

# New Zealand Addison's Network

National Co-ordinator:  
Jeanette  
ph//fax 06 877 4352  
jeanette@ramhb.co.nz

**PO Box 8562  
Havelock North**

Linda: ph: 06 877 8616  
email: alan.linda.@xtra.co.nz

Gary: ph 04 565 1783  
fax 04 565 3982

Hugh: ph: 06 877 6084

Karen: Northern Co-ordinator  
ph/fax 09 483 7043

email: K.Carson@xtra.co.nz

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## UPDATE JULY-AUGUST 2001 (No.13)

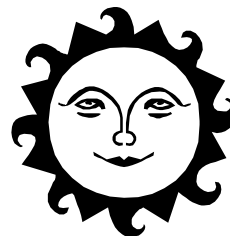
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In this issue we feature:

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- Announcing BOP Mini-Meeting, 15 September
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We are soon issuing an updated poster to endocrinologists and hospital clinics, in the same gold colour that we are using here. We hope that our decision to introduce colour will add some sunshine to all our lives!

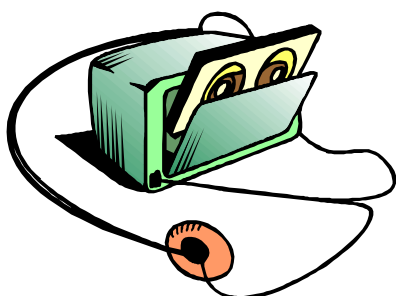


Wishing you all good health  
*Jeanette and Linda*

**WHY THIS ISSUE OF ‘UPDATE’ IS LATE!**

- to include a timely report of NZAN’s first regional meeting held in Auckland, 21 July.
- to announce the NZAN mini-meeting in Tauranga, 15 September.

The Northern Region meeting was a great success – see Lyn’s report below.



Professor Ian Holdaway’s keynote address, including questions from the audience, lasted two and a half hours. It covered a very wide range of topics.

Prof Holdaway is a skilled teacher, and tone and timing are fundamental components of his clear presentation. We have good quality audio tapes, plus photocopies of the accompanying slides, available to NZAN members and others interested, for \$10 per set.

Contact Kathryn (phone 09 445 6427, fax 09 445 6428), or Jeanette.

A few topics from the talk are transcribed in this issue.

**NORTHERN REGION MEETING REPORT –from Lyn**

This inaugural meeting for the Northern Region on Saturday 21 July brought together 33 Addisonians and their support people. Attendees came from all over the North Island, from Whangarei in the North to Wellington in the South, and from Whakatane in the East to New Plymouth in the West.

The formalities were kept to a minimum with a brief welcome to everyone followed by each

Addisonian being given the opportunity to introduce themselves and their support people to the wider group. These brief introductions paved the way for the interaction and socialising that was one of the highlights of the day.

We heard from Jeanette how NZAN has gone from strength to strength since its inception.

We were very fortunate to have Professor Ian Holdaway as our keynote speaker. Professor Holdaway spoke on “The Five-Year Anniversary of NZAN: advances in knowledge of Addison’s disease over this time, and the challenges for the next five years.” A very comprehensive subject which captured everyone’s attention and one which gave rise to many questions from the floor.

Professor Holdaway gave generously of his time and knowledge throughout the day answering questions not only during and after his presentation, but also throughout the open forum held during the afternoon.

The Open Forum was the opportunity for everyone to learn from everyone else. For most of those present Saturday was their first opportunity to meet other Addisonians and compare notes.

Jeanette followed up the Open Forum with a “Where to from here for NZAN” outlining opportunities and ideas for future development.

A big vote of thanks to those who contributed to the day, whether as organisers or attendees. Without you all the day would not have been so successful. Feedback from everyone suggests “A Great Day Was Had By All”.



## **BEHIND THE SCENES: Jeanette's perspective of the Northern Regional Meeting**

The seeds for regional meetings were sown in the November 2000 survey. Kathryn had the courage and the commitment to say "yes" to the question "would you be willing to organize a regional meeting". She held a meeting in her home, with Karen, Lyn and Andrea who'd said they would be willing to help the organizer.

The four blended their talents, with focus and enthusiasm, and proved the saying that if you want something done, involve busy people! Karen has three young children, is on the National Executive for Parents Centre, and uses her computer skills for operating a home-based business. Kathryn and her husband run a native timbers business. Lyn works full time in IT, for the last five years implementing a big computer system, and with her husband is a keen biker. Andrea works as an office manager.

The venue was well chosen, comfortable, with a cosy cafeteria for members to get to know each other during the breaks. Karen's husband Steve, and Lyn's husband Clive manned the kitchen for the day, so that food and beverages were kept flowing. The finger food was great.

The meeting was successfully promoted through the community diary section of local newspapers, and on outgoing lab result forms from Diagnostic-Medlab - some GPs passed on the news to their patients.

