

New Zealand Addison's Network

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NZAN Newsletter, July-August 2003 (No 19)

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Keep an eye on your letterbox for your
International Survey Forms!

From Professor Ian Holdaway, Medical Advisor:

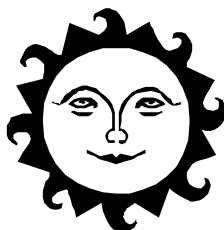
(from his address at the Northern Region Meeting)

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Audio tapes of Professor Holdaway's Keynote Address and the Open Forum at the Northern Region Meeting, and photocopies of the overhead transparencies, are available. See 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.



Increasing the Awareness of Addison's Disease in NZ: Milestones to report!

NZAN Pamphlet launched

A pamphlet suitable for display in GP practices and other health-related locations was launched in May. We hope its messages will help prompter diagnosis of Addison's disease, and appropriate treatment in emergencies.

Several people had input. Jeanette in particular wrestled with the words, and Karen Carson created the layout. Dr Grant Thompson, a Northland GP with an interest in Addison's disease, and Professor Holdaway checked the content for relevance and accuracy.

Some copies are enclosed with this newsletter for you to pass on to your GP, pharmacist, blood test laboratory, etc for displaying. It's the same canary yellow as our newsletter covers!

NZAN Letter to all GPs

A family who are members of NZAN have generously funded the mailing in July of a letter and some NZAN pamphlets to every GP in New Zealand, and also to emergency and general physicians.

The letter reinforces the important messages in the pamphlet, including symptoms, tests for diagnosis, and key points of management.

This is a wonderful gesture for the greater well-being of Addisonians – those already diagnosed, and those to be diagnosed in the future.

"It is nice to see it come to fruition but the real question is whether it will help to ease 'the path of life' for at least a few people. That is my aim!" said the sponsor, who asks to remain anonymous. **Thank you!**

Our Pamphlets now on Walls

In her GP's waiting room one day in May, Jeanette was seated facing a Perspex display board on the wall, which contained health related pamphlets. There was a phone number on the board! Jeanette made a fortunate link with Neville Osborne, the franchise holder for Medi-Board East (Bay of Plenty, Hawkes Bay and Waikato).

He happened to be in Havelock North a few days later, saw our new pamphlet, and was willing to include it, as a goodwill gesture to increase awareness of Addison's disease. He took away 1000 pamphlets, to put in 140 different sites throughout his region, including some GP practices.

In the first month, on average 3 pamphlets had been taken per site – which we understand is high for a new pamphlet.

Thank you Neville! We are hopeful that franchise holders of Medi-Board in other regions may be willing to include the NZAN pamphlet also. We'll keep you posted.

* If you have an idea for using our pamphlets to promote greater awareness of Addison's disease, please contact Jeanette!

****Stop-Press!:** Just before this newsletter was printed, Jeanette received a phone-call from Dr Leo Revell, a GP who writes a fortnightly medical article for the Waikato Times. He has three patients with Addison's, two of whom he diagnosed. He had wondered about Addison's as a topic for the newspaper. Receiving and reading the NZAN pamphlets and sponsored letter served as catalyst for the article, which was published 31 July.

Food for thought:

There are about twice as many Lotto millionaires in New Zealand in a year, as there are new cases of Addison's disease.

NORTHERN REGIONAL MEETING REPORT

It was clear from feedback that the meeting was thoroughly enjoyed by the nearly 50 Addisonians and support people who attended. Some were NZAN members, and some had heard about the meeting through the media advertising, and a couple of people came along to find out information for their Addisonian partners who were not attending.

Report from Lyn on behalf of the A-team:

The second Northern Region Meeting was held on Saturday 31st May 2003.

Once again Kathryn, Karen, Andrea and Lyn donned their thinking caps to come up with a programme that would both interest and be of assistance to all Addisonians and their support people.

Some 47 Addisonians and support people attended coming from all over the country – from Whangarei in the North to faraway Southland at the bottom of the South island. We were humbled to see how many people had travelled huge distances to get there for the day including four from the South Island.

Jeanette kicked the day off by welcoming us all and giving us all some background on how NZ Addison's Network came to be. She gave us an idea of some of the work going on, in particular the launch of the new pamphlets which was well underway.

Following the format that seems to work well for us we once again kept formalities down and encouraged each Addisonian to stand up and speak for a few minutes about their condition and how they manage it. This ensured full audience participation not only during the introductions but also led to much talk and laughter at each break.

After morning tea, Professor Holdaway's address fitted well with our theme for the day:

"Addison's Disease – A Practical View for Better Health". The audience participated fully, being quick to ask questions as they thought of them.

Lunch followed the keynote speech, which at least let Professor Holdaway catch his breath and fuel up for the busy open forum during the afternoon.

Immediately after lunch audience participation was encouraged once more when Karen Unwin, a senior nurse from the Endocrinology Department at Auckland Hospital took centre stage to give us a demonstration on self-injecting ourselves with Solu-Cortef. Karen firstly demonstrated from go to whoa the steps to ensure as pain-free injection as possible, then kindly assisted all those Addisonians and their support people who wanted "to give it a go" at the rear of the room while the open forum kicked into action.

The Open Forum was very lively. Addisonians and their support people participated enthusiastically in discussions, asking questions of both Professor Holdaway and each other all afternoon. We had thought to close off part of the room for the self-injecting participants but everyone was keen not to miss any of the discussion so with an eye on the needle they kept an ear on the forum.

A huge variety of topics were covered during the Open Forum including physical well being, Addison crises, OOS, depression, how different medications affect the Addisonian. Everyone had a question and everyone had their say. Once again Professor Holdaway very generously gave us his time and shared his knowledge. We hope he too gained from the day.

Once again I must voice a huge thanks to all those who contributed to making our Second Northern Regional Meeting such a huge success. Jeanette - for prodding Lyn, Andrea, Kathryn and Karen to organise the day. The A team – Lyn, Andrea, Kathryn and Karen -

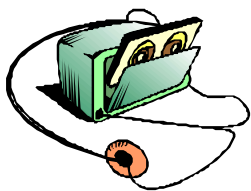
for putting together a day which stimulated much audience participation. Steve and Clive for their superb efforts in the kitchen letting us tuck into delicious food without having to give much thought to the cleaning up along the way. Professor Holdaway - for sharing his wealth of knowledge and experience with us during the day.

And of course huge thanks to Karen Unwin who gave us courage and provided support to increase our practical experience of self-injecting our steroids should the need arise at some time in the future.

