

# New Zealand Addison's Network

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## Update Newsletter, July 2002 (No 16)

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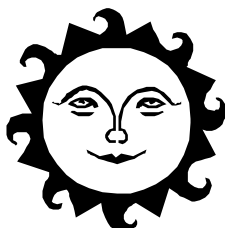
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**March 2002 Survey:  
Full results, plus commentary**

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



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

## Editorial – Survey Surprises

It's newsletter time again! For long-timers, a lot of the material may be familiar. But this edition of the newsletter also includes the full results of our most recent survey of members. As noted in some responses, we can become complacent - reminders are helpful.

When we are on a medications regimen that suits us, we are well most of the time. We need to know how to juggle the doses to deal with life's ups and downs. We need skills to smooth our path through emergencies and stresses, should they arise. Applying the right knowledge, using the right tools, and communicating our needs, enable us to safely live life to the full. It sounds easy!



Some responses from the present survey were surprising. Only half the respondents have injectable hydrocortisone (Solu-Cortef) at home. A quarter of the respondents said they were not confident about the circumstances in which they would need to take injectable hydrocortisone.

Experiences reported in this Update show that if someone with Addison's is acutely unwell with some intercurrent illness, chances are the importance of extra hydrocortisone by injection may be overlooked – by the person and their family, or by the emergency doctor ( see Karen's lesson below, and Karel's response in the survey.)

Being close to emergency services, or turning up at a New Zealand regional or provincial hospital, does not guarantee that you will receive a hydrocortisone injection promptly. As we have published previously, ambulances don't carry hydrocortisone. Having, and using, one's own injectable

hydrocortisone is empowering. It is easily obtained with a prescription from your GP.

If you don't feel 100% on your current Addison's medications regimen, don't feel alone! In the previous 1-2 years, 42% of survey respondents had made changes to their medications, most driven by less than optimal wellness. Three quarters of the changes led to improvement.

There is a lot of material in this Update, and in the overseas newsletters. In particular we draw your attention to Erin Foley's article on stress in the NADF summer issue, and Joan Hoffman's selection of topics in her June issue. Members of the Canadian Addison Society raise the possibility of future alternatives to injectable hydrocortisone for emergencies in their July issue. Enjoy!



### Administration news

A member family is kindly donating on-going administrative expertise for NZAN through their state-of-the-art business office, starting with the printing and distribution of this newsletter.

NZAN's resource material and records can now be more streamlined, while Jeanette also retains the information accessible for handling enquiries. The flyer is being delayed a bit, so it can be part of an integrated strategy, with a new starter pack, over the next few months. We'll report in the next newsletter.

The family is keen to help increase awareness of Addison's disease in New Zealand, and NZAN, by appropriate mailings to GPs, as well as through other media. They are requesting a low personal profile, and their secretary Annette is our link. Jeanette in particular appreciates the opportunity for significant reduction in her workload, with a better outcome for NZAN.

Sincere thanks to Linda for maintaining the database and preparing labels and members' contact lists over the past couple of years.

**Thank you !**

## Successful Central Region Meeting

NZAN's first Central Region meeting was held in Petone, Lower Hutt, on Sunday 5 May.

The 21 attendees, from as far away as Timaru, included 10 with Addison's, 2 with secondary adrenal insufficiency, one lady born without adrenals, and parents from three families with Addisonian children.

Special thanks to Gary Roselli, our pharmacist member, who organised and chaired the day, to Ngaire Hyde who organised the numbers, and to Darren Hunt who contributed good supplementary comments during the day, and wrote a report (see below).

NZAN very much appreciates that the Zuellig Pharma venue is available for future meetings, free of charge - and, at weekends, free of competition!

It's clear that the day worked well without a specified keynote speaker, drawing instead on NZAN's resource material, including overheads from Prof Holdaway's address in Auckland. Gary has described the format in some detail, as encouragement for other centres, large or small.



### Gary's perspective

I opened the meeting with greetings, apologies (one from Jeanette), and the brief history, aims etc of NZAN. I explained that the function of the meeting was to get their input – comments, topics, questions etc. The

agenda was as follows. First, all Addisonians gave a brief talk (I gave them headings like name, when diagnosed, how well controlled, how long, and interests, family, support etc). This started at 11.15am, and took longer than anticipated, until 12.45pm. Initially people were reticent – eventually they became very enthusiastic.

Lunch was hot soup with buns, savouries, curried eggs, scones, pikelets, bowls of fruit etc, sandwiches, and date loaf. The cost was \$10 per person. Zuellig Pharma supplied the venue, tea, coffee, milk, fruit juices etc free of charge. We had an excess of \$70 for NZAN. Two new members joined, and 3 renewed their subs on the day.

I hassled people back from chatting by 1.30pm, and showed overhead projector slides with discussion. The Star Diagram was very useful, and I threw subjects at the audience, rather than answer questions. This part finished at 2.20pm, and we went to the "Your Topics" part of the agenda. While this was similar to 1 and 2, it was very popular – one or two people had indicated they may have to go early, but in fact everyone stayed until the end. We finished just five minutes before our nominated 3pm, with some photos taken, plus feedback-form filling (what they got from the day), to help with future planning.