The Northern Region team has documented the processes, the written material, and the lessons they learned, so that teams in other regions won't have to start from scratch.

The sparkle in people's eyes and the smiles as they met each other, and compared notes, was quite infectious. For me, it was a special delight to put faces to names I have known for up to 5 years. Margaret is one of our veteran members, diagnosed 42 years ago, and now aged 78. She radiated optimism and good health, an excellent role model. It turned out that she was one of the Addisonians Prof Holdaway studied when doing his thesis, quite a few years ago.

The only plan that fell through was photographs. However, we had a camera at the after meeting debriefing, and Vicki from Taranaki captured us all still smiling - (left to right) Kathryn, Andrea, Lyn, Clive, Jeanette, Steve, Karen.

### **MILESTONES**

Nov 96: NZAN launched  
 Feb 97: Mailouts announcing NZAN sent to all endocrinologists and hospitals  
 July 97 First 'Update' newsletter  
 Jan 98: Dr Braatvedt offered to be medical advisor  
 Nov99: First of our annual member surveys  
 Apr 00: 50<sup>th</sup> member joined  
 July 01: Professor Ian Holdaway took over as medical advisor  
 July 01: First regional meeting, in Auckland, with 33 attendees  
 Sept 01: First mini-meeting, Bay of Plenty  
 Next?!

## **ANNOUNCING: NZAN BAY OF PLENTY MEETING**

**SATURDAY 15 SEPTEMBER, 10am-4pm**

Fahey's Motor Inn (Cobb and Co)  
1237 Cameron Rd, Tauranga.

Attendance fee - \$25 for the first attendee, \$10 each for family and friends in your party (including morning tea, lunch and afternoon tea).  
*If the fee is a hardship for you, please talk to us about it*

**Contact: Colleen, phone 07 577 0840, or Jeanette**

*Some of our members in the Waikato and Bay of Plenty were disappointed they were not able to attend the Northern Region meeting in July. Jeanette will be on holiday at Mt Maunganui mid September. Colleen responded with enthusiasm to the idea of a mini-meeting, and promptly found a suitable venue. So it is happening! The programme will be essentially the same as for the Auckland meeting, with Jeanette facilitating Prof Holdaway's audio tapes and slides.*

## **MEMBERSHIP NEWS**

We welcome Robyn, Lis and Mark as new members since the March 01 Update. Marianne has also sent in a subscription on behalf of a doctor in the Bay of Plenty. We've received 80% of subscription renewals for the current year –if yours is overdue, there's a bright red dot on the top of your newsletter, and another invoice enclosed. All it takes is \$20 to secure your place on the mailing list for the November Update! If you don't respond, we'll assume you don't want to continue to receive mailings from NZAN. *If paying the subscription is difficult for you, please talk to us about it.*

Donations have been received from Andrea, Beryl, Beverley, Caroline, Chris, Dyan, GaryR, Graeme, Ian, Kathryn, Marianne, Marie, Michael, Ngaire, Pamela, Grant, and Mark – thank you.

## **MEDICAL ADVISOR CHANGE:**

### **THANKS, DR GEOFF BRAATVEDT**

Dr Braatvedt, NZAN's medical advisor for nearly four years, has requested to retire from the role. We value his unwavering support, the articles he has written for us, and the clear and helpful answers he has supplied to members' questions, for publication in the Update newsletters. Our sincere thanks, and our best wishes, Dr Braatvedt.

### **INTRODUCING PROFESSOR IAN HOLDAWAY**

Professor Ian Holdaway (MD FRACP BMed Sc) has been actively supportive of NZAN since the start, and we are fortunate that he is willing to share his extensive clinical and research experience for a term as medical advisor. He is currently head of the Department of Endocrinology at Auckland Hospital.

Professor Holdaway graduated in medicine from the University of Otago. His early postgraduate training was at Auckland Hospital, mainly in the Medical Professorial Unit and the Department of Endocrinology. He held research fellowships at Auckland Hospital, St Bartholomew's Hospital in London, and the University of Manitoba in Canada.

He then returned to the Department of Endocrinology at Auckland Hospital, and the Department of Medicine at the University of Auckland School of Medicine.

Professor Holdaway has made significant contributions to research and scholarship in Endocrinology, and has been awarded many major research grants, held many guest lectureships, and authored over 120 published papers. He has served on many committees and organisations, including the Auckland Medical Research Foundation, the Medical Research Council of New Zealand Clinical Assessing Committees, the Cancer Society of New Zealand, and as President of the New Zealand Society of Endocrinology. He also sees some private patients.

## **SOME MESSAGES FROM PROF HOLDAWAY'S KEYNOTE ADDRESS AT THE NORTHERN REGION MEETING:**

We have transcribed some sections, to retain the clear conversational style.