AUDIO TAPES FROM MAY 2003 MEETING IN AUCKLAND

Professor Holdaway's talk at the Northern Regional Meeting in May, covered many topics of practical value to Addisonians. Also, in the lively Forum session, in response to questions, he expanded on several topics from his talk, and contributed to the discussion of many other issues.

The tapes will be a great memory jog for participants, and are a mine of information for those who were not able to attend. Prof Holdaway's style is easy to listen to and understand.



Thanks to Andrea and Kathryn's thorough planning and refinements on the day, the quality of the recordings is excellent, and the questions from the audience are picked up clearly too.

Cost: \$15 for the 2 tapes of Prof Holdaway's address, including a photocopy of the overheads. \$5 for the Open Forum tape.

Contact: Jeanette (address on front page)

Self-Injection Victory by A-Team member Karen:

For this year's meeting, because of members' uncertainty and reluctance to use emergency hydrocortisone injections, we invited endocrinology nurse Karen Unwin to do a session on injections for us. She kindly gave up her Saturday afternoon and after showing how to draw up the Solu-Cortef, bravely led the way by demonstrating the injection procedure with saline into her own thigh.

Next, I went through the same procedure, at the front of the room, with Karen talking me through the steps, to reinforce them for others.

Then, at the back of the room, those who wanted to have a go were talked through the process so they could practice injecting saline into themselves or have their support person do it. Those who practiced reported that they now feel much more confident that they could actually do the injection should the need arise.

Karen's session added a really practical and fun(!) dimension to the afternoon. The surprising thing was that the actual "injecting" was not at all painful – we were told to put the needle in fast, before the nerves can figure out what is happening. The discomfort is more if you push the Solu-Cortef in too quickly.

Steve, my husband, didn't really want to do an injection into my thigh (he is needle phobic), but in the end was glad that he did because he now feels confident that if it came to the crunch he could do it. I think it was easier for him than he thought it would be!

I think the most important thing Steve and I learnt was that "emergency" injection is a bit of a misnomer - the word emergency conjures up life and death, whereas we would now be inclined to use the injection after I had vomited a couple of times or if I was vomiting and feeling like I was going downhill - definitely sooner rather than later. [Karen's crisis after repeated vomiting due to a tummy bug was reported in the previous newsletter, #18.]

And overall? "Once again it was fantastic to meet with other people who live with Addison's and other health issues and to chat about the stuff that no one else really understands."

We circulated draft Solu-Cortef IM injection guidelines with the previous newsletter (#18). We are preparing a final version in friendly format. Meanwhile, we suggest you add to your draft version, some extra helpful tips from the May meeting:

* Rather than pressing down on the top of the Solu-Cortef mix-o-vial, it's easier to dislodge the internal stopper separating the compartments if you turn the vial upside down on a table or similar, hold it with one hand, and firmly tap the glass bottom with your other hand as a fist.

* The injection may hurt more if the liquid is cold.

* To minimise pain, put the needle fast through the skin, and inject slowly through the tissue - choose your pace: 5-10 seconds is usually fine for the 2ml volume.

* If necessary, inject through clothing (eg, pantyhose, trousers) – that's better than not at all.

* Just in case it happens! A person who faints (you or your partner!), should lie flat on the ground, and not be propped up in a chair.

Robyn's perspective:

"While looking through the overseas newsletters and websites recently, one thing that interested me is the number of small sub-groups, within each Addison's organisation, who get together on a fairly regular basis. After being to two Northern Regional Meetings in Auckland in the last few years, I can see why these gatherings take place.

I got such a buzz out of talking to other Addisonians and listening to their stories. Professor Holdaway's presentation was very informative and interesting, and of great value

to my husband, Paul, who went to his first meeting this year in May. The injection demo was excellent, encouraging me to update my emergency kit and organise ways of carrying it with me. Paul and I both came away from the meeting feeling more confident about coping in a crisis situation and reassured that I am doing OK.

Even though we Addisonians are all so different, there are some common threads that run through all of our stories, and somehow sharing those things we have in common seems to give us confidence that we are doing all that we can to be well and have a good life.

I really enjoyed the informal chats during morning and afternoon tea, and can see that getting together with other Addisonians can be as formal, informal, as organised or spontaneous as we want or need it to be. It's got me thinking about arranging a meeting in Northland."



INTERNATIONAL ADDISON'S SURVEY Coming soon! Please Participate!

Along with the Australian, Canadian and UK Addison's groups, NZAN is participating in an International Survey, master-minded by the UK Addison's Disease Self-Help Group (ADSHG).

Survey forms will be posted to you in a few weeks. The instructions with them will be clear and detailed. The completed forms are to be sent to Jeanette at the NZAN Box number, and will then be forwarded to the UK.

A high response rate is needed for best possible accuracy of the results.

Margaret's Milestone: 80 years young

Margaret celebrated her 80th birthday in July. She was diagnosed with Addison's when she was 35. She joined NZAN in 1997, but had not met any other Addisonians until the Northern Regional Meeting in 2001. She subsequently shared her story (NZAN newsletter No.15, March 2002), and was a keen participant in the recent 2003 meeting.

We sent her a birthday card from NZAN members, and a photo of her with Prof Holdaway at the recent Auckland meeting. Margaret had been one of the Addisonians in Professor Holdaway's study for his MD thesis, about 30 years ago! "The photo caused a great deal of interest at my party", Margaret wrote.



Best wishes Margaret – you are a great role model!

Happy Birthday to NZAN member Bob, who turns 82 in September.



Finally being diagnosis with Addison's when he was being assessed for rest-home care at the age of 79 gave him the miraculous new lease on life that he needed. He is still living in his own home, gratefully taking his daily meds. His story was published just before his 80th birthday (NZAN Newsletter No 13, July/Aug01)

Membership Update

Since our last newsletter we have sent out several information packs, and we welcome seven new members: Carol, Colleen, Diana, Ann, Kelvin, Pamela, and Russell.

Some members haven't renewed their subscriptions for the current year – for them there's a reminder enclosed with this newsletter.

Members' subs make a practical difference, and also provide motivation for the effort that goes into sustaining and evolving NZAN.

Thank you to those who included donations - Beryl, Beverley, Chris, Colleen, Darren, Gary, Graeme, Ian, Jill, Jim, Marianne, Pamela, Shirley, [Receipts are written for all incoming funds, but we don't now routinely post them out. If you would like yours, please don't hesitate to ask.]

Bay of Plenty Meeting

Diane Goldsack arranged a meeting on Saturday 26 July 1pm-4pm at the Dominion Salt Head Office, Totara St, Mt Maunganui.