What surprised me was that everyone was so enthusiastic – said they'd had a great day, and would come again. All agreed they had learned something. I asked each of the non-Addison's people if they had got bored – each one said it had given them a better understanding of the condition.

I arrived home to a phone call from 2ZB (I think) who, along with the Hutt News, medical labs etc, had given us free promotion. The radio station asked me to explain Addison's, and how the meeting had gone.

Overall I was amazed at the interest from the participants – not one person avoided talking. I cannot think of anything I would do differently

if I were doing it again. I am sure everyone got their \$10 worth.



### **Darren's Wellington meeting report:**

Gary's welcome to participants was followed by an introduction from each Addisonian. Experiences with Addison's were quite variable, including people who have had it for many years, those recently diagnosed, parents with Addisonian children, and different causes of Addison's.

The type and dose of steroid replacement also varied widely. It was evident that (as we have often heard) diagnosis and management differed, with some having been diagnosed after long periods of time, often following considerable stress, and with a range in medical input (eg. some doctors with less knowledge; different specialists involved in care). This variety was also reflected in some different ideas about Addison's in general (as well as our own unique experience) and underlined the significance of being able to get together and share information.

After lunch had given us a further chance to share stories and views, Gary ran through some overheads describing Addison's disease and its management. This gave us the opportunity to review some of the basic medical facts for those who have had the disease for a while, and clarify them for those who were just beginning to understand it. The discussion moved on to look at other important aspects of managing one's life with Addison's, including nutrition, sleep, exercise, and social support. This began the last part of the day, which was an opportunity for everyone to ask questions of others.

There were a number of common themes, including the need to maintain a relatively stable lifestyle (but not boring!), that many seem to feel the heat more easily, and the importance of having an emergency steroid

injection available. The importance of adequate fluid intake in hot climates or heavy exercise was also stressed. The issue of DHEA was raised, and some of those attending had tried it with mixed results - one found it beneficial, while another had adverse effects.

Overall, the meeting helped us to make some personal links with one another, understand what it means to others, re-emphasize some important management issues, and share knowledge about what can be a very scary experience for those new to Addison's (and many aspects are still confusing after years of having it!). It highlighted once again that we all have our own experience, and that over time we tend to become the expert on managing our quality of life, "tailoring" how we deal with Addison's in partnership with others, including our doctors for objective medical guidance.

Lastly, thank you very much to Gary and Ngaire for organising the meeting, and for everyone who came and shared their valuable experience and ideas. It certainly felt like a worthwhile gathering for us all. Despite being well clued-up on Addison's from all my jabbering and the NZAN updates, my wife also told me that she gained some more understanding of what it is like to have Addison's, such as when and how I get run-down - although I don't think that's going to get me out of doing any housework!



Ngaire's comment to Jeanette afterwards:  
 "I've been diagnosed nearly 40 years, but it brought some things back to me that I've let slip - having the [Solu-Cortef] injection available, having a list of meds on the fridge. It reminded me to take care of myself. I do well, but I realise I could do better. I took a lady from nearby with us. She said as we headed in to the meeting 'I am so excited'." Kaye is one of our new members from the meeting.



## Star Diagram – reminder

This diagram summarises the issues to optimise, for living healthily with Addison's disease – medications, exercise, stress management, sleep, food, and fluid intake. Originally prepared to help focus discussion at the first regional meeting in Auckland last year, it has proved useful at several meetings since. It was published in Update Newsletter #13, July 01, and can be downloaded from our Website.

## How's your exercise programme?



There's no doubt that regular exercise benefits Addisonians. Jeanette is still doing her gym routine 3 times a week, "cardio" and muscle strengthening exercises. Her 70-year old neighbour, impressed at the improvement in Jeanette's well-being and stamina over the past year, has just started at the same gym, with a personal trainer. Sherryn does an aerobics class (circuit, step or kickfit) five days a week for an hour, and a yoga class for an hour and a half one night a week. Linda goes for a walk almost every day.... Please share your experiences.

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



## Membership

We welcome Kaye, Lesley, Mary, Peta, and Joy as new members since the March Update, and James has re-joined.

Most members have paid their subs – if yours is outstanding, an invoice and membership update form is enclosed.

Thank you for your donations: Beryl, Chris, Darren, Diane, Gary, Graeme, Ian, Jim, Lis, Margaret, Marianne, Pamela, Richard, Shirley, and Joan in the US.

## Book Donation: by Hayley Lewis

Hayley has donated to NZAN, on behalf of herself and her late mother, a copy of the book *Cushing Patients in the Netherlands* - "for the wonderful support that NZAN, as well as Laurens Mijnders from the Netherlands (ACIF), gave to both of us during my illness. As I have said before, I believe the book was so helpful in preparation for complete diagnosis, and would recommend Cushing sufferers to read it."

