

# New Zealand Addison's Network

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## NZAN Newsletter, December 2005 (No 25)

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### Season's Greetings

#### In this issue:

Jeanette's column, and thanks 2  
Membership update 3  
Subscriptions 3  
Reprinting NZAN's pamphlet 3  
Warm thanks to Mediboard 3  
White Florinef is here 4  
Keep a month's buffer of meds 4  
Regional meetings 2006 5  
Meetings held during 2005 6  
Travel Tips 7  
Members' diagnosis experiences:  
Charlotte 9  
Joel and Joshua 10  
Mary's Story 11

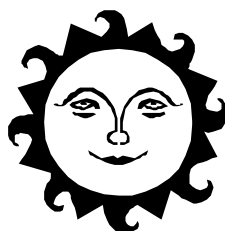


Wishing all readers  
good health and good stamina  
over the festive season,  
and through the year ahead.



Jeanette and the team

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



## Jeanette's Column



The arrival of this newsletter will hopefully reassure all on the mailing list that NZAN is still alive and kicking.

Putting this together, I've been reminded how big a task it is. Fortunately, for once, time has run out before I risk pushing myself too hard again!

The approaching festive season is a good time to acknowledge some key people within NZAN.

### **Sincere thanks to those who have contributed their time, energy and skills to NZAN during 2005, including:**

\* Professor Ian Holdaway, our medical advisor, whose clear and practical advice is much appreciated by members. I value the perspective and experience he shares, to help guide priorities within NZAN.

\* Annette Church who keeps our database, and the members' contact list, and does the magic mailouts. Her 'no problem' manner is a treat.

\* the several members who have arranged regional meetings, shared their news and experiences, kept in touch with me, and helped each other.

NZAN now has more than 150 members. Some 'old hands' diagnosed for decades, as well as those relatively newly diagnosed, clearly enjoy the meetings around the country, where they learn a lot from listening to others with the same diagnosis, hearing their tips and experiences, and participating in the discussions,

I am doing my best to gradually move NZAN onto a wider base, so that the load will be more evenly shared. Less progress has been made this year than I had hoped, mainly due to my own health issues. But another year is just around the corner! Please come forward with your ideas.

There still seems to be a lot of luck involved in how and at what stage a person gets diagnosed with Addison's disease, and then whether they adapt easily to have a 'normal life'.

The members' stories in this newsletter show very different experiences of the diagnosis process. Charlotte's fell into place easily. Mary's diagnosis in Hari Hari on the west coast of the South Island, was a regrettably drawn out affair.

Some members have suggested that mentors for younger members, and "buddies" for the newly diagnosed, and for new NZAN members however long ago they were diagnosed, could help make the whole process of living with Addison's disease less overwhelming and less lonely. We have many examples, where contact with our network has made a difference. If being a mentor or a "buddy" interests you, please contact me to share your ideas.

Beryl, Jessie, Phillipa, and others whose stories may seem stuck in the pipeline... apologies, they will be in a future newsletter, when there is opportunity for comment and context from Professor Holdaway. . I was not able to complete this newsletter sooner, and felt it would not have been fair to put the draft to him, so close to Christmas.



Belated congratulations, Phillipa, on training for and completing a half-marathon earlier this year!. Again next year?!

## Membership Update

In the May mini-newsletter we welcomed five new members since the December 04 newsletter: Gaye, Greg, JenniferH, Margaret and Valerie.

Since then, 13 new members have joined: Annalise, Charlotte, Grace, Jane, twins Joel and Joshua, Josephine, KarenP, Kay, MaryN, Sherrin, Shona, and Trevor.

Charlotte, Jane, Joel and Joshua, and KarenP were diagnosed during 2005. Mary was diagnosed in 2004. Trevor was diagnosed 54 years ago!

Three of the 13 were told about NZAN by their endocrinologist, two by their GP. Joshua and Joel's mum Sandra was told about NZAN when she phoned the Southern Cross Helpline.

That brings the tally to 154 members. Information packs have been sent to a further 10 this year.



## Subscriptions

One consequence of the slowdown with newsletters this year is that an invoice for subscriptions wasn't sent out as usual in March/April. Some members sent theirs anyway (thanks!), and some others wrote to ask what was happening.

After consideration and discussion, this is the plan!

\* An invoice will be sent with the first newsletter in 2006. That will be for the year from 1 April 2006. We will keep the amount at \$20 (no adjustment for inflation since we started in 1996!), because as usual there is the option for members to add a bit extra.

We hope that as many members as possible will also be willing at that time to pay the \$20 subscription for this year, 2005/06. That should give us the funds for the new print run of our pamphlets (see below).

