruise line brought it back to the Mediterranean. As Italy, the flag the ship flew under, had joined the EU at the beginning of January all announcements were in five languages.

"We stopped in Rome for four days at the end of the cruise, and that was the highlight for me. The centre area is reasonably easy to walk around and get to see the main sights. The Vatican is a ride on the Underground, and that was most interesting. It is a city I could go back to."

Lois was home less than a week, then down to NZ for a 10-day visit with family, back home for just a day, then off to Viet Nam on a business trip with her husband. Whew!



## MARGARET'S STORY – Reflections of a cortisone pioneer:

Margaret was diagnosed with Addison's disease 43 years ago, when she was 35. When she joined NZAN in 1997, she answered the database question, was she happy to have her name passed on to others with Addison's disease, "Sorry, it has always been a private thing."

But, over the years that she has been a member, she has sent snippets of information about her life with Addison's, which we've included in the Updates.

Early in the new year, Margaret sent Jeanette a couple of long letters - "All my life I have been a compulsive letter writer, and I do not want to stop!". So here she shares a fuller view of her busy and happy life, despite Addison's:

"I have rambled on, but this is a new experience for me. Apart from the epic July meeting, I have never talked about my Addison's. I felt so good after that get-together, for after 42 lonely years I had met people "just like me". The same problems, similar success stories - and not a bad looking bunch. I liked meeting that hard working committee - they did a great job. Now I have read Kathryn's and Lyn's stories [*in the November 2001 Update*], and I can relate quite well to theirs. I was hyper-active - super-energy - and with never being allowed to increase my dosage [over the early years], I had many trips to hospital with Addisonian crises.

The July meeting began to spring memories I had not thought of for years and years. I had a long spell in Auckland hospital in 1959 when they diagnosed the Addison's. I'd had 20 months of the usual vomiting, diarrhoea, and weight loss, plus darker pigmentation of the skin and depression. I was their first patient to be put on steroids - a magical drug which had been used in the UK for Addison's. The dosage was experimental for a while. Then they had my permission to do experiments.

One was a non-salt diet - I recall the special food wasn't very interesting or appetising, especially as I had been drinking salty water before I went in to hospital. We had a bach at the beach, used to get oysters off the rocks and I would drink the salty liquid. I think I drank the seawater in my daily swim. Our little coastal beach was unpolluted in those days.



After 5 or 6 days on the special diet, when I began to feel terrible, I collapsed and according to my room mates, the doctors actually ran - when the curtains were removed in the morning they were delighted to see me still there.

While I was in hospital, on two Saturday mornings they held lectures. The first was for GPs. I wore my second best nightie - my house doctor's words. The next Saturday was specialists - my best nightie. I wish I could remember all the questions, as I lay there like Exhibit A, plus my specialist's replies... what I think I recall may have no foundations at all.

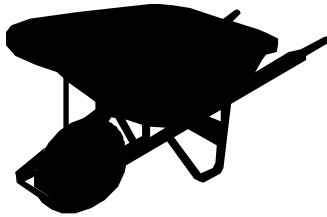
Before I left hospital, I went before five or six doctors who lectured on what life would be like in the future - the crises that would send me back for help etc, including the "never change the dosage or miss any tablets".

For years after, I had to collect the tablets from the hospital pharmacy. I took the tablets

five times daily – 6am, 10am, 2pm, 6pm and 10pm. It made a long day. I cannot be positive about the doses, but I believe I took 10mg, 5mg, 5mg, 5mg, 7.5mg. The 32.5mg seems definite, and wasn't changed for many years.

I was a very busy farmer's wife, jack of all jobs. We farmed out of Warkworth at Kaipara Flats. Farming was different in those days. The top-dressing crew lived in sometimes for several days if the weather wasn't good; it was a Tiger Moth plane. Then there was all the catering for shearing and hay making. On a one-man farm I was called upon at all times to help with work.

I grew all our own vegies, 2000 onions, 80 tomatoes, yards of beans, peas and carrots. No artificial fertilisers. I used to boast that my vegetables were in the garden 10 minutes before they were served on the table.



I am sure all my own vegies, plus all the fruit I enjoy, have helped my good health. Our home was burnt to the ground in 1959, three months after I came out of hospital, and the insurance assessor was amazed at the heap of molten glass – my preserves – no freezers in those days.

