

New Zealand Addison's Network

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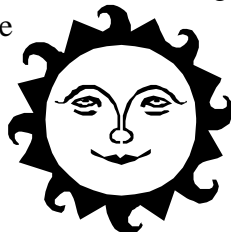
www.addisons.org.nz

NZAN Newsletter, November 2001 (No 14)

In this issue we include:

- NZAN Website launched
- Bay of Plenty meeting report
- Diane and DHEA; and other brief topics
- New UK Addison's manual
- Ready for emergencies?
- More topics from Prof Holdaway's keynote address in Auckland
- ACIF website address change
- Ideas for avoiding confusion of different round white pills
- Addisonian fitness and muscle function – research report
- Notes on dehydration – reprint from NZAN Update issue #8
- Members' contact phone list
- Kathryn's story
- Lyn's story

We are trialing a change of lettering to harmonise with our new website. We welcome your feedback.



STOP PRESS!

A Central Regional Meeting is taking shape for early 2002, probably in Lower Hutt. We'll keep members informed by email or snail-mail – and on our website!

Would you like to co-ordinate or help make an NZAN meeting happen for Addisonians in your town or region during 2002? If so, please contact Jeanette.

The organizers of the Auckland and Bay of Plenty meetings in 2001 have experience and tips to share about meeting formats, and local media advertising strategies that work.

The personal stories in this issue are by Kathryn and Lyn, two of the energetic co-organizers of the inaugural Northern Regional Meeting in July.

Wishing you all good health,
Jeanette and the team

NZAN WEB SITE LAUNCHED:

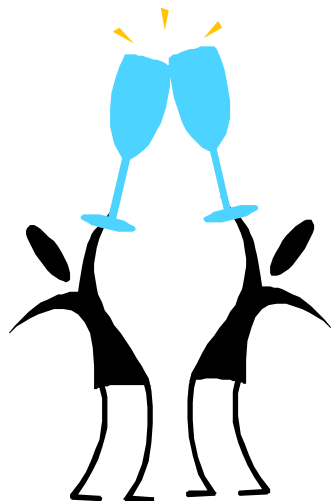
Our own web site is now out there, in cyberspace! Raise a glass, and point your browser at www.addisons.org.nz.

We are starting simply – a “poster” in cyberspace, explaining why NZAN exists, what membership benefits are, with a notice board (a cyber-corkboard!) that we’ll keep current, and with copies of our newsletters for downloading as PDF files. If there is another feature you’d like to see on the website, please contact Jeanette.

Our site has links to the websites of other Addison’s support groups internationally, and to clear sources of information about management of Addison’s disease.

Costs of setting up and hosting the site until December 2002 are being met by a grant from Bristol-Myers Squibb, manufacturers of fludrocortisone.

Thank you!



For those without Internet connection, these are the membership benefits we have listed on the site:

- Three newsletters per year (March, July and November) 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 meetings
- Opportunities for questions to the medical advisor, currently Prof Ian Holdaway (Auckland)
- Opportunities to participate in members’ surveys

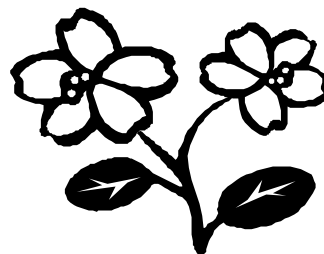
We will track the site traffic, with interest! So far the Internet has been a minor source of new members. More than half our members have first heard about NZAN from their specialists. Only 7% have so far found us through the Internet.



MEMBERSHIP UPDATE

We now have 77 members. Diane, Janice, Julie, Karen, Katrina, Rosemaree, Ray and Vicky, have joined since the last Update. Thanks for your donation, Diane.

November 23 was NZAN’s fifth birthday, and also the 75th birthday of Marjorie Hill, one of our foundation members. Thanks for helping to launch the good ship NZAN, Marjorie – and may you long continue to enjoy the sail!



POSTAGE SPONSORSHIP

We are pleased to acknowledge sponsorship from pharmaceutical supplier Zuellig Pharma, for the envelopes and postage of this NZAN Newsletter.

BAY OF PLENTY MINI-MEETING REPORT...

...from JEANETTE

Thanks especially to Colleen's commitment and her husband Graham's support, and Danielle's enthusiasm, the BOP meeting on 15 September went well. Building on her experience with the Auckland meeting, Andrea helped make all local newspapers and radio stations in the broader Bay of Plenty and Waikato areas aware of the event. Doctors informed their patients. Colleen followed up and fielded the several enquiries.

Fahy's Motor Inn in Greerton, Tauranga, provided excellent facilities, graciously, and at special rates. Feedback from participants said the format worked fine. We felt that it was a good decision to have at least the first meeting in a region, on neutral territory. For part of the time, Professor Holdaway's taped voice flowed clearly from the ceiling tiles, and Jeanette kept up with the slides on the overhead projector. This is an option for other centres too.

...from DIANE

I had the pleasure of attending the first Bay of Plenty Addison's Network meeting held Saturday 15 September, after only finding out about NZAN and the meeting two weeks prior - from my pharmacist. Although only a small group - nine people - we had a very informative day, learning new information from each other and from the tapes of Professor Holdaway's presentation at the Northern region meeting.

I found it great to actually meet others with the same condition and discover that we all do survive (once diagnosed) and can lead outgoing lives. Those present ranged from those who have known they have Addison's and have been on medication for over 20 years (myself included), to one who had been diagnosed a few weeks

previously and was just starting on the road to recovery.

I look forward to more contact with NZAN - newsletters and more meetings, as one thing the meeting spelled out to me was, we need to be informed as individuals about our condition so we can make safe decisions for ourselves, and we can do that through sharing experiences.

