

# New Zealand Addison's Network

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## NZAN Newsletter, March-April 2003 (No 18)

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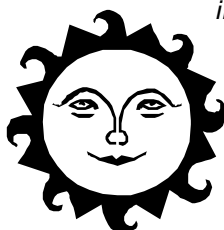
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**Wishing you all good health,  
Jeanette and the team**

**Reminder: Northern Regional Meeting  
Saturday 31 May, 9am-4pm**



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

## EMERGENCY LETTERS AGAIN PROVE THEIR VALUE:

In the previous newsletter we focussed on emergency letters. We gave guidelines, supplied the UK ADSHG and the NADF examples, and encouraged NZAN members to tailor their own letter featuring their specific medical conditions.

The Australian Addison's Disease Association now has a letter also - "Important Information Regarding Addisonian Crisis"-for Addisonians to carry when travelling, and to have in the home (see recent AADA newsletters for more information). An endocrinologist and the ambulance service were closely involved in the wording.

Would it be benefit NZAN members to have a single format of letter, perhaps "registered" with the ambulance services, as is happening in Australia? The topic may get some hearty discussion at the Northern Region Meeting on 31 May. Such a project would need a volunteer to be its champion!

### Reminders:

1. Have your personalised letter which includes very clearly what to do in an emergency for a person with Addison's disease.
2. Carry the letter with you, and have it readily accessible in your home (eg on your fridge).
3. If you are in an emergency, make sure that you (if possible) or the friend or family member with you, are as persistent as necessary, to ensure that you get appropriate treatment.
4. If there is any uncertainty that Solu-Cortef is needed, then it should be given, rather than withheld. Don't worry if the person doesn't look "sick enough" – yet! The injection won't do harm, and it may save a life.



## Jill finds out that migraines can precipitate an Addison's crisis:

Long-time NZAN member Dyan already knows that migraines can increase her cortisol needs, and can therefore precipitate an Addison's crisis (see her story in the July00 newsletter No.10 - also available on the website).

A recent new member, Jill, found that out the hard way.

"Last December I was transferred to a new endocrinologist and he handed me a copy of NZAN Newsletter No.17. This was such an eye-opener to me with all its information and such a comfort to know about all the other Addison's patients 'out there' in New Zealand. I was diagnosed seven years ago and have managed the disease reasonably well till now.

"I was in for a bit of a shock. I have always had migraines and over the past year they have increased to a marked degree (I'm 67). I went to a neurologist and he put me on to a new medication to be taken when the first sign of migraine appears. I took the first dose and it worked marvelously, but the following day another migraine struck, followed by another a few hours later, and in the end I had had 10 migraines over four days and stopped counting at that stage. Then I began hallucinating and went to the after-hours clinic where I was assured that all the weird things I was seeing were a symptom of migraine.

"Next morning my husband found me on the floor and well into an Addison's crisis. He found things very similar to what was described in your No 17 newsletter - the hospital emergency department was very reluctant to administer a hydrocortisone injection and without my husband and daughter's insistence I wonder if that would have happened at all. In spite of my steady recovery after that, most medical people I spoke to, including my GP, still query whether I was in an Addison's crisis.

"What has surprised me, and what I want to alert other Addisonians to, was that a series of migraines could cause so much stress. It did not occur to me to double up on my hydrocortisone intake as I had no fever. I should have been alerted by the hallucinating, as that was a major symptom when I was hospitalised prior to my original diagnosis - if that ever happens again I'll know what to do.

"I do have my own Solu-Cortef injection kit - I have had that from when I was first diagnosed. My problem was that I did not expect to be unconscious and unable to tell people where it was and what to do. After 7 years without trouble, my husband had completely forgotten the routine we'd discussed previously and he did not think to take my handbag plus injection when he loaded my in to the car and dashed to the hospital.

"I want to thank you and others for your efforts on behalf of the rest of us. You probably saved my life as my family really battled for me, having heard me discussing your article. Now we all carry an emergency letter, based on the (US) NADF one in the November 2002 newsletter, using that almost word for word and adding the name and contact numbers of the endocrinologist I see.

"I would be very interested in receiving any previous files by email, also in becoming a member of NZAN. Please advise how."

Jill adds: The series of migraines that led to the Addison's crisis were probably caused by the new medication (Imigran) I took at the onset of the first migraine. Most of the doctors I saw in hospital said that this wasn't possible with this wonderful new "clean" drug, but one told me that the drug is so efficient that once it has worked, in a rare number of patients it can then "search" for another migraine to fix, and create one if there isn't one there.



**Copies of the NZAN POSTER are included with this newsletter, updated, for doctors and hospital clinics to display and to pass on to their patients with Addison's disease.**

### Jeanette's diversion

This newsletter is late, mainly because I had an unexpected spell in hospital in March, while a lung infection was diagnosed and treatment was started. Fortunately, it's a penicillin sensitive bug, so it should resolve OK. It rather wiped me out, however, and it has taken a few weeks to get back close to "normal". I am very grateful to the several doctors in Hawkes Bay and Auckland who helped me get back on track.

Yes, my experience was another example of the importance and value for a person with a chronic condition such as Addison's, of having an emergency protocol to hand over to ambulance and hospital staff.

My protocol lives permanently in my pre-packed emergency bag, together with a Solu-Cortef injection kit. It lists and describes all my medical conditions, my daily medications, what to do for me in an emergency, and the contact details for my GP and Endocrinologist and personal contacts. It includes the symptoms of an Addison's Crisis, and how to treat it, copied from our NZAN newsletters. I handed the protocol to the ambulance officers... and it was all plain sailing after that. My GP, who had instructed me to call the ambulance, also sent information to the hospital. So I was expected when I arrived. I needed extra hydrocortisone, but I was not close to crisis, so extra hydrocortisone tablets, at regular intervals, worked well.

A bouquet to the teams at Hawkes Bay Regional Hospital!