I served on the college PTA, the Plunket Committee, Church guilds, Women's Institute, and others. I wrote the school histories for the 75 years celebration, and again for 100 years. I followed all sports.

I have three children, who did all the usual things children did – sports, music, guides and rangers, friends to stay, and transport for school. They never missed out because of Addison's. I know they were upset at the ambulance arriving to take Mummy to

hospital in their younger years – they were only 2, 5 and 7 when I was diagnosed.

In 1972 my son married an Australian girl, so most years I have travelled to Adelaide, plus have enjoyed 3 more trips to the UK, plus Canada, the US, Japan, Alaska and Singapore. Alex and I travelled a great deal, and loved it all.



On our first trip overseas in 1976, the big OE, I was still on the original tablets routine, and nobody told me to increase them. We were away three months. It was before bottled water to drink was invented, hotel rooms did not have tea making facilities. I did get a solid methylated spirits little stove in Venice – it could boil a cup of water. I never drank water from a tap for 3 months! Not really because it was 'bad' but because it would be different for me. I think I have swallowed my tablets with every possible medium, fruit juice, wine, beer champagne, etc.

I had a letter for one of the leading hospitals in London, and no insurance. It took years to educate the insurance companies that, for example, broken legs from an accident should be able to be a legitimate insurance claim for an Addisonian.

After many years, I had a new endocrinologist, and he changed many things – including tablets only twice a day, I could increase them, and my trips back in a crisis became so much less. The calcium was disappearing rapidly from my bones. I went onto estrogen treatment for about 6-7 years. He helped me in so many ways. He also took my daughter as a patient – she's an insulin dependent diabetic, juvenile diabetes, diagnosed as "brittle" diabetes. I recall he was interested in

a family study for glandular weaknesses. We have thyroid problems too.

Now in spite of my three recent falls, a shattered shoulder, both bones in my right wrist, and then my left arm, I work for the Old Folk's dinner, the Hospice shop, Red Cross and Save the Children. I just need two new eyes. I have cataracts, with macular degeneration underneath, so there would be no better sight if they were removed. I've been a widow for 14 years, and live by myself, but now in Warkworth. I still garden, though on a much smaller scale.



It was a pleasure to meet Prof Holdaway again [at the July meeting]. In 1972 I was part of his work for his thesis. After the meeting he kindly sent me a copy of his thesis, most interesting – I scored rather well! I suspect he was a little surprised to meet me again after nearly 30 years. It was a good experience that I would not have enjoyed without NZAN.

Life had so much to offer – children, farm life, community work, and teaching, a great love for me. I went back teaching just to help out, but stayed for long spells, years. Now I have two daughters teaching in secondary schools, and a grand-daughter just graduated BA, and going back to do double honours degrees.

I will always consider myself one of the 'fortunate ones' – life has been good, and still is for me.



### MEMBERS' CONTACT LIST

Linda in Havelock North maintains this list for us. Thank you!

Please contact us to fill any gaps, or to make changes.

This list is circulated to members only.

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

**On the following 5 pages, we include some more excerpts, edited by Professor Holdaway, NZAN's medical advisor, from the address he gave at the July 2001 meeting in Auckland, ...**



## From our Medical Advisor, Professor Ian Holdaway:

### Qu1. Do people with Addison's ever need adrenaline in emergencies?

In Addison's disease of autoimmune cause, the inner part of the adrenal gland, the medulla, is not usually affected to any major degree.

The medulla is only damaged in TB or other disorders which totally destroy all adrenal tissue. Even in this situation there is no need to replace adrenaline production because most adrenaline and its relative, noradrenaline, is made in the nerve endings of the sympathetic nervous system.

Very rarely, an extremely ill person in intensive care may be given noradrenaline to maintain their blood pressure, but Addisonian individuals are not more prone than others to need such treatment.

### Qu2. What can I do about muscle cramps? (*Topic raised at the NZAN meeting in July last year*)

Muscle cramps, particularly spasms in leg muscles, are very common in the population in general, particularly as people get older. From a medical perspective, they are frustratingly difficult to treat, because the basic understanding of their cause is incomplete.

Low levels of sodium or potassium can both give rise to cramps, and this may be apparent on blood tests of sodium and potassium. If you have a low blood level of sodium or potassium, and you have cramp, that clearly identifies the most likely cause.