DIANE and DHEA

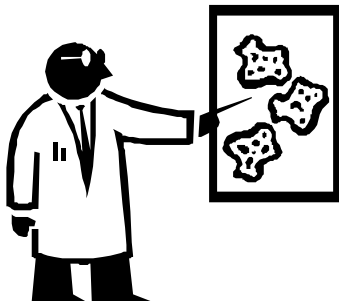
I have been using cortisone acetate for 21 years, after going into hospital in a comatose state. I have had no set backs apart from adding Fludrocortisone about 11 years ago. I enjoy tramping, have two daughters (21 and 19) and used to work part time, now full time. Two and half years ago I felt like I was pushing a barrow up hill, especially at the end of the day, so after a little bit of research with my pharmacist I had my DHEA levels checked. The result was below the readable level, so August two years ago I started taking 25mg DHEA. A blood-test showed that this boosted my levels a bit high and my skin was oily, so my GP and I dropped the level to 10mg per day. Subsequent blood tests showed this was too low so I now use 2x 10mg doses daily.



How do I feel? I wouldn't be without it. My energy levels are much higher, and I'm sure my skin tone is much better - I don't feel like I am ageing as fast as I was! I would recommend any one considering DHEA first get their levels checked, and then be alert for side-effects, and have regular tests to get the level right.

FROM DISCUSSIONS WITH OUR MEDICAL ADVISOR, PROFESSOR IAN HOLDAWAY:

* **A few people may have a confusing “de-energising” response to DHEA,** because of opposing interactions with other steroids such as estrogen, and consequent effect on cortisol clearance. Trying a reduced dose of DHEA may be the simplest way to solve this. Interactions between medications for Addison’s disease and other treatments will be the subject of a review in an upcoming newsletter.



* **Which is more common – primary or secondary adrenal insufficiency?**

At the Auckland regional meeting in July, Prof Holdaway mentioned that primary adrenal insufficiency (adrenal cause) is rarer than secondary adrenal insufficiency (pituitary cause). Noting that about 85% of NZAN members are “true” Addison’s, Jeanette followed up.

“The prevalence of Hypopituitarism is estimated at 100-150 patients per million, with about 10-20 new cases per million per year. Addison’s prevalence is 40-100 per million (Clin Endocrinol 41;757, 1994 and Lancet, 2;744, 1968), and new cases about six per million per year,” said Prof Holdaway. “My impression is that secondary adrenal insufficiency would be about three times more prevalent than primary adrenal insufficiency in New Zealand.”

That “secondary” figure doesn’t include people with adrenal suppression from medical use of corticosteroids, quite a large category, mainly those on long term steroids for asthma, chronic obstructive respiratory disease, and rheumatoid arthritis.

“Because these individuals retain normal aldosterone production, and because their stress responses are sometimes partly preserved, people with secondary adrenal insufficiency are less likely to get into medical problems, and NZAN may be seen by them as less relevant – although much of it is,” says Prof Holdaway.

SOURCING DHEA

DHEA can be obtained in New Zealand, from:

Pharmaceutical Compounding (NZ) Ltd,
35L Enterprise St (PO Box 34 897)
Birkenhead, Auckland

Ph: (09) 480 2660 Fax: (09) 480 2670

You need a prescription from your doctor. 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.

The cost is comparable to that of importing your own supplies. Your pharmacist may add a handling charge, but the usual prescription charges do not apply.

NEW UK ADDISON’S MANUAL

“Living with Addison’s Disease – an owner’s manual for individuals with the disease”, has recently been published by the UK Addison’s Disease Self Help Group.

A comprehensive launching pad for Addisonians, it identifies and gives guidelines for the topics we all need to understand. The authors, Sarah Baker and Katherine White, deserve hearty

congratulations for taking on and achieving such a mammoth goal!

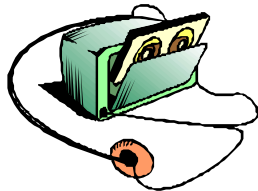
You can download your own copy of the 24-page manual from the UK web site www.surreyweb.net/adshg – there is a link on our NZAN website. If you'd like your own PDF file, email Jeanette. For a printed copy, A3 paper stapled down the centre, please send \$15 to Jeanette. (That fee contains \$5 royalty.)

The authors clearly state that the guide is addressed principally to UK residents and reflects UK medical practice.

The sections on medication strategies, and the tools appropriate for monitoring medication doses, in particular, may confuse some NZAN members. Comment from a New Zealand perspective will be included in a future NZAN newsletter.

REMINDER: TAPES FROM JULY MEETING IN AUCKLAND

NZAN members who didn't hear our medical advisor Professor Holdaway speak at the Northern Regional Meeting in July, can still obtain the tapes, which give a detailed context to many issues important for Addisonians.



The tapes are available for \$10 per set – including a photocopy of the slides, and a summary of the order of the topics. Contact: Kathryn, 14 Birkley Rd, Bayswater, Auckland; phone 09 445 6427, fax 09 445 6428; or contact Jeanette.



Robyn's Review: UK ADDISON'S MANUAL

Jeanette asked NZAN member Robyn, a primary school teacher in her early 40s, diagnosed with Addison's in April this year, if she'd be willing to read the manual cover to cover, and write a book review for NZAN! Robyn was keen.

“My first thought was - how great that a publication has come out that might have all that I need to know within it. The introduction is a simple, clear statement and the contents page is well laid out, easy to browse and refer back to. On flicking through the booklet I felt positive about the range of information it had in store for me.

“After reading it, I feel positive that this publication has the potential to be an excellent resource for Addisonians, with all they need to get started in terms of managing their illness successfully.”

It wasn't quite all plain sailing. The layout provides quite a navigational challenge, especially if small print is a problem for the reader. Robyn felt some questions weren't answered, some content conflicted with information she had received from other sources, and some advice needed more clarification.

The authors have asked for feedback, before the next printing early 2002, so Robyn's full review has been sent to them, and is available to anyone in NZAN who may be interested.

READY FOR EMERGENCIES?

Supplies?

Enough hydrocortisone or prednisone for three months can be supplied in one dispensing by your pharmacist. Some medications are made in only a few sites world wide. We can't be certain that supplies won't be interrupted by world events – so we advise you to keep a few weeks' supply of all your essential medications on hand.