**As mentioned in the mini-newsletter No.24 sent out in May, Jeanette now lives in Auckland.**

**NZAN's mailing address is now:  
PO Box 17-414, Greenlane  
Auckland 1130.**

**Jeanette's phone number is 09 636 8238;  
mobile 0274 494 048**

**Mail is being forwarded from the previous box in Havelock North, until 31 March 06.**

## Reprinting NZAN's Pamphlet

It's time to reprint our pamphlets - the canary A4 sheets folded in 3 - because we've almost none left. We welcome feedback from anyone who'd like to comment before we do this [please send to Jeanette]. We are not planning major change - we'll in particular update NZAN's postal address, contact details for co-ordinators, and the number of members.

In October 2003, when the last lot were printed, NZAN had about 100 members. Now we have more than 150!

## Warm Thanks to MediBoard

We are very pleased that the MediBoard Group is willing to continue its generous support of NZAN. The fortunate relationship started when Jeanette phoned the number on the MediBoard display in her own GP's waiting room, in Havelock North.

A trial in the eastern region was extended nationwide, and our pamphlet is now included with the 40+ displayed in Perspex holders, mainly in GPs' waiting rooms. Some of our new members over the past couple of years found out about NZAN this way. We know also that some people have used our pamphlets to clarify with their doctor whether their symptoms might be Addison's disease.

Company founder Ivan Myers says, "MediBoard has been in operation since 1996 and we believe it is now seen as a very effective way of distributing health-related pamphlets. We have installed pamphlet-holders in over 600 sites throughout New Zealand. We service these sites on a regular basis, replenishing the pamphlets and also keeping the pamphlet-holders neat and tidy.

"We find that doctors and the practice-managers really appreciate the free information resource, and the patients in the waiting rooms can browse the pamphlets where they will invariably find something of interest to them or their families."

## White Florinef is here

### Dear Santa – Please bring me a Pill Cutter Jeanette's update:

The white Florinef arrived in New Zealand at the end of November, and will take about 2-3 months to work their way through the distribution system.

We've been assured on email by Bristol-Myers Squibb in Australia that the only change between the pink and the white tablets is the removal of the colour; that all other excipients [all the fillers], the manufacturing process and the specifications are identical. The amount of colour is so small, that the difference in tablet weight is almost undetectable. We've been told there is no change in the dissolution profile for either tablet. (The main demonstration of equivalence to satisfy Medsafe was based upon dissolution profiles.)

The distributor arranged for me to fill a prescription with the white tablets. I was hoping to personally confirm ahead of their general release, that they behave as expected.

Practical issues! It is frustrating that the tablets are almost indistinguishable from 5mg hydrocortisone tablets. The white Florinef are

marginally thinner than hydrocortisone tablets, but the same diameter - and it seems to me that the scoring on one face of Florinef is clearly visible only in bright light. We'll have to be careful to have systems so that we don't make mistakes.

Adding to my frustration, I find the white tablets impossible to break in half without a pill cutter – in contrast to the pink Florinef which I can quite easily and cleanly break in half with my fingers.

A proportion of people take half a tablet, or 1.5 tablets of Florinef daily, so having to remember to take not only the pills but also the pill cutter when travelling away from home is a hassle they could well do without. It is a new learning curve, whether pre-cut halves carried around in a bottle will tend to break up on the cut edge, and/or be more likely to take up moisture along the cut edge if stored as halves. I'm hoping that Bristol-Myers Squibb can share some experience here. I'll keep members posted.

**Dear Santa – if there is a choice, please bring back the pink Florinef instead.**



Reminder:

**Don't let your supply of hydrocortisone, prednisone, and fludrocortisone run low – keep a buffer of a month's supply**

This advice applies for all medications essential for life, in these uncertain times. As there are few sites worldwide that manufacture our medications, this is a sensible precaution in these uncertain times, especially with the shadow of terrorism or perhaps bird flu.

This will enable you to have pink tablets in reserve, when you receive your first supply of white ones. So you can start the white ones straight away, and in the unlikely event that

you do suspect any difference, you have pink ones you can return to, for comparison.

Even without terrorism and bird flu, supply shortages in supply can occur sometimes. The UK had a shortage of Florinef for about 3 months in the latter half of this year. I haven't had a chance to clarify the reason, but apparently some Addisonians there had to halve their dosages until the new supplies came. [BMS Australia supplies New Zealand, but not the UK]

\*\* Check that all your medicines are stored in a cool dry place. The kitchen and bathroom are not good places. Tablets that are stored long term above the recommended temperature [typically 25 C, check with your pharmacist] and/or tablets that are exposed to moist air [for example when containers opened in a steamy bathroom] can lose some of their potency before their expiry day.