But you may have a low total body sodium or low total body potassium level, yet the blood level can still be in the normal range, but the total distribution through all the cells and tissues is reduced. (If you do a special isotope measurement on your total body potassium or total body sodium they may be low.)

For people with Addison's, who get cramps, especially after exercise, it is possible that there is an abnormality of adrenal replacement, particularly with fludrocortisone dosage.

Salt depletion (low sodium) due to insufficient fludrocortisone, is a common cause of cramp in Addison's individuals. However, if the fludrocortisone is over-replaced, then low potassium can occur, and that can trigger cramps too.

Stretching exercises of the muscles that you find are prone to cramp, can be helpful, before bed, or 2-3 times during the day.

If cramps persist after checking blood sodium and potassium levels, and after reassessing the replacement doses of hydrocortisone and fludrocortisone, then a 300mg tablet of quinine at bedtime is an option to discuss with your doctor. It is a standard cramp therapy, which is usually effective. Its only major side effect is the occasional development of a low platelet count.

### TAPES STILL AVAILABLE



Copies of the tapes of Professor Holdaway's complete presentation are still available for \$10 per set – including a photocopy of the slides, and a summary of the order of the topics. Contact: Kathryn, PO Box 101-631 NSMC, Auckland; phone 09 445 6427, fax 09 445 6428; or contact Jeanette.

Professor Ian Holdaway's presentation at the Auckland meeting in July 2001 gave a context to many important issues that affect people with Addison's disease.

In this issue of Update, we include edited transcript of the following topics:

- \* Some challenges with cortisol replacement and monitoring
- \* Optimising Fludrocortisone (Florinef)
- \* Addison's disease and bone density:

### **Some challenges with cortisol replacement and monitoring:**

What's new with regard to treatment of Addison's disease over the past five years?

"The unfortunate answer is that there haven't been any major studies that have compared one way of treating Addison's with another," said Professor Holdaway.

"That's what we would all like to have, but I doubt if that sort of study is ever going to be done, because there are not really enough people with the disorder to statistically show that if you take prednisone in the morning compared with lunchtime, or dexamethasone at night versus hydrocortisone in the morning, for example, that one way or treatment is better than another.

"For most of you, it is still an individualized decision. Some people seem to do well with prednisone and some people do well with hydrocortisone, and some take a mixture.

"How do you feel on your replacement? If things aren't right, you might make a little change, or try something different."

One of the problems in mimicking adrenal replacement is that cortisol secretion is episodic. Prof Holdaway showed on a slide, the blood cortisol levels throughout the day for a non-Addisonian individual.

"There is a diurnal rhythm, with blood cortisol levels highish in the morning, falling down to low levels later in the afternoon and early night, and back up again in the early hours of the morning.

"It's not just a big splurge of cortisol in the day, or even two or three splurges - it's produced in little spikes that start about 4am, in response to surges of ACTH, which are themselves entrained to some extent by the brain 'clock' near the pineal gland. Trying to imitate that beautifully modulated normal rhythm with tablets is pretty difficult."



Prof Holdaway showed a graph of blood cortisol levels through the day for a person with Addison's disease taking hydrocortisone.

The two or three doses of hydrocortisone a day, give rise to two or three peaks (without the brief spikes that are in the profile from a non-Addisonian), falling down essentially to zero in between peaks, especially in the morning before the first cortisone dose of the day.

"That's not very much like what normally happens, so you might look at that and wonder, how am I managing? There are obviously mysteries in this that we do not entirely understand.

“At the peak phase you are probably overdosed, and at some other times you have got much more than you would normally have at that time of the day, but it doesn't seem to lead to over-dosage effects, presumably because it's balanced out by times when you are a bit on the low side. But on the other hand, that might mean that you feel well when the cortisol is high and awful when it's low.

“It's possible that when cortisol levels are really low you might feel unwell, but what is not shown on this slide is what happens when the cortisol acts on the cells. Cortisol affects many body cells to keep our sugar and energy levels up, regulate stress responses, and many other actions.

“For cortisol, the half-life in the blood [the time that it takes to fall by 50%] is actually very short, just a few hours. But the enzymes and other chemicals that are regulated and made to work by cortisol, have much longer half lives than cortisol itself.