Action?

When you are away from your familiar patch, remember:

- Extra steroid tablets, easily accessible
- Anti-nausea pills or suppositories (especially if travelling to places where food poisoning may be a problem)
- Injectable hydrocortisone (Solu-cortef) and some extra syringes
- Plenty of water accessible
- Access to extra salt too, if in a hot climate
- Adequate personal labeling (eg Medic-alert)
- A letter from your doctor, which explains your condition, your medications, what needs to be done for you in an emergency, and if travelling by aeroplane, explains the need to carry injectable items in your hand baggage, and
- If you are traveling in some out-of-the-way place – more details of what a doctor or hospital should do for you in an emergency, preferably translated into the language of the country you are visiting.

Are the members of your family, and relevant friends, neighbours and workmates, clear about what to do for you in an emergency?



MORE EXCERPTS FROM PROFESSOR HOLDAWAY'S ADDRESS at the July Regional Meeting in Auckland:

When the usual daily dose of steroids isn't enough:

“Correct treatment in emergencies, in major illnesses, surgery and so on, really is an important issue. That's why you have a Medic-alert bracelet, and lots of information about your condition, because this is a time when Addison's can really harm you badly, if it's not handled properly. Occasionally fatalities will occur because people don't recognize that Addison's disease is present in a very ill individual, or don't treat it appropriately.

“There are mechanisms in the brain that recognize stress and signal the pituitary to release more ACTH so that the adrenals make more cortisol. People with Addison's can't do this. They need extra cortisone by injection – or, in some circumstances, extra tablets will be enough.”

Prof Holdaway gave his perspective, commenting also on a recent US review (UpToDate).

“So again there are multiple ways of dealing with this, and a number of suggested guidelines have been developed around the world.

“**Major illness** is usually relatively easy to define, there is no doubt about illness severity, e.g. traffic accident, broken leg, in hospital for an operation –you need high amounts of cortisone, that is usually given

as hydrocortisone intravenously every 6-8 hours - there are treatment protocols, and doctors are soon involved.

But what about emergencies where you are, for example, sitting in the middle of Thailand with vomiting and diarrhoea - what are you going to do?. In those circumstances, prompt injection of steroids, by oneself or a companion, is very important – see box.

Responding to vomiting and diarrhoea

“An important issue for people with Addison’s disease, is knowing and taking the right action, if an attack of vomiting and diarrhoea hits – which may be when one is out on a walking track, or in the middle of a third world country, or in a culturally different medical system, for example. Vomiting can quickly become a serious problem for people with Addison’s disease.

“If you can’t keep your tablets down, you can become cortisol deficient very easily. That’s bad enough, but you also get volume deplete very easily. The fluid in vomit comes not just from what you have eaten, but it’s also actually being sucked out of your circulating blood volume to some extent, so people with Addison’s disease that are vomiting can get dehydrated, blood pressure falls, and they collapse quite easily. Diarrhoea can do the same thing.

“If you are very nauseous, quite often the stomach won’t pass on the tablets terribly well to the digestive tract, so even nausea without vomiting can be a problem, because you don’t get the tablets down into the intestine where they get absorbed.

“So vomiting illnesses have to be treated quite seriously and that’s where the injections do have a definite role. It’s

pretty commonsense that if you are severely ill or injured, someone has to inject the steroids into you. The important point to remember is, if you are ‘just’ vomiting and ill, injections are also quite helpful.”

Discussion followed, on what point to take action. “I think if vomiting is fairly soon after the tablets were taken (about an hour or so) I would prefer to give an injection after that because those tablets have probably not been absorbed, there is a stress illness, and the individual needs extra anyway. If the vomiting is in the afternoon, and you have had your morning tablets OK, then you could possibly wait a bit and see if it settles down, but if there was a second vomit you might want to use cortisol injections then...

“So hopefully most of you will go through your lives, never having to have injected hydrocortisone - but again, it’s better to have it and not need it, than to need it and not have it.”

Moderate illness – quick to say, difficult to define. Professor Holdaway noted that for moderate illness, the US review favoured quite a lot of extra steroid, 100mg hydrocortisone a day (50mg morning and evening), or an intravenous shot. Double or triple the daily dose is the usual advice in New Zealand. But what is a moderate illness?

Prof Holdaway suggested the practical guideline, “It’s something you’d go to the doctor about – bad ‘flu, a foot that’s very sore after dropping a brick on it... If you are in doubt, take it, you won’t do yourself any terrible harm with a day or so of extra cortisone that you may not have really needed.”

“If you are so sick that you can hardly get out the door to see the doctor, I agree you really need it.”

Prof Holdaway described a problem we can all have: “You can sit around in a room like this and say ‘This is what I will do!’, but when you actually do get sick, you forget, or you just can’t be bothered taking this extra stuff, and you can get into trouble if it is not taken, that’s for sure.

“The downside of taking the extra steroids over a short period of time is not great. If you are someone who has other chronic illness or stress, so you are doubling up doses every second day, then it’s very easy to get into a pattern of over-dosage. But if it is a now and again issue, a nasty cold, wondering if it is flu, should I be taking extra cortisol, what should I do, what shouldn’t I do – if you are feeling actually fine in yourself and pretty bright on it, you probably don’t have to take extra, but if you are feeling any doubt, take it.

“For minor procedures, having a barium meal, an endoscopy, a gastroscopy, an MRI scan, no extra steroids are usually needed but if you are a bit worried about it, take a bit extra – it’s in your hands... Dental procedures can be both psychologically and physically stressful, so I would take a bit extra.

“Anticipation stress and psychological stress are two issues I am often asked about. Those are very difficult questions and in some ways it is your own prior experience that might tell you what’s best.