Hayley's mother passed away unexpectedly with cancer, just four months after Hayley's successful adrenal surgery. "My mother said she was so pleased to have the 'old Hayley' back, for which I remain proud for her today."

To borrow the book, please contact Jeanette.

## Gelatin Capsule Feedback

In the previous issue (March02), gelatin capsules were suggested as one way of avoiding confusion when taking different little white pills. Some members and overseas correspondents requested samples. Graeme posted the tip on the [www.healinglight.com](http://www.healinglight.com) forum – and a respondent commented that putting pills inside capsules is a good way of avoiding a taste one may find unpleasant.

## Members' Tips:

### 1. Keeping your meds at hand

#### Colleen's tip

"When away from home, I wear a locket which holds six 5mg hydrocortisone tablets. I bought it from a local boutique selling costume jewellery. However, I have since seen gold and silver lockets at reasonable prices at second hand shops in Tauranga. Mine has a chain long enough to slip over my head, which I think is more practical than having to undo a clip when you are feeling sick." The longer chain also means it doesn't sit flush against her clothing, Colleen added with a smile - remembering the advice we have previously published, to avoid keeping medications for long periods in containers that would be at body heat, such as in a pocket. At least every month, she uses up the contents as her ordinary meds, and puts "fresh" hydrocortisone into the locket.

### 2. Taking your meds on time

#### Jeanette's tip

Remembering her midday and afternoon hydrocortisone doses is a challenge, especially when away from usual routines. Jeanette now has a nifty compact Timex sports watch with 2 alarms. The alarm sound is subtle but clear, and can be 'silenced' by turning the watch face against her body, rather than having to fumble for knobs.



## Karen's Challenges:

### PART ONE

Karen's successful planned pregnancy with her third child, Matthew, after her diagnosis with Addison's, was featured in Update #11, Nov00. Karen was one of the enthusiastic co-organisers of the first Northern Region Meeting in Auckland, July 2001. Her own health concerns were, however, kept from view that day.

"Basically, back in July when we had our meeting I was at an all time low, barring the crisis I had when diagnosed! On the day of the meeting, I was able to get an appointment with my specialist and was really honest about how I felt. That day he cut my dose down from 40mg hydrocortisone to 25mg daily. It was tough going for the first few weeks (mostly tiredness, lethargy and extreme irritability), but I have been doing well since.

I also started on DHEA a few weeks later (10mg per day). Mentally I am much better - more back to my happy old self (pre Addison's!), increased libido, not so heat sensitive and so on. With DHEA I don't think I have any side effects. Possibly my skin is a little prone to outbreak, which is unusual for me because I actually have quite good skin (well God had to give me something good!). So I put that down to the DHEA, but other than that, nothing adverse.

At the same time I agreed with my specialist that I would attend Weight Watchers and commit to losing the weight. I joined a few days later, and have been going ever since. It feels like it has been a long hard struggle, but yes here I am 17kg lighter (only another 20 to go!!) and feeling and looking so much better. We had talked about using the drug Reductil to help, but when I saw my specialist in December he decided that I was doing well enough on my own and didn't need it.

I have been doing moderate exercise - mostly walking and swimming, but also increasing my daily "activity" and trying to "play" more with the kids on the trampoline, swingball etc. So yes, in a way exercise has played a part - but not as bigger part as I want it to... I am breaking myself in gently! One of the things I want to do is interact with the physiotherapist who has volunteered as NZAN's exercise advisor.

In hindsight, I think the weight was on for two reasons - one was that my Addison's was not stabilised, and while trying to get my ACTH levels (and skin colour) back to normal I was

"overdosed". Secondly, I think that I was extremely unhappy, and the more unhappy I got, the bigger I got - a bit of a vicious circle!

So now I am on 25mg hydrocortisone (15, 5, 5), half a Florinef, 100mcg thyroxine and 10mg DHEA and am "stable". I find I hardly ever have to increase my dose. I attend Weight Watchers weekly.

**Comment from  
NZAN's medical advisor,  
Professor Ian Holdaway:**

Reduction of corticosteroids should be gradual, 2.5-5mg hydrocortisone or 0.5-1mg prednisone each 1-2 weeks, with careful monitoring of symptoms and, if possible, blood pressure. Symptoms of tiredness, lethargy, extreme irritability, and muscle aches, are a warning that you're cutting down a bit fast. If you are dizzy or have a BP lower than 100mm systolic (the upper number in the blood pressure reading), this may indicate not enough corticosteroid or fludrocortisone.



*The March 2002 Survey Results enclosed with this newsletter, show that 31 respondents (65%) reported admission to a hospital, for diverse reasons, since their diagnosis with Addison's. Only six people reported delays getting medications on time in a hospital ward. However, this shouldn't happen at all.*

*Karen's acute illness and hospital admission in 2001 were unlucky in several respects. Professor Holdaway's comments following her story, below, remind Addisonians of the importance of being assertive and proactive to get appropriate care.*

**Karen's Challenges:  
PART TWO:**

One day In September I suddenly had severe abdominal and chest pain. I was initially seen by a doctor at White Cross, who suspected a Gall Bladder problem, and said that normally they would give pain relief, but as I had Addison's he would be cautious and send me to hospital, particularly as I was a bit dehydrated.