If you get three months supply at once, we suggest you ask your pharmacist to pack your hydrocortisone, prednisone, and fludrocortisone each into three smaller containers, or where possible to leave them in their original packaging. Hydrocortisone tablets conveniently come in sealed bottles of 100. This saves exposing them all to moist air when opening the bottle, and also makes it easy to tell when you are nearly at your one month buffer point. Instead, you could transfer about a month's worth at a time, into a smaller container for your daily use, but that won't have the advantage of the correct label.

**If you have an email address, but it isn't on the members' contact list, please send it to Jeanette. That makes it much easier for us to send you meeting notices and other information between newsletters. ([Jeanette.c@paradise.net.nz](mailto:Jeanette.c@paradise.net.nz))**

## Regional Meetings 2006

The following are some of the meetings planned:

### **Nelson / Marlborough: Saturday 11 or Sunday 12 February.**

Which date is still to be confirmed. Speak up now, if only one of those dates would suit you!  
Venue: the new lounge at Grace Church in Richmond, Nelson.

Contact: Grace 03 547 4464 or Pauline 03 544 4813

[see brief introductions below]

### **Timaru: probably February.** Contact Dyan 03 684 5633

### **Auckland: Saturday 8 April.**

Venue: again, the Grey Lynn Community Centre,

Contact: Karen 09 483 7043

Karen intends a further couple of meetings during the year.

### **Wellington: May again,** organized by Gary Roselli.

Local member Mike is planning a presentation on Travel Insurance – if you have any questions on this topic, send them to Gary [[pamandgary@xtra.co.nz](mailto:pamandgary@xtra.co.nz)]. If possible, Pauline will again coach members in giving themselves IM Solu-Cortef.

### **Whangarei:** attendees in November were keen for another meeting, perhaps mid-year. Contact Maureen 09 436 3136



We encourage members living outside the centres which currently have regular NZAN meetings, to consider arranging a meeting this year in their district.

It isn't important to have a large number present at the meeting. Even five can have an interesting and worthwhile time, sharing and comparing, and generating questions for clarification later. Please contact Jeanette if

you'd like help to raise the NZAN flag, so to speak, in your neck of the woods.

We try to notify members 4-6 weeks ahead, in a newsletter if possible, or by email and snail mail to members in the broader area, requesting RSVP. Then a follow up phone call about a week before.

If we send a separate notice, it hasn't so far been to the whole membership. Being practical, we make a judgment call as to how far people would be likely to want to travel.

If you would be like to kept informed of meetings coming up outside your area, please contact Jeanette. [For example, would Waikato and Bay of Plenty members like to also be informed of Auckland meetings?]



### Pauline's Pearl

PaulineB is a West Coaster originally, living in Nelson these days. She needs replacement hydrocortisone and fludrocortisone and some other meds too, because of treated Cushings disease. In 2004 a pituitary tumour wasn't completely removed by surgery and radiotherapy, so she also had her adrenals removed. It's been quite a challenge stabilizing her wellness.

She keeps her morning pills beside the bed with her water bottle, and takes them on awakening. Her husband Pete brings her a cup of tea a bit later.

One day – "You haven't taken your pills yet."  
"Yes I have."

The pills were indeed still there – but only one pearl stud earring. The other must have felt just like the two pills...and was never seen again.

"For Christmas Pete bought me a nice set of pearl earrings, with a piece of string tied on each as a joke. He said, If you swallow these, we can pull them back up!"

**Grace** did a Google search on the Internet after her pharmacist told her a few months ago that cortisone acetate was no longer available to fill her prescription. Perhaps she was the last Addisonian in New Zealand still on cortisone acetate!

He had no suggestions about what to do next, and her regular GP was away. Finding NZAN was a welcome surprise. She hadn't seen a specialist since diagnosis with Addison's nearly 20 years previously. She has since had a thorough specialist review, switched to hydrocortisone, added some fludrocortisone, and some DHEA, and, yes, really will try hard to give up smoking in the new year.

### Meetings held during 2005:

- Auckland in May and December, thanks to Karen Carson and Andrea Bunn
- Wellington in May – thanks to Gary Roselli and to Pauline Dennehy who demonstrated and coached self-injection with Solu-Cortef
- Whangarei in November, thanks to Maureen Bourgaize

Feedback from participants confirmed that all of these meetings went very well. There isn't time or energy to provide detailed reports at this time! If you weren't there, we can only encourage you to come along next time.

One topic that has come up at a few meetings, is disturbed sleep patterns. We have mentioned it before in newsletters.

Running low on cortisol overnight can be the cause of waking in the early hours – around 3-4-5 am. If that is the problem, then taking one's last tablet as one turns out the light, perhaps 2.5-5mg hydrocortisone or 1mg prednisone, can fix it. A few members have tried it, and found they sleep through, and wake more refreshed.

