

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

ABOUT: The Inquiry into Childhood Rheumatic Diseases

FROM: [REDACTED]

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[REDACTED]

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My son was diagnosed with Systemic Juvenile Idiopathic Arthritis at the age of 20mths. SJIA can affect the joints, eyes and organs in your body. This disease can be randomly started by a simple viral infection which in turn sends the wrong messages to your brain and that tells your body to attack its good cells creating inflammation in the body. It causes severe pain in the joints, high fevers, body rashes and joint swelling all of which my son experienced.

My son has been on this journey for 3 ½ years and has been in unmedicated remission for 1 year now. Although you might think this is a great outcome which it is compared to the alternative he has not been completely pain free since his original diagnosis in 2018. He still requires a daily anti-inflammatory to help keep his pain under control and to avoid using the immunosuppressant drugs which he was previously on.

It has been a journey of heart ache, pain and constant fear for us. One I don't wish on anyone especially a child who can't understand why we have to do all these horrible things to them. We're very lucky our kids are so resilient. I often find myself thinking how I would have coped with all of this if it was happening to me. It's still one day at a time for us 3 years on. Some days are good and some days are bad. Its a constant struggle to get the help we need due to lack of services in our rural community of Mt Isa and the lack of knowledge surrounding this disease in the medical industry.

### **1. The impacts on my child and our family**

Our whole world was turned upside down in the wake of our sons diagnosis. We were away from our home for 3 1/2 weeks and our support system in the most stressful time of our lives.

We watched our son go from attempting to walk and crawl to becoming totally immobile. He changed from a happy little boy full of life to someone who would cry constantly and become distressed all the time. We would have to give him nurofen and panadol over the weeks before diagnosis to try and calm him. Unfortunately this would only be a short term fix and as soon as it would wear off we'd be in the same situation as before.

Once we finally got admitted to the hospital our son endured 3 1/2 weeks of constant tests, needles, poking, prodding, medications, distress and travel. During this time we were seen at 3 different hospitals Mt Isa Base Hospital, Townsville University Hospital and The Queensland Children's Hospital.

In order to do some of these test he was sedated several times. He was also wrapped in a sheet and held down on around 10 occasions to put cannulas in to take his blood and receive antibiotics for what they thought was a bacterial infection. This has been one of the most traumatic parts of this whole experience and still haunts me to this day. Watching your child at [4am](#) (after 3 more failed attempts of getting a cannula in) in the morning after no sleep every night screaming and just looking at you to help them as a parent is the most gut wrenching thing I have ever had to witness. He had a portacath inserted into his chest approximately 4 months after his diagnosis to receive an infusion of a biological medication called Tocilizumab which would enable him to function on a daily basis. This medication was given every 2 weeks after failing the original treatment of methotrexate injection and oral steroids. He still has his portacath in at the moment and this is accessed every 6 weeks to flush his port out and re block it. He has a fear of needles and gets very distressed now when he has to get it flushed. It requires 3 people to hold him down to access his port. He screams uncontrollably and thrashes around during the procedure and continuously yells "let me go! No needles, no needles". Once the needle is in he luckily he calms down. I do believe this is trauma that he has suffered during the original process of being diagnosed and that everything that happened during this time is still affecting him to this day and produces like this create the flight or fight response. My son was also on Methotrexate which was injected into his stomach once a week. On the weeks when he would have an infusion the nurses at the hospital would do the injection for him. On the weeks where he didn't have treatment at the hospital my mother in law (nurse) would come over and inject him as we were honestly too scared to do it ourselves. This lasted about 4mths until my husband felt confident to do it himself. I would have to hold him while my husband injected him. He would become distressed and nervous as he knew now that needles meant pain. We made this process as normal as possible and I feel that it helped him in the end. I also became confident enough to do the injection on my own. It still made us feel awful that we had to do this to our son. Its not something any parent should have to do.

As our son was on immune suppressing medication it meant he was constantly sick in the first year after diagnosis. Every time we went to a play group or to a friends house to play he would end up getting a cold. He always ended up with more sever symptoms than other children and for longer of periods of time. Most of the times when he got sick he required hospitalisation if he had a fever. This was 3-4 days on IV antibiotics in the hospital to try and help his body fight off an infection. In the end this became quite isolating for our whole family. I was scared to take my son places as we feared he would get sick. It became apparent that our life had not only changed medically but socially as well. My daughter struggled a lot with this as did my son. They were ripped of their child hoods and of just of having fun. Our life became about keeping everyone safe, appointments with several different specialists and travelling away from my daughter and husband. This has all caused long term damage 3 years on. My daughter suffers with anxiety and has a lot of resentment towards her brother which makes it very hard for them to have a positive relationship. She often feels left out and that she isn't as important as her brother. I also personally suffer a lot of trauma and anxiety over what has happened to my son and family. We are constantly having to advocate for the best care for our son to Drs, GPs and people

outside of our families who don't understand this disease. It becomes very frustrating and defiantly wears us down at times.