Members who went to the Auckland meeting, were able to discuss what they learned, and share with those who couldn't get there. Diane planned to include discussion of the topic: Is it possible to recognise cortisol shortage within yourself, and what to do about it? "I will be encouraging people to think about their crisis action plan before it is needed."

Diane's report will be in the next newsletter.

INSURANCE

We are still gathering information. An ear to the ground suggests the travel insurance climate may have been changing over recent years, and not in favour of Addisonians.

In our previous newsletter, Linda told us that her travel insurance policy for an Easter trip to Sydney had a \$100 loading for her Addison's. She had been warned that a longer trip, or one further afield, may not be covered at all.

Policies differ in the premium loading, and in the excess - the amount of the claim you have to pay, before the insurer takes over. A key factor is whether the country you are visiting has a reciprocal arrangement for hospital cover – that is so in the Australia and the UK.

The best policy that could be found for an Addisonian heading soon to the UK via the US, has the insurer paying medical expenses for Addison's, only when they exceed \$10,000. (The US does not have a reciprocal arrangement with New Zealand for hospital cover.)

One of our overseas members resident in Tasmania reports a great response from the insurer when she had a crisis in Auckland two years ago, during a stopover en route with her husband to a holiday in Noumea ...and spent a couple of days' in Middlemore hospital instead.

The New Zealand/Australia reciprocal arrangement for hospital cover applied. But also, the insurance company were excellent with their medical advisor keeping in close contact with the hospital, the doctors, and Allison's husband. "All extras were covered – extra hotel accommodation, cancellation fees, phone calls, taxis and ambulance fees, etc. They even paid for a hire car to get us from Hobart to our home in Launceston, as our car had been stolen and written off while we were away!"

The additional premium paid for covering Addison's disease was \$50. As Allison says philosophically – "perhaps I didn't do individuals with Addison's disease any favours with my claim!!"

In the UK in the 1970s, the insurance risks for Addisonians taking replacement steroids were considered similar to those of people taking high dose steroids – and Jeanette's memory is that "reasoning" couldn't prevail. Perhaps the information the insurance

companies in New Zealand have today about Addison's disease is unfairly negative about the insurance risks of the disorder? Someone raised with us whether having one's emergency kit of Solu-Cortef and appropriate emergency letters from one's doctor might be a benefit for reasonable insurance. That's food for thought!

Please share your experiences with travel and other insurance over the past 2-3 years. And please include whether you declare that you have Addison's disease when getting quotes or taking out insurance, especially for travel.



Career environments that best suit Addisonians?

At the NZAN meeting in Auckland in May, Robyn shared her decision about swapping full-time primary school teaching, for part-time relief teaching. Two other participants at the meeting shared that they also had found full-time school teaching too demanding after their diagnosis of Addison's.

We know that adrenal hormone replacement in tablet form, is not a perfect substitute for a functioning adrenal gland. School teaching is a profession that doesn't provide flexibility with regard to the timing of energy demands - some can be anticipated, some can't. Many Addisonians can't be sure they'll be "on form" on a particular day, for the hours needed at a stretch. Personality comes in too.

Perhaps the key to the optimal work environment for an Addisonian is: Do the circumstances allow you to sometimes say: "Yes, I'm willing and able to do that, but not right now."?

Please share your experiences of how you have adapted to the challenges of your workplace.



From NZAN's Medical Advisor, Professor Ian Holdaway

We are including in this newsletter just a few excerpts from Professor Holdaway's keynote address at the second Northern Regional Meeting in May. Attendees had the opportunity to influence the topics covered, by submitting questions with their registration.

We hope to publish some other excerpts in future newsletters – but, no guarantees!

We encourage you to get a set of the tapes.

Topics summarised in this newsletter:

- Is autoimmunity becoming better understood?
- The genetics – how at risk of Addison's are other members of your family?
- What's the best way to check if you are on the right doses of medication?
- What do adrenal hormones do in the body?

One point Prof Holdaway clarified at the start of his address, was the convention that the hormone produced by the adrenal glands is usually called cortisol – but the chemically identical hormone taken in tablet form is usually called hydrocortisone. They are exactly the same substance.
Convention can be a strange thing!

Is Autoimmunity becoming better understood?

It's a fairly common problem, medically speaking. Normally, early in our life as a foetus, the proteins in our body are

recognised as "self", and the immune cells that would normally react with them are deleted so we don't start making an immune attack on our tissues.

But in certain susceptible people, these immune cells can reactivate later in life and start thinking that the body's own adrenal tissue, or thyroid tissue, for example, is foreign, and so start attacking it. Why this happens is unclear, but there is often a genetic tendency for the disorder.

Autoimmune disorders can lead to generalised types of autoimmunity (lupus erythematosus, rheumatoid arthritis, etc), or the disorder can involve just one specific tissue or organ (eg autoimmune Addison's disease.)

The damage to the tissues can be from antibodies directed against proteins in cells (such as the enzymes involved in making cortisol), or can be by "activated" lymphocytes attacking tissue cells and starting a cascade of reactions that cause them to die.

Is there anything recently known about these conditions that might be hopeful for the future?

The big thrust has come from transplant research. When you transplant someone's pancreas or kidneys, for example, into another person, the body immediately says "foreign protein" and immune cells attack the introduced tissue and normally the transplant is rejected very promptly.

So therefore a whole series of medications have been developed to try and dampen this process down. Interestingly, cortisol itself is quite useful. At high doses it will suppress the immune reaction. Most of those who have had kidney transplants will be on a cortisol-like steroid such as prednisone at high dose to try and stop any rejection.

Recent research has used antagonists opposing the chemical mediators of immune

reactions to reduce autoimmune damage (eg tacrolimus and pimecrolimus, which act on molecules involved in the process, called the cytokines; and there's Infliximab, an antibody which mops up an important chemical in the immune pathway, TNF-alpha.)

I have not heard of any studies using these agents in people with adrenal conditions. One of the difficulties in the autoimmune field is that people may seem to have the setup to get the disorder (in Addison's disease, the presence of adrenal antibodies as a marker that they may be going to get adrenal deficiency), but we know there are a number of people walking around who have got these antibodies, but never get Addison's disease. Just because the antibodies are there, it does not mean these will march on to kill the adrenal gland.)

Why this is so is not known. It would thus be a major step to test a family, see who has antibodies, and then use these drugs – which have side effects, and are expensive. You would not want to be using these drugs in people who may never be going to get the disorder anyway.