I hadn't taken my Addison's meds since breakfast - I am ashamed to admit I clean forgot. I was in so much pain that I basically was just pacing the house. I couldn't eat or drink either, it just hurt too much!

I didn't even think of a Solu-Cortef injection, to be honest - I tended to think of that as being more for tramping-type situations where no medical help is around. I probably wrongly assumed that the A&E would dose me as I needed...ha ha. Also at that point I wasn't even thinking about Addison's, I was thinking, "this is it!".

When we got to the hospital, I was in agony, and had been all day. We were whisked straight up to Acute Assessment (about 8pm). I didn't see anyone until 10pm, and was given no pain relief. By this stage I was getting dizzy and was feeling like I was dying!

By 11.00pm my husband Steve was starting to worry as I'd had no food, no meds and no liquid since lunchtime. So, after asking about 3 times for some IV fluids, he went out to the desk and said firmly exactly what Prof Holdaway had advised [NZAN Update #13]: "If my wife doesn't get IV fluid and some hydrocortisone shortly she will go into crisis - she also needs pain relief". Well wouldn't you know - 5 minutes later I had hydrocortisone, fluid and morphine.

We gave them a full history and told them who my endocrinologist was, etc. They charted the meds and then admitted me. Next day they didn't give me anything other than fluids until I asked. I asked for each dose of

hydrocortisone. Then the next morning the nurse wouldn't give it to me because someone had written 'withhold' next to all my meds!! By lunch I was really dizzy and losing my faculties so I rang and asked for my meds, and to see the doctor. The doctor came, gave them to me, and said the endocrinologist was going to come and see me.

To cut a long story short - I was in there five days and had to ask for every hydrocortisone dose. I had IV fluids for about three days. My potassium dropped very low and they became alarmed and I had to take tablets as well as the fluids for one day. We phoned my endocrinologist who said to double meds. I never saw the hospital endocrinologist, even though the registrar had said it was urgent. I saw only the pharmacist, who wanted to check my meds, which was rather ironic, I thought, as once he made them up I had a jolly hard time getting them!

I was in hospital for five days, then had an ECRP to see if they could remove any of the gallstones - but they couldn't as they were too small and had passed through. The reason it took so long to get the ECRP was because of a conference in Sydney - I couldn't even go privately.

Two weeks later I had my gall bladder out privately - a completely different situation with regard to Addison's meds. They gave me the correct dosages, and gave me extra fluid and hydrocortisone during the op. It all went really well and I went home after one day in hospital. They were really pleased with my progress and I felt great.

What a difference - the private hospital listened to my needs and acted on them. In the public hospital I saw the doctors for only about 30 seconds each day (I'm not kidding!) and if you weren't in your bed when they came round you didn't see them until the next day. The nurses wanted to give me my meds, but couldn't because they weren't charted or were withheld by the doctors!

At the time I felt the gall bladder episode was a real setback, as I had just started Weight Watchers and was losing weight (I had no control of the food I could eat in the public hospital). But in the end it was just a glitch on the radar and now I am better than ever!

So all in all, I have been really working on my health - body and soul!



### **Comment from Professor Holdaway:**

1. The appropriate use of injected hydrocortisone needs to be constantly emphasized – but as mentioned by the writer, people naturally forget about this when a major illness or crisis hits them. Sometimes a partner or relative is the best person to remember and initiate this.

2. People with Addison's disease need to be assertive and proactive to get appropriate care.

If patients are having difficulty getting Addison's medications on time in a hospital ward, and especially if they are not in a medical ward (eg they are in surgery, othopaedics, eyes/ENT, gynaecology etc), they or their relatives should demand firmly that the medical registrar on call, and the endocrinologist on call, should review their case immediately. If necessary shout – it is amazing what a loud voice can achieve!

Not giving regular steroids to an Addisonian patient (plus a supplement if the individual is ill) is unforgivable. Many hospitals will permit self-medication, and the patient should ask the Doctors and/or the Pharmacist about this. Pharmacists are often attached to hospital "teams", but can also be asked for specifically, usually via the Charge Nurse on the ward.

## Bay of Plenty get-together

Colleen is hosting a get-together for local NZAN members on Saturday 27 July. (Colleen organised the successful Bay of Plenty meeting in September 2001.)



## Primary and Secondary Adrenal Insufficiency (AI):

### The differences... reminder

Addison's disease, primary adrenal insufficiency, is failure of the adrenal gland to secrete the glucocorticoid hormone cortisol (hydrocortisone), in response to the trigger of adrenal gland stimulating hormone (ACTH) from the pituitary; and failure to secrete the mineralocorticoid hormone aldosterone, in response to the trigger of the aldosterone stimulating hormone, renin, from the kidney.

