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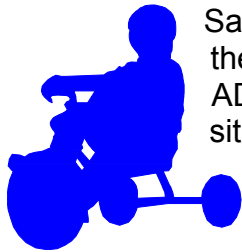
ALISTAIR'S STORY:

Alistair's diagnosis with Addison's Disease at the age of 12 was rather sudden. The only warning sign was reducing energy levels over a few weeks, perhaps months. One day he collapsed at school, became unconscious, and was put straight into hospital. "Addison's was diagnosed, and I stayed in hospital some time, while a workable regime was established."

Now Alistair is mid-fifties. Over the past year, some new symptoms have been confusing –involuntary muscular jerking in bed; out walking, suddenly his right leg especially 'gives way' and he falls over. Until last year he umpired senior cricket for 10 years – but he was finding that he just couldn't move quickly enough, his legs had slowed down. Looking back, there had been a slow decline in mobility and stability over 10-15 years.

When Alistair read the adrenoleucodystrophy (ADL) story from the Australian Addison's News, that we sent NZAN members with the March Update, it rang a bell. It arrived just a week before his review with his endocrinologist, and he took the article with him. Blood samples were promptly taken, and sent to Adelaide, and the diagnosis was confirmed. Then numerous tests were organised. The huge uncertainty of ADL is the most frustrating health situation he has faced. His freedom of walking is somewhat restricted now, and he has put on some weight as a result. At about the time NZAN members receive this newsletter, Alistair will be getting clarification from a senior neurologist about his condition.

Just a few months after Alistair's own ADL diagnosis, his 3 year old grandson Sam was admitted to hospital with severe dehydration. Alistair made the paediatrician aware of his own Addison's and recently diagnosed ADL, and also told his own endocrinologist about his grandson's situation.



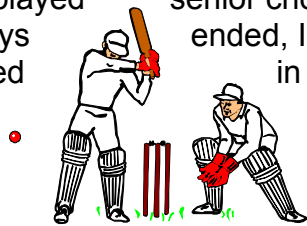
Bloods were promptly sent to Adelaide, and the dual diagnosis was confirmed for young Sam. ADL is very rare, and can be very difficult and slow to diagnose, if not suspected. The extent to which Addison's itself is inherited is usually not at all clear-cut. But ADL is a more clearly inherited disorder, expressed in males only; females being carriers. So Alistair's only sibling, his sister, and her three daughters are being tested too.

Sam is believed to be the only ADL sufferer in his age group in New Zealand. He is currently being closely monitored with 3-monthly MRI scans. The best treatment to stop disease progression is a bone marrow transplant, and Sam's 14 month old brother is a compatible donor. "We've been told that a bone marrow transplant is likely to be needed for Sam, and it'll be a first in New

Zealand,” says Alistair. “The specialists are linking with expertise in Adelaide and New York. We’ve been told that Sam’s early diagnosis gives a high probability of successful outcome - if all goes well, he will start school on target at age 5 with his peers. It’s made us more like soul-mates. We both bring our bottles of pills out, and take them together.”

But back to Alistair’s life with Addison’s. “When I was diagnosed, I was told it would be necessary for me to adopt a sedentary lifestyle, with little or no manual activity. I followed this advice, and chose to join the accounting profession. During my University days I worked part time for a chartered accountant. Then I worked for 26 years in the banking profession. For the last 10 years I have expanded my accounting client base, and have established a couple of business interests.”

“For the first 3 years after diagnosis, I played little sport. But I soon became bored with being the odd one out. The doctors at the ‘cortisone clinic’ that I attended 6-monthly agreed for me to try swimming first, then cricket, then rugby. I found that I coped well, and developed a very active interest in sport, and for a number of years played senior cricket, rugby and water polo. When my cricket playing days ended, I umpired at senior level for 10years. I was also interested in squash and swimming, but not competitively.”



Since diagnosis, Addison’s crisis.

Alistair has experienced only one “A couple of years after diagnosis I was at an international Boy Scout Jamboree in Auckland. A ‘flu epidemic’ hit, I joined the band of sufferers, and was admitted to Greenlane Hospital. This was before Medic-Alert, or at least before I became associated with them. As a result I could not get my prescribed medication in time, and went into an Addison’s crisis.” Alistair regularly attended the Addison’s clinic in Christchurch until he was 23. Then he went to Auckland, for the next 10 years. His Addison’s gave no particular problems, he’d get prescriptions when he saw his GP, and he didn’t have a review with an endocrinologist until he went back to Christchurch – and that was triggered by something else.

A sports injury in Auckland had required a cartilage operation, and a consequence was deep vein thrombosis. Certainly not the outcome he wanted, but it’s not particularly uncommon, he says. He needs to take blood thinning medication permanently. However, Alistair has been in the relatively unusual and “unlucky” situation of having clots break away on several occasions – always, so far, going to his lung and stopping there, causing pain, easily identified. When having a clot fixed in Christchurch hospital, he mentioned his Addison’s, and was promptly put back in the system for 2-yearly reviews. At his first review, his prednisone dosage was adjusted downwards. He was changed to hydrocortisone a few years ago, and now takes 20mg hydrocortisone, and 0.2mg Florinef daily.

In 1991, he had both hips replaced. The surgeon attributed the situation to his relatively high prednisone dosage in earlier years, says Alistair. Looking back, he never needed to adjust his medications despite being active in many sports - that confirms that his dosage was probably on the high side. But the real answer may not be simple, he says. "Subsequent bone density scans have showed no problems in other bones, and I've never broken any bones, before or after that."

For getting through all this surgery, his clot history was far more of an issue than his Addison's! Before the hip replacement could be done, his blood had to be thickened again, that took about 3 months. After the first hip replacement, there was a 3 month wait before the second one. Then his blood had to be thinned again before he could be sent home. But on the date he was due for discharge, the new right hip dislocated. It popped out twice more, and there was no choice but re-do the operation. So he had Vitamin K therapy to thicken the blood for that, and then he had problem with a dislodged clot, but all came right.

After the hip replacements, his work situation changed. He'd been general manager of a bank that was taken over, and he was suddenly displaced. That was an opportunity for enjoyable extensive overseas travel, all of which happened without any Addison's related problems.

"I consider Addison's as something readily controlled by drugs. My family and work and social colleagues are all aware that I have it, and that I require medication at regular times of the day. They are also aware of my more recently diagnosed problem. I am extremely fortunate to have the degree of caring and support of all of these people. I have led a full and happy life."