We currently have no specialist care in Mt Isa and frequently have to travel to Brisbane to seek care. This means time away from my husband and daughter (8yrs) and time off work for the both of us. Although we have very understanding workplaces this often is with short notice and ends up being 2-3 days at a time as we have to travel so far. The appointments never seem to line up with the flight schedule either and as we are not consulted prior to the bookings being made we either have to reschedule which can mean longer waiting times for appointments or we just have to take what is given to us. The financial cost of having to pay for our own transport to get to and from the airport/hospital is quite expensive. We pay around \$140 and then also need to provide our own meals while away. There is also the impact this has on my family. It means more time away from my daughter and husband. My daughter suffers from separation anxiety when I have to leave her and gets quite distressed which is very hard on me as her mother.

My son is now in unmedicated remission and has been for a year but still has a lot of episodes of pain and becomes fatigued quite often. A simple head cold or fall in the playground can cause havoc on his little body and increase his pain and discomfort. He has still been required to visit Brisbane approx. 4 times since being in remission. He has still been in pain and they are still trying to figure out why. His blood work, x-rays and ultrasounds have all come back clear so they are unsure why he is still experiencing pain so often. It is frustrating as a parent to not have any answers. They say this can be "normal" but it shouldn't be normal for a child to live in pain and have to deal with that throughout their life. It's simply not fair!

## **2. What it has been like for us getting treatment for our child**

My son had approximately 3 weeks of fevers and irritability before we were admitted to the hospital by a head paediatrician at Mt Isa Base hospital. We were seen several times in ED which included a lumbar puncture and I also presented to several GPs with complaints of fever, unsettled and unusual behaviours (seemed to be in pain) and unable to move properly. I was told it was a viral infection on several occasions and not to "worry about it" or that they didn't really know what was wrong with him and to see how he goes over a few days.

Eventually he was prescribed a course of antibiotics which produced what we thought was an allergic reaction. He came out in a rash all over his torso and face. I raced him to the Emergency Department where I met the head paediatrician who went through the history of what had been happening over the course of the last 3 weeks. She immediately admitted us into the hospital to find out what was wrong with our son. Over the next 4 days my son received several courses of IV antibiotics, blood tests, cannulas (veins kept rupturing) and monitoring. After 4 days we were no closer to a diagnosis as the levels of inflammation in his blood were not subsiding with the antibiotics and he was still spiking high temperatures daily. They decided he was in need of more intense investigation so we were sent via Royal flying doctors to Townsville University Hospital. I was given about an hour's notice that we would be flying out. I was able to take 1 small back pack with me and had no idea how long I would be away from my family. My daughter was 4 years old at the time and this has caused lasting affects on our

family unit. She found it very distressing to be away from me during this time. My husband and daughter drove over to Townsville the next day to join us at the hospital where they were lucky enough to get free accommodation after a few days at the Ronald McDonald House in Townsville. This was a home away from home and such an important part of keeping us all together as it was located across the road from the Hospital.

We then spent the next 1 ½ weeks in the Townsville Hospital trying to find out what was wrong with our son. He endured several procedures including a CT scan under general anaesthetic, countless blood tests, antibiotics and repeated cannulas as they continued to fail (also contributed to every nursing shift change having to unwrap the cannula and physically check the site and disturbing it rather than just flushing and making sure it was working efficiently).

The blood tests were repeated every few days to see how his inflammation levels were going. This however didn't give us any answers as he wasn't responding as well to the antibiotics as they hoped. After many weeks of interrupted sleep, pain, trauma and distress of the cannula process they approached me to try and attempt another cannula. I had an emotional breakdown and I remember cradling my son in my arms so distressed that I felt like I was going to walk out of that hospital if they even tried to touch him again. An overpowering sense to protect him took over me and I fought for them to give us more of answers and options in how to try and treat him.