The main cause of Addison's is autoimmune damage – other causes, such as TB, are rarer today.

Tallying 74 NZAN database forms from members with primary Addison's, 52% wrote into the symptoms box, either increased pigmentation/ tan, or salt craving, or both. Some had these particular symptoms for years. As the box does not involve a checklist, but relies on memory, and as some people have left it empty, the true incidence of these symptoms at diagnosis would have been higher.

Secondary adrenal insufficiency is when the adrenal gland doesn't produce cortisol, because it doesn't receive the right trigger from the pituitary gland. This may be because the pituitary gland has failed, or been surgically removed (eg to treat Cushing's syndrome); or because steroids taken for other disorders, such as asthma or eczema, have also reached the pituitary and suppressed the signals that should be reaching the adrenal gland to produce its own cortisol.

People with secondary adrenal insufficiency don't get the salt craving (because they still produce enough aldosterone to preserve mineral balance), or the tan (because their pituitary doesn't overproduce ACTH). But they can get the same symptoms of cortisol lack – in particular, severe fatigue, muscular weakness, nausea and vomiting.

### Question: Is Solu-Cortef relevant for people with Secondary Adrenal insufficiency?

People with primary and secondary adrenal insufficiency are essentially in the same boat, both needing a replacement glucocorticoid medication. But Shirley, one of our treated Cushing's members, wonders how relevant some of the material in the newsletters is for her. In particular, is having injectable hydrocortisone on-hand for emergencies, and understanding when and how to use it, important for people who have secondary adrenal insufficiency due to hypopituitarism?

### Answer: from NZAN's Medical Advisor, Prof Holdaway:

Yes, individuals with secondary adrenal insufficiency may on occasions need injected hydrocortisone similar to those with Addison's disease. This occurs less often with secondary adrenal deficiency because these individuals still have normal levels of aldosterone and do not have the same risk of low blood pressure and collapse when they cannot take or absorb their replacement treatment. Nonetheless, those with severe illness, accident or stress still need an increase in replacement steroid, and if the person is vomiting or unconscious this must be given by injection.

Whether an individual with secondary adrenal insufficiency needs to have injectable hydrocortisone available is an individual decision, usually best made in consultation with their GP or endocrinologist. All Addison's individuals are strongly encouraged to have injectable hydrocortisone (Solu-Cortef) on hand.

## Jill's Story: Addison's disease

In 1995 when I was 49, my life was ticking along nicely. My job in local government was exciting and demanding, my husband and I had a very busy social life, our two daughters were almost grown up, and on most Saturday mornings I managed to play golf.

Many months and several GP visits later, I knew that my life wasn't ticking along as well as I thought. I was losing weight, had a craving for salty foods, tired very easily, my skin was too tanned for the short time I'd spent in the sun, I frequently had cramp, continually felt breathless and couldn't shake off a persistent cold. When I commented to my doctor about how awful I felt, his response was that I wasn't getting any younger!



At this point, I found another GP who was more interested in my health than my age and over the next few weeks she conducted a number of tests to try and identify the problem. Still no conclusions were reached, so in February 1996 off I went to a chest physician at the local public hospital for more tests, none of which highlighted what was wrong. However, when my blood pressure showed a marked difference between standing up and lying down, the specialist wondered whether I had Addison's disease.

What on earth was Addison's disease? The only literature we found in the public library said the disease was fatal which wasn't at all reassuring. The next morning I blacked out in the shower so I was admitted to hospital the next day for a series of blood tests over the next 24 hours, by which time it was conclusively proven that I was an Addisonian. I was put on a daily dose of 25mg of hydrocortisone (15mg early morning, 5mg at noon at 5mg at 4pm) and 0.1mg fludrocortisone. I felt better immediately.

Two years later with the consent of my GP and endocrinologist, I cut out the 4pm dose of hydrocortisone as I was having trouble



sleeping and felt I would be better off with just 20mg hydrocortisone. I am still on this dose (fludrocortisone intake is unchanged), but my GP also prescribed sleeping tablets (3.5mg per night) which have been of tremendous help. I wear a MedicAlert bracelet, always carry a supply of hydrocortisone and fludrocortisone tablets in my handbag and have an emergency information card in my wallet.

One of the most worrying aspects of Addison's disease for me (and for many others too, when reading their histories) was the increase in weight. I am 5'1" tall, and went from just over 8 stone to almost 10 stone and my GP suggested I refrain from buying any clothes for the next couple of years! It took more than three years and a lot of hard work to get back to my pre-Addison's weight.

On a brighter note, since my diagnosis in 1996, my life has changed dramatically. Two years ago, Rodger (my husband) was offered a two-year contract in the UK in the Derbyshire village of Buxton (population 22,000) working for a privately owned company that manufactures thermostats. This was too good an opportunity to turn down so within a month of Rodger accepting the position, we were ready to go.

