

# New Zealand Addison's Network

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## UPDATE MARCH 2001 (No.12)

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Greetings, fellow Addisonians

In this issue we feature:

- NZAN's relevance in 2001
- Introducing NZAN's team changes
- Postage sponsorship
- Subscriptions due!
- Membership news
- Enthusiasm for regional meetings
- DHEA – more evidence it's good for Addisonians
- North American NADF survey results published
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- NZAN milestone publication – the best from Updates 1-11
- Members' contact phone list
- Anne's story
- An interview with Joan Hoffman, editor of Addison News
- Results of the NZAN November 2000 Survey

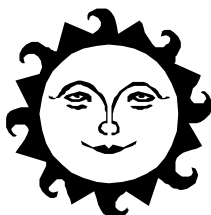
### **NZAN'S RELEVANCE IN 2001**

NZAN is part of an international community of Addison's Disease support groups, in frequent contact with each other, helped by the Internet.

In today's global world, with so much information available at our fingertips, one may well ask, what is the value of a national network like NZAN?

First – there's the information. NZAN members receive up to date material, from diverse sources, for better understanding of their own situation, and for sharing with their health care professionals. Yes, the "lone surfer" can find a lot of information on the Internet, but may need help and experience to work out what is sound and balanced and useful, and what is less so. We expect people who contact us will dip differently into the basket of what NZAN offers, and take what they need.

Wishing you all good health,  
Jeanette, Anne and Linda



Second – there's 'referencing' and personal sharing. Rare disorders like Addison's are lonely. Networks like NZAN provide links to others with the same disorder – through the contact phone list, and the regional meetings that we hope will start this year.

Third – sending NZAN Updates to endocrinologists and endocrinology clinics, and articles from specialist contributors, help increase the knowledge level about Addison's "in our patch". *We encourage you to share your Update Newsletters with your GP.* (Some members have told us they do, and have trouble getting them back again!) *You* are a means for the continuing positive education of the health professionals in *your* community.

Fourth – what happens when we leave home base?! Concern about safety when travelling was one of the key motivations for staging the first International Conference for support groups for Addison's, Cushings and Acromegaly in Oslo in 1996.

In their responses to the November 2000 Survey, some members reported reassuring experiences with emergency hospital admissions. But a few members reported less than optimal recognition of their Addisonian needs when admitted to New Zealand hospitals over recent years. Addisonians can't be complacent.

- Medic-Alert is a minimum self-labelling, and doesn't necessarily hasten appropriate treatment;
- The simplest effective extra to carry is a letter from your specialist, detailing your medical conditions, and what to do for you in an emergency.

Some Addison's support groups overseas have established more detailed ID cards for use by members – see for example the

Australian system, in past newsletters and on their website. These cards can also be available to interested NZAN members.

If you are travelling overseas to countries where English is not the first language, consider taking information about Addison's and your emergency needs translated into the local language. That's a specific way the international network can help you.



## INTRODUCING NZAN'S TEAM CHANGES

While we have been baking in summer heat in New Zealand, Jill has been counting snowflakes, building snowmen and testing the effectiveness of thermal underwear in the UK.

We've three new names on our letterhead now, to share the load of enquiries from members and others:

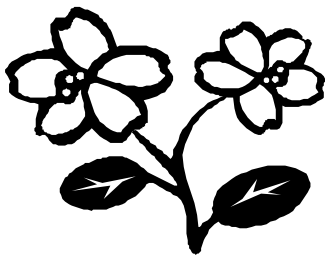
- Gary Roselli, a pharmacist in Wellington, has 36 years of Addison's experience. One area he is progressing for NZAN is sponsorship opportunities
- Anne White in Napier has taken over the library from Shirley, and the starter packs, and is helping with the Update newsletters – her story appears later in this issue.
- Linda Thompson in Havelock North is helping especially with the membership and endocrinologist databases. She has updated and expanded the contact phone list in this Update, in line with members' feedback in the November 2000 survey.

Sincere thanks to the several other members who volunteered their time and help for NZAN on their Survey forms. We'll be staying in touch with you!

Thanks also to those who gave positive feedback about NZAN. It is certainly helps motivate us when we feel swamped .

### POSTAGE SPONSORSHIP

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



### SUBSCRIPTIONS DUE!

Subscriptions are now due for the 2001 year. Invoices are enclosed.

Our photocopying bill is quite hefty. You receive about 50 pages of information, local and overseas, in each mailout. The same package goes to the endocrinologists and endocrine clinics in New Zealand, as well as some specialist physicians with an interest in Addison's disease.

Members' donations help us to maintain the subscription at \$20 – thank you.