Apart from transplants, the other big area of research is people who are developing diabetes and have got to the stage where it looks like they need insulin, but they may still have about 5% of their insulin-making beta-cells left. We would like to 'hit' them as hard as possible to stop them killing off the rest of their insulin-producing cells. There isn't a good analogy in the adrenals, because by the time someone presents with Addison's disease, virtually every cell in the adrenal cortex has been damaged. But there may be some future spin-offs from this research.

In summary - preventing immune destruction of tissues is an area where there is a lot of research going on, mainly generated through the transplant field. Screening families and perhaps doing something up-front to try and prevent the development of Addison's is certainly a possibility for the future.

The Genetics – How at risk of Addison's are other members of your family?

The incidence is about six new cases per million per year – that means about 20-25 new cases per year in New Zealand. The prevalence (the number of people at any one time who have the disorder) is between 40-100 per million adults. A prevalence of 50 would mean about 200 people in New Zealand with Addison's disease.

Autoimmune Addison's disease can occur in families, but more commonly it is "sporadic" (one-off), and the other members in the wider family tree don't have it.

60-70% of people with autoimmune Addison's disease have positive adrenal antibodies. The presence of antibodies directed against adrenal cells is a good marker early on, but they tend to disappear as time goes on.

Addison's disease is a frustrating condition to try and give counselling about. We can't be entirely sure who is at risk. The following two points are about the only useful information we can give at this time:

1. Sole Addison's disease is familial in about 1/3 cases. That is, if the only medical autoimmune condition someone has is Addison's disease, then there is about a 1 in 3 risk that another family member may develop Addison's, or one of the other autoimmune endocrine disorders.

2. If an individual has other autoimmune disorders as well as Addison's (eg an underactive thyroid or diabetes or myasthenia gravis or some other linked condition), then about half of the family members are likely to have some autoimmune manifestations – Addison's or something similar.

It is important when giving advice about the risk for other family members, to know whether the individual has just Addison's - in

which case the chances are not very high, or whether they have multiple endocrine problems, when it is more likely.

Another area linking Addison's disease to autoimmunity is the Polyglandular autoimmune endocrine disorders. These comprise combinations of thyroid problems (over or underactive), diabetes, B12 deficiency, Addison's disease etc. There are two types:

PGA-I (due to a gene defect, autosomal recessive – need two bad copies of the gene, one from each parent), and
PGA-II (can be recessive or dominant inheritance, linked to HLA-tissue type).

There are also some rare genetic syndromes which include Addison's disease – for example, adrenoleucodystrophy and adrenomyeloneuropathy, which are transmitted by the mother (the gene is carried on the X chromosome) and appear in males (X-linked). As well as Addison's disease there is damage to some of the nerves and spinal cord, and occasionally in the brain itself.



Checking that your medication doses are right for you

“This involves the art of medicine as well as the science.”

Prof Holdaway has covered this topic in detail previously (in particular, newsletter No.15, pages 13-17). The present discussion was a reminder overview. In this excerpt, we are highlighting some helpful points he made.

Reminder:

The dose range of replacement glucocorticoid, per day:
Hydrocortisone 15-30mg
Prednisone 2.5-7.5 mg
Dexamethasone 0.25-1mg

A process to help you and your doctor review your hydrocortisone / prednisone and fludrocortisone doses:

A. Monitor symptoms, clinical signs, BP, weight

Are you feeling well and on top of things; any anorexia (loss of appetite); energy levels, and the like.

Clinical signs – the amount of pigmentation present; blood pressure lying and standing (more important for fludrocortisone, but cortisol does influence this a little); weight, because if you are on too much cortisone, weight tends to go up.

Assessing the replacement dose of corticosteroid is partly your own introspective look, and your doctor's assessment on talking with you about how you are. At the end of the day, that's one of the most valuable things - so that's why it is useful to have a medical advisor who knows you, and who knows something about the disorder.

It may be more important that they know you, than that they know all about Addison's, because they often will pick up on things from you or from talking to your friends, that you are just not quite right in some way. These features can be subtle.

On the over-dosage side, weight trending up a bit... but we all tend to do that as we get older, so the question becomes how much of that is due to cortisol and how much might naturally occur... Muscle weakness, thinner skin and little stretch marks that can come up if you are on too much cortisol. The under-dosage side shows as fatigability, loss of strength on formal testing of strength, BP being on the low side, etc

B. Keep a watch on bone density

Perhaps it doesn't warrant as high as Number 2 on the list, but I think that people should have their bone density measured every few years, particularly women (probably it is not so important in men). That's because a subtle feature of too much hydrocortisone is that it will make the bones a bit thinner. Normal

levels of cortisol are good for bone health, but too much is bad. Measured how often? No magic answer! Pre-menopausally, there is no need to worry much, but a measurement around menopause, and after that about every 3-5 years is wise. Pre-menopause, if there are worries such as the occurrence of a fracture or a family history of osteoporosis or a need for lots of additional hydrocortisone, then get a bone density done for sure.

* A normal bone density doesn't mean that you haven't been a bit overdosed with hydrocortisone, but at least it is reassuring.

* If bone density is a bit low, that would make one more careful with replacement therapy. There are many causes for low bone density – it may be a genetic thing again – whether your parents had strong bones. If you have low bone density, it doesn't prove you have been on too much cortisone. But it is something you would want to keep a watch on.

C. Biochemistry tests.

Cholesterol - Keep a watch, it is increased if cortisol is a bit high.

Blood and urinary cortisol

There are "pros" and "cons" for measuring these. Also, these are applicable only if you are taking hydrocortisone, not prednisone or a mixture of the two (prednisone does not show up in blood assays).

Blood levels need to be related to the correct normal range for the time of day.

"Levels that are wildly out on multiple occasions would be cause for concern, particularly low levels. But a key thing to remember is that when you have low levels of cortisol in the blood, especially over just a few hours, it doesn't mean you are likely to feel unwell at that time. That's because the actions of cortisol on the blood vessels and the immune system and brain are quite prolonged. These downstream effects of cortisol usually last for many hours. You would need to have a low blood level for quite

a few hours before you would feel cortisol depleted."

24-hour urinary cortisol is often slightly raised during appropriate replacement therapy for Addison's disease, and so is at risk of misinterpretation.

Are serum ACTH measurements useful? No large study suggests these are useful for monitoring treatment for Addison's.

D. Fludrocortisone dosage is a bit easier to monitor than cortisone dosage:

* You and your doctor would look at your blood pressure, and your weight. If you are underdoing the fludrocortisone a bit, you might lose a kg or two, whereas with too much fludrocortisone you might put on a kg or two because of fluid retention, sometimes with oedema (that's the pitting when you press your fingers into your ankles.)