I retired from my job, we found tenants for our house in the country, and off we went with our three suitcases to a new challenge across the other side of the world. We arrived in December 2000 and spent our first year in a two-bedroomed apartment a block away from the shopping centre. Despite the conditions over the first few months (It was dark at 4pm and freezing cold with plenty of snow) we settled down into our new lives in England.

I became a member of one of the two golf clubs in Buxton, joined an informal walking group and gradually became accustomed to a whole new lifestyle after almost 40 years in the workforce. However, I did obtain temp office work in the Buxton Police Station for four months last year. This was a fascinating

place to work with each employee being subject to Home Office clearance for possible counter terrorist activities. In January this year we moved again, this time into a two-bedroomed bungalow a little further from the shops, but in a much quieter part of town.

The National Health System in Britain is very 'interesting'. I was originally paying £24 for two months' supply of medications, though the doctor's appointment was free. After eight months of this, the pharmacy suggested I prepay for my medications that would save me around £17 with each two-monthly prescription. It took me another four months to discover that people with Addison's disease were entitled to FREE medication. It wasn't something that my GP told me about – in fact it was a distant relative of Rodger's here in England who suggested I make enquiries.

I also see an endocrinologist at the Royal Hallamshire Hospital in Sheffield twice a year for a check-up. On my visit to him in March we discussed the potential benefits of DHEA. As DHEA hasn't yet been approved by the British authorities, he was unable to prescribe it, but suggested I try obtaining it through a health food shop. However, the health food shop didn't have approval to sell the product either, so through a contact in the USA I obtained three months' supply. I started taking a 25mg capsule daily in early April and I do feel better (Rodger caught me whistling recently!).

I also sleep more soundly than before, though I still take the 3.5mg Zopiclone sleeping tablet. Possible DHEA side effects of acne, increased facial hair and tender breasts have not occurred so far. Two days after starting on DHEA, my GP put me on HRT, so some of my new sense of well-being could be attributed to this. One major benefit of HRT treatment is that my 'heat waves' have finally ended after enduring them for seven years.

We return to New Zealand just before Christmas 2002, which means we have a few

frantic weeks of hectic activity before our younger daughter's wedding in February.

Six years after being diagnosed with Addison's disease, I have well and truly come to terms with my health. I have the occasional 'duvet day', but with golf three days a week plus walking and shopping, thankfully there's not much time left to feel sorry for myself.



### **Comment from Professor Holdaway on DHEA and HRT**

The dose of DHEA differs somewhat in New Zealand compared with overseas countries. The formal studies of DHEA in Addison's have usually used a micronised DHEA preparation that seems to be less well absorbed than the local preparation of DHEA made in New Zealand by Pharmaceutical Compounding in Birkenhead, Auckland. Whereas the overseas studies used doses of 25-50mg DHEA daily, the NZ preparation seems to be better absorbed, and doses of around 10mg daily may be all that is needed. I generally start people on 10mg, and then measure the blood DHEAS level (the sulphated form of DHEA), 2-4 hours after a dose, to check that it is not too high. Using the full 25-50mg dose locally may lead to acne, increased hair growth, and other side effects.

The use of Hormone Replacement Treatment will have to be reassessed for individual women in the light of the recent findings of the Women's Health Initiative study in the US, and will be a topic in a future newsletter. Short term use of HRT remains a safe option to relieve difficult menopausal symptoms. If individuals decide to stop HRT, remember that you may need slightly higher doses of hydrocortisone once estrogen replacement ceases, perhaps up to an extra 5mg hydrocortisone per day.

**Note: See also comments in the survey results, DHEA question, p6/11.**

## NZAN Website Traffic Report

Almost 300,000 kB, equivalent to about 1,000 newsletters, has been downloaded from the NZAN website so far this year (to mid July). Just over 80% of that traffic is from outside New Zealand – from 31 countries. As well as being regularly visited by the web crawlers, spiders, etc that “feed” search engines, the NZAN site is linked from a large number of Addison’s-specific and broader health sites. Our most recent new member found out about NZAN on the Internet.

A new website, with good Addison’s disease content and links, targets people who have diabetes as well as Addison’s:  
[www.addisons-diabetes.gkznet.com](http://www.addisons-diabetes.gkznet.com)

## Addison’s in magazine articles

An article giving good factual information about Addison’s disease appears on p39 of the July 29 issue of Women’s Day. We didn’t know about the article until we saw the magazine, and unfortunately NZAN isn’t mentioned.

Also, in an article about Australian singer Helen Reddy in the July issue of the Australian Women’s Weekly, it’s reported that she has Addison’s disease.