“In other words, the half life of the cell effect of cortisol is much longer than the half life of cortisol in the blood. So people with Addison's can get away with just taking cortisone 2-3 times a day, and remain well, because the cellular effects keep going even when the blood levels are low.”



Prof Holdaway illustrated that point with an example. “A patient of mine, on cortisone because of a pituitary problem, takes a bigish dose of hydrocortisone (35mg) as a single dose in the morning. That's all he has ever done, for many years.

“He gets up at 4am in the morning, and takes his hydrocortisone [and his thyroxine for hypothyroidism – because he has secondary adrenal insufficiency, he doesn't need fludrocortisone]. He then runs in the hills for

three hours, and then he works a full day as a welder. After work he runs for a further 1½ hours. He recently did a 190km run in South Africa. That's one extreme.

“Yes, he has to take his hydrocortisone when he does his main training schedule, which is first thing in the morning, but as you can imagine if you measured his blood level of cortisol when he is doing his afternoon run, he has probably got no cortisol detectable in his blood at all (that's been tested and confirmed).

“In this case the effects on the cells of this big surge of cortisone in the morning is still lasting quite well through the day and enabling his muscles to work and his lungs to provide plenty of oxygen for a 1½ hour run later in the day. And similarly when he did his 190km run he must have had times churning along there when his blood cortisol was very low.

“So it is difficult to approve of this treatment schedule when it doesn't seem physiologic, and you think that this doesn't look a great way of replacing cortisol. However, it is obviously difficult to know how important the timing of tablets actually is.

“What about the symptoms of under-dosage and over-dosage with hydrocortisone or prednisone?

“Unfortunately, as you all know, these symptoms are often fairly vague. Do you feel a bit more tired, are you running out of steam at different times of the day? Any assessment of these symptoms is bedeviled by the fact that people without Addison's disease run out of steam later in the day and feel tired and sleepy, so it's very hard to judge whether this is this just the person and, yes, their profile is they are always going to feel that way no matter what happens, or is it because they haven't got the dosage of their tablets right. So it's a judgment that you and your doctor have to go through.

“What about tests that will help guide the dose of cortisone?

"This is a difficult area, because when you look at what scientific papers there are on the matter, and everyone's experience in general in measuring these things, the ACTH from the pituitary, the amount of cortisol in the blood, and the amount of cortisol in the urine don't actually provide enormously helpful information.

"24hour urinary cortisol may be a bit more useful - that's where you collect urine for a whole 24 hours, send it to a laboratory and they measure the cortisol in the specimen. But again because of those spikes that we just saw, when blood levels are high you filter a lot more cortisol into the urine.

"So most people taking hydrocortisone replacement for Addison's disease often have a somewhat elevated urinary cortisol, and if you look at that and think 'that looks a bit high', and reduce the dose, you can run into trouble with not enough cortisone replacement.

"Most of the cortisol in blood circulates bound to a protein – it's only the unbound bit that gets into the cells to do its job, and it's only the unbound bit that spills over into the urine where it can be measured.

"A person with Addison's taking hydrocortisone would spill out a lot of cortisol into the urine when the blood levels are at their peak, and it would look as if they have too much cortisol in their system, but it's because of the way the medication is being taken, and isn't of itself a problem.

"So it's a trial and error situation. Some people, such as the runner I mentioned, seem to manage on a single biggish daily dose of cortisol. But fiddling with the doses is not unreasonable for those who are not feeling very well throughout the day. Rather than pushing the total dose up, spreading it more over the day might be worthwhile, trying to more closely imitate the normal pattern."

Whilst the target is indeed optimal replacement of cortisol, that is often an elusive ideal.

"Most advisors are saying that probably our replacement doses are somewhat excessive. But countering that, there is very little evidence to show that usual cortisol replacement doses do any harm...

Which leaves most people with the feeling that it is better to err a little on the upper side, rather than on the lower side of replacement dosage.

However, the mineralocorticoid replacement is often underdone, and this can contribute to impaired day-to-day functioning, possibly even more than the cortisol replacement."

### **Optimising Fludrocortisone (Florinef):**

Prof Holdaway pointed out in his address at the Auckland meeting last July that in contrast to the situation where cortisol is often a little over-replaced, the mineralocorticoid aldosterone is often under-replaced.

Not having enough mineralocorticoid puts one at greater risk of an Addison's crisis, and also can affect how well an Addisonian feels on a day to day basis.