A couple of older members with different sleep problems shared that their meds regimen for years has included 10mg hydrocortisone in the evening, which is a higher dose than most people take then. They realized it would be a good idea to have their medication regimen reviewed by an endocrinologist.

The key message is – if you regularly have sleep problems, tweaking your dosage timings might help. It could be worth asking your doctor about.

#### Reminder:

The NZAN Guidelines for Self-Injection of IM Hydrocortisone can be downloaded from the NZAN Website [www.addisons.org.nz](http://www.addisons.org.nz) For a printed copy of this 8-page booklet, please contact Jeanette.



## Travel Tips

In April, an email came from a member, KarenC: “In May we are off to Europe for 6 weeks. This is the first time I have travelled overseas since being diagnosed. When you travel overseas do you take any documentation on Addison's for just in case? Do you have any hints & helpful advice?”

The information is rather scattered through our newsletters, and it seemed timely to pull it together.

Mary, whose story appears in this issue, is planning a 6 week trip to Europe with her sister next year, and wrote “I will be reading up some of the Addison's newsletter back issues for handy hints.” So hopefully the compilation will help her too.

The items can be found in the Table of Contents File, which can be downloaded from the Newsletters page of the NZAN website, and is updated after each newsletter. [The

material in Newsletter 7, which isn't on the website, has been reprinted in later issues.]

- Are you well labelled, in case you need an emergency trip to an unfamiliar hospital? No.7, pp2-3
- More tips for travellers. No.7, pp 3-4
- Lois's Travel tips for Addisonians in Asia (from NZAN Newsletter No.10, July 2000):
- Emergency information in foreign languages No.13, p6
- Emergencies, are you ready, No.14,p6
- .Are you prepared for emergencies? Addisonians their own worst enemies; letters speak for you, No.17, p2-3
- Safety tips for travelling, especially overseas. No.17, p5
- Emergency letters again prove their value No.18,p2

In short, when you are planning a trip overseas, it is important to do your Addison's homework!

This is a reminder summary – not claiming to include everything!:

- If possible, take enough meds to last your time away;
- Have a means of keeping at least your day's supply of pills on your person;
- Keep all but the current few tablets in their original pharmacy labeled containers;
- Take at least 2 injectible hydrocortisone [Solu-Cortef] kits, and some extra syringes, ensuring that you and your traveling companions know how to use it;
- Don't put all your meds into checked baggage - keep at least a few days' supply in your hand luggage;
- Ensure you are well labeled– eg wear Medic-Alert bracelet or pendant, and in your wallet, carry a Medic-Alert card and copy of your doctor's letter;
- Have a letter from your doctor explaining what medical conditions you

have, and what meds you take, and what treatment you need in an emergency. If you are traveling by air, include in the letter that you need to take injectible Solu-Cortef plus syringes into the cabin. Also, attach instructions for treating an adrenal crisis. NZAN has some material translated into foreign languages. [see Newsletter 17]

- Have access to extra salt, especially if you are in a hotter climate than you are used to.
- Stay well hydrated – make sure you have plenty of water accessible
- Choose your food and beverages wisely to minimise your risk of food poisoning – stick to water that is bottled or has been boiled, fruits that you can peel, meals that have been freshly cooked, etc. Avoid ice in drinks and ice-creams from wayside stalls.
- Pack anti-nausea pills or suppositories (especially if travelling to places where food poisoning may be a problem)
- Make sure your traveling companions know what to do for you in an emergency.
- Ensure you have medical insurance. You may find you get a better deal, if you demonstrate to the insurer that you have a sound plan and the necessary items for minimizing the risk of an Addison's Crisis.

And some additional advice about traveling in Asia, from member Lois, originally from Christchurch, who lives there (Newsletter No10, July00):

"I think anyone contemplating a holiday in Asian countries should "go for it". When one is on holiday the aim is to fit in as much as possible, and this can entail racing around like a mad thing in the tropical heat. I would advise travellers to allow an extra day or two if they are contemplating a busy tropical holiday.

"I travel with hand wipes so that I can clean my hands and sometimes utensils before eating. I also take a packet of straws with me, but usually drink tea and coffee in restaurants. Maybe living here in Asia for so long I have built up a bit of immunity to these "bugs", but I can honestly say that in all my years of traveling, I have not fallen ill. "

If you have feedback, or something to add to the list, please let Jeanette know. This will be a useful section for the Addison's Checklist being compiled.



**The updated members' contact list is enclosed with this newsletter. To help protect privacy it is available only as printed copy, and only to members.**

**If you see any details that need changing, please let Jeanette know.**



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

## Members' Experiences

It's good to be able to publish experiences where the path from GP visit to diagnosis to stabilization of Addison's disease proceeds as effectively as we'd hope it could for everyone.

