

# New Zealand Addison's Network

Jeanette: Ph/Fax 06 877 4352  
e-mail: jeanette@ramhb.co.nz  
Jill: Ph 06 357 1758  
e-mail: cheer@xtra.co.nz  
Hugh: Ph: 06 877 6084

PO Box 8562  
HAVELOCK NORTH



---

## UPDATE JULY 2000 (No.10)

---

Greetings fellow Addisonians

### **MEMBERSHIP**

NZAN'S membership continues to grow steadily - it's now 58. Since the March 2000 Update we welcome Jim, Gwen, Karel, David, Shirley, Kim, Raewyn and Dyan, and Jean who has joined to receive our information on behalf of her grand-daughter. Starter packs have been sent to a further four people who have made contact with us.

Thank you to Gary, Ian and Jo (all renewing members) for your donations. *Donations help us ensure that starter packs of information about Addison's Disease and NZAN are sent to anyone who asks, and Updates are mailed to all endocrinologists and hospital endocrinology clinics in New Zealand.*

NZAN has so far had direct contact with more than 85 Addisonians in New Zealand – and there are probably another 80-160 'out there'.

About 85% of our members have primary Addison's. The others have treated Cushings Syndrome, adrenals that needed surgical removal, no adrenals since birth, or some other syndromes that include inadequate adrenal function.

The end result for us all, is adjusting our lives to taking replacement doses of hydrocortisone or prednisone, and Florinef. That's the common ground for making NZAN 'home base'.

Twelve subscriptions are overdue. If yours is overdue, there'll be a bright sticker on the top of your Update. All it takes is \$20 to secure your place on the mailing list! If you don't respond, we'll assume you don't want to continue to receive mailings from NZAN. *If paying the subscription is difficult for you, please talk to us about it.*

## PHARMACISTS MADE AWARE OF NZAN

Our pharmacist member of NZAN has helped with some direct marketing of NZAN to the (approximately) 1100 pharmacists in New Zealand. Gary arranged for an article about NZAN to be placed in the May issue of Pharmacy Interactions, the monthly publication of the Pharmacy Society. We'll include a space on the next members' survey, for you to give us feedback about whether your pharmacist has mentioned NZAN to you!

## AWAY FROM HOME? FORGOTTEN YOUR BOTTLE OF PILLS?

We've all done it sometime - been away from home, maybe just at lunchtime, or unexpectedly delayed, and realised we don't have our hydrocortisone or prednisone with us. Missing a dose is unlikely to ever be life-threatening for an Addisonian - but it can make us cross with ourselves and worried that we may not function at our best over the following hours.

If you can give proof of your adrenal insufficiency (eg show your Medic Alert bracelet or necklace), you can pop into the nearest pharmacy for the dose(s) you need.

The empowering legislation is Section 44(m) of the Pharmacy Act, under which a pharmacist can dispense up to 3 days supply of medication in an emergency.

## ANOTHER SURVEY PLANNED FOR THE NOVEMBER 2000 UPDATE :

It was clear from the high response rate to our November 1999 survey, and the comments members made, that members are keen to participate in surveys relevant to them, to learn more about how they fit in the spectrum of Addison's experience in New Zealand.

We intend to include another survey in the November 2000 Update. If there is a question or an issue that you'd like included, please let us know before the end of August.

## TRIMMING YOUR GLUCOCORTICOID DOSE MIGHT HELP SHARPEN YOUR MIND AND MEMORY!

Do you want to improve your memory, improve your clarity of mind - read on...! Sounds like a TV Infomercial? Should you phone an 0800 number for a "wonder programme"? No!

One of the signs of hydrocortisone or prednisone over-dosage is poor memory ("what you hear, or what you read just doesn't sink in"), and poor mind function ("you just can't string it all together"). If Addisonians, especially those with a few miles on the clock, comment on this to friends and family, or sometimes to their doctor, they may be told - "you're not getting any younger, it's just age, it happens to me too".