## Members Contact List

This list is circulated to members only.  
 For any changes, please contact Jeanette

**This is your newsletter!  
 We need your contributions!  
 Please send to Jeanette,  
 your stories, tips, ideas, and  
 questions for our medical advisor.**

## NZAN Milestones, updated,

Nov 96: NZAN launched  
 Feb 97: Mailouts announcing NZAN sent to all endocrinologists and hospitals  
 July 97: First ‘Update’ newsletter  
 Jan 98: Dr Braatvedt offered to be medical advisor  
 Nov 99: First of our annual member surveys  
 Apr 00: 50<sup>th</sup> member joined  
 July 01: Professor Ian Holdaway becomes medical advisor  
 July 01: First regional meeting, in Auckland, with 33 attendees  
 Sept 01: First mini-meeting, Bay of Plenty  
 Oct 01: Website launched  
[www.addisons.org.nz](http://www.addisons.org.nz)  
 May 02: First central region meeting, Wellington  
 July 02: Centralised administration for NZAN  
 Next?

## HAYLEY’S STORY

### Because of adrenal surgery to treat Cushings syndrome, Hayley is now an Addisonian

My name is Hayley Lewis. I am 39 years of age, no children, Andy is my husband. We were married in September 2001. We live in Wanganui. We both work, Andy at a meat company, and myself in a lawyer’s office.

I have had Cushing’s Syndrome. My adrenal glands were surgically removed, and so I take hydrocortisone and fludrocortisone replacement, the same as people with Addison’s disease. This is my story leading up to and after diagnosis of this irritating condition.

In May 1998 I woke one morning to find my eyes had swollen, so much so that I felt my sight was slightly impaired. A week later the same puffiness was still there so I went to my local GP who prescribed eye drops which did nothing to make the swelling go down. I wondered then if I was allergic to something in my home or something I had eaten, so I began to eliminate things from my diet and

change things within the home. I decided to have the 8 hours sleep I thought I needed. Still the eyes remained puffy.

Time went by and another visit to the GP in March of 1999. By this time my face was filling out and began showing redness. I can remember saying to my GP that I had been feeling out of sorts and I couldn't quite pinpoint the reason, and my eyes were still puffy, but he could not shed any more light onto the situation. He ordered a blood test and rang the result back as fine, nothing to worry about.



In September 1999 I changed GP's. About this time I noticed facial hair appearing and Andy noticed a "hump" type formation on the back of my neck. Most of the time my face and neck were red. I had noticed daily, that strands of hair had fallen out in large quantities - my hairdresser said it was natural for at least 100 strands a day to fall out. In the meantime I was working five days a week, feeling okay at work but when the weekends came around my eyes got puffy again, and I felt drained of energy and spent most of the weekend just sitting around at home. Going out and socialising with friends on the odd occasion was a real effort. I was subjected to criticism about my facial hair and whether I was pregnant or not. This last remark was as a result of the increase in weight especially around the stomach area over several months.

Six months later, March 2000 I went to my new GP again. I was due for my annual smear test. At this consultation my GP prescribed another blood test which showed a discrepancy in the white blood cells. I then had five blood tests in five weeks and each time the result came back worse than the one before. My blood pressure was up a little and my cholesterol levels were up also.

I was advised at this time to cut out sugar, fat, oil, butter and salt from my diet to hopefully bring the cholesterol levels down a bit and lose a bit of weight. When I have done this before I have lost weight, but this time, it seemed I was putting on weight. My shape was changing - my upper torso was protruding further than my breasts and my stomach was becoming very rounded.

A daily pattern seemed to have emerged for me. First thing in the morning I didn't feel so bad, but as the day progressed, the aches and pains and skin stretching feelings I got, along with blurry vision, light headedness and tiredness just got worse. By 6pm at night I felt exhausted and like I was going to "pop".

My GP then referred me to a blood specialist. I had to wait another four weeks to see the specialist, and during that time my condition became progressively worse - instead of just the weekends feeling tired and lethargic, it was seven days a week.

At this time my legs had a reddish, blotchy look, I noticed that bruises on my legs and arms didn't go away in a hurry and were quite a deep purple colour. I developed "old age" blood spots on my arms which continued to appear. Striae (stretch marks), had vividly appeared on my lower stomach, also on the top of my left leg, under my arm and under my breasts.

My first meeting with the specialist was on 8th June 2000. My face and neck was swollen, my stomach felt like it was going to burst, it felt like I had something stuck in my throat, my eyes were watering all the time, my ankles, knees and fingers had swollen. I had aches and pains in my upper and lower back and behind my knees. My skin was still "blotchy" in appearance. April was the last time I had had a period. I was tired all the time and for the first time in my life that I can remember, had lots of dizzy spells. My family and friends commented to me that my personality was "not like it used to be".

At the end of the consultation the specialist prescribed another blood test, a chest x-ray and an Overnight Dexamethasone Suppression Test because he suspected Cushing's.

I, and my family had never heard of "Cushing's". My mother in particular was curious and having access to the Internet, typed in the word "Cushing's". She printed out all the information that she found on the Internet so I could read about it. That I did and sent four e-mails to addresses I had found on the Internet. I had a response from Jeanette of New Zealand Addison's Network and also Laurens Mjinders of ACIF. At least two to three times per week I would e-mail my dear friends, the support I got was second to none.