The fludrocortisone dose is often underdone. If you are not well, then both the glucocorticoid and the fludrocortisone need addressing. (see also NZAN newsletter No.15 pp13-17.)



The Actions of Adrenal Hormones in the Body

Cortisol, a vital hormone for maintaining life, has several important roles:

- Maintains blood sugar levels in the normal range.
- Keeps blood pressure normal. It acts on the walls of blood vessels to allow them to respond to the normal chemicals that make them contract and expand as needed. In an adrenal crisis, when you lack cortisol, you can't maintain your blood pressure, not necessarily just because of the blood volume, but also because the vessels can't respond to their normal signals.

- Stops excessive inflammation. Cortisol has an immune suppression effect. The immune system is set up to kill bacteria & viruses, and defend us. Cortisol puts a brake on the immune system, so that it doesn't "go wild". This action is especially utilised in people with serious conditions like bad arthritis or lung disease, who might be given high doses of hydrocortisone or prednisone to try and reduce the underlying inflammation of their condition. Even at normal levels cortisol has an important role in maintaining immune function.
- Maintains bone health. If we overdo the cortisone we can get thin bones, but at normal levels it has a permissive role in maintaining bone turnover.
- Permits normal brain function. Cortisol has important functions in the brain that are not well understood. It interacts with receptor sites for serotonin in the brain, for example, which allow normal brain function.
- In parallel with aldosterone, it assists with water and electrolyte balance

And cortisol has other actions too....

Aldosterone's main role is to keeps blood sodium and potassium concentrations normal. This is very important, especially for potassium, which needs regulating very tightly to keep muscle function and heart function normal. Aldosterone also maintains blood and tissue fluid volume

DHEA

Weak male-type hormone. (see previous articles in NZAN newsletters...)



We hope to print some more material from Prof Holdaway's address in future newsletters.

Reminder: SOURCING DHEA

You need a prescription from your doctor. There is no government subsidy.

Several NZAN members obtain their DHEA from:

Pharmaceutical Compounding (NZ) Ltd,
 35L Enterprise St (PO Box 34 897)
 Birkenhead, Auckland
 Ph: (09) 480 2660 Fax: (09) 480 2670

You can deal direct and have the capsules couriered to you, or you can take the prescription into your local pharmacy, who can source on your behalf. Your pharmacist may add a handling charge, but the usual prescription charges do not apply.

Unless you request otherwise, some pharmacists may source DHEA of another brand. As mentioned in previous newsletters, different brands of DHEA seem to vary in potency – despite having the same nominal content of DHEA. That means that doses between brands are not necessarily directly comparable. The dosage range among NZAN members that we know are taking the Auckland product is 10-25mg daily.

The cost is comparable if you import your own supplies from eg the US – and a prescription from a doctor in New Zealand is still required.



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

Hyperventilation:

Do you feel easily fatigued or breathless? Not making headway in your attempts to get fitter? Wondering if your Addison's meds need increasing? You might be a chronic hyperventilator.

People can be quite indignant at the suggestion that something as "simple" as their breathing may be costing them wellness.

There's a good book 'Hyperventilation Syndrome' by NZ physiotherapist Dinah Bradley, from which most of the facts in this summary have been taken.

Chronic hyperventilation is a breathing pattern disorder in which over-breathing becomes a habit, usually in response to prolonged stress or tension. The balance is disturbed between the oxygen-rich air we breathe in and the carbon dioxide-rich air we breathe out. The tissues in the body become more alkaline. A bewildering array of symptoms can be felt, and at times these appear out of the blue. Some of the symptoms mimic serious disease. And some mimic things people with Addison's disease already have to deal with: "dizziness...Muscles ache. Metabolism is less efficient. Exhaustion and chronic tiredness soon follow, with feelings of physical and mental depression."

An important message is that hyperventilation is correctible – although retraining may take several months (as Jeanette found out a few years ago!)

"'Good breathing' means moving air in and out of the chest with the minimum of effort and using the chest muscles to their best advantage". Twelve breaths a minute is about right.

It's easy to check your breathing. "Stand in front of a mirror, breathe in, and observe what part of your chest moved *first*, which part of your chest moved *most*, and did you breathe in through your nose or mouth?"

"If you breathed in fast through your mouth, and you could see and feel your upper chest heave first, and you felt little or no stomach movement or drew it in, you might have a disordered breathing pattern."

How does hyperventilation happen? For anyone, with or without healthy adrenals, "over-breathing is a normal reaction to stress or strain. It only becomes abnormal when stresses and strains reach levels that lead to chronic hyperventilation and outbreaks of symptoms. Even if the original stresses and strains are dealt with, in certain people the respiratory centre in the brain is reset, and the over-breathing becomes habitual – despite the symptoms it causes. Even though the bad times are over, the increased breathing rate stays."

REMINDER: Away from home? Forgotten your bottle of pills?

Reprinted from NZAN Newsletter No.10, July00:

We've all done it sometime - been away from home, maybe just at lunchtime, or unexpectedly delayed, and realised we don't have our hydrocortisone or prednisone with us. Missing one dose is unlikely to ever be life-threatening for an Addisonian – but it can make us cross with ourselves and worried that we may not function at our best over the following hours.

If you can give proof of your adrenal insufficiency (eg show your Medic Alert bracelet or necklace), you can pop into the nearest pharmacy for the dose(s) you need. It is your right.

The empowering legislation is Section 44(m) of the Pharmacy Act, under which a pharmacist can dispense up to 3 days supply of medication in an emergency.

Newsletters from Addison's Support Groups overseas:

Subscribe directly with Annette

It's no longer realistic to automatically include copies of overseas newsletters with our own newsletter.

However, members can receive copies of any they would like, on a one-off or on a regular basis, at no extra charge. These can still be included with the NZAN newsletter. Some are also available on email.

All you need to do is contact Annette Church: Annette@icib.co.nz, ph(09)379 5772; ICIB, PO Box 5734 Auckland.

We'll continue to feature some overseas highlights in future NZAN newsletters.

The latest issues available are:
 Addison News #39 March03; #40 June03
 ADSHG (UK) Newsletter #68 June03
 ADSHG (UK) Webnewsletter 1, April03
 Australian Addison's News #41 Apr03; #42 June03
 NADF News Vol XVIII, No 1, 2003
 The Canadian Addison Society Newsletter, #31 Jan03; #32 Apr03

In the June 03 issue of Australian Addison's News (and on their website www.addisons.org.au) you can read about the strategy for their Addison's Awareness Week (16-29 June). We've been told it was a great success.

