

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

About: The inquiry into Childhood Rheumatic Diseases

From: Lynnette Ahumada and Family

Date: 21st of January 2022

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

Our family has been impacted by JIA Juvenile Idiopathic Arthritis – Oligoarticular JIA and Chronic Uveitis due to JIA. we are hopeful that by hearing our story and the stories of others, that the poor children suffering from these diseases can access the care and best treatment that they deserve.

My daughter is currently 10 years old. She was diagnosed when she was 1 year old. She has lived with JIA now for 9 years and it has been a very hard and traumatizing journey so far. Multiple surgeries including her eyes as she also has Chronic Uveitis in her eyes due to her JIA. She has mild glaucoma and mild cataracts. Her JIA story began when she just had turned 1 year old and she woke up one morning and I stood her up in front of her walker because she had just started learning how to walk. She fell down screaming and crying. We were worried and oblivious as to what was going on. So, we got her up and tried again to see if it was that action and she started crying and screaming again and would not stand up. I took her pyjamas off and looked at her closely and we noticed that her right knee was hot to touch and the size of a cricket ball. We took her straight to emergency at the children's hospital. They took bloods etc. and then came and said "Her bloods are not showing up with anything so you can go and if anything, else happens please come back so we can look into it further". 1 week later her left knee does the same thing and her right knee is still the same. So we went back to the hospital. Unfortunately for us it was towards the end of November and we were told that specialists that could help her were not back in until early next year after the holidays. So, we booked to see the Specialist mid-January there on the spot. It was 6-7 weeks of carrying her everywhere. She could not walk, she couldn't even crawl because she could not put any weight on her knees or legs at all whatsoever. It was the longest 6-7 weeks we have ever lived through. After the specialist saw her for only 2 minutes, he diagnosed her with JIA and started her on treatment straight away. We were in the hospital for 1 week getting her started. This was how our JIA journey began.

She has had failed medications one after the other. One made her sleep during school so the fatigue was too much and was causing it to be too emotionally draining for her as all she said she wanted was 'to be a normal kid'.

She has on multiple occasions had Fluid in her knees that had to be drained by putting a thick needle in her knee to take out and then given steroid injections to hopefully stop the inflammation.

She also was once in her routine Infusion at the hospital and the medication she was on at the time caused her to stop breathing 20 minutes into her infusion. She went Blue and purple. The most traumatizing experience ever. As you can imagine I do not leave her side whilst she has her infusions. Too scared to. Clearly, they had to change her medication after that but you can imagine how traumatizing that could be for my daughter and myself. She was hardly eating as she said she didn't want to choke (because that's the feeling she got when she couldn't breathe) and she was trying to not fall asleep at bed times as she said "I am scared that I won't wake up." This time in our lives was

very hard and we worked hard to work through it so that she would eat normally again and sleep as its important for her health. Luckily, she was back to herself after 6 months of constant monitoring and talking through things.

Uveitis is our 2nd scare as it can have a risk of visual loss and she has had to deal with a lot of Steroid eye drops to fix the inflammation but with fixing the issue of inflammation then the steroid drops are also causing high eye pressure and high eye pressures led her to have emergency surgeries in her eyes one by one because the pressure was too high. So although the steroid was fixing inflammation it was also causing high eye pressure which was terrible. We visited the hospital once weekly for months.

JIA today impacts her in various ways. The medications she is on doesn't allow her to be able to play in the sun or do sport days at school n the sports field or anything in the sun because it interacts with her medications. She cannot get sunburnt. This stops her from doing all outside activities with her class. Unfortunately, she will always feel different whilst she is on her medications.

The side effects of her medications is another issue she has to live through. She gets tired easily. She once went through chronic fatigue and was falling asleep during her school classes. So, we had to get off that one and start a new medication. But unfortunately, we are on our 2nd last drug and I was told the last one is one they don't use a lot so there are no factual experiences and findings with it so that has me quite uneasy and hoping that this one works.

Every infusion day which is every 4 weeks, she dreads the canula being put in as it's a different experience with each Nurse that puts in it her arm.