## Membership update

We now have 90 members. Since the Nov02 newsletter we welcome Beverley and Jean who saw our contact information in Woman's Day magazine, and Maureen, Jill and Deborah whose endocrinologists told them about NZAN. We've sent out information packs to four others as well.

## Annual Subscriptions due 1 April

It's that time of year again! An invoice is enclosed. Because our income is supplemented with some sponsorship and donations, the subscription is still the same as when NZAN started in 1996 - \$20. Some members have asked if they can pay ahead for a year or two – yes, if you'd like to! Annette keeps a great handle on the database!



## DRAFT: NZAN Practical Guide for giving an Intra-Muscular Hydrocortisone Injection

As mentioned in the Nov02 Newsletter (No.17), we have put together detailed information on this topic, trying to anticipate and answer people's doubts and questions.

We are doing our best to help remove barriers of knowledge or confidence, so that all Addisonians can receive timely injection of hydrocortisone in emergencies.

Are the explanations clear enough? Have we missed something? We're sending out the draft for comment, as part of this newsletter (pages 17-20), before supplying it as a stand-alone document. We welcome ideas for improvement from our members and from doctors and other health professionals who receive our mailings. **Please send to Jeanette your ideas for improvement before Tuesday 20 May 2003.**

## Summary Instructions for IM Injection of Hydrocortisone (Solu-Cortef):

These are slightly adapted from the NADF summary instructions – which are not currently available on NADF's website, but are accessible scanned onto <http://addisons-diabetes.gkznet.com/articles.htm>

### To administer IM hydrocortisone Injection (Solu-Cortef):

1. PRESS DOWN on plastic top of bottle to force liquid (in top) to mix with powder (in bottom).
2. SHAKE GENTLY to mix.
3. STERILISE top of bottle (not essential).
4. PULL OUT plunger of syringe part way.
5. INSERT SYRINGE into bottle and force plunger down to insert air into bottle.
6. TURN bottle and syringe UPSIDE-DOWN, be sure that end of needle is in the solution.
7. PULL BACK (down) on plunger to load ALL THE SOLUTION into the syringe.
8. WITHDRAW syringe from bottle.
9. PICK injection site: best choice is THIGH (front outer); other choices are DELTOID (upper arm near shoulder); HIP (side just below hip bone); GLUTEUS (buttock, upper outer quarter).
10. STERILISE site (not essential).
11. PINCH muscle and INSERT needle (hold syringe like a dart, stab quickly, insert all the way.)
12. PULL BACK on plunger slightly to check for blood. (If you see blood, withdraw needle and re-insert nearby.)
13. PUSH DOWN on plunger to deliver solution – do this as quickly as possible.
14. WITHDRAW needle, put PRESSURE on site for 1 minute to stop bleeding.
15. GET TO A&E FOR FURTHER TREATMENT AS SOON AS POSSIBLE. Appropriate fluid replacement is very important.

## Karen's Tummy Bug Emergency

Karen recently experienced how rapidly an Addisonian crisis can develop, when a tummy bug hits which causes vomiting and diarrhoea. The situation was a surprise for her husband too.

Monday morning 9am, in an email to Jeanette: "My family all have colds and [husband] Steve had a vomiting bug on Saturday and now [young son] Matthew has it ... hopefully I won't get it!"

Friday evening: "I am sad to say I did not escape the tummy bug. On Tuesday I started feeling nauseous at 5pm, then vomiting and diarrhoea both started together suddenly, and every time I moved I was sick. By 9pm when Steve came home from work I was semi-conscious. We called the ambulance and I have been in hospital since, released three days later. Yes an Addison's crisis! It was a shock to us as I had been so well under control.

I had taken my morning and lunchtime doses of hydrocortisone, but not my 4.30pm dose. I took it just before I started vomiting, but didn't keep it down.

Hospital great - got all my meds and excellent care this time. I think it's better going in by ambulance and the ambulance guys said to us to not hesitate to call earlier next time! "

If Steve hadn't come home when he did I would have tried to give it to myself, but when he got home he dithered about giving it to me, and then I said that I thought he'd better get an ambulance (I knew I couldn't go in the car to the Emergency room).

Karen took her injection kit with her in the ambulance, which contained a sheet with relevant personal information, information about Addison's its symptoms and what to do in a crisis, her meds and dosages, the names of her endocrinologist and GP, and her insurance. She forgot to actually take her

meds with her. "Steve had told the ambulance people on the phone that I had Addison's and they seemed to have some idea about it."

"Fluids and oxygen were given in the ambulance on the way. They got the hydrocortisone in pretty much as soon as the doctor came in and saw us. They also gave me something to stop me vomiting or feeling nauseous. "

North Shore Hospital deserves a bouquet for the way her Addison's was addressed this time, she says! Having an appropriate emergency information sheet helped, and going in by ambulance –the ambulance phoned ahead, and the hospital accessed her notes from an admission for gall bladder problems earlier in the year.



### Comment from Prof. Holdaway, NZAN's medical advisor:

"In hindsight, it would have been best for either Karen's husband or the ambulance officer to give the injection. There is a natural tendency to hold off if uncertain or if there is an impression that someone else with greater skill or knowledge will shortly be available. But delays often occur (traffic, the doctor is busy in A&E etc), so there's no substitute for getting the injection in early on. There's almost no chance of doing harm, whereas there's every chance of shortening the period of illness or even saving a life."

What about having in the home, electrolyte solution such as Gastrolyte, or anti-nausea medication such as Maxalon?

"I don't think these are needed routinely – but if an individual is prone to recurrent vomiting or gastroenteritis, then this could be addressed with the family doctor or endocrinologist."

## Reducing your risk of gastroenteritis / "tummy bug":

Eating food contaminated with micro-organisms such as *Campylobacter* or *Salmonella* is one frequent cause of gastrointestinal upsets.

Germs which cause gastroenteritis can also be caught from other humans, or from pets, or from other sources such as the soil. The more people you (or your family) mix with, especially in a confined space, the more your chance of infection.