Activities planned throughout Australia included:

- Helen Reddy, a fellow Addisonian, as inspiration
- Dinners/ functions with guest speakers
- Launch of Dr Ladhani's book "Survey of Addison's Disease Patients and Aspects of Management in Australia"
- Newspaper and magazine articles on Addison's Disease
- Press and TV interviews

The Australian and the UK websites are well worth a regular visit, to explore all sorts of information and individuals' stories.

REGULAR EXERCISE – it's important for everyone, Addisonians included!

As Prof Holdaway reminded us at the recent Northern regional meeting - not only physical exercise, but mental exercise too, scrabble, crosswords, etc.

Any offers of a Crossword Puzzle for the next newsletter will be welcomed!



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

Robyn's Story

Robyn's symptoms of Addison's disease gradually worsened over a couple of years. Although the symptoms included salt craving, and the tell-tale tan, the diagnosis was missed until she saw a new doctor. He made the correct diagnosis there and then, confirmed it with tests, and Robyn was promptly started on replacement hydrocortisone and fludrocortisone. But her recovery was slow. Two years down the track she has resigned from full-time teaching, and from next term will be relieving 2-3 days per week, in order to have a more balanced life, with more stable wellness...

I was diagnosed with Primary Addison's Disease in April 2001, when I was 43. I am 5' 3" and usually weigh about 56 kg. For about 2 years before my diagnosis I suffered various symptoms that I now realise were Addison's related. I lost weight (6 kg); could only eat very small amounts (poor appetite); craved salt, and used salty foods to help me feel better when I felt nauseated; had some joint pain in my hips and knees; lost a lot of muscle strength, and felt extremely tired at the end of a day. For six months before my diagnosis I vomited most mornings (very much like morning sickness). I carried salt crystals with me to suck when I felt nausea coming on. I also became more and more breathless, initially just after exercise, but eventually during normal everyday activity.

My GP was kind and supportive, but every time I went to her, these symptoms were put down to severe stress that I had been under. She loaned me a book on hyperventilation [see box], but it didn't seem a diagnosis personal for me, and I didn't pursue it then.

A couple of weeks before Easter I saw my GP again, concerned about nausea. She ordered blood tests for liver function. They came back a bit abnormal but she said she'd retest them in a month.

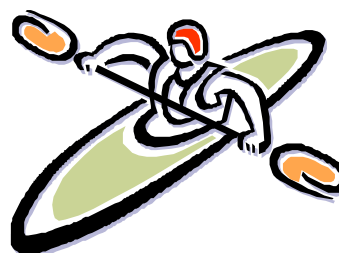
After a few more days of vomiting I decided I couldn't wait another month - I needed help now! I rang a Naturopath friend of mine to ask her advice and she put me on to another doctor who she felt had a special skill with diagnosis. I made an appointment to see him the day after the Easter holiday break.

During Easter I became so unwell I couldn't eat and I was so exhausted that it was an effort to breathe. Moving about was almost impossible. I knew there was something very wrong and was relieved to be going to the doctor on Tuesday.

I sat with him for a very long time, while he asked questions and 'studied' me inside and out. He also spent a lot of time sitting and

thinking. I think it was my 'tan' that led him to Addison's disease. He said he hadn't come across or studied Addison's since Medical School. In fact, he almost seemed amazed that he had remembered it. That may not have been the case, but at the time it seemed like a 'miracle' to me. He took my blood pressure lying and standing and sent me for an ACTH stimulation test the next morning. The lab rang him that afternoon with the results. My 9am cortisol was 38 (normal range 170-700) with no rise after IM synacthen (ACTH) - the 930am cortisol was 30, and the 10am was 38 (normal should be more than 750). He put me straight onto what he described as a maintenance dose of 25mg hydrocortisone and 0.1mg fludrocortisone, and referred me to a specialist whom I saw about a week later.

Ironically the tan was one symptom that wasn't worrying me. I just associated it with getting older, because my mother had a similar tan when she was very unwell, "flat on her back", at the end of 1981, aged 49. The doctors didn't know what was wrong with her. In the new year she gradually got back to work, but had little energy, got sick again, then hepatitis B was diagnosed, and she died a few months later. Perhaps she also had Addison's. I have a brother who has insulin-dependent diabetes, and a sister who doesn't have any diagnosed medical conditions.



For the next 9 months I slowly but gradually recovered. I saw my GP every month and had regular tests. My liver tests were still abnormal when the Addison's diagnosis was made, but were nearly normal a week later.

My endocrinologist believed my slow recovery was at least in part due to hyperventilation syndrome. I was referred to a physiotherapist who specialises in breathing problems. My

diaphragm definitely wasn't working properly, just as all my other major muscles were very weak. I had got used to breathing at the top of my chest. With the help of the physiotherapist, I did exercises to get my diaphragm working again and after 6 weeks or so my breathing was back to normal.

Now that I have more experience with low cortisol symptoms, I don't believe that hyperventilation significantly contributed to my 'unwellness' during the months after diagnosis. The extreme fatigue, dizziness and weakness I was experiencing I now believe were related to low cortisol.

After diagnosis the only symptoms that immediately left me were the salt craving, the nausea and the lack of appetite. Because I didn't collapse and end up in hospital I was never given a boost of hydrocortisone. I was put onto a maintenance dose of 25mg hydrocortisone and 0.1mg fludrocortisone. I accepted, as I had been told, that my slow recovery was understandable. And after reading the cautions in Addison's literature about the possible side effects of too much medication, and the advice to be on the lowest possible dose that keeps you well, I was very wary of taking more than I had been prescribed. Before Addison's, I had not been on any regular medication and have to admit to being a bit 'paranoid' about having to take 'pills'. I am now tempted to believe that if I had taken a boost of hydrocortisone for a while then tapered slowly back to a comfortable maintenance dose, I may not have taken so long to recover.

Going back to teaching (9 months after diagnosis) felt great. I was still struggling with fatigue and dizziness most of the time, but was determined that I was going to figure things out. I was convinced that subtle changes to the amount and timing of my dosage would eventually see me 'symptom free'. Two years later, I'm on 27.5mg hydrocortisone (15mg at 6.10am, 7.5mg at 10.45am, 5mg at 3.45pm – to fit with school breaks); 0.15mg fludrocortisone (at 6.10am)

and 10mg DHEA (taken with breakfast). I have found that the DHEA has taken away the "down" feeling that goes with fatigue.