She expresses here and there "I just wish I could be a normal healthy child and not have to go to the hospital all the time and miss out on things."

She also has to do a lot of catch-up work with me at home due to her appointments and infusion days.

Not only does it impact her but it also impacts us because emotionally, it takes a toll on me but I don't let her see that.

My daughter has an older sister and as a sibling of someone with JIA is also an issue that doesn't get spoken about often, BUT it is real. A few years ago, we went through a hard time with our NON-JIA child because she felt that her sister got more attention than her and she was acting out etc. I am a qualified counsellor and I luckily have the tools to be able to work through these things with her but it is definitely something that affected her as a sibling of a sister with JIA.

I also cannot work due to her JIA because of the reasons that follow:

- If a parent sends their child to school sick, believe it or not, it is me that gets called from school to let me know that there is a sick child or has been at school so I have to go pick her up. My daughter is the one that has to get picked up because of her Immune system being compromised. But I do believe that there should be a rule at schools that it is the parent of the sick child that should get called to come and take there child back home until they are better.
- Getting her to all her hospital appointments
- If ever she is not well then, she has to stay home and possible it will be a visit to emergency depending on what it may be.

I studied and have a diploma of Counselling and I also volunteer my time with Arthritis QLD as a peer mentor and I also am a online moderator for the JIA Facebook page. But I unfortunately cannot make an income due to her JIA because I'm finding it hard to find work from home work so that I can work and be there for my child if need be. That is very hard on me.

It affects us socially because if we have plans but we find out that somebody within our circle is unwell then we cannot spend time with them and we have to cancel going to that event etc. it affects her socially for the same reason and she misses out on a lot at school including day camps, swimming carnivals, sports days etc.

The cost of the constant medications and hospital parking especially when we are there a lot is hard on us also.

My daughter sees Rheumatologists, Ophthalmologists and a glaucoma specialist at the children's hospital as well as spends 1 day a month in 5B for her Infusion Day.

We are easily spending 2-4 hours in total at the hospital for 1 regular appointment. That includes waiting to be seen and being seen by the Dr.

On infusion day, we get there by 7:45 – 8:00 am and we are there until approx. 2pm depending on how smooth the day is going for the nurses and 5B that day. They know her in 5B and they are very friendly and we appreciate them all as well as her Rheumatologists and Eye Drs.

Covid has been such a scary and hard experience. Currently, we have been voluntarily self-isolating since the 1/1/22 due to the high numbers that was rapidly increasing in QLD and in Brisbane. She is immunocompromised and because of all the medications she is on, she is not allowed to get her 1st COVID vaccine until the 24th of January and so we as a family of 4 have to make the sacrifice and right decision to make sure that she doesn't get it before she is vaccinated and at least protected a bit. So it has been Voluntary home isolation for us and until she goes back to school.

As a mother of a child with JIA, I remember when she was first diagnosed and going through it even before the DR diagnosed her, I was so scared and felt so alone.

As time went by and finding support through the Drs and reading information on JIA and different experiences then I didn't feel so alone. Then I heard of JAJA through my Rheumatologist and my daughter and I were asked by the TV show **A Current Affair**, to help with a segment which aired in November 2020. It really opened up my eyes to so much more but it was more about bringing awareness to JIA because everybody I knew thought that Arthritis only happened to older adults and that it's a 'Later in life' experience. So My husband and I have had to educate our family and friends on it and I find myself talking about it with new people we meet because it naturally comes up when they see that our daughter doesn't do things like all the other children do.

Things that I believe would personally help my daughter and us as a family living with JIA would be:

- **Government funding for research of JIA and better solutions to help the children so that their quality of life is better.**
- **Bringing more awareness to JIA**
- **Support for parents of kids with JIA because of only 1 income household.**
- **Mental and emotional support not only for the kids with JIA but also siblings and parents.**
- **Schools should have different rules about not letting sick children attend school and if a child attends school sick then that sick child is the one that should go home, not the one that has a compromised immune system.**

Thank you for taking the time to read our story and how JIA impacts us daily and has for the past 9 years.

Lynnette and Family.