The germs need to enter the stomach for infection to proceed. Washing your hands before touching your mouth, and before touching anything that will contact food that will then go into your mouth (such as cutlery or plates) is the best way to avoid catching these germs.

Antibacterial hand wash gels used without water can be purchased from pharmacies. These are effective products to use if you are in an at-risk environment, without access to appropriate washing facilities.

An Addisonian who has more than one episode of vomiting, especially if they have diarrhoea as well, can progress to crisis quite quickly, over just a few hours. It's important to act promptly with intra-muscular Solu-Cortef injection if possible, and also go to A&E for IV fluids for rehydration, and more IV or IM hydrocortisone as needed until oral tablets can be tolerated again.

*Note: What we call "tummy bug" or "gastroenteritis" is usually referred to in the US as "stomach flu" - but it is not caused by influenza virus. These upsets are usually caused by bacteria, or sometimes viruses or certain parasites. The most common symptoms are diarrhoea, vomiting, fever, headache, and dehydration.*

Reprinted from NZAN Newsletter No.14, November 2001:

## Responding to Vomiting and Diarrhoea

from Professor Ian Holdaway's presentation at the Northern Regional Meeting, July 2001

"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 drawn 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 particularly 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 obvious 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."

**Reprinted from NZAN Newsletter No.13, July/August 01**

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

The policy is that no ambulances carry hydrocortisone, says Dr Tony Smith, chief medical advisor for the Order of St John northern region. 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.

## Prof Holdaway answers Joy's questions

**Question 1:** How long does it take the liver to process cortisone acetate before it is available for the body to use?

**Answer:** Within minutes

**Question 2:** If more cortisone acetate is taken than is required by the body on any one day, will this cortisol still be available to be utilised on another day or it is expelled as waste?

**Answer:** It is degraded within hours and inactivated and excreted in the urine. Excess levels can occasionally cause their own problems - high BP, fluid retention, bone density reduction etc, so trying to get the correct replacement is important.

**Question 3:** Which adrenal hormone regulates our body temperature?

**Answer:** The adrenal is not involved - thyroid hormones help maintain normal body temperature.

**Question 4:** If I am feeling abnormally cold, is this an indication that my fludrocortisone levels are too low or my cortisone acetate levels?

**Answer:** If an individual is very short of either hormone then blood pressure may fall and a shock state develop in which the person may feel chilled and collapsed - but minor or modest deficiency shouldn't affect sensations of body temperature. However, everyone is different and it remains possible it could be a warning in your case - but rather than taking extra "on spec" it would be good to get a blood cortisol level at the time to see if it is low.

### Robyn's Secret

"I often don't feel 100%. But I don't like to think or say negative things about myself, as I'm always doing my best to be as well as I can be.

So when people ask "How are you?", I just say "I'm fine". To me that means I am coping with however I am feeling at the time, I'm being patient with myself."

(Robyn is writing her story for a future newsletter.)

## REGIONAL MEETINGS:

**Reminder: Second Northern Regional Meeting**  
**Saturday 31 May, 9am – 4pm.**  
**Kohia Teacher's Centre, Epsom, Auckland (Gate 2 entrance)**

### **PROGRAMME**

**Welcome and Opening**  
 by Jeanette Crossley

**Introductions**  
 Opportunity to introduce yourself and your support people (maximum 5 minutes). This is not compulsory

Morning Tea  
**Keynote Speaker**  
**Professor Ian Holdaway**  
 NZAN's Medical Advisor

**Questions and Answers**  
 Prof. Holdaway will answer any questions you may have arising from his address.

Lunch  
**Emergency Injections**  
 How to administer and when to use emergency injections of steroids.

**Open Forum**  
 A chance to ask the group any questions you may have

Afternoon Tea  
**Where to From Here**  
**Close**

The programme and the registration form were posted to members in early April.

To help the organisers with planning, **please let them know as soon as possible** if you are interested in attending. Contact Karen 09 483 7043, email [kcarson@xtra.co.nz](mailto:kcarson@xtra.co.nz)

Professor Ian Holdaway, NZAN's medical advisor, will be keynote speaker, sharing a wealth of experience with the broad topic:

"Addison's disease – a review and recent advances".

The questions and topics you are invited to send in on the registration form, will help determine the focus.

Attendees at the July 2001 meeting were very enthusiastic – Addisonians and their family and friends. Come along and help make this another great day!

### **Report:** **Second Central Region Meeting** **Wellington, 31 March 03:**

Planned by Gary Roselli (central region co-ordinator), Ngaire Hyde and Nicole Gibbs, the meeting was held in Petone, on Sunday 30 March, 11am-3pm.

#### **Nicole reports:**

Gary chaired the meeting, which was attended by seven people with Addison's, one with treated Cushings, and two partners. Many had been at the previous gathering in May last year, but I was new to the group.

For the first hour or so we briefly introduced ourselves, and shared how we had been diagnosed. The stories were different, but we recognised the similarities - eg. weight loss, fatigue and nausea.

Over a lovely lunch we mingled and discussed various medication regimens and our daily life with Addison's. When we re-gathered Gary showed some of the overheads and played parts of Prof Holdaway's tape from the July 2001 meeting in Auckland. We also looked at and discussed some of the results from the NADF North American Survey published a few years ago. The group also discussed medication regimens, taking extra medication when ill, changing from prednisone to hydrocortisone etc.

It was very rewarding for me to meet with the others, most of whom have lived with Addison's /Cushings for many years, some for

more than 30. My husband Tony found it very useful to listen to their introductions. It also gave him more insight into how it is possible for an Addisonian to go into a crisis quite quickly, without necessarily having the control to take our own medication when we need to at those times.

Overall, I got a lot of useful information to educate myself with. I'm sure the Auckland meeting will be a success!



## **CHECK YOUR PILLS when you collect them from the Pharmacy!**

We've previously noted, with some frustration, how confusing it can be to distinguish similar little white pills - 1mg prednisone and 5mg hydrocortisone, for example.

Members' experiences show that pharmacists make mistakes too. They're human!