I can be very well on these dosages and feel they are right for me at the moment. However, my job (teaching 5 year olds) requires very different amounts of energy each day and during a busy week I am very unwell with low cortisol symptoms Wed – Fri, and then need to rest and recuperate all weekend. I also think my body finds the change from holiday time to term time difficult to adjust to.



So, rather than trying to 'beat' the Addison's and make it fit into my lifestyle, I've decided to fit my lifestyle to Addison's. I've resigned from full-time teaching and I'm going to relieve 2 or 3 days a week. I'll be able to choose when I work and I'll have the time and energy to exercise and will hopefully have more control over the amount of energy that I'm using each day. I'll also be in a position to keep my eyes and ears open for other work opportunities.

Having Addison's has brought me many positive opportunities. After some years of knowing I needed to take better care of myself, I was finally forced to do so. I told myself that Addison's is a blessing in disguise. It finally made me stop and look after myself. I actually enjoyed the slow recovery period at home, using it to learn more about myself.

I can no longer get away with not having enough water during the day, or enough sleep at night. Learning to pace myself, think about priorities, and practise new ways of eliminating stress has been, and will be, an on-going challenge. I am also learning to think about what is best for me without worrying so much about pleasing others.

I can no longer take my slim build for granted! I have slowly gained weight because I have tended to eat when my energy is low. I am now going to weight watchers to help lose the

12 kg I had gained. So far I've lost a kg a week so I'm fairly certain I'll get back to my 56kgs. I am fairly sure that my metabolism has changed being on replacement steroids and that I will no longer be able to get away with eating whatever I feel like without putting on weight. So healthy eating habits and lots of exercise is also on the plan.

Once I get fit and well again I am looking forward to getting out on the sea in my kayak. My husband, Paul, and I have a long list of spots along the Northland coast to explore. Walking is another thing I'm keen to have more time for. I may even get brave and join our local tramping club.

Having a 'life after work' will also enable me to follow my boys and their interests with more energy and time. Matthew (17) is playing in a band at the Paihia Jazz festival in August (he plays electric guitar) and Kim (20) is coming up from Hamilton to sing a song or two with them. We'll all stay up in Paihia for the weekend – I can't wait!

I have always been reasonably fit and healthy. Apart from the odd allergy, I seldom get everyday illnesses and having Addison's hasn't changed this. I have had one bout of food poisoning since my diagnosis. I went to A & E in Whangarei in the middle of the night and was treated promptly and carefully. I was in hospital for 2 days, given intravenous hydrocortisone and fluids, and sent home with a tapering plan. The letter from my doctor that I carry with me every day was a big help as an initial guide for the on-duty doctor. It certainly is very comforting knowing that my local hospital took care of me so well.

I have come a long way in managing my Addison's but realise that there is much more to learn and figure out. Having confidence to make my own decisions about my medication (with the support of my doctor), increasing hydrocortisone when necessary, and experimenting with different dosage splits during the day, have been a big breakthrough for me. Now that I am about to reorganise my

lifestyle, as well, I am looking forward to getting on top of the low-cortisol symptoms I experience so often.

Finally, I'd like to say a big thank you to 2 people who have showed a lot of care and support over the last 2 years, since my diagnosis.

My husband, Paul, coped so well having to do everything at home on top of his busy schedule, when I was so unwell for the first few months after diagnosis. He has been incredibly patient and a great listener.

Our national co-ordinator, Jeanette, has been an amazing source of information, and has given up a lot of time helping me to get to grips with using my medications to 'be the best that I can be'.



Joy's story

Another slow diagnosis of Addison's disease - her symptoms started during her second pregnancy.

I was diagnosed with Addison's when I was 35. During my mid twenties I often felt dizzy when I stood up quickly, particularly after I had been squatting. As my family had a history of low blood pressure I wasn't overly concerned about this. But I noticed that I was often very lethargic at morning tea time so I added sugar to my coffee in order to boost my energy levels. I retired from fulltime teaching and I had my first baby a month before I turned twenty-eight. I had terrible morning sickness for the first three months but other than that my pregnancy was easy.

Two years later I was pregnant again. This time I had no morning sickness but I craved salted peanuts. I had stopped adding salt to the vegetables that I cooked because my husband had high blood pressure. Little did I know then that it was the salt in the peanuts

that I really wanted. Just after my baby was born I got a bout of diarrhea and I remember feeling very weak and faint. Fortunately my mother was staying with me at the time to help with the new baby, and it didn't take me long to recover.

As my baby grew, people began to comment on my lovely suntan, but I thought this was due to my recent interest in gardening. Besides, I thought that I looked great. I had lost weight which pleased me, but I couldn't stand for long periods of time, as I got so tired. I had been troubled with pains in my sides at night for about eight or nine years but nobody was able to tell me what was causing them. I was sure it was my kidneys that were hurting.

The X-rays, CT scan and ultrasound examinations revealed nothing but a cyst on one of my kidneys. The doctors didn't think it would be causing my pain but they offered me no other help.

I decided the pain was probably due to a food allergy so I tried eliminating tomatoes, which I loved, but this didn't solve my problem. Some mornings the pain was so intense that I had to get out of bed early and get my body upright as the side I was lying on always hurt the most. Sleeping on the couch with my body propped up on a 45* angle helped. Some days I was so sore and so tired that I sat around all day, but I found that movement actually helped the pain go away so I was better to start working. Nevertheless I had days when I felt so bad that I did virtually nothing all day.

Most of the time I lived a fairly normal active life as a mother of two young children. I taught part time and was very involved in the local playcentre. But when I got a tummy bug I got so weak and dizzy that once I fainted twice in the middle of the night. The first time I hit the kitchen floor so hard I woke my husband up. The next time I was sitting at the dining room table and I fainted forwards so my husband called the ambulance. On

the way into hospital, at about midnight, I could hear the ambulance staff discussing what they should do with me. They took me to A&E where they weighed me and asked if I had been dieting (I was about 55kg). They examined a mole on my back and wondered if it was cancerous. They asked me about my marriage as I was sleeping in the spare room so I wouldn't keep my husband awake. I begged them to let me go to sleep. After nearly an hour they agreed and I was wheeled down to a ward and put in isolation. I went to the toilet and felt dizzy so I rang the buzzer for a nurse. She didn't come so I convinced myself that I could make it to the bed, which was about four metres away. I walked out of the toilet and fell to the floor. The nurse arrived and I told her that I had fainted. She said I must have slipped because I had socks on! I always had cold feet and therefore wore socks to bed.