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

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

### MEMBERSHIP NEWS

We welcome Chris as a new member since the November 2000 Update. He's the third person to find out about and join NZAN thanks to the May 2000 article in

the Pharmaceutical Society of New Zealand's monthly publication "Pharmacy Interaction".

We now have 66 members. Thank you Marianne for the donation included with your survey form.

### ENTHUSIASM FOR REGIONAL MEETINGS:

The survey responses indicated that members are keen on the idea of regional meetings – 75% of the responses were positive, with just a small number unable to attend if there are meetings in Auckland, Wellington, and Christchurch.

In each of those regions, one or more members have offered to be coordinators, and some other members have offered to help the coordinators. We are contacting these people separately, so that plans can proceed.

Members in some smaller regions also volunteered to coordinate and host meetings – Taranaki, Dunedin, Hawkes Bay, and Hamilton. At this stage, these are being considered as a second series, each under the wing of a main centre, building on the experience gained.

The proposed starting point in each region is a day meeting with the following components:

- (a) an interactive session\*,
- (b) an appropriate speaker, and
- (c) a meal during which discussions can continue informally.



\* One strategy that can work well if for each Addisonian present to give a "5 minute talk" about themselves - with the clock on to ensure everyone gets a turn, and the order perhaps decided "from a hat". The only "compulsory" bit is some information about their Addison's - how

long they've had it, and what medications they are taking. The rest of the 5 minutes can be about whatever they like - their family, their career, their sports interests or achievements, their values, their hopes or their dreams...

Then after a refreshment break, comes "questions and answers time", to each other. That can be interesting and helpful. The interchange may generate some questions or issues to address with endocrinologists or others - or even lobby government!"



## **DHEA – MORE EVIDENCE IT'S GOOD FOR ADDISONIANS**

Some members have asked – what is the situation now with DHEA?

DHEA (dehydroepiandrosterone) is an "androgen precursor" made in the adrenal glands, and usually present in below normal amounts in the blood of Addisonians.

The question being asked for several years now is: does replacement with DHEA help Addisonians achieve better quality of life? At first there were doubts, and some of the early studies were unclear. Then a German study (see Update #8 Nov 99), indicated significant benefits worth pursuing. Joan Hoffman has prepared a concise summary of the studies to date, in the Addison News Issue 30 enclosed with this Update.

The latest study to be published in the medical literature (late 2000) was done in the UK. Participants took 50mg DHEA daily, or placebo, in a trial with double blind crossover design. Lots of tests and measurements were done, including: "Cognitive function and psychological symptoms were assessed by structured interview, and patients completed a 15-

item profile of mood state, which covers 6 subscales of mental health – tension, depression, anger, vigour, fatigue and confusion. This profile was obtained each morning and evening for 2 days before baseline and at the end of each treatment phase, with simultaneous saliva samples for hormone measurements."

The outcome? "In summary we found that oral DHEA replacement in Addison's disease is biochemically effective, well tolerated, and associated with improvement in psychological well-being, mood and fatigue. Importantly, two-thirds of our patients at the end of the study wished to continue DHEA replacement therapy... Our observations suggest a significant physiological role for DHEA in humans, and its addition to existing steroid replacement therapy in Addison's disease should be considered further."



### **How to get DHEA:**

DHEA is not available as a subsidised medicine in New Zealand – yet!

But to fill a doctor's prescription, NZ pharmacies can access DHEA from a pharmaceutical compounding company in Auckland.

NZAN member Ian read about DHEA in his NZAN Updates, enlisted his doctor's support, and gets his supplies through his local pharmacy at \$33.70 for 100 25mg capsules. Other capsule strengths are also available. Ian has been taking 25mg DHEA daily for 6 months now. No adverse effects, no clear benefits, he says – but he is doing pretty well anyway, will keep taking DHEA, and may consider trying a higher dose.

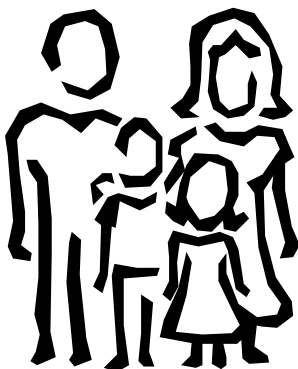
DHEA can also be imported with a NZ doctor's prescription, with the Ministry of Health's "blessing", from eg the US. Using a credit card minimises currency conversion surcharges.

Blood levels of DHEA-S (the sulphate ester) can be measured to confirm initial deficiency and the extent to which blood levels rise after regular consumption of DHEA.