**It's a good habit, to look over your pills when you collect them – are they the same as usual? If not, don't hesitate to check with your pharmacist.**

An NZAN member was recently dispensed 5mg prednisone instead of 5mg hydrocortisone by her pharmacist. At first, feeling a bit more energetic seemed a good thing! Then after a few days she noticed symptoms consistent with glucocorticoid overdose, including heart palpitations, and not sleeping well. Close inspection of the pills revealed the small indented P symbol. She had taken 5mg prednisone in the past – she then recognized the original 5mg prednisone bottle, over which the 5mg hydrocortisone label had been put by the pharmacist!

Over the past few years, Jeanette has twice been issued the wrong Addison's medication. Once, in hospital, the pharmacy assistant

brought cortisone acetate, insisting it was the same as hydrocortisone, mg for mg. On the other occasion, her local pharmacist issued 5mg prednisone instead of 5mg hydrocortisone – and labeled it hydrocortisone. She was quite unwell at the time, but didn't suspect the tablets until more than thirty "5 cent sized" bruises appeared over her body. (She wondered whether the gift-wrapped soap that was sent with the replacement packet of correct pills was to wash her mouth out with, because she had been a bit cross on the phone!?)

The Dec02 edition of Australian Addison's News also includes a member's experience with the wrong dispensing of medication.

## **WHITE FLORINEF UPDATE**

We mentioned in the previous newsletter that Florinef tablets in the US were changed from pink to white towards the end of last year. We understand from Bristol Myers Squibb Australia that the only change was removal of the pink dye. But there have been several seemingly independent reports on Internet forums of some Addisonians in the US becoming unwell after making the change from pink to white Florinef.

Some samples of the white Florinef were sent back to Australia for analysis. NZAN has been told that those samples tested 'normal'. That means they contained the correct amount of fludrocortisone. We understand that BMS cannot explain people's varying reactions to the white formulation in the US. A possibility is a 'placebo-like' effect, in that people are responding even though there is no significant difference in the tablets. We understand that investigations in the US are continuing.

White Florinef is not yet registered in New Zealand. Our pharmacist member Gary Roselli, who is also our Central Region Co-ordinator, is keeping a finger on the pulse with Med-Safe, on behalf of NZAN.

**Reminder** - Reprinted from NZAN Nov02 Newsletter, No.17

We recommend that Addisonians follow our previous suggestion, to always keep a buffer supply of hydrocortisone (or prednisone, or cortisone acetate, if that's your glucocorticoid) and fludrocortisone – i.e. **don't wait until you have almost run out before filling your next prescription.**

One benefit from this strategy is that, in the event of a brand or formulation change of a medication, when you fill your first "new" prescription, you'll have 2-4 week's supply of the "old" pills on hand. If you suspect the new ones are not performing as expected for you, you'll be able to switch back to the former ones to clarify the situation

## Karen's Continuing Weight Loss Challenge

Losing excess weight – or preferably avoiding putting it on in the first place - is a big challenge for some Addisonians. With determination and patience, it can be done!

Karen (height 1.63m) had a 32 kg weight loss goal. For our March 02 newsletter, she reported 15 kg lost since joining the Weight-Watchers programme. She updates us: "I have been taking Reductil for the past four months to help shift me off a six month plateau. It is working! I now just have to work on the exercise (as in making time for it!) and I should be able to lose the last 12kg in the next year or so. I feel good now and certainly look a lot better than I did at the last meeting [Auckland, July 01]."



## DHEA, more

In our newsletters over the years, we have kept members up to date with the evolving story of DHEA, and its possible benefits in the management of Addison's disease.

As more clinical trials with DHEA are carried out, and their results published, and more individual experiences accumulate, it's becoming clearer that there are some Addisonians who "swear by DHEA", and some who "swear at it".

The UK ADSHG included with their recent members' newsletter, an article from the health section of the BBC News website 4 Nov02. Dr Eleanor Gurnell, a member of the UK team that has been extensively studying DHEA replacement in Addison's disease, was quoted: "A sub-group of patients seemed to benefit incredibly, and some didn't notice much difference. It is something we will have to look at further."

We look forward to the profiles from the researchers of which Addisonians are likely to get most benefit from DHEA. Professor Holdaway comments that individuals who feel that their health remains impaired despite treatment and review by an endocrinologist may be more likely to benefit – although more specific indications for treatment may emerge, such as problems with reduced bone density (osteoporosis) which might potentially benefit from use of DHEA.

Although almost all primary Addisonians have low levels of DHEA, there isn't a simple dose replacement formula. Differences in the way different brands are formulated, even with the same amount of active ingredient, seem to add to the complexity, and may affect the potency.

With the knowledge available now, the art is to find the dose that gives benefits, such as enhanced psychological well being, while minimising the side effects of oily skin or increased body odour, and keeping the blood level around normal for age.

Several NZAN members taking DHEA get their capsules from Pharmaceutical Compounding in Auckland. That enables comparisons from the same baseline. Some are taking 25mg with no adverse side effects.

Some are taking 10mg. One female member, now mid-30s and diagnosed with Addison's 9 years ago, has found 10mg too much: "After 6 months of taking 10mg DHEA per day, I have stopped. I was getting extremely heavy painful periods, and bad pimples, mainly in my hair. I stopped, and the pimples have gone. The periods are slightly better. All else is going well."

### Insurance Questions?

In a future issue we plan to have an expert address this topic. We need your input first! **Please share your experiences good or bad and send your questions to Jeanette.**

Linda writes: We're going to Sydney for Easter, the first trip there in 23 years. I have been asked to pay an extra \$100 for our travel insurance because of my Addison's. I'm going to dispute this as both times I've been to Rarotonga, I haven't had to pay anything extra. We have a BNZ gold card so this is what we normally use. I'll be interested if you've heard of any others who have been told their pre existing condition is a risk. The underwriters [AIG] also said that if we travel further than Australia or even for longer in Australia, I may not be covered at all. We're planning on going further afield next year, so you can see why I'm brassed off!!