The loss of aldosterone production may progress slowly over several years, so that an Addisonian's need for fludrocortisone may start off low at diagnosis, but gradually increase.

"There's a potential trap that individuals may feel a bit weak and tired, and so with their doctor they increase the hydrocortisone or prednisone part of their replacement, but that doesn't really fix the problem.

The person either puts up with that level of unwellness, or the glucocorticoid dose is increased a bit more. These people may not be receiving fludrocortisone, or may be taking an inadequate dose.

“If you measure a blood renin level (the hormone that signals mineralocorticoid requirement), and the result is really high, that means the kidneys are crying out for more mineralocorticoid. So the correct thing isn't to increase the cortisone, it's to give a bit more fludrocortisone.”

“The renin level in the blood is quite a good marker, it stays at pretty much the same level during the day, and is not used enough by doctors and endocrinologists to get a feel for how much fludrocortisone individuals with Addison's disease need”.

(The blood for renin measurement can be taken at any medical laboratory, and is sent to a major hospital for analysis. The collection laboratory needs to check the blood handling and processing requirements.)



“You can also judge the appropriateness of the fludrocortisone dose by the levels of sodium and potassium in the blood. If you haven't got the dose right, those might be altered and the blood test from your doctor will show that. But it is a very crude guide. If they are abnormal then something is really not right at all, whereas you could still not be on enough fludrocortisone and blood sodium and potassium could be normal.

“Another way of judging fludrocortisone is by measuring your blood pressure. Your doctor should be doing your blood pressure test lying and standing, because if you are not retaining enough fluid with the fludrocortisone, you will get a low blood volume and feel a bit woosy and faint on standing.

“So if your blood pressure falls quite dramatically when you stand up then you're not on enough fludrocortisone. A fall of systolic (upper limit) blood pressure of more than 10-14 mm of mercury on standing should alert the doctor to this possibility.

“An average replacement dose of fludrocortisone is 0.1- 0.2mg per day.

Many Addison's individuals are on insufficient mineralocorticoid - the correct dose is established by lying and standing blood pressure measurements, and blood sodium, potassium and renin assessments.

Making sure the mineralocorticoid dose is sufficient is important to avoid having to increase the glucocorticoid dose to cover symptoms of mineralocorticoid deficiency.

This is especially important in those taking prednisone as their glucocorticoid, since this medication has no mineralocorticoid properties, by comparison with hydrocortisone or cortisone acetate which have partial mineralocorticoid effectiveness (20mg hydrocortisone provides the equivalent of about 0.05mg fludrocortisone.)”

“Fludrocortisone has a relatively long half life in the body, so it isn't usually necessary to take it more often than once a day. However, as with glucocorticoid replacement, tablets are trying to mimic finely a modulated glandular response, and it isn't possible to get it perfect.

“The correct dose of mineralocorticoid also depends on the climate one lives in. Addisonians need to be alert when travelling to a hotter climate, for example on holiday.

Since more perspiration means more loss of sodium and fluid, and hence possible sudden weakness, faintness, and tendency to Addisonian crisis can occur, especially if there is added stress as well.

“Extra fludrocortisone (1/2-1 tablet) can be taken in anticipation, but as it can't kick in for a few hours, the short-term fix is salt – and plenty of fluids to minimise the extra risks due to dehydration.”

Professor Holdaway gave the example: “If you are walking around in Singapore and began to feel a bit faint, it's better to have a salty drink or some food with salt on it or a salt tablet, rather than waiting until the next day and increasing the fludrocortisone. That's going to have a much slower effect.

“Care is needed if the fludrocortisone dosage is increased too much, since this can cause fluid retention, increase blood pressure excessively, and lower the blood potassium level. Changes are thus best done with your doctor's guidance.

“If extra potassium is needed, it can come from more fruit such as bananas, or from Slow K (Slow Potassium) tablets. This can be one slight downside of pushing fludrocortisone too much. Extra potassium is indicated if the blood level is less than 3.5mmol/L”



## **Addison's disease and bone density:**

What about the risk of osteoporosis for Addisonians?

Osteoporosis is a condition in which there is a slow loss of bone mass. The reduction in

bone strength increases the fracture risk. “It's painless until you break something.

“So are people with Addison's disease liable to get this problem? I think the good news is that overall, most people with Addison's disease have normal bones.”

