

## From NZAN Newsletter No15, March02



### **MARGARET'S STORY – Reflections of a cortisone pioneer:**

Margaret was diagnosed with Addison's disease 43 years ago, when she was 35. When she joined NZAN in 1997, she answered the database question, was she happy to have her name passed on to others with Addison's disease, "Sorry, it has always been a private thing."

But, over the years that she has been a member, she has sent snippets of information about her life with Addison's, which we've included in the Updates.

Early in the new year, Margaret sent Jeanette a couple of long letters - "All my life I have been a compulsive letter writer, and I do not want to stop!". So here she shares a fuller view of her busy and happy life, despite Addison's:

"I have rambled on, but this is a new experience for me. Apart from the epic July meeting, I have never talked about my Addison's. I felt so good after that get-together, for after 42 lonely years I had met people "just like me". The same problems, similar success stories - and not a bad looking bunch. I liked meeting that hard working committee - they did a great job. Now I have read Kathryn's and Lyn's stories [*in the November 2001 Update*], and I can relate quite well to theirs. I was hyper-active - super-energy - and with never being allowed to increase my dosage [over the early years], I had many trips to hospital with Addisonian crises.

The July meeting began to spring memories I had not thought of for years and years. I had a long spell in Auckland hospital in 1959 when they diagnosed the Addison's. I'd had 20 months of the usual vomiting, diarrhoea, and weight loss, plus darker pigmentation of the skin and depression. I was their first patient to be put on steroids - a magical drug which had been used in the UK for Addison's. The dosage was experimental for a while. Then they had my permission to do experiments.

One was a non-salt diet - I recall the special food wasn't very interesting or appetising, especially as I had been drinking salty water before I went in to hospital. We had a bach at the beach, used to get oysters off the rocks and I



would drink the salty liquid. I think I drank the seawater in my daily swim. Our little coastal beach was unpolluted in those days.

After 5 or 6 days on the special diet, when I began to feel terrible, I collapsed and according to my room mates, the doctors actually ran – when the curtains were removed in the morning they were delighted to see me still there.

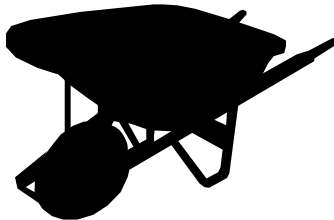
While I was in hospital, on two Saturday mornings they held lectures. The first was for GPs. I wore my second best nightie – my house doctor's words. The next Saturday was specialists – my best nightie. I wish I could remember all the questions, as I lay there like Exhibit A, plus my specialist's replies... what I think I recall may have no foundations at all.

Before I left hospital, I went before five or six doctors who lectured on what life would be like in the future - the crises that would send me back for help etc, including the "never change the dosage or miss any tablets".

For years after, I had to collect the tablets from the hospital pharmacy. I took the tablets five times daily – 6am, 10am, 2pm, 6pm and 10pm. It made a long day. I cannot be positive about the doses, but I believe I took 10mg, 5mg, 5mg, 5mg, 7.5mg. The 32.5mg seems definite, and wasn't changed for many years.

I was a very busy farmer's wife, jack of all jobs. We farmed out of Warkworth at Kaipara Flats. Farming was different in those days. The top-dressing crew lived in sometimes for several days if the weather wasn't good; it was a Tiger Moth plane. Then there was all the catering for shearing and hay making. On a one-man farm I was called upon at all times to help with work.

I grew all our own vegies, 2000 onions, 80 tomatoes, yards of beans, peas and carrots. No artificial fertilisers. I used to boast that my vegetables were in the garden 10 minutes before they were served on the table.



I am sure all my own vegies, plus all the fruit I enjoy, have helped my good health. Our home was burnt to the ground in 1959, three months after I came out of hospital, and the insurance assessor was amazed at the heap of molten glass – my preserves – no freezers in those days.

I served on the college PTA, the Plunket Committee, Church guilds, Women's Institute, and others. I wrote the school histories for the 75 years celebration, and again for 100 years. I followed all sports.

I have three children, who did all the usual things children did – sports, music, guides and rangers, friends to stay, and transport for school. They never missed out because of Addison's. I know they were upset at the ambulance arriving to take Mummy to hospital in their younger years – they were only 2, 5 and 7 when I was diagnosed.

In 1972 my son married an Australian girl, so most years I have travelled to Adelaide, plus have enjoyed 3 more trips to the UK, plus Canada, the US, Japan, Alaska and Singapore. Alex and I travelled a great deal, and loved it all.



On our first trip overseas in 1976, the big OE, I was still on the original tablets routine, and nobody told me to increase them. We were away three months. It was before bottled water to drink was invented, hotel rooms did not have tea making facilities. I did get a solid methylated spirits little stove in Venice – it could boil a cup of water. I never drank water from a tap for 3 months! Not really because it was 'bad' but because it would be different for me. I think I have swallowed my tablets with every possible medium, fruit juice, wine, beer champagne, etc.

I had a letter for one of the leading hospitals in London, and no insurance. It took years to educate the insurance companies that, for example, broken legs from an accident should be able to be a legitimate insurance claim for an Addisonian.

After many years, I had a new endocrinologist, and he changed many things – including tablets only twice a day, I could increase them, and my trips back in a crisis became so much less. The calcium was disappearing rapidly from my bones. I went onto estrogen treatment for about 6-7 years. He helped me in so many ways. He also took my daughter as a patient – she's an insulin dependent diabetic, juvenile diabetes, diagnosed as "brittle" diabetes. I recall he was interested in a family study for glandular weaknesses. We have thyroid problems too.

Now in spite of my three recent falls, a shattered shoulder, both bones in my right wrist, and then my left arm, I work for the Old Folk's dinner, the Hospice shop, Red Cross and Save the Children. I just need two new eyes. I have cataracts, with macular degeneration underneath, so there would be no better sight if they



were removed. I've been a widow for 14 years, and live by myself, but now in Warkworth. I still garden, though on a much smaller scale.

It was a pleasure to meet Prof Holdaway again [at the July meeting]. In 1972 I was part of his work for his thesis. After the meeting he kindly sent me a copy of his thesis, most interesting – I scored rather well! I suspect he was a little surprised to meet me again after nearly 30 years. It was a good experience that I would not have enjoyed without NZAN.

Life had so much to offer – children, farm life, community work, and teaching, a great love for me. I went back teaching just to help out, but stayed for long spells, years. Now I have two daughters teaching in secondary schools, and a grand-daughter just graduated BA, and going back to do double honours degrees.

I will always consider myself one of the 'fortunate ones' – life has been good, and still is for me.