## INTERNATIONAL NEWS

Choosing material from overseas newsletters for an International Section proved too complex – so much selection! We'll continue to feature some highlights in future NZAN newsletters. If you'd like to receive copies of the newsletters from overseas groups, please contact Annette Church - [Annette@icib.co.nz](mailto:Annette@icib.co.nz), ph 09 379 5772; ICIB, PO Box 5734 Auckland.

## OVERSEAS MILESTONES

**In the UK, The Addison's Disease Self Help Group** is holding its first Annual General Meeting as a formally constituted association, the ADSHG Charity, in London on 10 May, 2003. They have many plans and projects underway that can benefit Addisonians - we look forward to continuing news of their progress. We encourage you to explore their website, [www.adshg.org.uk](http://www.adshg.org.uk) which is updated monthly. A twice-yearly 'webnewsletter' was launched in April, to accompany the bimonthly newsletter. Deana Kenward, founder of ADSHG, and writer of its 68 newsletters so far, is nominated as President. Congratulations and best wishes to Deana, and to the incoming committee.

**The Australian Addison's Disease Association:** Singer Helen Reddy, who has Addison's disease, will help launch their second Addison's Awareness Week, 16-29 June. Several regional activities are planned. (Are you willing to help make this a Trans-Tasman co-operative venture? Please contact Jeanette with your ideas!)

## INTERNET FORUMS

Recently Peter Stewart, webmaster for the Australian Addison's Disease Association, set up an email list, for people who want to discuss or hear what others are saying about Addison's and related topics.

"I can see benefit to having cross-Tasman discussions," he says. People feel more connected talking to others in their own part of the world. I have gathered that already from their questions." Late April there were 41 subscribers, most from Australia, but some also from NZ, US, UK, Netherlands and even Africa.

You can sign up for the list on the home page of the AADA website [www.addisons.org.au](http://www.addisons.org.au). The confirmation email you receive also describes how to subscribe to the daily digest version.

There's a glitch at present that needs fixing, Peter admits. When people press 'reply' to a post, it goes to the sender, not the list therefore many threads end up being sent direct and missing the list.

There are several forums on the Internet where Addisonians share and learn. One with a large population, predominantly in the US, is [www.healinglight.com](http://www.healinglight.com). It typically has about 100 postings a day, on several themes. Forums become communities with personalities. Some people post almost daily, others once in a blue moon. Been there lately?



## **PROMPT DIAGNOSIS BRINGS ITS OWN CHALLENGES!**

### **Jeanette's perspective**

Jeanette empathises with Nicole (her story follows) that "escaping" the characteristic and debilitating symptoms of prolonged undiagnosed Addison's disease brings its own problem. It is hard to adjust to the sudden transition from a reasonably healthy life, to a diagnosis that brings with it a life-long need to take daily adrenal replacement steroids. Maybe it isn't true, one wonders?!

"In 1973, in my early 20s, I was about to head to the UK to take up a postdoctoral research fellowship. I needed a routine medical check, as part of the rules. The astute doctor at Student Health noted my rather low blood pressure, and my history of multiple endocrine disorders, and sent me to the Endocrinology Department at the hospital for

an ACTH stimulation test. The result was border-line.

"I had been under a lot of stress, but hadn't noticed any particular symptoms of unwellness. I took off to the UK, on replacement steroids, and had the ACTH test repeated there a couple of months later.

"The diagnosis was apparently quite definitive. But for a while I sometimes wondered 'in the dark of night', the extent to which a couple of months of cortisone replacement might have altered the ability of my adrenals to respond under the test conditions, and perhaps they were still quite normal. I know I am not the first person to try weaning myself off the medication, to 'prove' to myself that it really was needed (**not recommended!!**). It was reassuring to learn, several years later, that most people with the syndrome that I have, polyautoimmune syndrome type 1 (=APS1 = APECED), do indeed get Addison's disease.

"My diagnosis of Addison's was 30 years ago. The regimen was cortisone acetate 25mg in the morning and 12.5mg in the afternoon (equivalent to 30mg hydrocortisone daily, which is my dose now); fludrocortisone 0.1mg in the morning (which I still take). Blood tests were seldom done in those days to monitor progress. I was young, healthy, and didn't have any medical or energy problems with regard to Addison's. Glucocorticoid doses in those days were slightly higher on average than is more usual now, and that probably helped minimise periods of fatigue.

"The only hassle in those years, was not being able to get appropriate travel insurance. Pre-existing conditions weren't covered. It was an impossible battle – steroids were steroids, in the eyes of insurers, with perceived adverse effects including making bones break easily, whether at high doses or replacement doses. Fortunately I didn't get ill while travelling. But when young, one feels invincible! Looking back, there were some close shaves, because I didn't realise the extent of the risks I was taking. "

## NICOLE'S STORY

**Nicole learned about Addison's, and then about NZAN, from a magazine article. Published in the New Zealand edition of Woman's Day 29 July 2002, it was written by the Australian Addison's Disease Association, as part of their Addison's Disease Awareness Week. It was first published in the Australian edition – with Australian contact details for more information. However, in the New Zealand edition, no contact details were included. The first NZAN knew of the story, was seeing it in print. We contacted the magazine, and were pleased that "our flag was flown" a few weeks later.**

Hi, my name is Nicole. I was diagnosed with Addison's disease in early August, 2002. I am 32 years old, married to Tony - painter & decorator. We have two boys – Caleb 5yrs and Kyle 3yrs. We live in Upper Hutt, near Wellington. I switched my Marketing/Product Manager career for a very active fulfilling parenting role when Caleb was born. Now that Caleb is at school, I'm working again since February, part-time, and really enjoying that. I seem to have just enough energy for everything and then collapse by about 8.30 - 9pm until 7am the next morning, and that's without me feeling like I am pushing myself.

I have never had an adrenal crisis. I thought I was reasonably healthy - although I'd been constantly tired and had very little energy - but I do have two very energetic boys to add to that equation!. I was losing weight – but I had been trying to, so that didn't seem a problem. I did however take a pot-luck guess, after reading an article about Addison's disease in the NZ Woman's Day in late July, that I should perhaps get a test for Addison's disease.