“If you know something is coming up that will put a bigger demand on you, what should you do with your steroid doses? If you know that when you have climbed Mount Ngaruahoe, or when you’ve done something extra, that you felt pretty unwell, then I would take a bit of extra steroid in anticipation of any similar upcoming major issue. If you have no idea at all whether this upcoming stress, perhaps a big job interview, is going to put a high demand on you, then that is difficult

- if you are worried, by all means take a bit extra, such as 5-10mg hydrocortisone.

“Virtually all of the guidelines say that psychological stress is not an indication to increase your dosage, that in general you do not need extra cortisone, but I don’t entirely agree with that. If your spouse suddenly keels over and dies that’s an awful stress and if you measured cortisol levels in everyone in which that happened, the remaining spouse’s cortisol levels would certainly go up for quite a bit of that day.

So I do not think it is unreasonable for severe psychological stresses to take extra. But how far down the line do you come? Just going out driving in Auckland traffic in the morning is stressful, so there have to be some common sense decisions about what’s unusual or severe.”



Tips for Getting Attention at A&E:

From Professor Holdaway at the July forum in Auckland:

“It can be difficult. It’s the time when one has to be forceful. State that I (or my partner, etc) have Addison’s disease, under-active adrenal glands, they are very ill, they need immediate medical treatment, this is an emergency, they have to come in right now. If you are in a waiting room, say we need to see the doctor right now, we can’t wait, there is going to be a crisis here, and that’s just what you have to say.

If you yell and shriek a bit, sometimes that’s counter-productive, but if you are absolutely firm, then people get the message pretty quickly.”

PLEASE SHARE YOUR NEWS, YOUR STORIES, AND YOUR QUESTIONS

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

Our next survey has been postponed until March 2002. Are there things you'd like to clarify with your fellow Addisonians? Please send Jeanette your ideas for survey questions *before the end of January*. Our regular surveys are a vehicle for health professionals to "screen" research ideas too.

If you have a question, or a topic for discussion, that you'd like passed on to Prof Holdaway, please send it to Jeanette.



ACIF WEBSITE URL CHANGE AND NEW BULLETIN BOARD

ACIF stands for the Addison and Cushing International Federation, informally established at the first (and, so far, only) international conference of support groups for Addison's Cushings and Acromegaly in Oslo in 1996. Jeanette was there – so NZAN is essentially a foundation member.

For the past five years, the Dutch Addison and Cushing Association (NVACP), Laurens Mijnders in particular, has maintained ACIF contact information on its website, and helped enquirers find support groups or found new ones - now in nearly 20 countries.

The NVACP has a new website, at www.nvacp.nl. It includes some English-language pages. On 1 November an English-language bulletin board was launched for a trial period..

How the ACIF will evolve is currently being discussed between participants. It is likely that the NVACP web site will continue as the location of a comprehensive ACIF register of international groups.



Special thanks to Annette Church, business secretary to an Auckland member, for transcribing the tapes of Professor Holdaway's Auckland keynote address, and answers to questions, so that we can more easily publish the topics in our newsletters.

IDEAS FOR AVOIDING CONFUSION OF DIFFERENT ROUND WHITE PILLS

Lois, our member in Malaysia, was perturbed when her new Florinef supply was white, rather than the familiar pink. They now look frustratingly similar to her hydrocortisone supply.

The Florinef available in New Zealand is likely to become white too, but not in the short term, John Murray, commercial manager for Bristol-Myers Squibb (New Zealand) tells us. We'll keep you posted.

Meanwhile, the confusing issue of look-alike tablets already exists for some people, and may increase with the trend to more prescribing of generics.

Some Addisonians take a mixture of hydrocortisone and prednisone daily. Both are little white pills – for the brands in New Zealand, 1mg prednisone is a bit

smaller than 5mg hydrocortisone, with an indented P or 1. There isn't an international code for tablet size or marking.

Whilst NZAN member Mike reckons that 5mg hydrocortisone and 1mg prednisone are easy to tell apart, Jeanette and her local pharmacist felt they could easily be confused!

Although we can't do anything about the pills themselves, we can at least influence the packaging!

Our tablets are usually dispensed in 20ml polystyrene 'pottles', light resistant but not opaque, with white screw-on lids. Usually these containers are brown – but Amcal pharmacies have blue, and Unichem pharmacies have green ones.

Suggestion - buy a few containers of a different colour, and re-use them at your usual pharmacy, so that, for example, your hydrocortisone is always put in a brown pottle, and your prednisone always in a blue one. That gives you extra coding, *as well as* what is written on the label.

What if you want to put some into your bag or pocket, but not the whole pack? A couple of options:

* Blood testing laboratories use 5ml size clear polystyrene tubes, with firm-fitting press-in stoppers in red, green or blue. Two or more of these tubes can be firmly held together with a rubber band. Write the tablet name on the body of the tube with permanent marker, decide your lid colour coding - and stick to it! (This system has passed Jeanette's unofficial pocket testing for robustness!)

* Some special labs use 1.5ml conical plastic tubes, available in see-through pink, green, yellow, blue, and 'plain'. These have integral clip on lids. The unit cost is only about 15 cents, but they are not so easy to obtain by the handful.

* Another possibility: small pills can be put inside #3 size coloured capsules – the capsules come as two halves, which fit together. Vets do this for some cats' medicine! *We're exploring this option further, to clarify whether absorption rate of the tablets might be altered, and will report more in the next NZAN Newsletter!*

For any clarification, or to share ideas, contact Jeanette.

JEANETTE'S GYM DIARY – *enjoy it?!*



I've been attending for seven months now, every other day - except occasionally. After the first month, I reached a plateau with regard to what I can achieve.

On 'good days' I speed up a bit and programme in steeper hills on the treadmill, and on 'bad days' I struggle a bit, and keep the path horizontal. I still have a tough time with the same low weights that I started with on the muscle strengthening gear – and on the 'bad days' do fewer repetitions.

It's frustrating to still wilt rather easily. Stamina eludes me. But greater overall fitness these days means the amount of walking and the extent of arm and shoulder movement essential for ordinary day to day activities no longer stress me. I am definitely benefiting from an overall higher level of fitness than previously.

