

To: The Standing Committee on Health, Aged Care and sport

About: The inquiry into childhood rheumatic diseases.

From Rebecca Kane

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1/02/2022

Thankyou very much for the opportunity to make a submission to the committee in respect of its current inquiry into childhood rheumatic diseases.

I myself have been impacted by Rheumatoid arthritis since I was 9. I am hopeful that by sharing my story it may help other children who are suffering.

It was the year 2000 that my life changed. Up until the age of 9, I was a healthy, happy and energetic child.

I would swim every day and do gymnastics. I always tried to keep up with my older siblings, so I started BMX racing. I was good at Gym and hoped I might be able to be a gym teacher one day.

When I was 9, I developed a septic hip and had to have surgery to drain it along with anti-biotics. After this I was expected to make a full recovery but for months after I was in so much pain in different joints, every day.

I could not get out of bed and was missing school. Mum would help me to get to the toilet and get dressed and even eat. I ended up doing distance educations for quite a while.

I was eventually diagnosed with Rheumatoid arthritis. I was placed Naprosyn which did not work so I was then put onto Celebrex. When it was apparent the Celebrex was not enough, they added in Methotrexate. My Ra was still out of control so Prednisone and Salazopyrin were added also.

Some of the side effects were horrible, like rashes and mouth ulcers and the prednisone caused fluid throughout my body.

I was able to get onto medication before any major deformities occurred.

In order to be able to get to school and hold a pencil, my mum would take me to physio each morning to dip my hands in wax.

I could no longer do the sports I loved and had to learn/to try other sports.

Some of my friends at school got annoyed with me for missing school and no longer being able to run and play.

I would do hydrotherapy to keep my joints moving as the warmth helped with the pain.

I had hand splints made up for sleeping at night and needed braces/supports for my hands and ankles for my flares which would generally last 3-5days and move to other joints.

I have had many hospital stays and tests as my blood tests have been so high but it turned out to be really bad flares. The hardest flares to deal with are my hips.

I've been seeing a Rheumatologist 2hours away 3monthly since I was 10. The travel is exhausting and when I was working it was difficult to get the time off especially as I also had other appointments like physio, ot, hand therapist, eye doctor, paediatrician, gp, counselling and podiatrist. Not to mention the expense. As a child it also meant mum giving up work to take me to these appointments.

At 14 I was diagnosed with depression and social anxiety.

Over the years the medications stopped working and I've had to go onto others like Humira, (fortnightly injections) Actemra (monthly infusions) and now I'm on Enbrel (weekly injections). I still need prednisone during a bad flare. I've been on and off Methotrexate since I was 10.

I went into remission for a few years and went off medication but after the birth of my first child my RA came back with a vengeance. I was no longer able to dress myself or get out of bed let alone feed my baby. I went back on Methotrexate and had to bottle feed. I was told if I were to have any more children it would come back worse.

Years of trialling many different medications and combinations we finally found Enbrel worked best for me along with Salazopyrin

After 10 years since having my first child and stable on Enbrel we spoke with my rheumatologist and is we decided I could have another baby without too many issues due to the medication I was on working.

I now have a healthy 20month old and the experience as a mother to this baby compared to my first is so different. I never dreamt I'd be able to feed/hold/pick my baby up and cuddle them without pain.

I still developed a strong bond with my eldest who did need extra help and care from family as did I.

I still now need day sleeps and have a walking stick for bad pain days. I would not be able to work full. I would love to go back into childcare but the long days on my feet are too much on my joints.

I need to see a podiatrist for orthotics and a hand specialist for splints. I see a physio for synovitis and sciatica and plantar fasciitis.

An OT came out to the house to see how to make everyday living easier like turning taps.

There is an insane amount of heat packs in my house.

My husband does most the cooking as I find cutting up vegies difficult.

My memory has been affected and unscrewing medication bottles can be difficult, so my husband makes my medication up.

When doing housework, I need to break it up and rest in between.

I suffer from insomnia some nights.

I have lost strength in my wrists and ankles.

My Rheumatologist orders x-rays of my hands and ankles every few years to check for any damage.

I can't hang washing on the line without struggling.

The winter is especially hard for me still. We constantly have the heater on in the winter.

I need regular eye tests as of previous medications my eyesight has diminished.

If I'm invited to events, I may need to cancel at last minute or make sure I don't do too much beforehand as I know if I get run down I end up in a flare.

My immune system is weaker, so I get run down easier.

Keeping up friendships is harder work.

Lockdowns due to covid did not change my family's life as much other than my son remote learning as we do not go out a lot anyway.

I recently joined the young women's arthritis support group and have made some wonderful friends through that and find talking to others who understand helpful.

When I was younger the support groups were all older people there was no children's groups.

I found having a pet to be very beneficial as they are always there and up for cuddles on hard pain days.

I do think I went through a period of grieving my old life and wanting to be able to do all the things I used to be able to do but now I've learnt RA is a part of me. Whilst this diagnosis has altered my life and my path, I still feel I have been able to fulfill a rewarding life and learnt to live with my condition and limitations. It taught me to appreciate the little things and the people in my life.

I feel very blessed to have the people/family I have in my life.

Thank you very much for considering my submission.

Rebecca Kane