“There is, perhaps, a slight tendency to have lower bone density and sometimes osteoporosis, particularly if people have for one reason or another been on a reasonably high dose of corticosteroids, or if the disorder has gone on a long time, or in particular if they have other risk factors.

“For instance, a strong family history of fracture increases your risk of osteoporosis, and people who have already had broken bones or fractures might well have a higher risk of having osteoporosis, especially if they have a low calcium intake.

“There has been a study of bone density in Addison's which many of you would know about, done by Dr G Braatvedt from Auckland as principal author, with the help of many people with Addison's disease in New Zealand. In general, most individuals had bone density close to normal.”

Prof Holdaway recommends having bone density checked, particularly women with Addison's disease. “Because of the bone protecting effects of estrogen, that's a consideration for using HRT after the menopause, although it's always an individual decision. The risk of reduced bone density in the Braatvedt study was related to the duration of the Addison's.”

Professor Holdaway has written a concise article “Bone densitometry, a patient's guide”, which outlines the measurement of bone density, and some treatments that are available. It can be accessed on the Karori Medical Centre website: [www.kmc.co.nz](http://www.kmc.co.nz). In ‘health topics’, select ‘bones and joints’, and then the bone densitometry article.

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 Adrenoleukodystrophy was diagnosed in his mid-fifties. No.11,pp7-12

**Anne**, diagnosed 1998 with adrenal insufficiency due to long term steroids for eczema, aged 53 – a semi-retired librarian, involved with English as a second language No.12, pp7-9

**Bob**, diagnosed 2000, aged 79 – clarification of the diagnosis enabled him to continue living in his own home No.13, pp13-14

**Danielle**, diagnosed 1992, aged 24 – mother of two, lived in Japan first 3 years after diagnosis No.13, pp12-13

**Dyan**, born without adrenal glands, tells her story at age 24. No.10, pp8-10

**Gary**, diagnosed in 1959 with Addison's probably caused by TB, aged 25. A pharmacist, he considers himself "lucky to be still in business doing what I enjoy, taking part in competitive sport, and travelling extensively. We all must just be aware of our limitations." No.10, pp10-12

**Karen**, diagnosed 1998, aged 32 – her third pregnancy, after her diagnosis with Addison's, was 'very uneventful', with the perfect outcome of the birth of Matthew. No.11, pp7-12

**Kathryn**, diagnosed 2000 aged 59 – a keen diver, tramper, international traveller, and helps run the family business No.14, pp14-16;

**Lois**, diagnosed in 1980, aged 40. She lives in Malaysia, but returns to Christchurch, her original home, for annual medical checks, and to see family. No.10, pp12-14, also No.15, p8

**Lyn**, diagnosed 1995, aged 40 – a keen biker, works in IT industry No.14, pp16-19

**Margaret**, diagnosed 1959 aged 35 – a busy life, farming, family, travel, and community service. No.15, pp 9-11

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<p><b>from Professor Ian Holdaway, current medical advisor</b></p>
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Addison's and bone density.

**from Dr Geoff Braatvedt, medical advisor 1998-2000**

**NZAN Update Number 5, November 1998**

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**NZAN Update Number 6, March 1998**

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- Q2. Should people with Addison's disease take more vitamin C than usual?
- Q3. Lidy asks "*I have been prescribed Serzone as an anti-depressive which works via adrenaline activation. Will I get the full benefit of this, being an Addison's patient?*".
- Q4. Which steroid replacement is best?
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- Q2. Does the normal adrenaline response decline with age?
- Q3. What is an ACTH test? What controls ACTH?
- Q4. Should cortisol in the blood or urine be measured as a test of replacement dosage?
- Q5. Does the calcium intake of patients with Addison's disease matter?
- Q6. What happens to the adrenal gland in Addison's?

**NZAN Update Number 8, November 1999**

- Q1. Can patients with Addison's disease avoid jet lag on long distance, cross time zone travel by giving extra Hydrocortisone?
- Q2. Does the dose of hydrocortisone change with age?
- Q3. Does Addison's disease affect your ability to cope when sleep deprived? Q4. Do patients with Addison's cope less well with night shift work?
- Q5. My bone density is low and my GP has started me on Rocaltrol and calcium tablets. I take 10 mg of prednisone for my Addison's disease. Are there any problems with this?

**NZAN Update Number 9, March 2000**

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