Two of our new members at the Auckland meeting, diagnosed earlier this year, were fortunate that their GPs had been on the ball when presented with some of the Addison's symptoms, even though the individuals didn't understand their significance at the time.

Both were constantly tired, but unable to sleep well in the months before diagnosis. Joel was losing weight. Charlotte was almost pleased she wasn't putting on weight, despite not dieting.

As well as symptoms that are rather non-specific for Addison's, they both in hindsight had some increased pigmentation and slight salt craving when they went off to their GPs, but didn't realise these were symptoms of an illness. Charlotte thought nothing odd about her slight craving for salt, because she has always preferred savoury to sweet.

In contrast, **Mary** had a terrible time getting diagnosed in Hari Hari (Westland), finally getting the steroids she needed in 2002.



### Charlotte

Charlotte went to her GP six months ago, not because of symptoms that were concerning her, but because she needed a medical certificate to start a diving course.

A couple of years previously her GP had put her on thyroxine for low thyroid function, but had taken her off again after a few months. Aware of that history, and because of her "healthy tan" in May, [Had she been sunbathing? No, no, no...!], her GP referred her to a specialist. A constant stream of people had commented to Charlotte, perhaps

enviously, that she looked so brown, where had she been?

Charlotte expected something like a Molemap would be needed, and was surprised that her appointment was with an endocrinologist about 6 weeks later, on a Monday. She had some blood tests, an ACTH stimulation test, and saw the specialist again on the Friday. She filled the prescription for hydrocortisone and fludrocortisone on the way home, and started them Saturday morning.

"When telling me the diagnosis, my endocrinologist said that I'd think I hadn't been feeling bad, but I'd feel "1000%" better than I was feeling then, and realize just how bad I had been feeling. I didn't believe that was possible. But within 24-36 hours of starting hydrocortisone I found out that was indeed true."

"Looking back, I did have several characteristic symptoms, but I had rationalised them. For three months I hadn't been sleeping well, and couldn't last beyond 9pm. But I put my tiredness down to not sleeping well. My weight had been stable for many months despite not dieting." She didn't consider herself particularly weak, and although her blood pressure at diagnosis was low [especially on standing], she had only occasionally felt dizzy. And she had dismissed those occasions as "just headrush" from getting up too quickly.

"For the first 3 months I took 15mg hydrocortisone and 0.1mg fludrocortisone on awakening at about 6.00am, and 10mg hydrocortisone at 3.00pm. For the second 3 months my endocrinologist has me taking 5mg prednisone on awakening, and 1mg at bedtime, as a comparison. I haven't felt any difference between taking hydrocortisone or prednisone. But it is much easier not to miss a dose of prednisone! When I am going to bed, I prepare my pills for the morning, and take one literally as I turn out the light. In the six months since diagnosis, I have had only 3 nights broken sleep.

“For the first three months, I had monthly B12 injections, and daily iron tablets as well. At my 3-monthly appointment I was put back on thyroxine, and am taking 50 mcg in the morning.”

Was she pleased she'd participated in the NZAN meeting in December? “Yes! I came away feeling more relaxed, and lucky I'd been diagnosed early, and stabilized easily. The only depressing thing about Addison's for me [so far!] has been the weight gain. I now weigh 73-74kg, that's 5kg more than I was before – I am 5'8" tall.” That's something to raise at her next specialist's appointment in the new year. Charlotte recognizes that “family genes” probably don't help, as other members of her family tend to put weight on easily. She has done Weight Watchers in the past, and will probably do that again.

Charlotte is now 44. She was born in the UK, and was a detective in the London police force for 20 years. When she came to NZ in 1999 she became an investigator for the serious fraud office. Now she works from home, investigating insurance fraud. Home is a boat. She and her partner are involved in charters also, which involves catering, which Charlotte enjoys... food.... Yes, Weight Watchers again in the new year, she says. It's better to stay ahead of those potential extra kg.

And the diving course? “I haven't yet done it, only because of an unrelated ear problem which hasn't resolved yet.”



## Joel and Joshua

Seventeen year old Joel was at the Auckland meeting with his twin brother Joshua, and his mum Sandra.

Joel's diagnosis of Addison's disease was confirmed in July. His mum took him to the GP in April, concerned about a lot of symptoms developing since Christmas -

weight loss, fatigue, sleep problems, thirst, feeling cold, irritability, inability to handle relatively minor infections. He'd been very sick with the flu, and also after the meningococcus vaccination. Sandra was wondering why Joel's eczema scar tissue especially inner thigh and behind his knees was turning very dark. [He did have some salt craving, which she recognised in hindsight.]