Going to the gym, however, is something I schedule in and do in 'automatic' mode. On the alternate gym-free days, I have a

lightness of being, a feeling of temporary reprieve!

I've heard about endorphin 'highs' as a reward for regular gym workouts. Some people claim they feel great after the gym. I don't. Rather, I still marvel that I am almost always feeling OK as I leave, not a crumbling jelly.

So I've been exploring the 'enjoy' word - regularly used by people in the gym, as a casual pleasantry, and with the assumption that you'll agree - "are you enjoying it"? They usually found me reacting like a dog biting their ankles - Enjoy being here? No!! Do you? Usually they'd say, Yes! What exactly does that mean?, I'd pursue. At last, after some fun discussions, I feel I do understand, almost. I choose to go to the gym every other day, and I believe that frequency is necessary for me, so that I can enjoy the confidence it gives me that I now have greater control over my life.

REMINDER: Pam Young, NZAN's Exercise Advisor.

We are fortunate that Pam Young, senior physiotherapist at Auckland's Greenlane Hospital is willing to be NZAN's exercise adviser. She may be contacted through Jeanette, or directly by email (PamY@adhb.govt.nz) or phone 09 522-3313 in the evenings, or 09 630-9956 during working hours. *If you do contact Pam directly, please identify yourself as a member of NZAN..*



REPORT: Addisonian Fitness and Muscle Function

It's timely to mention a report published this August in the journal *Muscle & Nerve* (Volume 24, pages 1040-1049):

"Quadriceps function in Addison's Disease". It is not easy to read, but it tackles a topic that frustrates many Addisonians.

The starting point was acknowledgement that muscle weakness and fatigue are commonly experienced by people with Addison's disease, with the problem being greatest for the muscles closest to the trunk. This study starts to try and quantify the symptoms, and find the physiological basis behind them. The authors point out that general fitness and physical activity have not previously been systematically evaluated in patients with Addison's disease.

This study involved nine Canadian women in their early fifties, and nine matched controls, women with normal adrenal function.

In short, differences in task performance and muscle function were found between the two groups, but it wasn't clear how much of the difference might be due to the Addisonians being less fit and less active.

Although the difference between the two groups was not statistically significant, there was a trend for the Addisonians to be less active (hours/week) and expend less energy (Kcal/week) than the women in the control group. And the Addisonians did have lower general cardiovascular fitness, compared using heart rate response to a sub-maximal step test.

"Inactivity may ... contribute to decreased strength and increased fatigue in Addison's disease. For example, in older adults, it is known that inactivity results in generalized weakness and poor endurance, which frequently develops into a state of frailty. Yet numerous studies of older adults report that those individuals who exercise regularly, including those with chronic disease, increase their strength and cardio-respiratory fitness with activity."

“It is possible that the symptoms of muscular weakness and fatigue in patients with Addison’s disease relate to a decrease in physical activity. Individuals who are less fit will perform activities of daily living at a lower intensity, and [other authors] suggest that low fitness is a risk factor for functional decline, independent of disease. Generally patients with primary adrenal failure who are receiving conventional glucocorticoids and mineralocorticoids function adequately, but they might tend to adopt a sedentary lifestyle to compensate for the symptoms of weakness and fatigue. Inactivity will affect muscle performance, which in the long term can lead to an overall decline in physical function.”

The quadriceps (thigh) muscles were studied because they are one of the primary weight bearing groups, and loss of strength in this muscle group has been identified as a strong predictor of physical disability.

The physical demands of daily living that involve the quadriceps muscle can be reproduced in the lab by repetitive sub-maximal exercise. All of the Addisonians stopped the fatigue task before the test endpoint. (It was rather a tough test, however, because two of the controls stopped early too!)

OK, so achieving a good level of physical fitness may be harder for people with Addison’s disease, than for people with normally functioning adrenals. But when we are fit, will our muscles work normally? As already mentioned, that’s still unclear, and the answer is probably yes and no – “yes”, in broad terms, but “no” on a micro-level.

It’s possible that our muscles don’t work as they might, in terms of strength and endurance, in part because of some atrophy of type II muscle fibres (“fast twitch”). For example, the muscles of

corticosteroid-treated animals show preferential atrophy of the type II (fast twitch) muscles. Whether that is the case for human Addisonians on replacement corticosteroids isn’t known.

A report in New Scientist (9 September 2000) pointed out that marathon runners need muscles that use oxygen efficiently, and can sustain a lower speed of contraction for a very long time – type I (slow twitch) muscles tend to make up at least 75% of marathon runners’ leg muscles. Fast twitch (type II) muscles are a disadvantage for marathon runners. So that’s a plus for Addisonians!

“However, it is also possible that the disease or conventional drug treatment might slow contractile properties independent of an alteration in fibre type.”

As members have seen in the stories from New Zealand and overseas, several people with Addison’s have successfully completed marathons.

So it seems that Addisonians who enjoy the challenge of a marathon, and train for it, Lyn on her bike, and even me on my treadmill, are in harmony with our physiology - making the most of our slow twitch muscles!

Whether DHEA supplementation improved muscle performance for the women in the Canadian study will already be known to the researchers, but is not yet available to us to report to you.



Hugh, one of NZAN’s marathoners, takes DHEA and swears by its benefits. But, alas, that puts the Olympics out of reach – DHEA is one of the anabolic androgenic steroids on the banned substances list!



In view of our recent focus on activity and fitness, we're reprinting the following piece from NZAN Update #8, November 1999 –when our membership was just half its present size:

NOTES ON

DEHYDRATION: – A BIG ISSUE FOR OLYMPIAN ATHLETES, AS WELL AS FOR ADDISONIANS:

In spring 1999 Jeanette attended a World Congress on Food Science and Technology in Sydney. Physical stamina not being her forte, she felt a bit out of place in the session 'Feeding the Olympians'! Fortunately there were no practical tests – and it was somewhat reassuring to be facing similar issues to the physically elite.