The symptom that alerted me was that a couple of years or more ago my tongue had developed blue/black marks. I had mentioned this to my doctor when I first noticed it, he tested for Vitamin B12

deficiency, but nothing showed up. I don't think Addison's was considered, since I wasn't presenting any other symptoms and was reasonably healthy.

I also knew that I already had an autoimmune disorder. I get arthritic type pain in my joints. Five years ago my doctor told me that my positive antinuclear antibody result was consistent with autoimmune connective tissue disease. My mother has Graves disease (overactive thyroid). I have positive thyroid autoantibodies, but so far my thyroid function had tested normal.



So in August 2002 when I was at my GP's (I see 2 GP's at the same surgery) I asked to be tested for Addison's. When she asked why, I explained my pigmented tongue, autoimmune family history, and I am constantly tired, so best to check it.

She explained that a blood test was not going to give me an immediate answer, but would indicate whether they needed to investigate any positive results further. The first results came back normal, including Vitamin B12, sodium, potassium. That was the end of it I thought.

A couple of days later the nurse rang. The ACTH level was elevated – 243 when it should be in the range 1.3 – 15. The nurse said that the doctor would refer me to an endocrinologist for further tests. I decided to go privately to get in earlier as I was now panic stricken. (My husband always says I am a worrier!) The doctor gave me the name of a specialist whom I contacted to get an appointment. By this time it was mid-August. I could not get into that specialist until mid October – 2 months away.

That period was very stressful for me. I couldn't stand the wait. I suddenly felt sick!

It was about a week after this that a small follow-up article in the NZ Woman's Day gave

Jeanette's contact details for the New Zealand Addison's Network. Jeanette was away from home, but luckily picked up her voicemail messages and returned my call giving me Gary Roselli's name to ring to talk with.

With one thing or another I didn't ring Gary. I suppose it was because I hadn't actually been diagnosed officially, so I thought best to wait and see what the specialist comes up with. But when I was probably at one of my lowest points emotionally, Gary rang me. (Jeanette had passed on my name and number to him.) I had a very reassuring talk with him.

I probably still wasn't convinced I had Addison's disease as I didn't have all the normal symptoms: rapid weight loss, low blood pressure upon standing, fainting, vomiting/diarrhoea, increased skin pigmentation, salt cravings. But a week later I went back to my GP, as I wasn't feeling myself. I saw my other GP who had been discussing this case with his partner and he thought I should have the ACTH stimulation test. I did so. A week later the results came back, positive for primary Addison's. [My base line cortisol before the ACTH was 265 nmol per litre one hour later it was 283. It should have risen to over 300.]



Deducing that I still have a small reserve of cortisol production, and from other tests that my aldosterone reserves were still OK, my GP started me on 20mg hydrocortisone daily. He also arranged for me to see an endocrinologist at the Hutt Hospital in a couple of weeks - well before my private appointment!

A couple of days after starting the hydrocortisone (a Saturday), I was sent to hospital experiencing nausea, dry mouth, feeling like my heart and blood flow were racing. All the tests came back fine and I was discharged that day and told to decrease my

meds to 15mg. It may have been too much hydrocortisone, or perhaps an anxiety attack.

My first visit with the specialist was a few days later. He put me back onto 20mg hydrocortisone. I saw him again a couple of months later. My hydrocortisone wasn't changed, and he added fludrocortisone 0.1mg daily – he said my aldosterone and renin levels were still in the normal range, but deteriorating.

I had a problem with fluid retention after starting the Florinef, and put on 3kg in a week. I talked with my GP, and cut the dose down to a quarter of a tablet daily. A couple of months later I had a dizzy spell while chairing a meeting one evening – and went home. I had my BP checked next morning, it was low, and after talking with my GP put the Florinef up to half a tablet daily, which I am still taking.

I haven't lost the extra weight I put on, however. Recent tests have shown that my thyroid function has declined, and my specialist said that may be influencing my weight. If that is the reason, it will be fixable when treatment gets sorted.

Life was an emotional roller coaster for the first months after my diagnosis. At times I have felt grief for the life I no longer have, being dependent on steroid medication for life. I constantly had questions. Every ache, the slightest unusual twitch I was questioning the Addison's link. I have found it very helpful reading the newsletters and learning of other people's experiences and strategies for coping with Addison's and other Endocrine Diseases. Contacts in NZAN have helped me a lot. Jeanette put me in touch with Karen, because we are of similar age, and both have a young family.

My husband Tony has been a tower of strength and keeps me laughing. I even get breakfast in bed on the weekends now! My GPs have been fantastic and very helpful in getting me "educated" and on a happy plateau.

Overall I have more energy than before diagnosis. I was proud of myself over the Christmas period. I had 27 guests at our house, I planned Christmas dinner down to the finest detail and even managed to enjoy a couple of glasses of champagne to celebrate! I kept my dose at 20mg hydrocortisone throughout the period and felt good, despite my hands seizing up.

When I saw my specialist in February, he increased my hydrocortisone dose from 20mg to 25mg because my ACTH was still high. I noticed soon after that dose change, that the pigmentation faded around my knuckles and in skin creases and on my palms. There is still pigmentation on my tongue, but it's fading too. I feel that I am getting very well looked after.

Addison's is a rare disease, but I now know of four other people within the Wellington region, who are perhaps not in the network. My own experience makes me wonder how many other Addisonians are walking around as yet undiagnosed.



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

## **COLLEEN'S STORY**

### **An account of "Secondary" Adrenal Insufficiency**

Colleen prefers that her story is not included in the website version of this newsletter. If you are interested in reading it, please contact Jeanette.



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

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

Your feedback is appreciated – it is fuel in the tank of the NZAN engine!

Smile time - from a recent AADA newsletter:  
I stopped at a friend's shop recently and found him stalking around with a fly swat. When I asked if he had got any flies, he replied: "Yeah, three males and two females".  
Curious, I asked him how he told the difference. He replied: "Well, three were on a beer can and two were on the phone."