### **THE VALUE OF NETWORKS**

Prof Holdaway believes networks like NZAN have value for Addisonians. "Join a group, learn about your condition so that you know more than your doctor, and certainly more than a person at A&E if you turn up there in a crisis, so that you [or your support person] can tell them what the situation is, and what has to be done. The more people know about the conditions they have, the better. The old days of "let the doctor look after it, he'll know what to do" are pretty much gone. It's an individual arrangement between you and your medical advisor, and (with a smile) sometimes it's a moot point as to who knows more about the condition. Because Addison's is an unusual condition, there are many GPs who are not well up on the management of Addison's disease.

"Support groups disseminate what is known about the disorder, and new research findings etc. They encourage members to keep records, and to get copies of letters from their doctor. Make the most of appointments with your specialist – when you think of questions, write them down and take them with you and ask them. It's a good idea to take a friend – two pairs of ears can be better than one."



### **ADRENAL GLAND HORMONES – what they do and how they are regulated**

The adrenal glands have an outer cortex, and an inner medulla. In Addison's disease both areas are usually damaged. Prof Holdaway gave a clear explanation of the hormones made in the adrenal glands –cortisol, aldosterone and adrenal androgens in different zones in the inner cortex,

and adrenaline and nor-adrenaline in the outer medulla. He showed with slides the tidy system by which cortisol and aldosterone production are regulated by feedback loops in a person without Addison's.

"Most importantly, the inner zone of the cortex secretes cortisol – an essential hormone for life. When you try to talk to people about what cortisol does, it's always a bit tricky, because it acts on virtually all cells of the body - there are receptor sites on the nucleus of cells right through the whole body. It mainly enhances proteins in these cells that are important for energy pathways – for glucose metabolism, and getting energy into the muscles and liver etc. It is very important in stress. It is often called one of the "stress hormones" because [in non-Addisonians] it goes up under conditions of stress and enables our bodies to fight infection and inflammation, and toxic effects and so on, so you need cortisol to defend yourself against attack from illness. For replacement we usually use cortisol itself – hydrocortisone is another name for that."

"The cortex also makes aldosterone, the hormone that retains salt. You need aldosterone to keep your blood pressure up, and the normal sodium and potassium levels in the blood. If aldosterone is deficient, it is replaced with a synthetic form called fludrocortisone (Florinef). This does the same job as aldosterone.

"The inner part of the adrenal, the medulla, releases adrenaline and a bit of noradrenaline. They are the fight-flight hormones that make you run fast when a bull is charging towards you, it revs up muscles. It is one of the few hormones that acts in a very quick way, in a few seconds, or a minute, to have its effect. Most of the adrenaline in the body comes from nerve endings, so if the adrenals are not there, there are other places that make it and you still have fairly normal levels of adrenaline, so don't have to replace it"



## **DHEA – worth considering, especially for women**

Prof Holdaway reminded us that all the steroid hormones are made from cholesterol. Although they all have different key functions, there is also a bit of overlap. Progesterone, for example, shares a bit of mineralocorticoid activity.

“DHEA is one of the steroids made from cortisol, and is a weak androgen, which means it has weak male hormone effects. It circulates as a sulphate, so is more commonly called DHEAS. It is one of the hormones which have excited interest because levels in the body fall with age (like growth hormone, testosterone, oestrogen). At 70, people have only 20% of the levels they had at age 20. Having observed that, people said, is that natural, is that what we should be doing, or might it be better to keep these levels high so they don't fall with age? Would that make us all live forever? Or make us all feel better when we got older?... So that is a fertile area of research. The answer to that important question is not known. We are not really talking about that issue now – rather, we are talking about the fact that in Addison's disease the levels are very low, particularly in women, because the adrenals are their only source. You don't find such a low level of DHEA in men with Addison's, because the testicles do make some. And males have a lot of testosterone that dominates DHEA. But in women it can be quite an issue if their DHEA is low.

There has been a range of studies, most of which have been reasonably positive. It is not a miracle drug, obviously – otherwise everyone would be on it. But it definitely seems to have some benefits. There have been several dose finding studies – it seems about 25-50mg a day gives best effects. If you go too high, especially in women, you start getting side effects, and those side effects are just what you'd expect if it is a male pattern hormone – a bit of acne, slight increased hair growth around the moustache and chin area, slight muscularity increase, although that might be good for strength.

Virtually all the studies are in women. It's really been in the psychological area that the biggest push has been – it seems to have increased well

being, reduced depression, and improved sexuality. Libido and sexuality in females, something that endocrinologists have to get involved with a bit, is a pretty tricky area, because many things are involved in libido and sex drive, how happy you are, what your relationship with your partner is like, your finances, everything really, but it is hormonally driven, oestrogen from the ovaries has a role, but in women probably male hormones like DHEA have a definite role, they seem to enhance sex drive in particular.