Fatigue during exercise occurs for several reasons – a toughie is the "psychological" one that athletes battle with called "central fatigue", essentially loss of motivation, loss of the will to win. Physical and biochemical contributors to fatigue are loss of muscle potassium, carbohydrate depletion, dehydration, over-heating, and muscle damage.

The key tools for minimising fatigue when exercising hard are carbohydrates, and sufficient fluid. Even when they know how important fluid replacement is, athletes tend to swallow less fluid than they have lost in sweat. One study showed 690-1270 ml per hour fluid loss in sweat, but only 290-620 ml per hour voluntary fluid intake. And when they are dehydrated athletes overheat more rapidly, adding to the fatigue.

Sports drinks are convenient, and are good because the makers have used considerable technology to get an appealing taste, says Louise Burke, head of the department of sports nutrition for the Australian Institute

of Sport. So people consume them in amounts greater than for other drinks.

They contain 5-8% carbohydrates, some electrolytes (usually about 20 millimolar sodium), and flavour. The flavour of the rehydrating drink is very important – if it doesn't taste good, athletes drink even less, Louise pointed out. It's helpful that we have an elite group doing product trials for us, isn't it!

Also, drinks are more appealing when cool, rather than cold. Icy cold seems refreshing if you are hot and bothered, but it can be too bracing for people to consume in large volumes. Intake should begin before fatigue is felt. For events needing high energy consumption for more than 90 minutes, the carbohydrate intake should be 30-60 grams per hour, which is equivalent to 600ml–1200ml (3-6 glasses) per hour of 5% glucose solution.



A solution of about 5% glucose in water (50 grams per litre) can be as effective as the "brand names" provided you adjust the taste with something you like, such as citrus or other flavouring, so that you'll want to drink it. And preferably add about ¼ of a level teaspoon of salt per litre (that is equivalent to 20 millimolar).

Summer is almost here. Avoiding dehydration is as important for Addisonians as it is for Olympic athletes. "Water is medicine" for us. The same golden rule applies for us as for Olympic athletes: **to minimise fatigue, drink more before you dehydrate.** (It's somewhat reassuring to know that the elite athletes often don't get it right, either!)



MEMBERS' CONTACT LIST

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

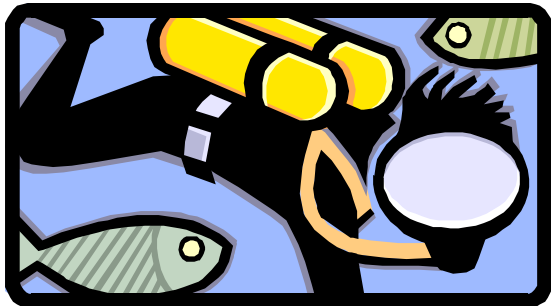
Please contact us to fill any gaps, or to make changes.

This list is circulated to members only.



KATHRYN'S STORY:

I am 60 yrs old and have been married to Glen for 39 yrs. We have one daughter Evette and a grandson Lee. Glen, Evette and I have a small timber yard so that helps keep me busy both manually and mentally with all the paper work involved.



I have led an active life – hockey, cricket, surfing, tramping/walking and diving. I still go tramping/walking and diving and enjoy wood-turning.

I have had Hypothyroidism since 1993. That was picked up by my GP and once I was stabilized on thyroxine, it hasn't interfered with my life at all.

One Friday morning in mid May 2000 I went back to bed feeling dizzy and all I wanted to do was sleep. In the past when I'd been sick, which luckily wasn't very often, my family would leave me alone as all I want to do is sleep. So nobody knew

how bad I was. By Monday morning I knew something was very wrong so got Evette to take me to my GP. He said "You've got the flu and there is nothing I can give you". I didn't have the strength to argue. He also said "If you don't feel any better in a couple of days, get a blood test". I did have a blood test and it came back with sodium levels down. However the nurse phoned to say everything was normal.

Friday morning my friend Julie, who had been in and out all week trying to make me eat and drink, took me back to the doctor (my GP's partner this time). I couldn't stand and couldn't sit without my head being supported. The doctor told Julie to take me for a blood test. She said "No I'm not taking her anywhere, as she can't even walk" and made him do it. Spoke to the doctor about 5pm and he said "I want you to go to the hospital now".

Glen picked up a letter from the doctor and thought I was only going for tests and then coming home. I wasn't much help by then as I didn't even know which way was up. In fact I remember very little of that whole week. Woke up next morning in ICU on a sodium drip. The first four days were pretty vague. On the fifth day they took the drip out but then I was only allowed 800mls of fluids per day as the sodium was being washed out of my body.

On the seventh day in the afternoon the doctor gave me hydrocortisone. I didn't sleep very well that night BUT woke up next morning feeling alive again. I was up and showered and ready for action by 6.30am. (Prior to that the nurses had to hassle me into getting out of bed). Went home three days later knowing I had Addison's and would be on medication for the rest of my life, but not a lot else. I had spent 11 days in hospital, two in ICU.

I was taking 20mg hydrocortisone in the morning and 10mg at night, and 0.1mg

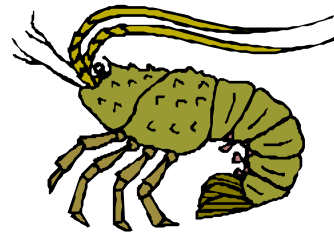
fludrocortisone in the morning. I went walking every day, for a bit longer each day. The weather was cold and windy but fine and it was great to feel the wind blowing through my hair. Plus a mountain of paper work kept me busy. But after four weeks things still weren't right. I was on an emotional roller coaster, bursting into tears for no reason, couldn't stand loud noises, wasn't that keen on driving during the day and couldn't drive at night as my long sight was all fuzzy.

I went to my GP and he spoke to an endocrinologist and then he put me on 15mg hydrocortisone in the morning 5mg at midday and 5mg late afternoon. That sorted the problem out. My GP also arranged to have my first endocrinology appointment, which was still a few months away, bought forward to the following week. I went back to work after six weeks, but still didn't drive at night for another three weeks.