**DISCUSSION DRAFT:**

## **Injecting intra-muscular hydrocortisone (Solu-Cortef): BACKGROUND**

We are here focusing on the practical aspects of giving an intra-muscular injection of hydrocortisone (Solu-Cortef).

For an Addisonian, injecting hydrocortisone yourself in an emergency, or having a companion do it, can save your life, especially if you are isolated away from emergency medical services.

It can also save you a lot of hassle and frustration, trying to explain to a health professional about your rare condition, and your need for extra hydrocortisone at that time.

Addisonians in need of extra hydrocortisone do not function well mentally, and are not good advocates for themselves. It's important to understand that matters won't improve on their own – the issue is, how fast will they get worse. Therefore simple threshold rules are wise – erring on the side of caution.

Usually, if you have vomitted more than once, you have an urgent choice to make: either give your own injection, or go to get it administered for you, recognizing that it could be a while before you get it. (See Karen's Tummy Bug Experience, page 5) See also the summary from Professor Holdaway's talk in Auckland July 2001 (reprinted page 6).

Other circumstances in which an Addisonian requires hydrocortisone injection include serious accident, significant blood loss, or drowsiness as a progression of flu or other illness, especially involving high temperature.

You might carry injectible hydrocortisone for many years, and not need it. But if crunch time comes, two things are certain.

- You won't be thinking at your sharpest.

- Someone with you may be faced with doing an intra-muscular injection for the first time.

**The likelihood that you or a companion or family member will proceed without delay, to give what could be a life-saving injection of hydrocortisone depends in large part on the clarity and completeness of the written instructions you carry with the injection materials.**

Our purpose here is guidelines that describe as clearly and completely as possible what to do – and the logic. There is a short summary also at the end. We suggest that you copy these pages, make any extra notes needed for your own situation, and include them with your injection kit.

Especially if you are traveling away from home, and away from easy access to doctors who know you – arrange two complete injection sets. There is psychological benefit in having a spare. Also if you do need to use one, you don't have the spare any more!

### **Acknowledgements:**

These detailed guidelines have been compiled with encouragement and help from NZAN's medical advisor, Professor Ian Holdaway.

We are grateful for published material to build on, from the US NIH website [http://www.cc.nih.gov/cc/patient\\_education/p\\_epubs/mngadrins.pdf](http://www.cc.nih.gov/cc/patient_education/p_epubs/mngadrins.pdf) and the US NADF (currently accessible on <http://addisons-diabetes.gkznet.com/articles.htm>).

We thank Christine McGrail endocrine nurse specialist at Auckland hospital, and other health professionals and members who have made us aware of aspects that needed clarification, and how to achieve that. We thank Wendy Schubert for additional information from the NIH nursing team.

## **DISCUSSION DRAFT: NZAN Guidelines for injecting intra-muscular hydrocortisone (Solu-Cortef)**

### **A. Items required for IM injection of hydrocortisone:**

- \* **one vial of hydrocortisone (usually 100mg Solu-Cortef mix-o-vial, which includes 2ml liquid),**
  - \* **one 5ml (OR 3MLM) syringe, disposable plastic,**
  - \* **one 20 G 1-inch needle for filling the syringe (yellow hub),**
  - \* **one 23 G or 25 G 1-inch needle for injecting the Solu-Cortef (orange hub).**
- For a large or obese person, a longer needle may be needed (eg 22G 1½ inch - black hub).
- \* **sterile alcohol swab,**
  - \* **cotton wool or gauze**– the injection site may bleed afterwards, and need gentle pressure for about a minute. A sticking plaster as well is optional.
- \*and the instructions, personalized for you!** *We recommend that you get help from your doctor or nurse to confirm the best needle gauge and length for your body build, and the best injection site(s) – and write this into your instructions, preferably with a picture, where “X marks the spot”!*

### **Notes about syringes, needles and technique:**

1. Syringes and needles are not part of the pack of Solu-Cortef obtained on prescription in New Zealand. Some pharmacies do supply syringes and needles, but most people get them from their GP.
2. Store the needles and syringe in such a way that the packaging doesn't become damaged, breaking the sterility. Putting everything inside a zip-lock snack-sized plastic bag is one option that works. Putting that bag inside a solid container gives greater robustness – label it clearly, especially if it isn't see-through!

3. Syringes and needles usually come separately. A 5ml syringe works well, and is less fiddly to use than a 3ml syringe. But a 3ml syringe is also OK. Avoid a 2ml syringe, which would be completely filled by the liquid, and therefore harder to use.
4. It is convenient (but not essential) to have two needles – one to draw the solution into the syringe, which may become a bit blunted when it goes through the latex; the other one for injecting into the muscle. (A blunted needle needs more force to get through the skin, and may hurt a bit more.)
5. Syringe needles are colour coded for gauge (size of the hole). The sizing system may seem “reverse logic” the *smaller* the number, the *bigger* the hole. The needle for getting the liquid out of the vial and into the syringe can be the same length and hole size as the one used for injection (usually 25G, orange hub) – that is the simplest option. However, it is easier to draw the liquid up if one uses a needle with a bigger hole, such as 20G 1 inch (yellow hub - easy to remember, yellow hub and yellow plastic on the vial.) (Nurses at the US NIH told us they use 23G, which would perform very similarly to 25G.)
6. For injection into the thigh or buttock muscles of an adult of average build, the usual needle length is 1 inch. (The ½ inch needle on disposable syringes used by diabetics is not suitable.) For a person who is very large, or overweight, with a lot of fat under the skin, a 1½ inch needle may be needed to get the medication into the muscle, and not just into the subcutaneous tissue. *[Injecting into the fat under the skin is not dangerous for the person – rather, the hydrocortisone won't be absorbed into the body very effectively, so the benefit of the injection will be much less.]*
7. It's common sense to have the injection site as clean as possible. A foil

wrapped alcohol swab in your kit can be used to clean the injection site, as described below. However wiping with a sterile alcohol swab is not essential – it does not instantly sterilize the skin around the injection site, or the latex on top of the bottle.

