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NICOLE'S STORY

Prompt diagnosis of Addison's disease after seeing symptoms described in a magazine article

Nicole learned about Addison's, and then about NZAN, from a magazine article. Published in the New Zealand edition of Woman's Day 29 July 2002, it was written by the Australian Addison's Disease Association, as part of their Addison's Disease Awareness Week. It was first published in the Australian edition – with Australian contact details for more information. However, in the New Zealand edition, no contact details were included. The first NZAN knew of the story, was seeing it in print. We contacted the magazine, and were pleased that “our flag was flown” a few weeks later.

Hi, my name is Nicole. I was diagnosed with Addison's disease in early August, 2002. I am 32 years old, married to Tony - painter & decorator. We have two boys – Caleb 5yrs and Kyle 3yrs. We live in Upper Hutt, near Wellington. I switched my Marketing/Product Manager career for a very active fulfilling parenting role when Caleb was born.

Now that Caleb is at school, I'm working again since February, part-time, and really enjoying that. I seem to have just enough energy for everything and then collapse by about 8.30 - 9pm until 7am the next morning, and that's without me feeling like I am pushing myself.

I have never had an adrenal crisis. I thought I was reasonably healthy - although I'd been constantly tired and had very little energy - but I do have two very energetic boys to add to that equation!. I was losing weight – but I had been trying to, so that didn't seem a problem. I did however take a pot-luck guess, after reading an article about Addison's disease in the NZ Woman's Day in late July, that I should perhaps get a test for Addison's disease.

The symptom that alerted me was that a couple of years or more ago my tongue had developed blue/black marks. I had mentioned this to my doctor when I first noticed it, he tested for Vitamin B12 deficiency, but nothing showed up. I don't think Addison's was considered, since I wasn't presenting any other symptoms and was reasonably healthy.

I also knew that I already had an autoimmune disorder. I get arthritic type pain in my joints. Five years ago my doctor told me that my positive antinuclear antibody result was consistent with autoimmune connective tissue disease. My mother has Graves disease (overactive thyroid). I have positive thyroid autoantibodies, but so far my thyroid function had tested normal.



So in August 2002 when I was at my GP's (I see 2 GP's at the same surgery) I asked to be tested for Addison's. When she asked why, I explained my pigmented tongue, autoimmune family history, and I am constantly tired, so best to check it.

She explained that a blood test was not going to give me an immediate answer, but would indicate whether they needed to investigate any positive results further. The first results came back normal, including Vitamin B12, sodium, potassium. That was the end of it I thought.

A couple of days later the nurse rang. The ACTH level was elevated – 243 when it should be in the range 1.3 – 15. The nurse said that the doctor would refer me to an endocrinologist for further tests. I decided to go privately to get in earlier as I was now panic stricken. (My husband always says I am a worrier!) The doctor gave me the name of a specialist whom I contacted to get an appointment. By this time it was mid-August. I could not get into that specialist until mid October – 2 months away.

That period was very stressful for me. I couldn't stand the wait. I suddenly felt sick!

It was about a week after this that a small follow-up article in the NZ Woman's Day gave Jeanette's contact details for the New Zealand Addison's Network. Jeanette was away from home, but luckily picked up her voicemail messages and returned my call giving me Gary Roselli's name to ring to talk with.

With one thing or another I didn't ring Gary. I suppose it was because I hadn't actually been diagnosed officially, so I thought best to wait and see what the specialist comes up with. But when I was probably at one of my lowest points emotionally, Gary rang me. (Jeanette had passed on my name and number to him.) I had a very reassuring talk with him.

I probably still wasn't convinced I had Addison's disease as I didn't have all the normal symptoms: rapid weight loss, low blood pressure upon standing, fainting, vomiting/diarrhoea, increased skin pigmentation, salt cravings. But a week later I went back to my GP, as I wasn't feeling myself. I saw my other GP who had been discussing this case with his partner and he thought I should have the ACTH stimulation test. I did so. A week later the results came back, positive for primary Addison's. [My base line cortisol before the ACTH was 265 mnol per litre one hour later it was 283. It should have risen to over 300.]



Deducing that I still have a small reserve of cortisol production, and from other tests that my aldosterone reserves were still OK, my GP started me on 20mg hydrocortisone daily. He also arranged for me to see an endocrinologist at the Hutt Hospital in a couple of weeks - well before my private appointment!

A couple of days after starting the hydrocortisone (a Saturday), I was sent to hospital experiencing nausea, dry mouth, feeling like my heart and blood flow were racing. All the tests came back fine and I was discharged that day and told to decrease my meds to 15mg. It may have been too much hydrocortisone, or perhaps an anxiety attack.

My first visit with the specialist was a few days later. He put me back onto 20mg hydrocortisone. I saw him again a couple of months later. My hydrocortisone wasn't changed, and he added fludrocortisone 0.1mg daily – he said my aldosterone and renin levels were still in the normal range, but deteriorating.

I had a problem with fluid retention after starting the Florinef, and put on 3kg in a week. I talked with my GP, and cut the dose down to a quarter of a tablet daily. A couple of months later I had a dizzy spell while chairing a meeting one evening – and went home. I had my BP checked next morning, it was low, and after talking with my GP put the Florinef up to half a tablet daily, which I am still taking.

I haven't lost the extra weight I put on, however. Recent tests have shown that my thyroid function has declined, and my specialist said that may be influencing my weight. If that is the reason, it will be fixable when treatment gets sorted.

Life was an emotional roller coaster for the first months after my diagnosis. At times I have felt grief for the life I no longer have, being dependent on steroid medication for life. I constantly had questions. Every ache, the slightest unusual twitch I was questioning the Addison's link. I have found it very helpful reading the newsletters and learning of other people's experiences and strategies for coping with Addison's and other Endocrine Diseases. Contacts in NZAN have helped me a lot. Jeanette put me in touch with Karen, because we are of similar age, and both have a young family.

My husband Tony has been a tower of strength and keeps me laughing. I even get breakfast in bed on the weekends now! My GPs have been fantastic and very helpful in getting me "educated" and on a happy plateau. Overall I have more energy than before diagnosis. I was proud of myself over the Christmas period. I had 27 guests at our house, I planned Christmas dinner down to the finest detail and even managed to enjoy a couple of glasses of champagne to celebrate! I kept my dose at 20mg hydrocortisone throughout the period and felt good, despite my hands seizing up.

When I saw my specialist in February, he increased my hydrocortisone dose from 20mg to 25mg because my ACTH was still high. I noticed soon after that dose change, that the pigmentation faded around my knuckles and in skin creases and on my palms. There is still pigmentation on my tongue, but it's fading too. I feel that I am getting very well looked after.

Addison's is a rare disease, but I now know of four other people within the Wellington region, who are perhaps not in the network. My own experience makes me wonder how many other Addisonians are walking around as yet undiagnosed.