

New Zealand Addison's Network

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NZAN Newsletter, April 2007 (No 26)

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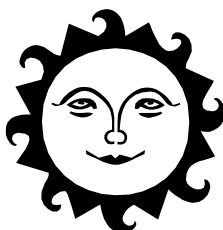
Meetings coming up:

Wellington, 27 May
Auckland, 9 June
Christchurch, 25 June
Bay of Plenty May/June
Nelson, May/June
Northland, May/June
see inside.....>

**Wishing all readers
good health and good stamina**

Jeanette, Gary 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



CHANGE OF NATIONAL CO-ORDINATOR An Update from Jeanette

This newsletter is to let you know that NZAN is awakening from hibernation! ☺

Proof is the several meetings being held over the next few months – so far Wellington, Auckland, Christchurch, Bay of Plenty, Nelson and Northland [more details below].

An important change is that NZAN will be co-ordinated through its next phase by a nucleus of members in Wellington, led by Gary Roselli, currently our central region co-ordinator. My sincere thanks to them, in response to my letter last September, which explained that I cannot continue my active role with NZAN.

I am helping with the practicalities of the transition [including writing this newsletter] and will remain supportive, and a sounding board. During the transition phase, I will keep the website 'alive', and also keep encouraging the distribution of our pamphlets. We are very fortunate that MediBoard continues to distribute our pamphlets to many GPs and hospital outlets throughout New Zealand. Several of our members have learned about Addison's disease, and about NZAN, by picking up and reading our pamphlet.

It is important for me to make clear, however, that I have stepped aside from the management of NZAN. I no longer have the time and energy to do what is needed. The new team will shape and enact the future of NZAN.

Gary Roselli can be contacted on 04 565 1783.

Gary will be overseas for several weeks during the year. When away, he clears his voicemail regularly. During those times, if you need help or information more promptly, contact Don Christie on 04-970 1188, email kichitak@yahoo.com.au

NZAN's postal address, and the link from the website to my email address, will remain unchanged meanwhile. I will promptly forward material to Gary as appropriate.

After the Central Regional Meeting in May [see below], the Wellington team will be clearer about what strengths and skills they have locally, and what they may be keen to co-opt. Gary now has a copy of the membership forms and database. Members can be assured of the same level of confidentiality as has applied previously.

NZAN's membership "pre-hibernation" had reached more than 150 throughout New Zealand, and I was overloaded. To function optimally, the new team in Wellington needs ideas, energy and action from members in other regions. We hope that some "new faces" will volunteer to help arrange meetings on a reasonably regular basis, in regions and districts throughout New Zealand, sharing the load with those who have been active for the past several years. To help those who may otherwise hesitate to volunteer, we have tips and guidelines for formats for meetings, which can be sent email or snail-mail on request.

**If you'd like to be involved in the new era of NZAN, please let us know.
Come along to the next meeting being held near you – or arrange one in your district!**



NEW MEMBERS

We welcome Claire, Mary, John, and Lindsay as new members since our last newsletter. Several others have also contacted us, and are on our mailing list to receive this newsletter.

SUBSCRIPTIONS

It's a couple of years since we last sent out invoices for subscriptions. We are declaring an amnesty, and enclosing an invoice with this newsletter, for the year from 1 April 07.

We are keeping the subscription at \$20, the amount it has been since NZAN began in 1996. Members have the option of adding a bit extra as a donation, as many have done in the past - thank you. Please return the invoice form with your payment – on it are some questions whose answers will help us to help you.

A few members paid ahead – I will try and put a red dot on your envelopes. To keep things on an equal footing, your prior payment covers this year – but please return the invoice form, so that we have your feedback on the questions asked.

MEETINGS COMING UP:

CENTRAL REGION – Wellington.

Sunday 27 May, 1-4pm, at the usual venue in Petone. Contact Gary Roselli 04-565 1783.

AUCKLAND: Saturday 9 June, 1-4pm in Eden Garden, 24 Omana Ave, Epsom.

