

NZAN Newsletter 24 – Part 1

Jeanette's Update

2 May, 2005

Warm greetings,

This letter is being sent (email or snailmail), to let you know some of the information intended for the regular newsletter, No.24, which is running late.

In particular: there will be two NZAN Meetings in May, to which all Addisonians, family and friends are welcome:

- in Auckland, 14 May,
- in Lower Hutt, 29 May

In the second part of the newsletter, which you'll receive soon in the usual way, will be some members' stories, with comment and also some answers to questions from our Medical Advisor, Professor Ian Holdaway. There will also be some feedback from the International Addison's Survey that NZAN members participated in, late 2003. Also included will be members' news and views - so if you have some medical or personal news to share, please sent it by return mail to me!

Meeting Invitations:

Auckland Regional Meeting, Takapuna

Saturday 14 May, 11.30am until mid afternoon

Karen Carson, northern region co-ordinator, has arranged another informal get-together over lunch at the Blue Cat Café, 149 Hurstmere Road, Takapuna.

There is a private upstairs room, where reasonably priced beverages and snacks can be ordered. The cafe phone number is 488 6630 should you need it. You can park in the carpark behind Rendalls, walk through the walkway, and the Café is almost opposite the Post Office.

I attended the lively meeting at the café last October, and look forward to meeting more of our northern members this time.

For more information, contact Karen, phone 09 483 7043, email kcarson@xtra.co.nz

Central Regional Meeting, Lower Hutt,

Sunday 29 May, 11am – 3pm

The format will in part be similar to last year – with a bonus! Gary Roselli, central region co-ordinator, will chair first a round of self-introductions, and then discussion of topics raised by participants. These may focus into questions to pass on to the medical advisor – or articles for the newsletter.

Then Pauline Dennehy, a member who is a public health nurse, will demonstrate how to give a Solu-Cortef intra-muscular injection, as described in our NZAN Guidelines. While the Forum is continuing, attendees (and their family and friends) will have the opportunity to move aside from the main group one by one, and 'give it a go', under Pauline's supervision. She will have some Solu-Cortef vials for practice handling "the real stuff", but only saline solution will be injected.

Please contact Gary or Pauline if you'd like to attend:

Gary: 04 565 1783; email pamandgary@xtra.co.nz

Pauline: 06 368 2737 (home), email pauline.dennehy@midcentral.co.nz

Please bring a plate of finger-food to share for a light lunch.

Addisonians and their family and friends in the Central Region and further afield are warmly welcome.

Change of phone number and address for NZAN:

Earlier this year I moved back to Auckland from Havelock North, where I had lived for 15 years. I stayed with friends for a couple of months, then in early April moved to my new address in One Tree Hill. Ironically I'm not far from where I grew up, but that certainly wasn't my original intention.

So there are changes of phone number and box number – my email stays the same:

Jeanette Crossley
Phone/fax 09 636 8238
Jeanette.c@paradise.net.nz

NZAN,
PO Box 17-414, Greenlane, Auckland.

Meanwhile, my phone in Havelock North continues as a voicemail. Also, mail addressed to the Havelock North postbox is being redirected to the above Auckland box until March 2006, so no mail intended for NZAN should go astray.

However – there was a glitch in early April when the Havelock North post office returned some mail to sender, in error. I don't know if any NZAN mail was involved. Also, I haven't been at my administrative best over the past few months! So I apologise if you haven't had an expected reply from me - please contact me again. I am gradually putting into practice, strategies to lighten my NZAN load, and I believe members will see positive benefits.

Membership Update

We welcome five new members since the December newsletter: Gaye, Greg, JenniferH, Margaret and Valerie.

Margaret found our pamphlet in the Timaru library, Jennifer found a pamphlet at Taupo Hospital Outpatients, and the others found us on the Internet.

That brings the tally to 140 members (with a few not paid up!). Information packs have been sent to eight others.

