

KWANZ's Young Achiever - Hazel

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When Hazel was 22 months old we noticed her right knee was swollen. I took her to the doctor who did not know what was wrong with her and said to keep an eye on it. She was waking early in the mornings (about 5am) and screaming. We put it down to teething. When she stopped walking and started crawling I knew something was not right so we went to another doctor. This doctor suspected immediately what it was and we were referred to Timaru Hospital to the Rheumatologist. He diagnosed Hazel with JIA. We were blown away! We did not know that young children got arthritis!



Hazel was given non-steroidal anti-inflammatory drugs. These did not work and 2 months after she was diagnosed she had her first general anesthetic and the Rheumatologist removed the fluid build-up and injected a steroid in her knee. This treatment lasted 2 months, then swelling and pain came back and she ended up back in hospital getting her knee drained and injected again. After 3 rounds of this I asked to be referred to a Paediatric Specialist who was very knowledgeable in Rheumatology in Christchurch. By this stage I had

also found out about the JIA support group in Christchurch and had been up to Christchurch to an information seminar that had been organised by this group. Meeting this group, Kids With Arthritis NZ (in particular Adrienne Crowe) was a life saver for us. Knowing others that were going through the same journey as us was a relief. Being able to talk to them about their experiences and get advice was invaluable.

The Paediatrician in Christchurch put Hazel on Methotrexate (December 2008) she was 2 years 4mths old. Due to the Methotrexate taking so long to work in her body she experienced another flare up in January 2009 and had to have another GA to get the fluid removed and inject steroids into her knee.

The Methotrexate did keep the arthritis at bay for 1½ years. However, in August 2010 her LFTs (liver function tests) went up really high so our Paediatrician in Timaru decided to take her off the Methotrexate to protect her liver. She had 2 years with no flare ups – in remission. We had hoped that was the end of JIA for our daughter but it was not to be. In August 2012 we noticed her knee was swollen, the JIA was back. She had a GA to remove the fluid and inject more steroids into the area and she was put back on Methotrexate.

The Methotrexate is doing its job – she has not had a flare up since being put back on it. This time, however, the dose is higher and she's experiencing nausea (including vomiting) as a side effect. There are other not pleasant side effects such as an increased chance of skin cancer and she picks up bugs more easily due to being immune suppressed.

The arthritis she had also attacks her eyes; she has chronic uveitis and has

been on and off steroid drops for many years.

Hazel has blood tests every 6 weeks. These have been very hard for her as the first time the nurses did her bloods it took them 3 attempts and poor Hazel was a screaming mess at the end of it. Since then she (understandably) has had a fear of needles. We switched to finger pricks which were not as bad for her but recently we've had to switch her back to IV bloods as the quality of the bloods need to be better than finger pricks were providing. She still gets upset on the day of her bloods but knows she has to do them and tries hard to be brave.

Hazel is facing an uncertain future, not knowing if she will have to deal with Arthritis later in life. We can only hope that one day our daughter is free of this horrible disease and these experiences are a distance memory for her.



Please remember every journey is unique to that person. Sharing a personal story is an act of kindness; it lets others know they are not alone.

Please check with your child's Specialist or GP if this article has generated medical questions for you.

Disclaimer

The opinions expressed in this article are the author's own and do not necessarily reflect the view of Kids With Arthritis NZ Charitable Trust.