The issue of dose response isn't clear in the studies yet. Jeanette has been taking 10mg daily for the past year (25mg gave unacceptable side effects), and a recent DHEA-S blood test gave a result close to the mean of the group in the UK study who took 50mg DHEA daily for the three month trial period.

However, with all replacement therapies, it is hard to interpret circulating levels of hormones, after replacement commences. Overall, there are some encouraging reports, but there are still uncertainties in the DHEA story –it hasn't found its place in routine treatment yet!

*We encourage members to share their experiences with DHEA.*



### **THE NORTH AMERICAN NADF SURVEY PUBLISHED**

The report of a comprehensive survey of 665 North American Addisonians was published by NADF late last year. (The survey results had been previously summarised in NADF News, winter 1999.)

NZAN acknowledges with appreciation, several copies of the report for sharing with interested members including our regional coordinators, and doctors. If you'd like to borrow the library copy, contact Anne.

One surprising finding is that 70% of the respondents also reported hypothyroidism. An association between Addison's and hypothyroidism is well known, but surveys in other countries have shown a much lower co-association (20% in the 1991 Dutch survey, for example.)

From the information supplied on the database forms, 25% of NZAN's "true Addisonians" (59 members) have hypothyroidism.

The reason for the much higher co-association of Addison's Disease and hypothyroidism in the North American population surveyed is not known. However, the respondents represented only about 7% of the Addisonians in North America, and were those who had made contact with a support group, and so may not be representative of Addisonians overall.

The message for all Addisonians is clear – make sure your doctor keeps a watch on your thyroid function. It's a simple blood test!

*The database enabled us to easily check the co-occurrence of Addison's and hypothyroidism in NZAN's membership. We are reminded of the importance of keeping the database up to date. If you have had further medical diagnoses since you filled out your initial form, please let us know the diagnosis and your current medication. We're including a reminder on the enclosed Subscription Invoice.*

## LYN'S TIP FOR THOSE HAVING TROUBLE SLEEPING

We encourage all members to share their news, views, and tips for easier living with Addison's – thanks Lyn!



“I have found in all cases where I cannot get to sleep, or wake during the night and cannot get back to sleep, that if I throw off a blanket, I fall asleep immediately. Even during summer, when I have only a couple of sheets on the bed, throwing off a sheet seems to make the difference. While in bed, I seem to be hyper-sensitive to only a degree or two. It's amazing how tossing off a blanket works every time, even when I am sure I am not too hot!”

We note that Lyn also has treated hypothyroidism. Maybe that contributes to her blanket response.... In the March 2000 Update, Dr Braatvedt wrote when asked about faulty ‘thermostats’ and Addison's:

*There is no known effect of properly treated Addison's on heat regulation. Thyroid over and under-activity are sometimes associated with Addison's and should be checked out if you do feel unusually hot or cold in a persistent way. If your steroid dose replacement is right and your male and female hormone levels and thyroid function are all appropriately sorted, you should be no different from non-Addisonian patients. A number of patients did complain about abnormal 'thermostats' [in the November 1999 NZAN survey] and I'm afraid I have no good explanation for you apart from what is said above.*

## Announcing: NZAN PUBLICATION: “THE BEST FROM UPDATES 1-11”

The national and international scene has changed a lot since NZAN was formed in 1996. There is a strong international network of support groups now, and informative newsletters are sent to us as exchanges, and made available to members. (For back issues, contact Anne.)

We also have a lot of useful information in our own 11 Update publications to date.

So we are preparing a “50-page” compilation of ‘The Best of NZAN Updates, Issues 1-11, July 1997-November 2000 inclusive’. We're looking at the feasibility of including it in starter packs in future.

More than half our current 66 members have joined since November 1999 - so some current members might like a copy too. There's space for letting us know on the enclosed Subscription Invoice. We'll need to recover the copying cost of about \$4.



## MEMBER'S CONTACT LIST

The member's phone contact list has been updated, in accordance with your feedback in the November 2000 Survey responses.

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

This list is circulated to members only.

## ADDISON'S DISEASE INFORMATION ON THE INTERNET



The Internet seems awash with websites, and many include reference to adrenal disorders. Some have sound information, others are less complete or authoritative. Some “suddenly disappear” or change address!

NZAN is building a systematic index of websites, and what they contain. We reprint below, a short “core” set of sites.

We also draw your attention to Katherine's story, “On the Net with Addison's” in *Addison News Issue 31*, enclosed.