The linkage of high blood cortisol, and mind and memory malfunction, seems to have biological survival value. For example, a recent study showed that people in a war zone had prolonged raised blood cortisol levels, probably enabling those people to flee, their mind not functioning logically and their

memory not registering all the horror around them.

But for Addisonians trying to function to their best in society, "loss" of some mind and memory function is a big nuisance.

There's an opportunity - Addisonians who have been used to better memory and mind function in years past, and whose daily dose is nudging 30mg hydrocortisone or more (more than about 7mg prednisone), might retrieve at least some of it by readjusting to a slightly lower, "more appropriate" dose of medications.

NZAN knows of some Addisonians, in New Zealand and overseas, who'd been taking 25-30mg or more of hydrocortisone daily, and who've been pleased at the extent to which their thinking and memory sharpened, and their general wellness improved, when they re-stabilised onto a slightly lower dose.

**Warning!**: Trial dosage reduction only under the supervision of your doctor, preferably your endocrinologist. And cut down **slowly**. A reasonable guideline is: no faster than 5mg hydrocortisone (1mg prednisone) per month, as 2-weekly steps of 2.5mg hydrocortisone (0.5mg prednisone). If you try to cut down faster, or in bigger jumps, you may experience muscle aches, mood swings and fatigue that seem to say that you can't do without that extra. So you might end up back where you started, for the wrong reasons! And give each new level a long enough trial of real living, to check that it's not too low for you. Most Addisonians shouldn't go below 20mg hydrocortisone (5mg prednisone), and some will stabilise better on a bit more.

Final comment: Hydrocortisone, prednisone, and Florinef are coarse substitutes for a healthy functioning adrenal gland. Getting the right doses for best quality of life can be a real challenge for some Addisonians and their doctors - not too little, not too much, and there when it is needed at the 'right' times of day, helped by a relatively consistent life-style.

### REMEMBER THE LIBRARY

A wide selection of Addison's literature is available either by contacting Jeanette or Jill (see details on front page) or by contacting Shirley direct at:

12 Parramatta Place  
Botany Downs  
Howick, AUCKLAND

### THE IMPORTANCE OF LAUGHTER FOR ADDISONIANS

In the next Update, we're hoping to have a science-based but easy-read article which unravels why it is especially helpful for Addisonians to laugh, and enjoy jokes and the funny side of life. If you feel as though you've lost your sense of humour, the dosage and/or timing of your hydrocortisone may be playing a part.

We'll also be including a question about "sense of humour" in the next NZAN Survey. Until then, we suggest you keep a bit of a diary for accurate self-awareness, noting under what circumstances you are the first or the last to laugh and see the funny side.

Meanwhile, we recommend you start practising - at least one good hearty laugh every day!

## MEMBERS QUESTIONS

Our medical adviser, Dr Braatvedt, is “on leave” from Update this issue – but we look forward to his input again next time. We encourage members to continue to send in questions for him.

Meanwhile, we have passed questions from two members about injectable steroid, and travel, to our pharmacist member, Gary Roselli:

*Darren asks:*

- *Is Solu-cortef the only form of emergency injectable steroid in NZ?*
- *Is there anyway yet to get a pre-filled syringe in New Zealand, so that all you have to do is remove the needle cap and inject?*
- *If not, are there steroid injections other than hydrocortisone that would be adequate in a ready-to-use form?*

*Darren also comments: Mixing and drawing up the solution should usually be straightforward, but not necessarily if one is very ill or if someone else is doing it that does not know what to do, or has difficulty with the process. Working with needles in some situations can also be hazardous, or they can be lost...*

Gary’s response:

“The short answers are yes, no, and no. Solu-cortef is good for the job, because it converts to hydrocortisone, the same as the naturally occurring corticosteroid. Also, it dissolves very easily, and can be used IV (into a vein) or IM (into a muscle). Mixing and drawing up is very simple. Solu-Cortef is relatively inexpensive, so one could practice using

a bottle of it. It is the actual injecting that most people don’t like.”