This oasis in central Auckland is not far from the Mercy Hospital and Specialist Centre in Mountain Road. [Take the Gillies Ave off-ramp from the Southern Motorway.] Juice, water and biscuits will be available in the meeting room – a few steps away is a great café, reasonably priced. A suggestion is to come early and enjoy lunch in the café before the meeting – we have a copy of the menus. For more information, contact Karen 09 483-7043 email kcarson@xtra.co.nz, or Jeanette 09 636 8238, email jeanette.c@paradise.net.nz

Jeanette will facilitate discussion of some topics of importance to Addisonians. If there is something you would particularly like covered, please let Jeanette know.

There's no charge for the meeting – but a small donation will be appreciated towards the cost of the room.

**** Important!!:** Karen is overloaded with study and family commitments. We hope that someone in Auckland will volunteer to help arrange future meetings, and to keep in touch with members about them.**

CHRISTCHURCH: Sunday 24 June, 1-4pm at Shirley School.

Local organiser is Russell Stocks, phone 03 384 0035; email stocksr@shirley.school.nz. Jeanette will be arriving in Christchurch that day to stay with friends for a few days, and will contribute to the meeting by facilitating a discussion of some topics of importance to Addisonians.

BAY OF PLENTY: Co-ordinator Diane Goldsack is arranging a meeting in May/June.

Diane will contact local members. For more information, contact her phone 07 572 1430, email diane.goldsack@ihug.co.nz.

NORTHLAND: Contact Maureen phone 09 436 3136, email mbourgaize@actrix.gen.nz. Northland members meet approximately three-

monthly, in alternate homes. The next meeting will be in May/June.

NELSON: Pauline Banks and Grace Topliss are arranging a meeting in Nelson in May/June. They will contact local members. For more information contact Pauline phone 03 544 4813, email paulinepete@xtra.co.nz.

A Reminder about International Resources:

When NZAN started 10 years ago, the Internet was relatively new. Now anyone can easily access the websites of the Addison's support groups in the US, Canada, Australia and UK [as well as our own!] - Links are on our website. These sites contain some excellent material, and we strongly recommend that you explore them. There are also several Internet forums, either linked with those national groups, or independently moderated.

Local context matters too!

It has proven true over the years, however, that there is a need and appreciation for "local knowledge and contacts", and meeting and sharing experiences with others with the same medical condition. Also we can become complacent about the safety issues – and we benefit from reminders, such as to have our emergency protocols and our Solu-Cortef injection kit up to date and accessible to friends and family.

At the Wellington meeting last year, member Grant Pryde gave a talk about travel insurance. He reported quite a difference in approach between different insurance companies. If you would liked a copy of his summary, posted snail-mail, contact Jeanette or Gary.



HAVE YOU 'ICED' YOUR MOBILE PHONE? ICE = In Case of Emergency:

The topic was raised at the Auckland meeting last year by Karen McWha who was visiting from Blenheim.. She explained: "This is what I now have in my mobile phone, with my son John's name beside the ICE. The person accessing my phone would then have the ease of ringing John on my phone to get the information that they need. This would be especially helpful for me, as John is up with the play concerning my Addison's medication.

ICE showed its value at the time of the London bombings in July 2005. Rescuers looked for mobile phones and scrolled through the list of names in the phone looking for ICE, and the associated name and number for the next of kin or other nominated person, which they could ring to find out the name and the medications of the patient that they had. "

We reprint here with permission, an article from the Association of St John newsletter:

"St John Supports ICE (In Case of Emergency) Idea

Friday 14 July, 2005

St John supports the idea for people carrying mobile phones to include ICE contact details in their mobile directory.

Standing for In Case of Emergency, ICE will allow ambulance crews and other personnel to quickly contact a nominated person who can be informed in the event of an incident. Mobile phone owners should type the acronym ICE followed by a contact name (for example, ICE - mum or ICE - David) into the address book of their mobile phone and save the phone number. They should also agree and inform their ICE contacts of the arrangements.

The ICE idea was first promoted by the East Anglian Ambulance Trust and has achieved more awareness following the tragic events in London last week. A chain email campaign promoting the idea has since made its way to New Zealand.

St John Chief Executive Jaimes Wood says any means that people use to carry relevant information about themselves will be useful in an

emergency. Storing the information in mobile phones may be useful in some cases, though it should not be relied on as the only way.