*Please let Anne know of other websites you have found helpful. If you participate in Internet discussion groups, we encourage you to share your experience.*

### Overseas National Support Groups:

Australian Addison's Disease Association Inc. <http://addisons.org.au>

Canadian Addison Society  
<http://members.home.net/jsoutham>

**(US) National Adrenal Diseases  
Foundation (NADF)**  
<http://medhelp.org/www/nadf>

**ACIF** (Addison and Cushing International Federation, of which NZAN is a member)  
<http://www.spin.nl/nvap0302.htm>

### US Government Agencies

**National Institute of Diabetes and  
Digestive and Kidney Disease (NIDDK).**  
Comprehensive background information about Addison's Disease, which we have

printed to include in our ‘starter packs’.  
<http://www.niddk.nih.gov>

**US National Institutes of Health.** This site links to the NIDDK information above: [www.nih.gov](http://www.nih.gov)

**Joan Hoffman's “Addison News” site** (see interview this issue)  
<http://www2.dmci.net/users/hoffmanrj>

**Properties and Side Effects of Medications:** a comprehensive reference  
[www.rxlist.com](http://www.rxlist.com)

## INTRODUCING ANNE

Anne's career as a librarian is ideal experience for looking after NZAN's information resource. She's also keen to polish her Internet skills, and keep NZAN members up to date with useful websites.

After leaving school, Anne worked in libraries in Palmerston North, Taupo, then Wellington. She was head librarian at the Eastern Institute of Technology in Hawkes Bay for about 16 years, until five years ago, when she was 50. Her health has restricted future opportunities in the workforce.

Now Anne is enjoying semi-retirement, and a more balanced lifestyle. She has been a keen patch worker for many years. One of her hangings, worked on over a three year period, was included in an exhibition in a Hawkes Bay garden this month. Although during her librarian years Anne didn't read for recreation, she now enjoys reading too. She has been involved locally with the ‘English as a second language’ scheme, funded through the Dept of Education. She also adores her ginger and white cat Sherbet – who has 25 different miows, she assures us!

This is her story:  
I have had eczema all my life, or for as long as I can remember.



It flares at times and becomes infected to the degree that I am hospitalised. It was while in hospital in July 1998 with infected eczema that my Skin Specialist ordered some blood tests just before I was discharged. I was diagnosed as having Adrenal Insufficiency, and osteoporosis. I was 53 years old.

The long term use of steroids had caused the adrenals to close down. I remember feeling very tired and quite unwell for some time prior to that hospitalisation. I came home with a prescription for 20mg Hydrocortisone daily, 15 in the morning and 5 at 4pm.

I found that unless I was very careful I got very tired very quickly, and this often led to getting depressed. I found I could work only between eight and ten hours a week without getting overtired. Outside this I was doing some voluntary work. I could control the times I did this and usually managed to do it when I felt good. Stress levels were hard to control. When things were not good I was prone to breaking out in eczema, often badly enough to be hospitalised.



My endocrinologist focused mainly on controlling my osteoporosis. Unfortunately the first few medications we tried caused my skin to break out. Now I am now taking 0.25mcg of Rocaltrol daily for the osteoporosis, which does not affect my skin at all. But I wasn't learning how to incorporate Adrenal Insufficiency into my daily life. One day, nearly two and a half years after my diagnosis, it all got too much and I "hit the wall". I had found NZAN through the Internet. I made contact, and got some really good support.

Within a couple of days I visited my GP. I had written it all down so that I did not forget anything. I told him my whole story. I did not believe that I had to live such a restricted life. The first thing he did was to increase my Hydrocortisone dose to 30mg, and we have worked together over the following months, reducing it gently. I am now taking 25mg, and still feeling good most of the time. (I am about 5 foot 2 and weigh between 9 and a half and 10 stone.)

As soon as I started taking the higher dose of Hydrocortisone I noticed a difference. It was as if someone had "turned the light on". I felt much more present and alive. I do not get so tired so quickly and when I do I recover much faster. Something that really pleases me is that my brain is now working effectively whereas it was not on the previous dose of Hydrocortisone. I have not had a period of depression since the dose has been increased. I wear a Medic-Alert around my neck and carry a card in my purse. I do not get sick any more than I did before I was diagnosed with Addison's. However my skin condition has become more consistent. It never really clears.

The same visit that he increased my hydrocortisone, my GP referred me, at my request, for a second specialist opinion. That is unfolding comfortably for me so far.

I am not a sporty person. However, since I have had my diagnosis of Adrenal Insufficiency and osteoporosis I have developed the habit of walking as much as possible. I am fortunate to live in an area where there are many different and interesting places to walk. I also go to the Gym twice a week.

I try to live a peaceful ordered life, free from over-commitment. However this does not always work, and I find myself over-committed for the energy levels

available. When this happens I extricate myself as quickly and smoothly as possible, and give myself two or three completely free days.