Joel's GP promptly referred him to the general medical team at the Counties Manukau Clinic at Middlemore Hospital. “While we waited for an appointment, I took him privately to see a paediatrician. Unfortunately he didn't pursue Addison's, even though [I found out later] Joel's serum sodium result was low, and a 9am serum cortisol was in the low range, generating the comment on the form to consider a short synacthen test for adrenal insufficiency.

The paediatrician's letter to Joel's GP commented on his good colour, and included ‘I cannot find any distressing abnormality with Joel, and hope he still continues to grow to achieve his height potential.’”

Fortunately, the appointment for the hospital clinic came at the end of June. Their GP encouraged them to attend for a second opinion. At the Tuesday clinic, Joel was seen by a locum, whose uncle has Addison's disease. Joel was sent for an ACTH stimulation test, diagnosed, and started his meds on Friday night.

He was referred on to the endocrinology clinic, and seen there. Then, the family decided for accessibility reasons, to transfer to an endocrinologist whom they see privately, who has monitored both boys “He has been very accessible with phone advice, scripts, and prompt appointments when needed, which has made the adjustment much easier for the whole family to deal with.”

Although he was symptom free at the time, twin Joshua's ACTH stimulation test showed some cortisol reserves, but a blunted response. Like his brother he had positive

adrenal autoantibodies. It was considered just a matter of time.

Mum kept a close watch. First, Joel's symptoms had shown in contrast to Joshua's continued good health. Now, with the comparison of Joel stabilized on his meds and well again, Joshua was showing the same symptoms that had led to Joel's diagnosis.

A few days after the NZAN Auckland meeting in December, Joshua awoke feeling hot and unwell. He'd been feeling wrung out and exhausted all week. He didn't want to get out of bed to go with his brother to help Dad at work - something he enjoyed. Mum realized it was time for some hydrocortisone, same morning dose as Joel, as the specialist had primed her. He was still not wanting to get out of bed an hour or two later, and so his mum gave him a repeat 15mg of hydrocortisone. A trip to the GP confirmed the presence of an upper respiratory tract infection, and he started antibiotics.

Sandra emailed Jeanette later that evening: "He is soooo much better already. I gave him another 20mg late afternoon and he is currently sleeping like a baby after a comparatively busy evening talking to all his friends on the phone - that's more like my boy!!.

Today really showed me the impact that low cortisol has on Joshua's behaviour and sense of well being. Addison's sure does present rather a big learning curve! I think Josh understands things a bit better too after today. He commented this afternoon that **having low cortisol was like having a well trained and equipped army but without any ammunition to fight with.** I thought that wasn't a bad metaphor for one so new to this game!"

A few days later Joshua was checked over by his specialist, who'd fortunately had a cancellation. All things considered, he agreed it was time for Joshua to take daily replacement meds, the same hydrocortisone

as Joel [15/5/5], but 0.1mg fludrocortisone rather than 0.2mg for now.

Sandra tells us that their GP is a very good listener, and certainly willing to learn about Addison's. "I am very grateful that he referred Joel on as soon as he presented with symptoms. He has been wonderful moral support since diagnosis.

Sandra is also pleased to have talked with another mum whose twin boys were diagnosed some months apart 14 years ago - when aged 11.



## Mary's Story

### (1) Overview:

A dairy farmer and horse breeder, Mary lives in Hari Hari, South Westland, population including all children, 300. The nearest hospital is in Greymouth, 1.5 hours away. The nearest town is Hokitika, an hour away in the same direction. When Mary [originally from Christchurch] and her Coaster husband went to Hari Hari in 1976, the population was twice as large as it is now. A forestry settlement, a Ministry of Works settlement, and three timber mills are all now closed.

It's a lovely part of the world, Mary says. But it wasn't the easiest place to get a diagnosis of Addison's disease. She remembers the date she finally started hydrocortisone 13 March 2002, when she was 52. She'd been admitted to hospital on 4 occasions over the previous 10 years, severely dehydrated, with vomiting and diarrhoea and with the classic Addison's symptoms of pronounced tanning and salt craving. IV had fluids perked her up somewhat, and she'd be discharged. Then, at last, a diagnosis. She says she is very grateful that the new clinical physician from Iraq (who has since moved to Australia) was such a thorough and well educated doctor.

At the time of her diagnosis, there was a resident GP in South Westland, but that isn't

the case now. A GP contracted by the base hospital is flown over for a week per month, and spends one of those days in Hari Hari, the others between there and Haast. "We do have a good district nursing system and I think all I have to watch is getting scripts filled often enough - health willing. The base hospital in Greymouth has improved markedly over the past few years. Also, the endocrine clinic in Christchurch has been very good and both of these places have offered me support at any time which is good."