"We anticipate there will be benefits for ambulance and emergency service personnel from ICE number listings in mobile phones but next of kin and other important information, such as medical conditions and medication, should also be included in wallet cards, diaries and other similar personal items."



Margaret Morison's grand-daughter finds ADDISON'S ON THE WALL OF THE JANE AUSTEN CENTRE, BATH, ENGLAND:

Jane Austen moved with her family to Bath in Somerset, England, in 1801, when her father suddenly decided to retire there. She was 26 at the time, and lived there five years. She died in Winchester in 1817, and is buried in Winchester Cathedral. There is a Jane Austen Centre in Bath, and when a granddaughter of NZAN member Margaret Morison visited it last year, she was amazed to find a plaque on the wall about Addison's disease, and sent Margaret a photograph. This is the wording on it:

"ADDISON'S DISEASE BRIEF DESCRIPTION

Addison's disease is a rare hormonal disorder, affecting on average one in one hundred thousand people. It can occur in all age groups and is not specific to either men or women.

HISTORY OF THE DISEASE

The condition was first identified by Dr. Thomas Addison in 1849. The disease was not associated with Jane Austen until 1964. In his published article 'Jane Austen's Last Illness' used Jane's own accounts of her symptoms contained in her letters to establish a link and used quotations to substantiate his theory.

SYMPTOMS OF THE DISEASE

Sufferers of Addison's Disease would experience weight loss, muscle weakness, fatigue, low blood pressure and in some cases a darkening of the

skin. In a letter to her niece, Fanny, dated 23 March, 1817, Jane writes:

"I have had a good deal of fever at times, and indifferent nights, but am considerably better now, and recovering my looks a little, which have been bad enough, black and white and every wrong colour."

CAUSES OF THE DISEASE

Addison's disease can be caused by a deficiency of the hormone Cortisol which is produced in the body's adrenal glands. Among other responsibilities, Cortisol's primary function is to help the body respond to stress. In a letter to her brother Charles, dated 6 April, 1817, Jane states:

"A few days ago my complaint appeared removed, but I am ashamed to say that the shock of my uncle's will brought on a relapse..."

(The Austens had been expecting a considerable inheritance from James Leigh Perrot, which they did not receive upon the reading of the will.)"



ADDISON'S in New Zealand Geography

If you google "Addison New Zealand" the link to NZAN's website comes up first.

Second in the list is the link to a Wikipedia entry: "ADDISON is a small housing complex in [Takanini](#), [Auckland](#), [New Zealand](#). Located in [Papakura](#), one of Auckland's five satellite cities. Under the authority of the Papakura District Council. Addison can be considered a suburb of Auckland."

ADDISON'S FLAT near Westport is a place with gold mining history, that Gary Roselli has known all his life....his grandfather farmed nearby.

Googling revealed more details..."On 18th May 1867 gold was discovered about eight miles south of Westport on Waite's Pakihi near the foot of a hill behind the place where the school master's house was soon to be built. A negro, Addison and his party sank a shaft about thirty feet deep and struck gold in wash dirt that was four feet thick.. " [more at <http://nzhideaway.com/addison1.htm>].

LIFE INSURANCE – A TWIST! From an obituary, 1897

Last December, Nelson member Pauline spent a few nights at a bed and breakfast by the beach at Collingwood last December.

The room had several books with local history. Browsing one of them [Collingwood, the old Cemetery and Early History, by Chris Petyt], Pauline found the following entry, from the obituaries in the local newspaper:

"18 July 1895 Constantine Allan aged 32
4th son of David Allan

The disease of which the late Mr Con Allan died was "Addison's Disease" one of the rarest diseases known to the medical world, and about the treatment of which very little is known. It is an affliction of the "supra-renal capsules", two little organs connected with the kidneys, the functions of which are also somewhat a mystery to medical men.

We might state that an insurance policy on his life taken out in 1886, with the A.M.P. Society, had accumulated nearly 70 pounds profit by way of bonuses, the sum assured being 300 pounds, on which about 85 pounds had been paid in premiums. This is the bright side of life insurance. The deceased's estate is worth over 500 pounds."



The members' contact list is enclosed with this newsletter. If you see any details that need changing, or if you have inadvertently been left off the list, please let Gary know.