

Attention: The Standing Committee on Health, Aged Care and Sport

Submission for the Inquiry into Childhood Rheumatic Diseases and Juvenile Arthritis

[REDACTED]

Date: 24th January 2022

[REDACTED]. I am seven years old, I like horse riding, dancing, bushwalks and playing with my friends. I am about to start year 2. In 2020 I was diagnosed with juvenile arthritis. It all started when my knee started to get sore but we did not know why. I had to see lots of doctors and have lots of tests to find what was the problem.

Since I was diagnosed I have had lots of time off school because I was too tired, feeling too sick or was in too much pain. My year 1 teacher was really kind and always helped me at school. She let me have lots of rests when I was tired or hurting. She let me use the iPad when my hands were too sore to write. My teacher also helped me by giving me medicine and ice packs when I was hurting. She was always nice to me.

I need to have medicine every day. The first medicine we tried was Naproxen and this made me feel really sick. I stopped eating and had lots of tummy aches. It did not help stop my arthritis. I now have Celebrex each day which helps but I still have some flare ups. Some days I wake up and my body hurts all over. During my last flare up I had a sore ankle, but the arthritis was in my big toe. It took three doctors to figure this out! I had to use crutches which was hard at school. My school has a lot of stairs! Some days I need to stay home from school because I am too tired to use the stairs. If I had a magic wand, I would make my school not have stairs. I needed to have an injection in my toe to stop the pain.

Some things I would like you to know about juvenile arthritis are:

- I spend a lot of time going to lots of different appointments. This means I miss school and spend too much time in waiting rooms. This can be really boring when I just want to be at school with my friends.
- Not many people know about juvenile arthritis. My teacher, my parents and I are all learning about my juvenile arthritis at the same time. This can make me worry a lot when we are trying to figure out what is happening.
- I would like the doctors to be able to help me and know the answers.
- I would like a scientist to find a cure for juvenile arthritis.