And so not surprisingly when DHEA is given, and questionnaires are done and a proper double blind studies are performed, it does increase sex drive and sexual responsiveness in many, although not everyone. It has subtle biochemical effects. It produces extra growth factors like IGF1 (insulin-like growth factor 1) - it increases that a bit which ups muscle strength and endurance. And it has good effects on your cholesterol - it ups your good cholesterol, the high density form (HDL) that you want, that sucks the cholesterol out of your arteries and back to the liver; and it lowers the baddie cholesterol, the low density lipoprotein cholesterol.



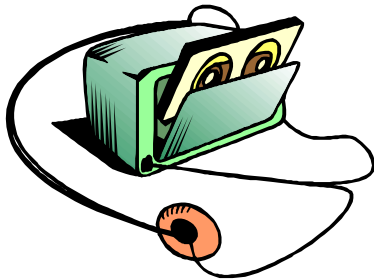
The side effects in those that experience them are usually very mild. In fact, when you look at the formal studies, it is very rare for people to drop out because of side effects - whereas if you look at a blood pressure study or a cholesterol lowering study, you find 10-15 % drop out because of side effects. Should everyone be on it? There isn't an answer to that. For those who feel well, there is probably no particular need to be considering it. For those women who feel that they are not sort of balanced right, then why not, you might have a trial. (Jeanette will know more about getting hold of DHEA in NZ. It is getting easier, but it is not funded by the government.)”

Professor Holdaway presented some slides from a publication in a medical journal. “This shows a global psychological health score. These are properly done studies, with a placebo so you don't know, and the doctor doesn't know, if you are on the active tablets or not. People take this for 4

months, fill out questionnaires before and after 4 months of treatment. For those on placebo their well being scores stay about the same, as you'd expect. If you are on DHEAS, then after 4 months, your global psychological well being is improved by about 30%, a highly significant change.

Similarly, if you look at depression - for those taking DHEAS there was almost a 50% improvement in factors that are depressive in nature. So there was clearly less tendency for depression on that agent.

That was a short study. What happens when you take it for 2 years, does it wear off? We don't know. So many things affect how we feel in life... But this trial result is as good as you'd ever see with an anti-depressant tablet, that's for sure."



## **OTHER COMPREHENSIVE TOPICS TO HEAR ON THE TAPES:**

- Fine tuning the best replacement strategy for you – with comment on the different approaches in different countries. New Zealand mainly uses hydrocortisone and prednisone as the glucocorticoids; Australia uses some prednisolone instead of prednisone; some parts of the US are tending to favour long acting steroids like prednisone and dexamethasone.
- Blood and urine tests that are sometimes used for monitoring dosage appropriateness – which are useful (eg renin), which are usually less useful (eg cortisol), and why.
- Guidelines for when to increase doses of hydrocortisone (or prednisone) and fludrocortisone,
- Dealing with emergencies – including the importance of responding quickly and

seriously to vomiting illnesses; how to be taken seriously in an emergency.

And more.....

Prof Holdaway included in his talk, some material from a recent review for endocrinologists about treating adrenal insufficiency. On the US-based Web Site [www.uptodate.com](http://www.uptodate.com) is a section which doctors access by subscription, and also a Patient Resource Centre, with free access to detailed articles - for example, "Patient information: Adrenal insufficiency", which complements the review that Prof Holdaway discussed.

We think it is important to point out to NZAN members, however, that the glucocorticoid regimes favoured in that article are not universally adopted outside of the US, or indeed used in other parts of the US. As Dr Braatvedt has also said in his answers to members' questions, there is no consensus about which replacement glucocorticoid is best for people with Addison's disease. The crunch test is wellness - if you don't feel well, it is worth talking with your doctor about switching from one to another type or dosage of steroid agent, or changing the timing.

## **PROF HOLDAWAY'S SUMMARY SLIDES:**

### **Highlights of the last 5 years in research on Addison's disease:**

- **Increasing use of long acting steroids for treatment (mainly USA)**
- **Osteoporosis research**
- **DHEA**
- **The genome project**

### **Challenges for the next 5 years in research on Addison's disease:**

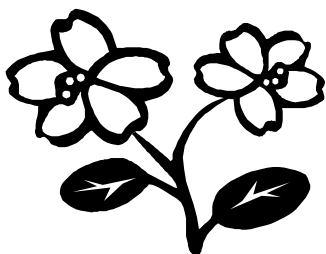
- **Further improvement in treatment and monitoring:**
- **Gene therapy**
- **Transplants**



**In case you have wondered:  
NZ AMBULANCE OFFICERS WILL  
INJECT HYDROCORTISONE**

At the Northern Regional Meeting we were uncertain, so we have followed up. Dr Tony Smith, chief medical advisor for the Order of St John northern region, says the policy is that no ambulances carry hydrocortisone. Ambulance officers do not have a procedure that covers hydrocortisone use, but they are expected to use common sense. They would be expected to use the patient's own medication if the underlying problem and rationale was explained to them. If in doubt, they all know they can call their designated medical authority to get direction. In big cities that should take less than 10 minutes. In smaller places that might take a little longer.