## B. Fill the syringe.

*When first packing your kit, we suggest you look at the vial, and read the instructions on the cardboard carton, to confirm that it will indeed be easy to push the liquid through into the solids compartment, gently agitate to get a clear solution, then pull off the plastic tag so the syringe needle can be pushed through the rubber seal, and the liquid pulled back into the syringe.*

1. Press down on plastic top of bottle to force liquid (in top) to mix with powder (in bottom compartment).
2. Shake gently to mix, and wait about a minute for air bubbles to disappear.
3. Remove plastic tab covering centre of stopper.
4. Take syringe out of its package and put biggest gauge needle onto syringe (e.g. the 1 inch 20G, yellow hub needle – or the 1-inch 25G orange hub if that is all you have), and remove the protective cap.
5. Pull out plunger of syringe to about the 2ml mark.
6. Insert needle into bottle, and push plunger down to insert air into bottle
7. Turn bottle (and syringe) upside down – be sure that end of needle is in the solution
8. Pull back (down) on plunger to load all the solution (2ml) into the syringe.
9. Withdraw syringe from bottle.
10. If you have a second needle (eg 1-inch 25G orange hub), cap the needle that's on the syringe to make removing it safer, replace with new needle, and remove protective cap.
11. Remove any large air bubbles, by tapping syringe barrel, with needle pointing upwards – then push gently on plunger until a drop forms at the end of the needle. *Note: there is no need to worry if some air is injected into the muscle.*
12. Put cap back on needle, put syringe down, then prepare injection site.

## C. Know the most suitable injection site, for the person's body size, and muscle size.

*Having the best site(s) written down, preferably with a diagram too, means that you, or a companion, can just follow instructions, without having to figure out choices in a stressful situation.*

The easiest site for most people is the upper **outer** thigh (a few cm away from the imaginary midline), mid-way between knee and hip.

If the person is wearing tight jeans, for example, the upper outer buttock (gluteus muscle) may be more accessible; or the hip (side, just below hip bone).

If the upper leg muscles are not accessible, another option is the upper outer arm near the shoulder (deltoid muscle).

## D. Give the injection

1. If possible, wipe the injection site with a sterile alcohol swab - start on the spot where the needle will go, and wipe the skin with an increasing circular motion.

2. The usual practice is to hold the syringe like a pencil or a dart, stab quickly and decisively at a 90 degree angle, insert the needle all the way to the hub.

Bunching the tissue around the injection site by spreading fingers and thumb as wide as possible, and then closing together, is a useful thing to do with the other hand. The needle goes in at the peak. Bunching is especially relevant if the person is thin or small, or if the upper arm muscle which has little fat around it is being used - in these circumstances one can also put the needle just halfway, or at an angle between 45 and 90 degrees.

Bunching helps provide added reassurance that hitting bone is unlikely. *[It's a common fear – what if I hit bone?? It's very unlikely*

*using the needles, sites, and procedure described. Even if one did, there is no danger or lasting damage – just pull back the needle into the muscle before injecting, or pull it out and re-inject. What if I hit nerves?? This is very unlikely too using the injection sites described.]*

3. Pull back slightly on the plunger to check for blood. *If you see you have sucked up blood, withdraw the needle, and put pressure on the site for about a minute. Change the needle if you have a spare (it will be sharper), or use the same needle and re-inject nearby.*

4. Push down on the plunger steadily to deliver the solution – *this is done “without delay”, but because 2ml is quite a large volume, it takes 5-10 seconds.*

5. Withdraw the needle, and cap it straight away for safety reasons. Put pressure on the site for up to a minute with cotton wool or gauze to stop any bleeding.

6. If you are feeling fine after the injection, drink plenty of fluids to replace those lost due to vomiting and/or diarrhoea. If despite having the hydrocortisone injection vomiting persists, or you feel unwell, go to A&E promptly for replacement fluids IV.

Perhaps you don't feel that practising by injecting into an orange is close enough to the real thing?

Are you a bit on the thin side, or petite, with the niggling fear that despite what you've read above, pushing a 1-inch needle in to the hub might hit your bone?

Talk to your doctor or practice nurse about having a dummy run with 2ml of sterile saline solution. That was a great confidence builder for one person we heard about!

We are exploring including this at Regional Meetings when we have appropriate health professionals present.

currently available on NADF's website, but are accessible scanned onto <http://addisons-diabetes.gkznet.com/articles.htm>

### **To administer hydrocortisone IM Injection (Solu-Cortef):**

1. PRESS DOWN on plastic top of bottle to force liquid (in top) to mix with powder (in bottom).
2. SHAKE GENTLY to mix.
3. STERILISE top of bottle (not essential).
4. PULL OUT plunger of syringe part way.
5. INSERT SYRINGE into bottle and force plunger down to insert air into bottle.
6. TURN bottle and syringe UPSIDE-DOWN, be sure that end of needle is in the solution.
7. PULL BACK (down) on plunger to load ALL THE SOLUTION into the syringe.
8. WITHDRAW syringe from bottle.
9. PICK injection site: best choice is THIGH (front outer); other choices are DELTOID (upper arm near shoulder); HIP (side just below hip bone); GLUTEUS (buttock, upper outer quarter).
10. STERILISE site (not essential).
11. PINCH muscle and INSERT needle (hold syringe like a dart, stab quickly, insert all the way.)
12. PULL BACK on plunger slightly to check for blood. (If you see blood, withdraw needle and re-insert nearby.)
13. PUSH DOWN on plunger to deliver solution – do this as quickly as possible.
14. WITHDRAW needle, put PRESSURE on site for 1 minute to stop bleeding.
15. GET TO A&E FOR FURTHER TREATMENT AS SOON AS POSSIBLE. Appropriate fluid replacement is very important.

## **SUMMARY**

This is slightly adapted from the NADF summary instructions – which are not