

New Zealand Addison's Network

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NZAN Newsletter, December 2004 (No 23)



Season's Greetings



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

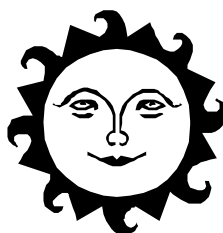
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Jeanette and the team



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



Jeanette's Column



Some hiccups in my life mean I haven't been able to get a Newsletter out with the usual variety of content before the Holiday Season. Hence this shorter one, which is only just in time for action by the dispatch team!

This is the only NZAN newsletter I haven't prior sent to our medical advisor Professor Holdaway for checking – only because of the time pressures - and so the content has been adjusted accordingly. Several interesting stories that are almost ready for publishing, are being held over for our next newsletters (see box page 4). It's great that members are sending their stories, and sharing experiences that are of relevance and interest to many others with Addison's disease. Thank you!

Some members have sent questions for Prof Holdaway. These too will be published in our next newsletter. The answers have already been passed on to those who asked.

Feedback has consistently indicated that the most keenly read parts of NZAN newsletters are the members' stories, and the medical advisor's contributions.

We are very fortunate that Professor Holdaway checks our newsletters for medical accuracy and perspective before they are published. He suggests corrections and improvements, and when appropriate adds comment and medical context that is printed with the stories.

NZAN's newsletters have a good reputation as an accurate and balanced source of information about living with Addison's disease. I'll do my best to continue the standard, so that members can take information from our newsletters to their doctors with confidence.

Sincere thanks to those who have worked with me during 2004 to help keep NZAN vibrant, including

- * Professor Holdaway our medical advisor,
- * Annette Church who keeps our database, and does the magic mailouts
- * the several members who have shared their time, energy and skills, in particular to arrange regional meetings



Membership update:

We welcome 5 new members since our previous newsletter, who range in age from 9 to 69: Brooke, Jacqui, Jennifer, RobertS and VickyB. Information packs have been sent to 5 others.

We now have 135 members.

Regional Meeting Reports

This year has seen meetings in Wellington and Christchurch, and, since our last newsletter, in Auckland, Mt Maunganui and Levin (reports of these follow). Next year, further meetings are planned in each of these places, and also in some new ones.

Has there been an NZAN meeting in your part of the country? If not, would you be willing to organize one? You are welcome to contact Jeanette or the regional co-ordinators for guidelines.

NZAN Regional co-ordinators:

Northern - Karen Carson

Midland – Diane Goldsack

Central – Gary Roselli

Southern – Patsy Fogarty and Russell Stocks.

Their contact details are on the members' list.

1. BOP / Waikato Meeting, 2 October, Report from Diane Goldsack, BOP / Waikato Co-Ordinator

We were a group of nine that met together at the Dominion Salt office at 2pm on Saturday 2 October, to share experiences and information. Three of us, Chris, Marianne and Rosemaree had traveled some distance from Hamilton area and Pokeno to attend.

The format was very relaxed as we went around the group and briefly shared our history. We also talked about how much replacement cortisone we took, in what form and how often. We discussed the differences between prednisone and hydrocortisone, and what these do in the body.

Of much interest was the question about warning signals for recognizing low cortisol levels and what to do in these situations. Ray was of great help here as he has had to give himself a Solu-Cortef injection on a number of occasions (or more to the point his wife has). He was also able to give us information about his warning signals for low cortisol levels. The concept of having an emergency kit and having to use it was new for the first time attendees, so they were keen for more information.

We took time out for afternoon tea and that allowed people to talk between themselves – which they did enthusiastically and it was hard to draw them back to a group discussion. However this is good also, as it helps to build relationships. We finished the meeting at 4.30pm. The group was an interesting mix of people with primary Addison's, secondary Addison's (two of these are a result of medication for asthma) and treated Cushing's.

I think the area meetings are good value as they allow people to meet others in a small group setting. The pre-contact beforehand, where I or Colleen ring around the people in the area to notify them of the meeting, is also valuable.

We have always had new people turn up to our meetings. This time one had recently been told about NZAN by her chemist (the same one who introduced me to NZAN), and I had contacted the other after a newspaper article about her having treated Cushings. As our numbers are growing in the Waikato area, I hope to plan a meeting in Hamilton early in 2005.



2. Auckland Meeting, October Report from Karen Carson Northern Region Co-Ordinator

The Northern Region had a get together on Saturday October 30th with nine attendees for a long lunch at a Takapuna café. Although it was primarily a social get-together we all shared and compared our diagnoses and how we manage our medication and living a "normal" life.

We were happy to welcome to the group new members Carol (diagnosed about a year ago) and Jennifer (diagnosed 25 years ago), and enjoyed hearing their stories. We caught up with Cheryl who managed to slip away for an hour or so to update us on her family's progress and new baby Charlie's health issues. Jeanette was in Auckland, and so joined us for the meeting.