In August went to Australia to stay with friends whose wedding I'd missed when I was in hospital. The thing that gave me a boost was seeing a documentary on Eugene Shoemaker. I didn't feel quite so alone with my Addison's, as at that stage I didn't know a lot about it. Having Addison's prevented him from going to the Moon, but he was chief scientist and organized the geological activities planned for the Lunar landing in 1969. His ashes were in a capsule aboard Lunar Prospector (launched Jan 1998), which orbited the moon for approximately 18 months, then was deliberately crashed onto the moon. So Eugene Shoemaker finally did make it to the moon.

In October my endocrinologist reassured me Addison's was not life shortening. But there was still lot I needed to learn. He gave me Jeanette's fax number, so I faxed her and got sent the NZAN Starter Pack. I read and reread all the information in it.

I got back into Tramping in October. It took a bit longer to get back into diving - I kept putting it off BUT then in December the mother-in-law said we need some crayfish for Christmas. The only problem was the wetsuit as I had put on 10 kgs. I have since put on another 5kgs, so guess it is time to go and buy another wetsuit.



In March 2001 I met up with Andrea, Karen and Lyn with the view to organizing a Northern Regional Meeting. Just meeting up with Andrea, Karen and Lyn and talking to Jeanette by phone was amazing. We all got so much out of it. And we did organize The Meeting. It was a huge success - however that is another story.

In June I had an opportunity to spend a week in a Tuscan Villa with six New Zealand ladies, so I thought I would take three weeks and go to Rome, Florence and Pisa at the same time. But could not get anyone to go with me at such short notice. I was not happy about traveling alone, but after talking to Lyn and Jeanette about traveling with Addison's, they both said do it, so I did and I had a wonderful time and met some great people.

I didn't get jet lag as I followed Jeanette's strategy for the flight, of taking a 5mg maintenance dose of hydrocortisone about every 5 hours once I left Auckland and then the morning dose local time on arrival at the final destination. I slept well on the Sydney/Bangkok and Bangkok/Rome sectors. I had my normal morning dose of pills including 15mg hydrocortisone at 5.30am Rome time and was at my hotel at 7.30am.

I couldn't check into my room until midday so left my luggage and went sightseeing. Booked into the hotel at midday, then continued sightseeing. There were so many things to see and do - the Colosseum, Trajan's Market, the Forum, Trevi Fountain, Spanish Steps, Pantheon just to name a few. What a wonderful feeling to be in a city like Rome, so much history, so old and so beautiful.

I took three sets of pills (one in my suitcase, one in my day backpack and one in my small bag), Solu-cortef injection, a letter from my GP, and a letter with emergency Addison's instructions in Italian (from NZAN) and I wore a Medic Alert Bracelet. I only had one day when I did not feel 100% so took 20mg extra and was fine the next day.



I am going tramping in Wairarapa for 2 weeks in November with three of my sisters, and then Glen and I are going to the Marlborough Sounds for three weeks over the Christmas break to do some diving, and catch a couple of crayfish and some Blue Cod.

Having Addison's has not changed my life a lot. I do get tired but manage to work around that as I have too many things that I want to do.

* * * * *



BBC Optimism, Error or British Under-statement?

Inspired by Kathryn's mention of Eugene Shoemaker having Addison's disease, Jeanette logged on to the BBC website report of his July 1999 moon burial: "He had wanted to be an astronaut himself and perhaps today he could have been. But in the early 1960's health qualifications were more stringent than they are now, and he was turned down because of a minor medical problem."

LYN'S STORY

Not sure how long I actually had Addison's before diagnosis but could conceivably have been quite some time. I spent the whole of 1994 unwell. Felt exhausted all the time and had chest infection after chest infection during the winter of '94. Many visits to the doctor complaining of fatigue during the year when I was told I was overdoing it, needed a good holiday all of which was probably true.

Despite the exhaustion pushed myself off to work each morning and tried to get some exercise in but in hindsight the exercise became less and less as the year progressed. Even a walk to the shops had me labouring up the hills to get home again - where had the gym queen and cyclist disappeared to?? Had my morning routine down to a fine art so I could stay in bed until the last possible moment and in 20 minutes could shower, dress, breakfast and get out the door.

The beginning of December really tested all my remaining reserves. We had flown to Melbourne to partake of a nine-day bike ride from Swan Hill to Melbourne – some 700km. This despite the fact I couldn't even manage a long walk, somehow I thought everything would come right once I was on the bike.

Right from Day One the temperatures soared from the low- thirties to the mid-forties day after day, and with us camping out there was no respite from the heat In air-conditioned hotel rooms. I woke in the tent each morning at 5.30am and wondered how I could drag myself out of the sleeping bag, let alone how I might bike up to 100km to our next campsite. And of course as each day in the searing sun passed my tan got darker and darker and darker until I resembled an aborigine. Despite what was by now total exhaustion I managed to bike most of each day. I would set off biking each morning and when unable to continue grab a ride in a support vehicle. There was only one day I didn't ride at all and most days I rode the full distance. Amazing what a good strong dose of determination can achieve.



The medical people who supported the ride checked me out but could find nothing specific wrong except for a very slow heartbeat, so I was instructed to drink 2 litres of electrolyte drink and back out into the heat. Biking into Melbourne on the final day saw me collapse on the hotel bed craving for Chicken Noodle soup (my salt fix).

My grandfather was always very determined and stubborn, and I think I have inherited double doses of these traits which make me push myself along despite the adversities. I like getting the job done and done well.

Back home and it was now even more difficult to drag myself off to work, so back to the doctor complaining once more of exhaustion. The week before Christmas I was back in the surgery, the blood tests had shown I had hypothyroidism and I was put on 100 micrograms thyroxine. However the first working day after Christmas had me phoning the surgery as I was now significantly sicker. The doctor "minding" the practice between Christmas and New Year checked my file and advised me over the phone to immediately increase my thyroxine dosage to 200 mcg. This from a doctor I had never met. A few days later I met my Waterloo.