This emotional outburst got them to contact the Rheumatology Team in Brisbane as they seem to have exhausted the treatment options in Townsville and were looking for another way to help us. As soon as they spoke to Dr Ben Whitehead he told them to send us to Brisbane as soon as possible. We were seen by a social worker who managed to get my husband a flight under compassionate grounds to avoid us paying the \$800 flight to get to Brisbane. However my daughter was unable to receive this so we had to pay her way from Townsville to Brisbane ourselves. We had 2 hours to arrange our things, get out of the hospital, park our car at our friends house and catch a taxi to the airport. We were also in a City that we didn't know well and found this whole process very stressful under the circumstances and the time constraints we were under. As we arrived at the airport they were closing the gate to the plane. I was unable to book our luggage on the flight so my husband and daughter had to miss the plane in order to get our luggage over to Brisbane. We were lucky that the flight crew were very helpful and rebooked them on a later flight. My heart sank as I ran towards the gate leaving my husband and daughter standing there. My daughter began to get very upset and I didn't even have time to comfort her.

My son and I arrived at The Queensland Children's Hospital and was helped to where we were supposed to go. We met with the head of Rheumatology Dr Ben Whitehead who took one look at my son and said I'm 99.9% sure your son has Juvenile Arthritis. He was displaying signs of SJIA as he was still having daily fevers of 40 degrees and rashes that would break out all over his legs and torso. He was immobile, in pain and had significant swelling in his hand, wrists, feet and ankles by the time we arrived in Brisbane. We were seen by several Drs over the next few days. The neurology team, infectious control team and rheumatology. My son was also sent for an MRI scan, bone density scan and was considered for a biopsy of a small uptake near his spine which was seen on the previous CT scan in Townsville.

After all the information was gathered it was confirmed that he had Systemic Juvenile Arthritis. We had never heard of this disease before. We were also under the assumption that arthritis happened to “old people”. Once the diagnosis was gained his treatment started relatively quickly. He was started on daily steroids and an injection of Methotrexate. The medication seemed to help pretty quickly, we noticed he was able to attempt to pull himself up for the first time in weeks and could move around a little more on his own. He was given his first Methotrexate injection by the nursing staff in the hospital however they entered the room in hazard suits with glasses and gloves on as this is a cytotoxic medication which I didn't really understand at the time. This shocked and scared me. I remember breaking down crying with fear of what this medication could be doing to my son as it appeared to be “dangerous” looking at the people about to administer it.

We spent 9 days in The Queensland Children's Hospital receiving treatment, plans for when we returned home, information and seeing other people in the hospital that would be apart of our journey I.e. Physiotherapist.

Once returning home we were admitted back into Mt Isa hospital for 3 days of IV steroids to continue to help with the inflammation levels in his body. He was so hyped up from the medication that he couldn't sleep for days, he was over eating to where he nearly threw up and was having major roid rage episodes. This was again 3 days away from my daughter and husband, more time off work and time stuck in a hospital room on my own.

Our journey continued with the “trial” period of Methotrexate and oral steroids which is set out in the guidelines before being eligible for the biological drug Tocilizumab. We went through 3 months of torture trying to wean him off steroids and watching the pain instantly come back. We watched as he went 1 step forward and 2 steps back constantly. He was in so much pain and we couldn't stop it. Once we had waited out the 3 months he was eligible for the Tocilizumab but before we could have the infusion they inserted a portacath so had to wait for a few weeks to be able to use it. When he had the portacath inserted within 24hrs he developed an infection in the sight. We were due to fly out the next morning but instead ended up back in Brisbane Hospital for 4 days on an IV antibiotic drip. Once the infection had subsided we were able to fly home To Mt Isa only to return again in 2 weeks for his first Tocilizumab infusion in Brisbane. After he had his first infusion we noticed an improvement within the first 48 hours. He was moving better already, we were able to wean him from the oral steroids. As he required the infusion once a week in the beginning he would often become neutropenic which was a side affect of the medication he was on. It means he couldn't fight an infection properly if he was to catch a bug and could become quite sick. When he was nutropenic they were unable to give him the infusion. This would sometimes happen weeks in a row and he would start getting more and more pain in his joints resulting in more regression. They eventually spaced out his infusions to every 2 weeks and he responded quite well. If he caught a cold or was sick he couldn't access his treatment as it would escalate his condition. It was a very stressful time as by the middle of the second week we would start to notice more stiffness and limping as the Tocilizumab started wearing off. After the first year he was responding quite well to his treatment. He was in hospital less and less for sicknesses and was moving much better. Between 2019 and 2020 he began having severe croup episodes and constant lung infections. In 2020 after about 6 months of issues he was admitted to hospital for bronchiectasis where he received 10 days of IV antibiotics and 14 days of oral antibiotics. This was also when his treatment for

SJIA stopped. He had been without infusion for a month prior due to being sick for so long so they said they would trial no medication for SJIA which had been in an upcoming plan for him anyway.