We came up with some possible ideas to pursue. I am investigating with a Manufacturing Jeweller the possibility of making up a "pill box necklace" - they are very excited about the idea...so watch this space. There are also opportunities for us to help educate the local hospitals and our GP's about Addison's Disease. All in all it was a good afternoon. For me it is always good to catch up with other Addisonians at our meetings, and I come away feeling positive and uplifted. We plan to meet again in March/April after the summer madness, and then every three months or so.

3. Horowhenua Meeting, 28 November

Seven members from Feilding, Palmerston North, Levin, Wanganui and Wellington met on Sunday afternoon 28 November in Levin.

Members introduced themselves, and shared their Addison's history. A major discussion topic was Addison's crisis. Three participants shared experiences when it would have been better for them to have injected Solu-Cortef before events took a downhill turn. There was acknowledgement that Addisonians tend to be slow to recognise when they need extra hydrocortisone, in particular the Solu-Cortef injection. [Reminder - Read the Solu-Cortef guidelines that were circulated with the previous newsletter!]

One of the participants, Pauline, a public health nurse, has offered to refresh members about how to give themselves IM Solu-Cortef injections at a meeting in Levin next year, probably in March. Members will receive a notice nearer the time.

Other topics discussed included DHEA replacement; depression prior to diagnosis that disappeared after starting Addison's medication; Medic-Alert bracelets – sometimes they are not taken notice of by health professionals, and what wording is best; higher costs for medical, travel and life insurance.

This brief report is from notes provided by Phillipa, who was diagnosed with Addison's about five months ago. She concluded "The meeting went for around two hours, and was seen as highly successful by those attending. For me personally, it was reassuring to see other Addisonians who remain physically active, and who are able to maintain a high quality of life."

Would you prefer PDF newsletters?

A few members have asked to receive their newsletters by email as a pdf file. If you'd prefer this method too, please contact Jeanette.



Some members' stories to look forward to in our next newsletters:

Beryl (77) recovered well, after a week in Whangarei Hospital. Her experience shows that for the well prepared Addisonian, a stay in hospital for other medical treatment and procedures can be a relatively hassle-free experience. She gave the OK for some wording changes from Gisborne, where she was watching her grandson play cricket for Northland.

Diane's story: Some people with Addison's "luck it", and quickly achieve a medications regimen that works well for them. For others there is more of a challenge. **Diane** shares her experiences getting to a medication regimen that gives her good energy.

Mary's story – share milking on the west coast of the South Island is an isolated lifestyle. Mary's diagnosis took a long time, but now she is very well, and has learned a high degree of self reliance.

Jessie would like to award a bouquet to the on-call doctor and the Tokoroa Hospital emergency staff. "I was unlucky enough to need emergency medical attention in March of this year, but lucky enough that it happened in Tokoroa."

Phillipa shares how a diagnosis of Addison's helped her gym fitness programme get back on track!

Peta sleeps better now

Peta, who was still overseas at the time of the Wellington meeting in May, sent us a note that she found the article on sleep patterns in the August04 newsletter very helpful.

“Ever since I've had Addison's I'd been waking about 5 in the morning a few nights a week. It drove me crazy because I was feeling “wrung out’ but quite awake and it was often impossible to get back to sleep! Since reading that I started taking half a tablet when I woke up early, and found that made a difference, and I got back to sleep until the alarm at 7am.” Encouraged, Peta then talked with her GP and switched her evening hydrocortisone dose to prednisone hoping that would enable her to sleep right through. She is happy with how that is working out.



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

If you have a topic for discussion, or a question that you’d like passed on to NZAN’s medical advisor, please send it to Jeanette.



The members’ contact list is enclosed with this newsletter. If you see any details that need changing, please let Jeanette know.



In our previous newsletter No.22 we included contributions from some of our younger members. This time we have news from a couple of our older members:

Bob celebrated his 83rd birthday in September. He is NZAN’s oldest member! Early November, he and his younger brother traveled to Brisbane to spend a week on the Sunshine Coast, visiting their elder brother (88) and his wife and family. “I hadn’t seen him for 27 years – you could imagine his big smile.

“My doctor didn’t want me to go at first, because I am prone to fluid on the lungs, and he was concerned about the effect of higher altitude flying. But an X-ray was fine, so he agreed. I had no trouble at all while away.

“We were on the 12th floor of a 14 storey hotel, in a nice suite with a wonderful view. My niece took us everywhere!”

Bob sends best wishes, and hopes there will be an NZAN meeting in Nelson before too long.

Marjorie’s 78th birthday was on November 23. That was also NZAN’s eighth birthday, and Marjorie was a foundation member.

In a recent note she writes: “Have just visited my doctor – I am having both hip joints replaced. He tells me his dog has Addison’s and is on 8 fludrocortisone a day. He has just increased mine to 1 a day, after 33 years of 4 a week. ...I now have 3 great grandchildren, 2 born this year. Take care and keep healthy. Many thanks to you and the rest of the helpers for all the work you do for the Addisonians.”