Report: First Meeting in Nelson, 13 February 05

This is a blend of notes and comments from organizers and some participants.

Almost a full turnout of Nelson and Marlborough members participated with enthusiasm in the first NZAN meeting in Nelson on Sunday 13 February, 1-4pm.

Pauline Banks (Nelson) and Karen McWha (Blenheim), shared the phoning to invite members, and Gary Roselli (NZAN central co-ordinator) chaired the meeting. Pauline and her husband Pete arranged the practicalities, and cheerfully helped everything flow smoothly.

Ten Addisonians and five support people met in a comfortable room at Radio Fyfreshire in the center of Nelson, by the Cathedral. Four came across from Blenheim. But the distance award goes to Mary who drove the 5.5 hours from HariHari on the West Coast! At the last minute she'd been unable to go across to the Christchurch meeting last July, so was determined not to miss this chance to meet other Addisonians.

The group included two Addisonians not yet NZAN members. One lady who'd responded to the notice in the local paper, had been diagnosed in 1953, and seemed to be enjoying good health – an encouragement for those more recently diagnosed.

Gary led the way for the Addisonians present to each talk about their own situation for about 5 minutes. Then after a tea break, various topics were discussed in a forum.

Using Prof Holdaway's overheads from the Northern Regional meetings, Gary covered the basics of adrenal insufficiency, which was of particular interest to the group because there were examples present of primary and secondary adrenal insufficiency, and Cushings treated by surgical removal of the adrenals. [Different ways to end up in the same boat!]

Gary reminded participants of the importance of keeping steroid medication with them at all times, increasing doses when ill (especially for flu and other feverish illness), and having a Solu-Cortef injection kit for circumstances when oral meds can't do the job, such as diarrhoea and vomiting, or nausea. He referred to the NZAN Solu-Cortef Guidelines booklet, and used Karen's Solu-Cortef kit to demonstrate (without actually breaking the seals!).

Gary used the Star Diagram (sent with our information packs, and downloadable from our website), to remind about the balance needed to live healthily with Addison's disease (meds, stress, sleep, food, exercise, and hydration).

There was plenty of interaction, and participants indicated they are keen to meet again.

Reminder: Solu-Cortef Self-Injection Guidelines

The NZAN Guidelines for Self-Injection of IM Hydrocortisone can be downloaded from the NZAN Website www.addisons.org.nz

For a printed copy of this 8-page booklet, please contact Jeanette.

We can still Think Pink for a while

Bristol Myers Squibb have told us that the change from pink to white Florinef (fludrocortisone) is unlikely to occur before September... maybe later.

Australian Addisonian Helen Reddy has published her memoirs:

Singer Helen Reddy is patron of the Australian Addison's Disease Association. Media articles timed with the launch of her memoirs at the end of March helped raise the profile of Addison's disease among the general public.

The book publisher said in a pre-release statement:

"With her song 'I Am Woman', Helen Reddy provided the feminist anthem of the 1970s. In this highly anticipated memoir, Helen reveals that she is much more than the entertainer who first graced the stage at the age of four.

"Helen Reddy became the first Australian to win a Grammy, to have her own prime-time variety show on a US television network and to have three number-one hit singles in the same year. Then, at the height of her career, Helen's world was shattered by the death of both her parents and also the news that she had a rare, incurable disease.

"In this riveting, frank and ultimately brave memoir, Helen reveals the emotional highs and lows that have shaped her as an artist and as a complex woman with a rich inner life sustained by a strong spiritual faith."

Helen Reddy was in New Zealand promoting her book during April, and was featured in the 16 April issue of New Idea magazine. NZAN was able to raise the profile of Addison's disease in New Zealand a bit more, with a "human interest" story about one of our members, northern co-ordinator Karen Carson, busy mother of three – a two-page article, with good photos.

Until Part 2 of Newsletter 24....

Wishing you best possible health, and good stamina!

Jeanette Crossley
(NZAN National Co-Ordinator)