So it's best to be prepared to give the hydrocortisone yourself, if possible, sooner rather than later. Giving an intra-muscular injection is a very simple procedure, Dr Smith assures us - simpler than doing up a zipper. The side of the arm is often most convenient, because of its easy access, but the buttocks are fine too. Don't bother about cleaning the skin with alcohol first. Don't worry if you squirt out a little bit, or inject a little bit of air. Just put the needle in to the hilt, and push the plunger. You can't do harm, and you may do a lot of good.



**POSTAGE SPONSORSHIP**

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

**FOREIGN LANGUAGE  
EMERGENCY INFORMATION.**

We now have emergency instructions for Addisonians in Italian, Portuguese, German, French, and Spanish, thanks to Marylou at NADF and Deana Kenward of the UK Self Help Group. If you'd like a copy, contact Jeanette.



**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.

November is NZAN Survey month. Are there things you'd like to clarify with your fellow Addisonians? Please send Jeanette your ideas for survey questions *before the end of September*. Our annual survey is 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. (We suggest that you listen to the tapes first - chances are your queries have been already been answered on them!)

**NZAN LIBRARY**

The library is back with Jeanette, at present. Anne, who introduced herself in the March issue of Update is still a keen NZAN member, however, and willing to share her library experience.

## SHARING THE “STAR”, FOR LIVING HEALTHILY WITH ADDISON’S DISEASE:

To live a full and happy life with Addison’s (especially if we have other health disorders to deal with as well), we need

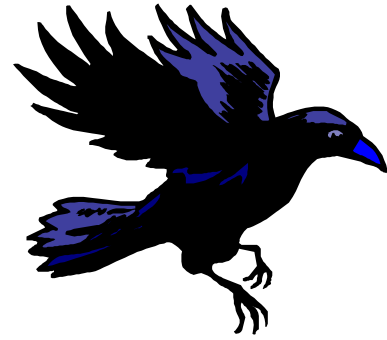
- confidence that the medical team appropriately identify and treat the needs of our particular situation,
- relevant up-to-date information, about what to do when under stress or ill,
- acceptance of constraints sometimes, and support from family, friends and the workplace
- the opportunity to clarify and compare notes with others with the same disorder
- recognition that healthy living with Addison’s involves more than our replacement medications.

With this last point particularly in mind, Jeanette put together for the Northern Region meeting, the Star Diagram which appears on the last page of this Update. (For an electronic copy, contact Jeanette.)

The key message is that we can over-focus on our medications, and lose sight of the ‘bigger picture’. For best health, we need to harmoniously integrate our exercise, stress management, sleep, food and hydration, as well as our medications.

Ironically, apart from the medications, this message applies to everyone, Addison’s or not. But people in general are casual, and delay achieving potential – there’s always tomorrow... The hydrocortione (or other glucocorticoid) that we take as medication controls our energy. To live full and healthy lives, we have to learn to be smart with energy use. Then, if we work on the whole balance to maintain wellness, and there isn’t another limiting condition, there is no stopping us!

It was an Addisonian (US President JF Kennedy) who made the dream come true that landed men on the moon. Networks like NZAN, and meetings like the inaugural one in Auckland, help give Addisonians more confidence to make their dreams come true.



### SHALL WE FLY – OR WALK?! - High cortisol levels dull the brain

High cortisol levels are not only a problem for Addisonians taking too much replacement medication– they are a problem for other mortals too!

Information is accumulating in the biomedical literature from several angles that ‘ordinary people’ (non-Addisonians) can have prolonged raised cortisol levels due to psychological stress, or depression, or to jetlag (chronic disruption of circadian rhythms). The excess cortisol causes shrinkage of the part of the brain that is involved in spatial learning and memory.

The diverse studies have been possible because of the precision of modern MRI scanning of the brain (the temporal lobes, or the hippocampus), easy ways to measure cortisol (saliva being convenient and non interventionist), and appropriate standardised tests of spatial learning and memory impairment.

The study involving air cabin crew was published in the biomedical science journal *Nature Neuroscience Volume 4 June 2001 pp567-568*, by Dr Kwangwook Cho from the University of Bristol Medical School (UK). Thanks Jill for sending us the article from The Times in the UK, and triggering Jeanette’s exploration of this topic! The Times headline was “This is your stewardess speaking: Er, where are we going?” The research was reported in some NZ newspapers as well.

To give a bit more detail, it was already known from animal studies that high and sustained cortisol levels cause shrinkage of the hippocampus, a part of the brain involved in memory and spatial

learning. It had already been shown that salivary cortisol levels in cabin crew after repeated exposure to jet lag were significantly higher than after short distance flights. To quote the author, the June 2001 study demonstrates “that significant prolonged cortisol elevations produce reduced temporal lobe volume and deficits in spatial learning and memory. These cognitive deficits became apparent after five years of exposure to high cortisol levels.” The study compared air cabin crew in an airline whose policy was less than 5 days between outward flights across at least 7 time zones; with those in an airline whose policy was more than 12 days between such outward flights (and shorter flights between).