*Karen asks:*

*a) What precautions should Addisonians take, for visits to countries with likely problems of increased infections and stomach upsets. What type of medication should I ask my doctor to prescribe?*

*b) Does the GP issuing the prescription for Solu-cortef also automatically provide the correct needles? When travelling can this provide hassles with customs and drug enforcement agencies?*

Gary replies: a) “Buccastem for nausea and vomiting, and Loperamide for diarrhoea can both be purchased from a pharmacy or obtained on doctor’s prescription. Prevention is best – avoid salads, fruits you can’t peel, and prepared meals that may have been sitting around warm, but not piping hot, for a long time. Two antibiotics suitable for emergencies are Amoxicillin or Doxycycline – they are “broad spectrum”, and also have minimal side effects.

It’s a good idea for Addisonians to keep a record of antibiotics they’ve had in the past, and had no adverse reactions to, so that they can be used again if the need arises. Take care what countries you visit. If hygiene is suspect, be careful what you eat. Have a companion to help, who could give you an injection (eg of Solu-cortef ) if needed.”

b) The doctor can prescribe disposable syringes, or you can buy them. It is better if there is a pharmacy label on them, as with all medications. This will get you through Immigration etc at airports. You may like a doctor’s letter as well, but it shouldn’t be necessary.”

\*\* see also Lois's story in this issue of Update – she has some travel tips!

**GUEST CONTRIBUTOR:  
DR WARRICK INDER,  
Christchurch Endocrinologist**

**Setting the scene:**

NZAN's diversifying membership, mentioned above, makes clear that Addison's Disease is not the only adrenal disorder treated with "physiological replacement" doses of hydrocortisone, and Florinef.

People with Congenital Adrenal Hyperplasia (CAH), have a genetic fault in their cortisol production line. Not only do they not make enough cortisol (like Addisonians), but also they over-produce some other steroid hormones (the sex hormones called androgens).

NZAN exchanges newsletters with the New Zealand Congenital Adrenal Hyperplasia Support Group, organised by Helen Mann in Christchurch. In a recent CAH newsletter we found an easy-to-read article by Dr Inder about the various types of steroids. We thought it would be helpful for our members to share with friends and family. So Dr Inder has expanded his article for us, and included some comparisons between Addison's Disease and CAH.

**STEROIDS**

Dr Warrick Inder  
Endocrine Department  
Christchurch Hospital

There is often confusion among the general public about the hormones and

medications known as steroids. The highly publicized disqualification of athlete Ben Johnson at the Seoul Olympics for using steroids is but one example of the use of "androgenic" or "anabolic" steroids by athletes.

*What are steroids?*

Steroids are hormones made from cholesterol via a series of gradual modifications along a production line. Each modification requires a specific enzyme. Steroids are produced by a small number of endocrine glands, the adrenal glands in both sexes, the testes in men and the ovaries in women. Steroids control a whole variety of body functions. If an enzyme is missing, as it is in congenital adrenal hyperplasia (CAH), the steroid production line is blocked. This leads to insufficient amounts of certain steroids being made but an overproduction of others. In Addison's disease there is adrenal gland failure which leads to deficiency in all steroids made by the adrenal gland.

*What are the different kinds of steroids?*

Glucocorticoids

The main naturally-occurring adrenal gland steroid is cortisol. It is essential for life and vitality, aids with salt and water balance in the body and influences the control of blood pressure. People can suffer if cortisol is produced in excessive or inadequate amounts. The production of cortisol from the adrenal glands is controlled by another hormone called ACTH which is produced by the pituitary gland at the base of the brain. If a person has abnormally low levels of cortisol, doctors usually replace this with hydrocortisone which is identical to the natural cortisol, but some doctors use synthetic versions such as prednisone or dexamethasone. In

Addison's disease doctors usually prescribe hydrocortisone 2 or 3 times a day, with higher doses in the morning to mimic the body's normal rhythm. In CAH, the aim of treatment is to suppress excessive adrenal androgens (see below) which are stimulated by high ACTH levels. Because ACTH rises in the small hours of the morning, to turn down this drive often the highest dose of medication is given at night. Overall, doses are similar in Addison's disease and CAH though sometimes people with CAH may require slightly higher total daily doses to suppress the androgens.