Since then we have still been back and forwards to the rheumatologist to try and work out why my son is still suffering what appears to be "arthritis" pain however his clinically fine. There is no answers as yet but we are hopeful that he will one day be pain free. It is hard not having answers for our son. It is a constant fight to be heard and sometimes sends us crazy that we just can't get the help we need to make his life better. We're very lucky that he is a strong willed little boy who is so happy and just enjoys life considering all he has been through.

His current medication of an anti inflammatory had to be compounded and sent from another state as there is no access to it in Mt Isa. This ensures a larger cost as we cannot claim it on his health care card. So what would normally cost \$6.00 costs approximately \$55.00. We have also had issues with supply coming on time. We had supplied the script but it took 10 days for it to be made and sent to Mt Isa which meant we run out. This caused significant pain to my sons joints and was unable to control it properly with Nurofen and Panadol.

### **3. Our Experience of awareness of this disease**

It's simple there isn't any really. We had never even heard of this disease before our son got it. Neither had anyone we know. It was a huge shock that someone so young could suffer this type disease. We didn't really know what this meant for our family or our son and it has defiantly been a learning curve for us. From medications to sustain his movement, pain management (a lot we have done on our on) or how his body copes from a big day of school to the signs of his disease might be playing up.

Most of the doctors I have met since his diagnosis have little understanding about this disease and it is usually us that needs to tell the doctor how to treat our son properly.

The kindy that my son attends had never heard of this disease either but have been very supportive and planned meetings with us when we began the school journey to become as informed as they could be to cater for our son. They are getting to know him a lot better so can tell by his behaviours if he is showing signs of SJIA or the pain associated with it.

There is no one else in our community of 25,000 people that have this disease. There is no awareness in our community of this disease as it is uncommon. It is often seen as an old persons disease and people are very unaware that it can affect young people. It can be that the people who suffer from this disease are seen as "normal " as there is no physical disability at times. However, it is always lingering in the background, waiting to strike.

### **4. How COVID has impacted us**

This has been one of the most uncertain times of our lives. We're concerned it will cause a flare if our son becomes infected with COVID-19 (he also has other medical issues related to his lungs). It has also meant that accessing specialist care has been harder. Our follow up appointment in Brisbane was due in November 2021 and we are still waiting to see anyone due to a back log in the system and the risk of

travelling at this time. We are lucky that our son no longer requires Tocilizumab (Actemera) which is a drug being used around the world to treat some patients with COVID-19. This has produced a world wide shortage of this life saving drug that ensures patients can function on a daily basis.

#### **5. What we think would help/recommendations**

- We need more awareness of this disease that is wreaking havoc on our younger community. We need quicker access to care and a more holistic approach to the treatment process. Children should not have to suffer the unnecessary pain they endure waiting for the next treatment to be approved (3 months) when the specialists can clearly see it is not going to work before being granted the next level of treatments. I know this is also very frustrating for the specialists as they have to jump through all the hoops to be able to treat their patients in the appropriate way.
- There are only a hand full of Paediatric Rheumatologists in this country therefore making to hard for some people to access services. We need more Drs and GPs training in this area to be able to address this shortage and increase the level of patient care.
- More investigations and supports for parents and children in remission from SJIA/JIA that are still experiencing pain. I feel like our children sometimes get put in a box that not every child fits into. Each case is different and I feel like they don't see that sometimes because of all the red tape they have to go through. If there isn't anything clinically to see you do get fobbed off sometimes. Pain isn't normal and I don't think it should have to be.
- Communication between hospitals and sharing of test results - We had to do the same tests repeatedly in the 3 hospitals my son received care in meaning general anaesthetics, more needles and trauma from being wrapped in a blanket and held down to put in cannulas.
- There is a greater need for support for our children and their families. It has taken me a long time to get help to deal with what has happened to my son and family and I did this on my own. It was never offered or encouraged. We were basically given a diagnosis, some info and medication and then sent home.

Thank you very much for considering our submission