Dr Sheline at the Washington State University School of Medicine reported in 1999 that for medically healthy women with recurrent major depression, shrinkage of the hippocampus was related to the cumulative duration of depression, but not their age.

In the journal Nature Neuroscience in 1998, A US neurophysiologist and assistant professor of psychiatry, Dr Sonia Lupien, reported the relationship between stress, cortisol, and memory impairment, at least in the elderly. About one third of the 51 healthy subjects who took part in the study – their average age was 73 – suffered from sustained high levels of cortisol over a five-year period. This group displayed poor memory recall when asked to remember images they had been shown 24 hours earlier. These individuals also took longer to find their way through a maze (especially designed to measure spatial memory) – and MRI scanning showed their hippocampus was 14% smaller than the groups with low or moderate cortisol.

The good news is that experiments in rats have shown that these brain effects seem to be reversible.

The work of Dr Elissa Epel at the University of California (published in the Sept/Oct issue of Psychosomatic Medicine) suggests that being a couch potato prolongs high cortisol levels – and the remedy is exercise!

In a published interview she said: “During severe stress, cortisol increases dramatically. It causes blood sugar to go into the muscles, so you can run from the danger. But these days we don’t need to run, and our stress is psychological. And we tend to be exposed to more cortisol that we’re not using or burning off with physical activity like running from danger. So we sit with it. Too much cortisol makes you vulnerable to infection and major disease, and can also cause the brain’s hippocampus areas to atrophy, impairing memory and the ability to learn.” Same story!....

Addisonians are a minority group. There are 99 insulin-dependent diabetics (and more than 300 non-insulin dependent diabetics) in New Zealand for every Addisonian. No wonder it is sometimes hard to get an endocrinology appointment without a long delay! So it is refreshing to see that “mainstream” research is throwing light on issues that also affect us: **inappropriate cortisol levels in the blood are linked with woolly thinking and memory problems – and the simplest “correction tool” is exercise.**

## JEANETTE WAVES HER FLAG FOR EXERCISE



“Earlier this year, at the end of my tether with regard to poor stamina and too frequent ‘crashing’ (I have other autoimmune problems to handle as well as Addison’s), I started a gentle every-other-day exercise programme at the local gym – treadmill, some strengthening exercises, the exercycle and stretching.

From my point of view, the results have been great. I have more confidence about the distance I can walk without becoming fatigued. Particularly rewarding was that the benefits for mind and memory function came first.

“Also, the change in my blood cortisol profile is consistent with the pot-pourri of research reported above about cortisol in non-Addisonians.

I was previously puzzled in a bit of a trap – I couldn’t manage on less than 30mg hydrocortisone per day without Addisonian symptoms, but on that dose my serum cortisol was higher than appropriate throughout the 24 hours, including overnight. I was experiencing spatial learning and memory problems. After three months of adherence to the gym-plan, my hydrocortisone dosage hasn’t changed, but a check showed that my serum cortisol now peaks and then falls, fitting the usual pattern for reasonably well managed Addisonians.”

The gym suits Jeanette, but there are other good options for exercising too:

### **LYN AND HER BIKE!**

Lyn, one of the Northern Region co-organisers, is a firm believer in the value of regular exercise for her. At the July meeting she radiated wellness and determination - and shared her dream to one day bike across the US.



“During the week I ride only in the afternoon. I am up at 4.45am and at work by 6.00am latest - sometimes earlier. I think getting up early and getting stuff done early is important TO ME. Late afternoon I usually do an hour on the bike (whether on the road or on the windtrainer) 3-4 days per week.

“In the weekend we do at least one decent ride (3 hours or so) and maybe a shorter one on the second day - all weather dependent. I don’t mind getting wet when I am out there, but even I don’t have the determination to head out into the pouring rain unless I absolutely have to. If we are on holiday cycle touring we usually do 5-6 hours

each day for five days, then have a day off, then off again.

“Whilst exercise is important to me, I am not obsessive over it, though I feel much better for making the effort. I think what it does achieve however is a good overall fitness which raises your self confidence, your self awareness, gives you a more positive outlook on life, and makes for a better quality of life overall. There is no doubt about it, if you feel good in yourself, life gets a whole lot better.

“We don’t just do biking - although that is our primary exercise at the moment. We also enjoy walking/hiking/tramping - just getting in the outdoors. I never go to the gym or go running - dicky knee put paid to the little running I used to do, and whilst I have gone to the gym in the past, I find more enjoyment being out and about.

“And yes, no doubt about it, I do get tired early evening. If I have a night out or special evening planned, I carefully manage the days round it so as not to overload. I NEVER have problems sleeping - maybe because I pack a lot into each and every day!