#### Mineralocorticoids

These steroids are also produced by the adrenal gland and are the major controllers of salt balance. The main one is called aldosterone. Low levels are seen in Addison's disease and the 'salt-wasting' form of congenital adrenal hyperplasia and doctors replace this with fludrocortisone (florinef). Too much florinef causes salt retention and high blood pressure which is one reason why doctors regularly check the blood pressure of people with Addison's disease and CAH.

#### Estrogens

These are the main female hormones, mainly produced by the ovaries. (Men also have low levels of estrogen, and will grow excessively and have thin bones if estrogen is completely absent.) Estrogen replacement is often used in post menopausal women to control symptoms such as hot flushes, and to prevent/treat osteoporosis (thinning of the bones). Another hormone called progesterone is made by the ovaries in the second half of the menstrual cycle to prepare the uterus to accept a fertilised egg if pregnancy occurs.

#### Androgens/Anabolic Steroids

These are the main male hormones. The most important is testosterone which is made in large amounts by the testes. However both the ovaries and the adrenal glands make significant amounts of androgens as well. In CAH, a block in the steroid production line results in insufficient amounts of cortisol and aldosterone being made. The pituitary gland senses that the cortisol level is low and sends out more ACTH. This ACTH then stimulates the adrenal glands to try and produce more cortisol which, because of the block in the production line, it cannot do. This leads instead to an overproduction of androgens which, if not treated, can cause genital abnormalities in girls, early puberty in boys, and short adult stature in both. In Addison's disease, adrenal androgen levels are low, but men usually have normal testosterone levels (in the absence of testicular problems). Recent research indicates that replacement with one of the adrenal androgen precursors called DHEA may produce significant benefits in people with Addison's disease. It is available over the counter in the United States, but not currently available in New Zealand. With a doctor's prescription, it can be imported (see NZAN Update Number 8, November 1999).

#### *What do athletes take?*

The steroids athletes take are androgens/anabolic steroids which are derivatives of testosterone. These increase muscle mass and strength, especially when combined with an exercise training programme which significantly improves athletic performance. It can also cause increased body and facial hair growth, deepening of the voice, acne, and balding.

Anabolic steroid use by athletes has been banned because it gives an unfair advantage. Prior to the advent of random drug testing anabolic steroids were widely used by athletes of both sexes. The dangers are widely appreciated, but have been overstated. It is safe and beneficial to give replacement testosterone to people with inadequate amounts due to certain medical conditions.

### *Conclusion*

Steroids come in a number of different forms. Some are essential for life, others are required for normal strength, bone structure and sexual function. Problems can occur with levels that are either too high or too low. In people who are deficient in one or more naturally-occurring steroid hormones, hormone replacement is usually straight forward when supervised by a specialist.

---

## **MEMBERS SHARE THEIR STORIES**

It's winter – time to curl up in front of the fire with some good reading!

The case histories you have received so far, have been in the overseas newsletters that we copy to you. In this Update, we are starting our home-grown series. *But*, continuing with a few each issue, depends on **you!**

As promised in our March 2000 Update, we've got Karen's story ready for sharing too, about her pregnancy with Addison's and life with her third baby, Matthew, born February 2000. It's an interesting read, but a long one, and for space reasons we're holding it until the

next Update. If Addisonian pregnancy is particularly topical for any member, please contact us for a pre-publication copy.

*We realise that not knowing where to start, and what information to include, makes some people hesitate and procrastinate. So we have designed a checklist to help, which Lois and Gary have prototyped for us – if you'd like a copy, drop us a line. If you'd prefer to send us some notes, and then have a phone conversation for us to fill in the gaps, that's fine too.*

The three members sharing their stories in this issue are, in alphabetical order!:

- Dyan, now 24, born without adrenal glands;
- Gary's whose Addison's was probably caused by TB.
- Lois, originally from Christchurch, who has continued living in Malaysia for the twenty years since her Addison's diagnosis at 40.