Mary had hoped to attend the NZAN meeting in Christchurch in July 04. But early calving and issues with builders of their new house prevented that at the last minute. So her first meeting with other Addisonians was the Nelson meeting in February 2005, a 5.5 hour drive each way. She is keen to attend other meetings.

## **(2) Diagnosis at last**

I was diagnosed at Greymouth Hospital, after being kept at home by my local Doctor for about 10 days only able to drink water and having intermittent vomiting and diarrhoea. I couldn't stand or walk much at all and was mostly sitting like a zombie or lying in bed. Someone came to the door once and I managed to open it and then spoke to him from a kneeling position. My blood pressure was very low.

Our District Nurse phoned the doctor a few times and recommended a hospital visit but the doctor said he didn't think it was necessary and I should take more fluids - what an effort that was. My husband was very concerned but I was really away with the pixies a good deal of the time. I lost 5kg over that period.

I'd had many episodes that had started similarly in the past, but they usually resolved after just a few days.

Eventually we decided that I was getting a bit terminal and insisted on hospital. The nurse

came and set up a drip. When the ambulance came I was bundled into it and taken the hour and a half to hospital. The nurse followed the ambulance for the first hour and the ambulance stopped a few times for the nurse to check me.

I was on a drip in hospital for five days and the recovery to normal was much slower than it had been on my four previous hospital admissions. The good thing was that the hospital physician was very thorough, quite stern with the staff and he had a fair idea what was wrong. He didn't think I was an alcoholic - this had been written on my notes on one of my previous admissions!. [My husband later arranged for it to be removed from the records.] I was discharged as soon as I came off the drip, but without being told what might be wrong, even though copious testing had been done and samples of everything had been sent to Christchurch and Wellington.

I was told at my 6 week follow-up with the hospital physician that he wanted me on tablets straight away. I was still nauseous, and had great difficulty swallowing them, and they hurtled back straight away. So I went back to hospital and was given IV hydrocortisone, then took a tablet the next day and felt stronger almost immediately.

I waited a week until I felt stronger, before talking seriously with my own doctor about his preventing me from going to hospital earlier when the nurse thought it would be a good idea, and we reached an understanding.

## **(3) The decades before diagnosis**

I was prone to bilious attacks all my life - either during times of stress or more often just after the pressure came off. I always liked savoury things and not sweets - Mum used to hide the Snax packets or I would eat them all. Most of my life also, I have eaten a great deal of seafood.

I had pneumonia twice (when I was 11 and 23), and broke my ribs twice (during the 90s). I always took longer than the rest of the family to recover even from a cold.

About a dozen years before Addison's diagnosis, my then GP had sent me off to see various specialists and the best they could come up with then was that I was prone to migraines, and was having silent ones. I would wake up in the night vomiting, often with no other symptoms of migraine. [I did also have many migraines with headaches and wavy lines in my vision.] The general consensus was to make sure that I kept well hydrated and if I felt dull or seedy to take Aspro Clear before anything developed. I was careful not to overdo anything and get plenty of sleep - and I could sleep the clock round without trying.

For years I just toughed it out. I remember when my youngest were still going to school in the late 80's and early 90's, I didn't always get up and get them off to school - just yelled until someone got up and when they left I staggered out and drank a pot of tea before heading for the cowshed to do only essential duties. I felt really bad about it at the time, but it really was the only way I could get the basics done, and it gave me an extra hour in bed, one of my favourite places then.

I went to Rarotonga in 1994, as our youngest son is a Cook Islander. I was there for a week on the way to the UK, and ended up in hospital for three days with supposed food poisoning - but I know better now, I am sure it was an Addison's collapse. After several bags of saline I was able to stagger onto the plane and sleep until Los Angeles. I had salty crackers and water for the flight and arrived in the UK feeling pretty good although my sister thought I looked terrible. I had several light headed times in the UK but just used to stop somewhere and have soup - nice and salty and easy to get down. I had been hospitalised in NZ about 3 months before this trip - one of the four occasions in the 1990s when I was just rehydrated, checked for bugs (which were never found) and sent home.

I know I had been very brown for the whole of the 1990s. Looking back at the notes for my hospital admissions, the endocrine clinic in Christchurch said that I should have been picked up on my earliest admission over 10 years ago. I'd been admitted very dehydrated after a bout of vomiting and almost but not quite unconscious. Doctors commented then on my good suntan but never told me what my blood chemistry was doing. It's clear in hindsight that they should have tested me for Addison's.

My Grandmother, an Englishwoman, had very brown, wrinkled skin in her later life and I thought I was just being like her. Maybe I was, as she had an overactive thyroid in her early 50's and maybe had Addison's too as she wasn't very active for her last 30-odd years, and was very thin. My family has a pattern of glandular weakness that I wasn't really aware of until my own diagnosis - pernicious anaemia, diabetes, Reynaud's syndrome, thyroid problems, six family members each with one of these disorders.