The next day the senior medical officer asked me whether I had just come back from the islands, as I was so brown. He then told me that there was nothing wrong with me and they sent me home.



Some months later I began to vomit when I cleaned my teeth in the mornings. If I hadn't had breakfast I would dry retch when I put the toothbrush in my mouth. After weeks of this I decided that I must be pregnant again even though my husband had had a vasectomy. I was also uncomfortable wearing any waisted clothing. I went to my GP and found that the pregnancy test was negative. She decided that I must have been eating too much fruit and this had formed a gas build up in my stomach. I didn't think she was right, as I had always eaten five or six pieces of raw fruit a day, but I took the medication she prescribed because I thought it might help and certainly wouldn't do me any harm. Little did I know!

The next day or two I felt worse, so I stopped taking the medication that she had prescribed,

but by this time my condition had deteriorated so much that I was unable to keep down boiled water or flat lemonade. I was also freezing cold during a hot Marlborough summer. I returned to the doctor but still my condition worsened. I began to get violent stomach cramps. I felt like someone was cutting across my stomach with a sharp knife. I couldn't sleep but I didn't want my husband to call another ambulance in the middle of the night and the hospital to tell me there was nothing wrong with me. I prayed to die. I was wracked with pain. I couldn't walk from the bedroom to the bathroom without fainting or sitting down and I carried a bowl with me to throw up into.

In the morning a nurse friend took me back to my GP. She saw me immediately and wrote a referral to the hospital. She thought that I had a blocked bowel. I knew that I didn't as I hadn't been able to keep anything down for days, but it got me into hospital legitimately and that was all I cared about. A male house surgeon examined me and agreed with my GP's diagnosis. The senior medical officer agreed. I think I even signed the papers for an operation! But a young female house surgeon saved my life. Instead of asking me about the last few hours and the last few days she asked me about the last few weeks, months and years. An extremely low salt level in my blood and my beautiful tan made her suspect Addison's disease.

As the lab test results for Addison's take several days and I was already in a crisis the doctors felt that I couldn't wait for a formal diagnosis before treatment so they put me on a saline drip and gave me cortisone intravenously. I woke the next morning like a new person. I walked down the corridor to shower unaided without feeling faint. I was back to normal and I could eat again without throwing up. I rang my husband from the hospital to tell him that I was feeling OK again and he immediately said that my voice had returned to normal. It had deepened quite considerably over the previous year.

I was prescribed 25mg cortisone acetate and 0.1mg fludrocortisone every morning and 12½mg cortisone acetate in the evening, and sent home after only one night in hospital. I have stayed on the same medication ever since (11years) until recently when I first visited an endocrinologist, who found that my fludrocortisone needed to be increased to 0.15mg then 0.2mg per day. After he increased my fludrocortisone to 0.2mg my periods returned. They had gradually lessened over the years since diagnosis.



When I was diagnosed in 1991 I sought a support group but found there was none. I was given a small information booklet written by Christchurch Hospital endocrinology department and I lived alongside a nurse who had a medical book on endocrinology which although very technical was quite helpful. The senior medical officer also got another Addisonian patient to phone me. She answered most of my questions. I eagerly sought to read everything I could about Addison's but I discovered that most of the material I found was either too basic to be of any use or so medically technical that I couldn't understand it.

In 1998 I found a reference to a New Zealand support group on the world wide web but there were no contact names, addresses or phone numbers listed on the site and it wasn't until 2002 that I found the NZAN website and became a member.

A few years ago I discovered that my uncle died of Addison's disease in Auckland Hospital in 1932. He was only 17 years old. He had been hit in the small of the back by the tray of a coal truck about 9 months earlier. I presume this damaged his adrenals glands. His older brother told me that the whites of his eyes went quite yellow before he died and he was so tired some days he couldn't do up his bootlaces. I think they only discovered the Addison's when they did a post mortem. His

death certificate states: "Addison's disease months".

Since being diagnosed with Addison's I have only had one adrenal crisis, which was brought about through having gastroenteritis, as I couldn't keep my medication in my system long enough for it to have any effect. My husband took me to the local hospital and I was seen by my GP who was on duty that evening. He injected me with Solu-Cortef and I went home again straight away.

Every now and then I think about returning to classroom teaching but I have decided to continue teaching part time instead as the pressures and stresses of a classroom teacher's job are not always predictable and are therefore difficult to accurately medicate for. I now work as a reading recovery and special needs teacher at three local schools and I generally keep very good health. During the winter terms I find that I often need more daily cortisone than during the summer months. If I don't increase my cortisone I suffer from a recurrent sore throat, become tearful in stressful situations and I retch in the mornings when I clean my teeth.



Joy speculates...

Is there a link between blood group and Addison's disease? Might her food choices have influenced that she got Addison's disease?

"I have recently read The Eat Right Diet by Dr Peter D'Adamo. He says that people with blood group B (like me) are prone to auto immune diseases.

"He lists beneficial foods for each blood group, which he claims act like tonics to the system, neutral foods and finally foods to avoid which he says can affect us like "toxins". I was astounded to see that all my favourite foods were in the blood group B avoid list - whereas the traditional country girl's diet that I was raised on and now tried to

avoid, because it had a high fat content, was mostly beneficial to my blood group.

"I have wondered for a long time whether my adrenal atrophy could have been caused by my food choices. I had suffered a lot of pain "in my kidneys" for years and this intensified over the Christmas New Year period when I was eating a lot of tomatoes, radishes, fruit and ham etc (on my "avoid" list, according to Dr D'Adamo). Now I wonder if I had stayed on a traditional kiwi diet when I left home whether I would have still developed Addison's disease.

"The year my second child was born (when I was diagnosed with Addison's) was particularly stressful as my husband was unwell and we lost all our investment capital through no fault of our own. After reading that book, I wonder if my body was stressed even further by the foods I loved to eat, eg tomatoes, peanuts, bacon and wholegrain bread, that were the mainstay of my diet.

"I think the possible link between blood groups, food allergies and Addison's disease merits further investigation. It would be good if we could reduce the risk of onset of Addison's disease in our children, by changing their food choices!"

Professor Holdaway comments:

As mentioned above, there are links between autoimmune disorders and tissue type (HLA type), but not strongly with blood groups as far I know. Whether food types can influence autoimmune disorders is not known, and research could certainly be done in this area. However, it seems likely that unravelling the cause and treatments for autoimmunity will come from better knowledge of the complicated factors controlling cell-mediated immunity in general.