### **Dyan's story:**

Dyan is 24. She works in the fruit and vegetable section of a Timaru supermarket, 7am to 4pm, and every second Sunday too. She walks an hour to and from work each day – and is intending to join a hockey team again next season. Self-reliant and independent, she lives alone – or rather with a big black Labrador, with whom she plays daily “tennis” after work in the park across the road.

Dyan is almost as rare as hen's teeth, because she was born without adrenals - a CT scan when she was 12 years old confirmed their absence. Quoting her

specialist's letter: "Dyan's presentation in early infancy with classic features of adrenal insufficiency, yet no obvious enzyme defect, has led us to label this disorder as congenital adrenal hypoplasia".

This is the history Dyan shared in the letter she sent when joining NZAN recently:

"It all started when I was 5 months old. It was not long after I stopped being breast-fed that I developed an ear infection. Treatment with antibiotics had little to no effect, and I continued to go 'downhill'. Lethargy and vomiting led to convulsions and unconsciousness. I was rushed to Timaru Hospital, where, according to my Plunket book, I had more convulsions, a couple of cardiac arrests, nearly dying on more than one occasion. I was fed IV through my ankle for two weeks.

At the time, my parents and I were living 5-10 minutes south of Timaru. After my stay in Timaru Hospital, I was sent home. One or two weeks later I had another cardiac arrest, and was transferred through to Christchurch Hospital. Many tests followed.

The diagnosis finally arrived: "non functioning adrenals". Initial treatment was liquid hydrocortisone, 5mls 3 times daily, and fludrocortisone tablets 0.1mg twice daily. The hydrocortisone worked fine, as long as it was fresh. After a while the medicine would go "off", and result in another rush trip to hospital for an injection.

As you can imagine, first off, my mother panicked a fair bit. She still does when I get sick – not that she'd admit it! There was worry when my brother was born (18 months after me), so he was tested at birth, and cleared.

And the worry over me was settled slightly when I was changed to hydrocortisone tablets. Teething caused problems, but increasing the dose seemed to control it.

Over the years the amount of pills has increased with age and weight. When I was 12, I was put on another pill as well for 6-12 months, to cover the lack of another adrenal hormone produced during puberty. A bone mineral density scan when I was 18 was fine.

Puberty also brought migraines, which seem to be related to lack of sleep and too much stress. Sandomigran tablets seem to control them. Asthma has also been another player in the game, hitting when I was 7 or 8 years old. Touch wood, it's nearly gone!

I last saw my endocrinologist in April of this year, and was extremely surprised to be told of the existence of NZAN. Any information I had ever found on the adrenal glands was either the wrong sort or thirty years out of date. The information pack sent is currently doing the rounds in my family. It has helped to explain a lot on a variety of topics.

People ask me what it's like to always be swallowing pills. I tell them I've never known any different. Now I'm glad to have information to back up why. "

In a phone conversation, Dyan rounded out her story. It had been a typical day. Pills at 4.45am, then out the door at 6am. She had walked to and from work, and then played with her dog in the park. "I can't stand not walking for at least an hour a day!"

She takes 15mg hydrocortisone (10 in the morning and 5 in the evening) and

0.15mg Florinef daily. She's 5ft tall, but a bit overweight for her frame. "Increased appetite and weight gain is a side effect of the migraine pills I have to take." She remembers being sent to a dietician when she was just six. "My brother always told me I was overweight. I put it on at puberty too."

"If I get very tired I might take an extra 5mg, or some paracetamol. But that doesn't happen often, only about once a month." She doesn't get sick more than other people – and if she does, she follows the doctor's instructions to increase her hydrocortisone dose until she is on the mend. The flu injection for the past couple of years has kept the flu away.

During childhood she wasn't as active as her younger brother. "I wasn't given the encouragement to go out and do things." I slowed down at intermediate school, and did what I could to get out of sport. But at high school she got more active, helped by the fact that she had to walk to and from school. "I'd previously been told that I wouldn't be able to manage sport. I tried hockey, and found that I enjoyed it. I enjoy the physical work at the supermarket too, but it is a bit tough on my knees and hips." She certainly doesn't view herself as restricted.