My chest x-rays showed no signs of abnormality, but the results of the dexamethasone test showed I needed another, higher-dose test, which meant three days in Wanganui Hospital. At the conclusion of this test the specialist treating me left the employ of the Wanganui hospital. I was then referred to another specialist. Three weeks went by and the "new" specialist telephoned me at work to advise that the results appeared to indicate Cushing's Syndrome. He then referred me to an Endocrinologist in another city.

I was again in contact with Jeanette of NZAN to let her know what was happening. Jeanette mentioned a book called "Cushing Patients in the Netherlands" which she suggested might be of interest to me. At this time I wanted as much information I could get so Jeanette loaned me the book from NZAN's library.

I was booked into the Waikato Hospital for Monday 24 July 2000 to undergo a Cushing's

Protocol for eight days. The night before my admission I read the book "Cushing Patients in the Netherlands" from front to back, which was ever so helpful. I felt fully prepared for everything that could possibly happen to me.

Part of the protocol was to undergo an MRI scan and CT scan. The MRI scan showed that both adrenal glands were two and a half times bigger than normal and full of nodules. I was immediately booked for surgery.

During the time leading up to surgery I experienced what I call a "chugging" sensation throughout my whole body, which was constant during the hours I was awake. Two days before surgery I got my period. It was so heavy I thought I was hemorrhaging. The next night, I had what appeared to be contractions for two hours. I was frightened. Then, 10 days after admission, I had a seven hour operation to remove both adrenal glands. It was intended and attempted, to do the laparoscopy approach but obviously the glands were too enlarged and therefore I had the big cut (64 staples later).

When in recovery after the operation on 3 August 2000, 99% of the symptoms I'd had, seemed to have disappeared.

I was discharged from Waikato Hospital a week later, and returned to work a couple of weeks after that. Most mornings for the first couple of weeks after my discharge from hospital, I woke with a terrible headache and backache for which I took two disprins every two hours to relieve the pain. I got the odd shooting pain in the stomach and pelvic area and I often got quite lethargic by mid afternoon. Although some days I had the attitude of "can't be bothered doing anything", I was positive and wanted to return to my previous self as soon as possible.

I have had just one day after discharge and before I went back to work, where the symptoms were quite different from "every day" happenings. I was awake most of the night one night with excruciating knee pain.

The knees just ached for about 10 hours. During this time it felt my stomach had subsided in size I didn't have that bloated feeling. My walking was a little wobbly, my knees and ankles were still swollen. I haven't had that since.

Originally I was told that recovery may take 12 to 18 months. Six months after surgery I began playing again the sports I love, squash, basketball, indoor netball. In April 2001, I came first in my grade at a local squash tournament. I played in the 2001 local basketball competition for 24 weeks from April to October. I was told by my team mates at Indoor Netball that I was a lot fitter now than before. I felt good. I felt normal then and I feel normal now. My weight reduction went from 76kg to 63kg in just a few months. I had always felt I was battling to reduce my weight for many years, however I'm quite content with my weight as it is now.

Approximately 12 months after surgery I had one night where I forgot to take my medication. It was 10.45pm at night when I felt drained of energy, could hardly move. I had a headache and pains were shooting down my left leg. I'd had a very busy day at work, I met a friend after work for a chat, then played squash a couple of hours later so by the time 10.45pm came I was extremely tired. It dawned on me then that I hadn't taken my medication at the regimental time of 5.30pm. I took my medication then, and woke up the next morning feeling great.

When I was diagnosed with Cushing's my job was quite routine, Receptionist/Telephonist for a local law firm. I often felt embarrassed greeting clients. I felt very conscious of how I looked. It was quite hard to cover a "moon face" and a rapidly expanding body. My appearance certainly did not give me much confidence in myself.

It's now 18 months since my adrenal glands were removed [May 2002]. My life feels like it's been kick started. I now find my employment more of a challenge as I now

have the added duty of Legal Executive which I thoroughly enjoy. I am trying to be the best I can be at my position as Legal Executive. Some days I feel I suffer from brain drain, but I'm sure it's because there is so much to learn and not enough time to learn it in.

Outside working hours during the summer months, I have taken on co-ordinating games of basketball for 28 teams, which again is a challenge. The mind has to be quite alert. It is rewarding through hearing from players that the competition is exciting and well run.

For the past 18 months I feel I have been on a roller-coaster ride. The highs have been that I have continued to be better medically, I have gained promotion through my employment, I married a wonderful man who continues to encourage me in everything I do. The lows have been - my mother died of cancer, my father suffered a brain aneurysm, and my bridesmaid passed away with melanoma. My feelings of despair have encouraged me to work hard and play hard to bring about ultimate happiness that I strive for.

I am lucky to have had the support of family, friends, work colleagues, NZAN and fellow sufferers of Cushing's and Addison's to help get me through a "glitch" in my life. I look forward to tomorrow every day. It feels great to be back again.



***Results of  
the NZAN  
March 2002  
Survey follow:***