My friends know that I have Addison's, and that I may suffer from lack of energy at times. People I work with either formally or on a voluntary basis, I tell on a "need to know" basis.



**Jeanette's email interview with  
JOAN HOFFMAN,  
EDITOR AND PUBLISHER OF  
"ADDISON NEWS":**

Joan Hoffman has a close finger on the pulse of what is being done internationally for and by Addisonians. Her upbeat and informative newsletters are a regular enclosure for NZAN members. This time, we're sending issues 30 and 31. I first wrote to Joan in 1995, then met her in 1996 in Oslo at the International Conference for Addison's, Cushings and Acromegaly Support Groups. I was struck then by her commitment and caring, her knowledge and her thoughtful wisdom. I now value her friendship too.

Joan and her husband Ron live in the small rural community of Pleasant Lake, Michigan, about 34 miles south-east of the state capital Lansing. Joan's first newsletter went to just over 100 individuals in the western US, in September 1993. Five years earlier, her daughter Amy had been diagnosed with Addison's, aged 11. Last year Amy had

two special milestones - her graduation from Michigan State University with a Master of Science in electrical engineering, and her marriage to Justin. Amy's particular professional interest is alternative sources of energy - we Addisonians sure need that!

***1. Joan, what prompted you to publish your first Addison News?***

In 1993 there was little information and few known Addisonians. Very few people had personal computers. I started passing along information to the few others when I found something that helped us.

Although our national organization was founded in the east and I live in the midwest part of the U.S., the greatest number of known Addisonians was in the west. That seemed the logical place to launch a newsletter. The western U.S. still has the greatest number of individuals and local support groups for Addison's.

There was early skepticism that there would be enough material for a quarterly newsletter; that certainly has not proved to be the case.

***2. How many do you now send out each quarter? How does that break down by country?***

The numbers vary. I usually send out over 900 in a mass mailing four times a year and maybe receive requests for another 100 between mass mailings.

Most copies are distributed in the U.S. A little over 40 go to Canada. Canada has its own newsletter but there are some who were my readers before Canada had an organization. I have continued to send to them and to some of their leaders. Around 30 go to other countries. Some of these are national leaders, a few are families with Addisonian children or have no national organization or other source of information.



***3. What sort of feedback do you get to your newsletter, and how do you handle it?***

Feedback is quite heavy for about a month after each publication. Sometimes I might answer 10 or more letters or e-mails a day. Telephone calls are less frequent but are often more urgent.

In general I weigh the urgency. Voluntary donations support the newsletter printing and mailing costs and I write each donor a personal, handwritten letter. There are some routine requests for material and referral. The kinds of questions that require some research don't get answered as quickly.

It is difficult at times to balance getting all this done and the other important things in my life. My husband and I are "retired".

***4. What situations are the most rewarding for you?***

It is rewarding to see some of the material I have published being applied and helping someone. That makes my day.

I like the challenge of exploring new and pertinent topics. This is best done the second month and part of the third month after publication. I look over the stories that people have told me, the chat on Internet, medical abstracts and the various newsletters of Addison's related organizations to which I belong. These all give me direction about the content of the next newsletter.



***5. What changes have you seen for Addisonians over the 12 years since Amy's diagnosis?***

There has been greater communication, specifically because of personal computers and the Internet. More Addisonians have

become known and there is more demand for medical information and support. Some of the information I see is good and some is very bad. I see more people turning to alternative medicine when answers aren't readily available through traditional medicine.

I think in the past the value of what people with Addison's experienced was grossly undervalued. Collectively Addisonians have lived thousands of years with the disorder and their stories are being told more and more. That's important. Also the fact there are so many variations tells me this disorder isn't as simple or singular as we often have been led to believe.

Of lesser importance are the little things which aid or hinder the mechanics of mailing. It was a time saver when adhesive stamps came into being, likewise the electric stapler (a gift from my son-in-law), and the upgrades in computers and software. Some downers have been the increases in postage and printing costs. Filing of material is both time and space consuming.

***6. What is your perspective of the challenges that face Addisonians in 2001?***

It will be necessary for Addisonians to carefully sort out information and apply what is fitting to their situation. I think there is always a need for Addisonians to develop skills to listen and to talk with physicians about their concerns so with physicians they are a team.

***7. What about your own challenges?***

Because of the demand for my past newsletter information, it seems necessary to find time to put the material in some organized form - by topics and indexed. How much more I become involved internationally remains to be seen. I like trying to pull together what is being done with Addison's worldwide; it seems inefficient not to make use of information already available elsewhere.