Dyan laughs as she explains that she has always been interested in biology. It was compulsory until 5<sup>th</sup> form. "Then in the sixth form I chose it as a subject – but the adrenal glands got just three lines on a page. I said, is that it! Is that all you are going to give me!"

Stress management? Not really, she says. "I avoid people that annoy me. I recognise my own short temper."

Dyan remembers an asthma attack, and a hernia, when she was a child. But for at least the past 10 years, migraines have been her only 'emergencies', 2-3 times a year. The letter she carries documents the cocktail to give for her migraines, and also IM or IV hydrocortisone. She also wears a Medic Alert bracelet. Because her father and grandmother also get migraines, she is able to be clear on the symptoms – "fuzzy eyes, and I can't see, like looking through water... My head splits, my temples throb, and pins and needles move around my body."

On her days off, Dyan goes into town, and walks the dog. She couldn't say 'walk' on the phone, but had to spell it, as the dog was nearby, and would be straight to the door with tail wagging, she said. She used to be member of the drama league, but had to give it up because of her working hours.

So is she a 'party animal'? "I'd like to be", she says with a laugh, "but working every second Sunday with a 7am start would cramp my style". She chooses not to drink alcohol. "My girlfriend and I were saying just the other day that we haven't been out for ages. At 24, we must be getting old!"

### **Gary's story:**

My name is Gary. I am 66 years of age, and have been diagnosed with Addison's for about 36 years.

Probably 4-5 years earlier, I developed the typical unwell symptoms – upset stomach, nausea, loss of appetite and general tiredness. I had always played a lot of sport, and gradually gave it all up as I got worse. For example, I played in

a regular four at golf, and it became a standing joke that it didn't matter if I was ahead after 12 or 14 holes, because the opponents would pick up the last ones as I wilted!

I saw one GP as soon as I was aware of the symptoms, and then two others. They failed to pinpoint my health problems, and a full examination by a specialist (who wasn't an endocrinologist) resulted in a diagnosis of functional dyspepsia, or "nervous tummy". I was put on Stelazine, a tranquilliser, with anti-nausea properties, and this helped a little. I kept taking it right up until I was diagnosed with Addison's.

In the last year before diagnosis, I got progressively worse. I am a pharmacist, and had great difficulty lasting the whole day on my feet, often working from a chair. I was sleeping 12 hours a day, lost a lot of weight, my blood pressure was low, and people commented on my tan. My memory was jogged when I saw part of "Dr Findlay's Casebook" on TV – the patient was tanned. I recalled something from a textbook, and that set me thinking. My GP laughed – he had seen the programme too. He sent me for tests, and told me everything was clear. One year later, I demanded to see an endocrinologist, he admitted me to hospital immediately, and the diagnosis was made.

I was born and bred in Westport. I had regular X-rays there, because TB was quite prevalent, but mine were reported normal. I came to Wellington when I was 22. When I was 27, an X-ray at a mobile clinic showed scarring of my lungs caused by TB - I don't know how I got it. The endocrinologist attributed my Addison's to TB. There's no

evidence that I have any autoimmune problems.

I was put on cortisone acetate, 37.5mg in the morning, 12.5mg in the afternoon (perhaps higher than average because of my lifestyle), and fludrocortisone 0.1mg daily. I took those dosages for about 30 years. About 4 years ago I was switched from the cortisone acetate to prednisone 7.5mg daily (5mg in the morning, 2.5mg in the afternoon), because of its longer duration of action, plus the 0.1mg fludrocortisone. I am 5ft 9 inches, and 80 kilos. My health generally has been very good, with the occasional episode where Solu-cortef was needed – usually after vomiting and diarrhoea in South-East Asia, etc (but I did not inject myself!). I always carry a vial of Solu-cortef when I travel, together with spare prednisone. I had a bone density test done about 5 years ago – everything great.