### **chaos1@xtra.co.nz ??**

No problem explaining my email address! Chaos is my husband Lindsay's nickname from a long time ago - the late 1970's really. The friend who gave it to him was killed in a helicopter crash in 1980, so the nickname has lasted in his memory. We also have a car and a ute with plates Chaos 1 & 2.

#### **(4) Mary's Reflections on her life before and after diagnosis**

I can do anything I want today and most days. I don't have to think of having a fall back position, for example if I am driving to town (1 hour away), I don't have to engineer company in case I feel too tired to drive home.

I can do a good day's work, longer in the spring, 10-11 hours. Some evenings I am quite tired, but now there is a good reason.

I only need a normal amount of sleep and not bed at 8pm and up at 8am. I can stay up until after 10pm and still get up at 6.30am.

I can cook an evening meal without several stops and a short horizontal rest. I have taken up swimming every day in the summer using the local school's very cold pool – I hadn't been swimming since I was a teenager. I have bought and use a 10-speed cycle and really enjoy that, plus I walk a great deal again.

I have pink gums and lips, hair on my arms, a reduced tan on my arms, legs and face. and a white body where the sun doesn't shine - it was beige with dark smudges on the wrinkles and folded bits.

I don't have aching and stiff legs for days after digging the garden - I can dig the garden in one hit instead of over several days.

I don't have blinding headaches, dry retching on cleaning teeth, a hacking and very repetitive cough often leading on to the odd vomit. I don't feel like I have continuous morning sickness. I can eat anything I want at pretty much normal speed - for as long as I can remember I had been notable for still eating when everyone else has well finished.

I do have a good appetite and don't feel the need to have lots of soups, crisps, savoury and salty foods. If I felt not right I would often

eat a whole tin of asparagus and even drink some of the salty juice it was in. I do take a bit of extra salt when I feel the need, but nowhere near like I used to.

I used to think my husband's breathing was really fast - now mine is the same speed.

I don't have cramps every day and don't have regular bouts of hiccups. I don't have continuous hay fever.

I used to take forever to shake off colds and flu. Now I don't get them.

I coped really well with the spring calving (by myself most of the time) about six months after being diagnosed. My husband was diagnosed with active, aggressive prostate cancer and had the operation just before our busiest time. We were both lucky in 2002 as I couldn't have coped without my Addison's pills and my husband would most likely have died if he hadn't had that blood test as he had no symptoms and we are told he would have been too advanced for treatment by the time he did.

#### **Any drawbacks?**

I have put on a bit much weight, although I have managed to lose a bit over the last few months. [I was on 30mg hydrocortisone for the first year]. I am still 66kgs and would rather be 60 Kg. But before diagnosis I was only 56kg on a good day. [I'm 5ft 2 and half tall.]

I have to take a few pills, and be aware if my health is not up to scratch.

I had only one child (our youngest two are adopted). My pregnancy was five months of all day morning sickness and migraines from the time of conception. Then it settled to just a bit of nausea, and after a normal labour our healthy son was born. We have never used birth control and I had fallen pregnant on my honeymoon in 1970. Maybe I had Addison's coming on for years, and it affected my fertility before it became an obvious nuisance.

**(5) Mary's update, December 05:**

We have had such a busy year, and I haven't done half the things I wanted to. My Mum was diagnosed with lung cancer in March, and I had nearly a month in Christchurch mostly at the hospital visiting her and just generally being there as were my four sisters. In a perverse way we had a lot of very good times with Mum then, but although the hospital thought they could ease her symptoms and give her several months at home, she took quite a sudden turn for the worse and died.

It was pretty shattering for all of us and I upped my pills for a few days to good effect. Our father died in 1967 so Mum had been the everlasting one there for everything and everyone. Now I am the oldest woman in the family, an honour not sought.

We have recently sold off our run-off block at Whataroa and that has eased the pressure here a bit and allowed Lindsay to go hunting more. I am accumulating time off for an overseas trip with my youngest sister - hopefully Autumn/Winter. We have booked tickets to Rome for a rail trip of Italy and France and then on to England - six weeks in all and we will do a cruise if possible in the Adriatic. This is travel on a shoestring and I am really looking forward to it.

I have managed a trip to Tokoroa to visit our youngest grandson just before he turned one. It was the first time since being diagnosed and, of course, no problems. In fact it was better as I used to be forced to stop driving from time to time being too tired and needing vast quantities of soup, water and peanuts or similar to nibble on.

Sometimes it still feels quite strange that I am now nearly normal! I have had a couple of times when the world has gone wonky this year, but fortunately with Lindsay telling me to swallow more pills or he would get the doctor in, that has sorted things.