The only day I suffered from nausea was the day I was admitted to hospital. The day unfolded with my husband heading out early to golf with me still in bed. When he returned at midday I was still in bed, feeling sick and dizzy. He called the doctor and my Mum. Before either arrived I had drifted into a coma and was delivered to Middlemore Hospital by ambulance. I remained in the coma until 8.00pm when a "drug cocktail" was administered in an effort to bring me round. A brain scan was done immediately I came round but it showed no problems

The morning after admission I was back to my best after the shots of hydrocortisone they had given me which brought me round. Rushing around helping deliver the breakfast, making the beds – you name it. And feeling better than I had in months, I could see how skinny I looked as I wolfed down all the food the kitchen could provide. Put nice little messages on my

daily meal sheet to get extra portions of jelly and ice cream.

Over the next few days so many blood tests were requested that I was the first bed visited in the ward each morning, and the little instruction book was pulled out for some of the weird and wonderful tests requested. Six days after admission a test showed problems with the adrenal gland that was confirmed with an ACTH test where the pre-test cortisol output was 20 rather than 270, and which was raised to 21 rather than around 540 after an injection of ACTH (Synacthen)..

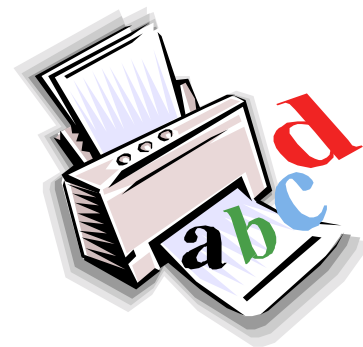
Once diagnosed the Auckland Hospital Endocrinology Department were consulted for medication and I was released one week after admission and went straight back to work.

Took a few months to get my medication correct and have tweaked it slightly since. I currently take 20mg hydrocortisone, 200mcg fludrocortisone, 100mcgs thyroxine early morning with an additional 10mg hydrocortisone early afternoon. When biking long distances I up my hydrocortisone and fludrocortisone dosage subtly. An additional 5mg hydrocortisone per 50km travelled after the first 50km and on a very hot day when we have a long and difficult ride planned I add an additional 100mcg fludrocortisone before leaving home to counter mineral depletion from sweating. These changes in medication are always made after consulting with my endocrinologist

I listen very carefully to my body and find that when I am biking and need more hydrocortisone the muscles of my thighs and upper arms ache as though they are badly bruised. The aching disappears within half an hour of taking an additional dose. Paying close attention to how I am feeling gives me confidence in knowing when things are going wrong and finding out why.

I refuse to feel sorry for myself having this condition. I get the most possible into every day. I never have problems sleeping always falling asleep the minute my head hits the pillow. I was forty when diagnosed and have probably achieved more since diagnosis than before. It's like I have been given a second chance and I don't intend to waste it. I do start my day early and rarely stay up late on working days except for special occasions. I don't bother much with alcohol, don't smoke and try to eat good healthy food – I am a salad nut!! Drink a couple of litres of water a day but must admit I don't drink as much as you might think biking, rarely getting through two 500ml bottles in 100km unless of course it's hot or really hilly.

I work in the IT industry, which can be stressful, and have most recently worked as part of team on a very large computer system implementation spanning some four years. I do find my memory is not as good as prior to getting sick, and I make lists to ensure I have a finger on the pulse.



And working in the normal air-conditioned office environment I get my fair share of coughs, colds and tummy bugs. I have never needed to take additional medication for the coughs or colds but always pay close attention when I get an upset tummy and medicate according to how I feel. I have had one crisis that saw me admitted to Middlemore with severe abdominal pain for an overnight stay with a Cortisol injection prior to admission. An Ultrasound suggested the problem was an

ovarian cyst and I have had no problems since.

I have had one bike crash which saw me picked up off the road by ambulance and taken to local A&E but managed on an additional 10mg dose of hydrocortisone rather than an injection. (I do carry an injection kit and two doses of Solu-Cortef with me on the bike at all times in case of accident or crisis miles from nowhere and my husband is dying for “the opportunity” to put that needle in my backside.)

I have travelled overseas extensively since being diagnosed, carrying all my drugs and injections without difficulty. I always carry a letter from Auckland Hospital with my injection kit and wear a medic alert bracelet at all times.

Prior to getting sick I couldn't say NO, I was superwoman getting up 5.00am to get a gym session in before working long hours at a full time job. After work I hurtled home and into interior design or paint finishing (like rag rolling, stencilling, marbling) jobs I had on the go. I hardly got a minute to myself from 5.00am through to 10.00pm then flopped into bed ready to do it again the next day. I tried to be everything for everyone and simply forgot to look after myself.

Things have changed since being diagnosed. I now put more time aside for me and mine, have stepped back from the interior design and paint finishing but still work full time. Biking is my recreation of choice though hiking and adventure travel rank right up there as well. We have plans to bike across America, mountain bike from Lhasa to Kathmandu, walk across France, so still heaps to achieve.

I am lucky to share my love of the outdoors, biking, hiking and adventure travel with my husband Clive and we do most things together. We decided 25 years ago that children might not fit our busy

lifestyles but are kept busy with godchildren, nieces and nephews.

I am not sure I can tell you why I manage to fit a lot in but it's probably a combination of factors. I keep fit with my biking and hiking and am lucky that I enjoy pushing myself a bit physically. I have a very positive frame of mind – always whether at work or at home. I am willing to try new things although must admit in this area I have a little less confidence than pre-Addison's.

I also think the earlier comment that I have been given a second chance is certainly key to how I feel about life in general. I am not going to miss out on anything I have in my long list of To Do's and my grandfather's determination and stubborn genes keep me pushing on even if I am having a less energetic day than normal. I can say that when I have a morning bike ride that really sets me up for a good day.