Heat has been a problem, especially playing tennis in Australia, with temperatures up to 45°C. All the loading with carbohydrates, electrolytes, fluids and extra fludrocortisone has little effect. After a few hours I get dizzy, and I have been carried off the court. I don't get tired generally, but after a weekend of tennis, it takes me about 3 days to "recover". I don't take extra prednisone, but did take a little extra cortisone acetate during a competition. I don't take sleeping tablets.

Travel poses a different set of difficulties, as far as medication is concerned, and I tend to 'split the difference', ie take an extra lesser amount of prednisone to see out the day. I find a 30 hour day easier to handle than a 20 hour day. Eating and drinking alcohol just in moderation is vital for me, and water intake must be stepped

up. It is wise for me to limit flying time to 8-10 hours, with a stopover for a day or two.

I am fortunate that I tend not to get sick – perhaps I have built up immunity at work! I don't get stressed. I still work 45+ hours per week. Friends and family all know that I have Addison's – most of them have seen me struggling at times, eg in the heat, on the tennis court, etc.

I think that probably more than any other illness, Addison's Disease must be managed by the patients themselves - only you know if you are well or not. We are fortunate to live in an age where the condition can be managed – after all, treatment was not available until the late 1950s. I count myself lucky to be still in business doing what I enjoy, taking part in competitive sport, and travelling extensively. We all must just be aware of our limitations.

*Editor's note: Gary was reluctant when asked to share some achievements in his life, but we encouraged him!*

Highlights in my life? Professionally, probably helping set up a medical centre with doctors, pharmacy etc. Sporting? I have won several NZ titles and teams events in NZ and Australia, and have captained NZ teams at the World Championships – over 60 and over 65. But I have never won a world title – yet!

### **Lois's story:**

Lois wrote us two case histories. The first disappeared into cyberspace when she forgot to press 'save'! With the doggedness that many of us recognize, she went through the exercise again for us, next morning:

I was finally diagnosed with Addison's in 1980, at the age of 40, after eight months of to-ing and fro-ing to various specialists.

I was told I was anorexic, I was in need of tranquilizers because I was turning 40 - endless excuses for a problem they could not solve. By this time I had lost about 10 kilos, as I was not eating properly. I just could not force food down, and I guess was becoming anaemic due to this. When I started vomiting in the morning my husband decided enough was enough, and we went to see a Dr Tambyah at Mt. Elizabeth Hospital in Singapore.

At this stage I was barely able to walk six or seven metres without having to sit down and rest. Dr Tambyah looked at me, looked at my notes and said: "I think I know what's wrong with you". I was admitted to the hospital, a 24 hour urine sample was taken, and next day he came and told me I had Addison's.

I was started on Cortisone Acetate and Florinef immediately, and within a day began to feel so much better. I was given a CT scan to see if there was any calcification of the adrenal glands, but nothing showed up so they said the glands had atrophied. I am at present taking hydrocortisone 10 mg BD and Florinef 0.1mg 1 tablet in the morning and 1/2 tablet in the evening.

I take my afternoon dose of hydrocortisone later than advised, and it does not present a problem for me with regard to sleeping. I find if I schedule it earlier in the afternoon, I am inclined to forget it sometimes, so it's easier to leave the pills on the table and take them with my evening meal.

I am also taking Renitec 7.5 mg daily for mildly elevated BP. My mother used to say she had high blood pressure, but having lived here in Malaysia for 38 years I was not really much aware of what she was taking. As I am an only child, I do not even have much of a family history to go by.

Basically my medication dose has changed little over the last 20 years. I am 5ft 3in in height and weigh 55 kilos so although I am LARGE in this country when it comes to buying clothes, I am rather small by New Zealand standards. I have no other health problems and rarely get sick with coughs or colds. I have had bronchitis twice in the last 4 years but have never had the flu as such.

All in all, I lead a life free of any major health disorders. In fact it was not until I began reading the Addison's Newsletters that I realised how fortunate I have been with my health. I was diagnosed in my forties, so it has not really affected my life very much from the health aspect. It has, though, affected my choices in life regarding travel.