“When I am majorly stressed (like trying to learn \*\*\*\*\* mountain biking where my ambitions are high and my skillset low) I do get shitty - big time - but it’s all over quite quickly.”

### **INTRODUCING PAM, NZAN’S EXERCISE ADVISER**

Regular exercise benefits everyone, including Addisonians. Walking, the gym, biking... Are you confused or cautious about how much is enough, and whether you have the stamina to cope?

We are delighted 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.*

## LIVING IN JAPAN WITH ADDISON'S DISEASE - DANIELLE'S STORY

When my second (and last) child was born in February 1992 I was 24. All went well. It was his 3-month check-up when I made the comment to my doctor that my pregnancy mask hadn't disappeared like it had before, and I had big bruise-like marks on my elbows and feet. He looked at my elbows and also my feet and knees, then turned over my hands to look at my palms. He asked me all sorts of questions then, was I tired, any nausea etc etc. He already had the idea that I may have Addison's, sent me for blood tests, and a couple of weeks later I had my diagnosis. Now that I have read some other case studies, I guess I was lucky my doctor spotted this straight off.

The name Addison's disease of course meant nothing to me. I just thought it like my thyroid, take a tablet a day etc, and I would be fine. I'd been doing that for 12 years. I saw a specialist, and then just my GP from then on.

At that stage we were planning to go and live in Japan. My husband was already over there, so it was a relief to learn that I could still go. I asked my GP for literature on the subject, and he copied me a page out of some medical journal that meant as much to me as if it was written in Japanese. I figured Addison's couldn't be too bad.



When we left for Japan, I took a six-month supply of medication with me. Eventually I met my doctor. He was a very young man, who could speak a bit of English. He was very concerned about me, and when giving me any medication or anything, he would say to me "If you catch cold come to me, I put you in hospital." From that day on I decided I would never go and see this man if I

was slightly sick – I would go for my prescriptions only when absolutely healthy.

When we lived in Japan, we were entitled to medical insurance through the town council, NZ\$125 per month for the family, not too bad. The council then paid 70% of all our doctors' costs and prescriptions. It was a good system, as you don't have to pay it all and then get reimbursed, you just pay the 30%. But I found out at my first visit that I could only get 2 week's medication at a time. They have you trapped, as if you get sick you don't have enough to double etc, so you need to see them. I just kept extra of my NZ medicine to compensate for this. One two-week visit would cost me around \$50 for my visit and medication.

I remember I used to get really pissed off with the two weekly thing. One day my lovely doctor said that if I travelled to a city nearby, there was a University Hospital and his professor would like to meet me. I thought I'd try this. What an expedition. I had blood tests, a visit, and then the wait for the medication, all taking over three hours. (Nothing is hurried in Japan!). The professor himself was great. He spoke very good English, and he said to me that although it was illegal, he would prescribe me more medication so I would only have to see him every 3 months. I thought this was wonderful. That little visit cost me nearer to \$500 because of the blood test, but the three month gap would be worth it, I felt. My only thing is, I am not one of those people who lie, or really think about doing it, so when my doctor saw me at a social function a few weeks later, he asked me when I was going back to see his professor. Not thinking, I said "August". Well, that was the end of that! When I visited my professor again, he accused me of telling someone – and I was back to fortnightly visits. I was really devastated for a while – if only he knew I didn't really tell anyone, I just answered a simple question.

While in Japan, I had two incidents that I thought at the time were food poisoning, but looking back, they may have been Addison's crises. I remember vomiting for close to 7 hours, then for 2 days being scared to eat anything. Once I didn't even take my medication as I already knew that it tastes a whole

lot worse coming back up again with the water. I did recover from these, although slowly, and the cause of them may have been erratic tablet taking, or even forgetting them altogether. I waited until I returned to NZ and saw my GP, who told me what these could have been, and then I learned that if I missed my medication I could actually get sick and end up in a coma. That information probably would have been good to have had up front, but we live and learn.

Well, I have been back in New Zealand for 3 years. Although at the moment I am going through big changes, I have a lot more control and I know my body better now, when to increase medications, etc. I do feel I am of the lucky ones, having not suffered too much with Addison's disease over the past 6 years. I hope I continue this way! Good luck, everyone.

