TO: The Standing Committee on Health, Aged Care and Sport
ABOUT: The Inquiry into childhood rheumatic diseases.
FROM: Cecilia Le
DATE: 21 January 2022

Dear Committee Members,

I would like to take this opportunity to thank you for raising this inquiry and assessing childhood rheumatic diseases. My daughter was diagnosed with Juvenile Arthritis at the age of 2 and has been suffering from this for the past 3 years. It has been a rollercoaster of a journey these past years and I would like to share some of my experiences as a mother of a child suffering from this disease.

When we first noticed that something was wrong with her joints, she was limping around with a very swollen knee. We took her to our local (and very good) GP who suspected it was Juvenile Arthritis. She told us to take our daughter to the Royal Children's Hospital immediately. So we took her in, and told them our GP's diagnosis – hospital staff had their own views, and said it was a hairline fracture that was causing the swelling. So back and forth to the hospital we went, getting x-rays, ultrasounds and blood tests, for a full 6 months before the hospital finally confirmed that she had arthritis. Even then, they were not 100% sure. By that time, the swelling in her knees was so big that she was unable to walk.

During this 6 month period, she was unable to walk as the arthritis had spread to both her knees and ankles. As you can imagine, watching a once energetic 2 year old lose their mobility without having a reason of why, is just heartbreaking. We would take her to the playground and she refused to play on the slides and swings, when she used to confidently run around to play on her own. The pain

Once diagnosed, the hospital staff at Royal Children's hospital were fantastic. We were put on a waiting list for an additional 2 months wait so that she could be put under general anesthetic to remove fluid from her joints. The Rheumatology team are also great, but very short staffed – there are only a handful of people working in the department, and pre-COVID, the waiting room used to be full of patients waiting.

With a child who suffers from Juvenile Arthritis, the biggest fear is that anything can cause flare-ups and take away her mobility again. And unfortunately, there is no answer to what causes these flare-ups. With COVID now in the mix, there really needs to be more support for these immunocompromised children. A simple cold could cause a flare, let alone COVID.

My daughter is a resilient child and is now 5 years old. She has arthritis in her knees, ankles, elbow and neck. Since it is in her neck, the risk of potential paralysis is increased – just writing this letter makes me feel sick in the stomach. On normal days she is a happy and bubbly child. But to put so much strong medication into her little body causes other side effects such as upset stomachs, anemia, mood swings, mouth sores and weight loss. She needs to get blood tests every few months to monitor her condition and the medication.

One year ago we had to switch her oral medication to subcutaneous injections that I need to administer myself at home. This happens every Friday night, and is one of the most traumatic events for her each week. Fridays are now known as the worst day in the world. For a 5 year old to have to go through this and wondering why she has to go through all these treatments whereas her little brother does not, is just unfair. And to not be able to answer her question of why she gets it and other kids she knows doesn't, makes it even harder.

I would love to have some support to boost awareness for Juvenile Arthritis – most people I speak to are either not aware that it exists, or do not actually understand how painful it is, and how much it impacts children. Not being able to move will have long term growth deficiencies and muscular-skeletal implications. And days where the pain is too much, missing out on school will greatly impact their education and day to day social interactions.

From a financial aspect, it has been a big out of pocket expense for us as a young family. The injections alone are $10 / week, plus other anti-inflammatory medication, supplements and vitamins that she needs to take to reduce the side effects of the medication. One bottle of Naproxen is $125 if not scripted and subsidized from the hospital. These medications to treat Juvenile Arthritis should be subsidized to a greater degree, or patients should have access to better funding initiatives to support them like other long term illnesses.

At the moment we are only able to visit the RCH once a quarter. Our last appointments could not happen due to COVID. My daughter also needs regular eye checkups to monitor any inflammations behind her eyes. Each time I would need to take time off work for a full day to take her to the hospital as there is no facility closer to home that offers these services. In addition, the hospital was unable to recommend or refer us to any local services that could help with her condition. The sad truth is that Juvenile Arthritis is not an area that is properly funded, so there are very few people who specializes in the area.

Since COVID has been added to the mix, my anxiety levels have increased ten-fold. I am trying my best to keep my daughter's arthritis under control, but not knowing how COVID will affect her whilst taking immune suppressants, makes me very worried. We've spent the last 2 years staying away from crowds and family gatherings to minimize her risks. My daughter will be starting Prep on the 31st January, and I am very uncomfortable knowing that she will definitely be more exposed to positive cases. It is hard enough to manage her injections weekly; the next stage in her treatment will be to increase these injections and put her on stronger medications which is certainly something I am trying to avoid as much as I can. The frustration lies with many people I talk to telling me that COVID has been very mild for kids, and it's just like a cold. The fact is that each 'mild cold' she has caught in the past has triggered flareups and has developed into an infection as she couldn't fight the cold. People really do underplay how severe this can be for Juvenile Arthritis patients.

It would be great if Australian families with kids suffering from Juvenile Arthritis have access to more support, both financially, as well as have better access to providers (physio, swimming, hydro-therapy for kids) who can help with supporting these kids. It takes great physical toll on their young bodies, but it takes an even greater mental toll, especially as they grow older and start questioning why they have it.

I am currently trying my best to spread greater awareness for this disease so that my daughter would feel comfortable about it, and receive the support and acceptance from her teachers and peers. But it would take a lot more than a few people to be able to spread this awareness. Without this awareness, my daughter would never be able to receive the support she needs to be able to

Thank you for your time.

Regards,
Cecilia Le