My husband and I usually travel to a different holiday destination every year, and certain countries have gone onto the back burner. I went to Egypt 8 years ago, and my suitcase was filled with bottled water, which I used for drinking and cleaning my teeth. I had no problem there although I was also VERY aware of what I ate - no salads or raw fruit that I could not peel.

I had also taken water sterilizing tablets, and one day we saw these *magnificent* strawberries. I decided to buy them and we went back to the hotel, put water and tablets into the ice bucket, and then put

the strawberries into that mixture. I don't think it did much for the taste, but you do get to the stage where you just long for something uncooked. Addison's has not affected my choices in my sporting life. I play golf here, but do start early in the morning, and I also go for morning walks when I am not golfing. With air conditioned cars, houses and shopping malls life is fine. Of course I don't go out in the heat of the day unless I have to. I do feel the heat sometimes when I am golfing, but put this down to age as much as to Addison's.

Sometimes only a little knowledge is a good thing. I never realised the problems other people have until I started reading the Newsletters. On the whole, I sail through life unaffected by my medical problem. I have never had an Addison's crisis, and my husband and friends who are all aware of my problem would hopefully get me to a hospital if I collapsed in front of them for any reason.

Having lived with the disease uneventfully for 20 years maybe I should give them all an update about what to do in an emergency - one does get a bit blasé about these things! There is a Medic Alert Society here in Malaysia and I do wear an emblem but have *serious* doubts that anyone would know what the bracelet even represents. It's not something that I have ever seen advertised here. I carry a card outlining my problem in my wallet and have extra supplies of my pills in my car, my husband's car, my golf bag and my handbag. I have on occasion had to use these when I rushed out and forgot to take my medication.

As far as stress management goes - nothing. I am a fairly placid person, and

sail uneventfully through my life, so that has never been an issue. I don't set myself impossible goals, and if I don't feel like doing something, I don't. I can honestly say that in my case I doubt that having Addison's has interfered with my life in any way that relates to the quality of life.

I am from Christchurch originally and met my husband, who is Chinese from Malaysia, when he was studying at University in New Zealand. Our three children went to New Zealand for secondary schooling and University, and are presently residing there. My mother is still in Christchurch, and at 92 is in residential care. I was sent to Prof Espiner at Christchurch Hospital by the doctor in Singapore, and have continued to see him once a year for the last 20 years. I guess I could find an Endocrinologist here, should I wish, as medical facilities have improved enormously since I was diagnosed, but I continue to go to New Zealand as I know him, and he knows my history.

I am basically a housewife here, as it is difficult for non-Malaysians to work, although I did some nursing when I first came here in 1962. I do some social work with handicapped ladies and enjoy that.

*Travel tips for Addisonians in Asia:*

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.

When I travel overseas I always carry my medication with me in my carry on

luggage and also have some spare in my husband's case, in case we should happen to lose mine. I also carry on the plane Solu-Cortef, in case of a real emergency, but have never had to use this. I feel have covered all bases as far as I can in this area.

Bottled water is available everywhere these days. Make sure you buy a medical insurance. Watch what you eat regarding raw foods and things like ice in drinks and ice cream from wayside stalls [both a big NO NO]. 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.

I do find from my own experience and that of friends and also from articles in the British papers, that more people are falling ill *after* flights. This is due in part to Non Smoking flights. Because they do not have to clean the air so much, the airlines change the air in the plane less frequently. It costs money to bring in freezing cold air and heat it up so they recycle it more often than they used to. I read an article in a London paper that *one sneeze* can be transmitted 20 rows ahead. The article said tongue in cheek that maybe we should all wear masks on board, I can't see that happening no matter how good the idea is. Certain things are beyond our control, so we can only do so much and leave the rest to fate!

Lois can be reached on email: mlo@pc.jaring.my

---

---

**PREVIOUS UPDATES FOR SALE:**

We have copies of all back issues and on request can post these to you for just \$5 for one issue and \$3 for each additional one.

*If you'd like copies of past issues, but paying is a hardship for you, please talk to us about it.*

*Wishing you good health  
Jeanette and Jill*

---