### **BOB'S STORY**

*In his cover letter Bob wrote: "I suggest that NZAN make it an aim to distribute notices for display in as many doctors' waiting rooms and other health clinics as possible, explaining the symptoms of Addison's and advising those who suffer from the symptoms to see their GP and ask for a blood test for early diagnosis. I was very grateful for what the A&R Unit doctors did for me, and in turn they said that they were helped by the tests my GP had taken before I was admitted to hospital."*

*Jeanette replies: Your point is well taken, Bob. A flyer has been on our to-do list for a while, but we haven't quite got there yet. Some Addisonians look back with sadness and even some anger, at the time it took for their unwellness to be finally "believed", and the diagnosis established. However, in fairness, unless the more specific symptoms are present (in particular salt craving and an inappropriate degree of skin tanning and pigmentation in areas not exposed to the sun), the diagnosis can be challenging - and for the Addisonian, a miracle. In Bob's case, his GP was concerned at his high blood potassium level (and presumably also low sodium although he didn't say so to Bob), and advised Bob to increase his salt intake. But Bob didn't have a craving for salt.*



**Thank you for sharing your story, Bob, and please accept our very best wishes for a happy 80<sup>th</sup> birthday in September:**

Indications that something was really wrong, started to show during 1999, when Bob was 78 years old. "I began to feel languid and to have a lack of interest in many things. I belonged to an indoor bowling club, and found that my quality of play had deteriorated. Before the end of the year, I began to get bent over, and as much as I tried, I could not walk as upright as I had previously.

"Things got gradually worse early in 2000, and I know that my daughters were concerned about me. I became afraid to drive, and relied on one of my daughters to take me on my doctor's visits, which were becoming frequent, and also to do my shopping. I thought I was becoming crippled up with arthritis. I fainted at home twice, and was taken to hospital for a check up.

"We discussed amongst the family that I should move into a rest home. An appointment was made for assessment. Then I was admitted to the Assessment and Rehabilitation Unit for further assessment. I was told next day that I had suspected Addison's disease, and they were awaiting confirmation from blood tests. In the meantime I was put on a saline drip. After 24 hours of IV hydrocortisone in the saline, I felt really good. I looked better, and had colour back in my cheeks. The next day I was tried out on a walker and the doctors were very pleased that I could walk so straight and at a much improved pace than when I came in a few days before.

"I was kept in for a few more days stabilisation, and then went home feeling a new man, on top of

the world. I felt so good that all the small chores about my home were no longer a bother for me. It felt wonderful to be able to live a normal life again. I even noticed my singing had improved when I sang the hymns in church.”

Bob explains that it hasn't been all plain sailing, however. After he'd been home for about three weeks, he had problems with fluid build up and needed hospitalisation. He has heart disease, and its medications, to deal with too. It has been a challenge to get the right doses of hydrocortisone and fludrocortisone to avoid fluid build up. He now takes 15mg hydrocortisone and 0.05mg Florinef daily, and frusemide diuretic to help counteract fluid retention. Leg ulcers that had been a problem over many years, healed once the Addison's medications were stabilised, although he needs to use a special ointment on the areas daily.

“I still drive, and I go for my re-licence in September. The plans for moving to a rest home are on hold for the time being.”

### **SOMETIMES OTHERS PUT IT SO WELL!**

Often we recognise ourselves in other people's descriptions – these are from an email listserv of people with Addison's:

- A mother of a young boy with adrenal insufficiency: “I can normally tell if his meds are increased enough, as he suffers from extreme tiredness when he is sick and increased meds bring him back to normal energy levels. If they are increased and his body doesn't need it, he goes completely over the top and is uncontrollable. He does suffer from back, head and abdominal pains when he needs increased medication, although this is intermittent, not constant. He doesn't suffer from nausea or disorientation, just gets extremely emotional and the slightest thing will reduce him to tears.”
- “I am a lot older than him, but his symptoms of low cortisol are about the same as mine. I have never had the

abdominal pain - I have joint and back pain and headache. But mostly I have a profound weakness...I end up in my chair and not giving a whit about what goes on around me.”

- “I think most of us struggle with stamina to some degree or another, depending on what we expect of ourselves. The other big factor is if I overdo it . . . On a good day, sometimes I get really excited and overdo it, and pay for it the next day (or two), feeling just exhausted. This whole thing seems to be about learning to manage energy in a new way.”

Jeanette agrees that “easy tears” are a helpful, uncontrollable, and sometimes amusing indicator of low cortisol. “I was feeling quite exhausted, and had missed the cue for a bit extra hydrocortisone, one day when I flew to a provincial airport on business, fortunately on a Sunday afternoon for a prompt Monday start. On arrival my luggage was missing. The tears were slowly but persistently dripping down my cheeks as I tried to explain at the airline counter that yes, my luggage was missing, but no, I was not broken hearted about it, just not well. The taxi driver was similarly confused at my state, gently dripping tears, but otherwise in energy-save mode. At the hotel I was able to get a couple of hours rest, the extra hydrocortisone I'd taken kicked in, and I was back on form to participate in dinner.”



### **MEMBERS' CONTACT LIST**

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

Pamela's email address is too long to fit on the list this time! It is:

[pamela.barnard@andersonlloydcaudwell.com](mailto:pamela.barnard@andersonlloydcaudwell.com)

Jill can be contacted in the UK at:

[rodger.cheer@btinternet.com](mailto:rodger.cheer@btinternet.com)

This list is circulated to members only.



