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

Submission for the Inquiry into Childhood Rheumatic Diseases and Juvenile Arthritis

Submitted by: Gemma Haskell, [redacted]
[redacted]

DATE: 24th January 2022

I am the mother of a 7-year-old girl who was diagnosed with Juvenile Idiopathic Arthritis (JIA) in August 2020. JIA has had an enormous impact on my daughter and our family. I hope that by reading my submission and the submissions of many other families that you can gain some insight into the nature of this terrible disease, the difficulties we have in accessing services, and the impact the disease. It is my hope that children who are diagnosed with JIA are able to access the care and treatment they require and deserve.

Thank you for taking the time to read my submission to this inquiry.

Juvenile Arthritis is estimated to affect at least 6000-10000 children in Australia. The true numbers are unknown due to misdiagnosis, disjointed services, and difficulty accessing diagnostic services. The cause of JIA is unknown and there is very little information available about the prognosis of the disease. JIA is one of the most prevalent, chronic childhood diseases, however, it is severely underfunded compared to diseases such as cystic fibrosis or Type 1 diabetes. Further research is desperately needed to accurately determine the prevalence of the disease and to direct evidence- based health services to improve long term outcomes for sufferers of this insidious disease. This research can only be conducted with adequate funding from Federal and State governments. Long term effects of JIA can include vision loss, joint deterioration, permanent disability, and ongoing mental health impacts.

JIA is an unpredictable and largely invisible disease, however the health, social, educational and economic impacts it has had on my daughter and our family have been far reaching, significant, and traumatic in the time since her diagnosis.

Children with JIA live with chronic pain and often experience severe and fluctuating pain daily, even when their disease is considered to be managed with medication. The medications my daughter uses to manage JIA have some awful side effects including constant nausea and fatigue. My daughter regularly experiences significant pain in her legs, hips, back and fingers.

This is having an immense impact on her physical and mental health. It is not normal for a 7 year old to have to sit out during break times at school as her legs are too sore to play with her friends, or to not be able to complete her classwork because her hands are aching. My daughter's teacher reported that there are many days where my daughter will burst into tears at school because the pain in her hands is stopping her completing work or participating in activities that she loves. Although technology has been very useful in supporting my daughter complete her school work, it is another way in which she appears to be different to her friends. My daughter is a bright, bubbly, social girl who loves school, however there are many days where my daughter comes home crying, or does not want to attend school because she is in pain, cannot do the things she enjoys, and is sick of feeling different to her peers. As a parent this is heartbreaking to witness.

Living with a chronic health condition means multiple medical appointments. Since her diagnosis my daughter has seen many health professionals including psychologist, occupational therapist, physiotherapist, rheumatologist, ophthalmologist, GP and paediatrician (all privately funded). These appointments require time off school, travel time, time away from friends, and time off work. My daughter has had, on average, at least one day off school a week since her diagnosis due to pain, fatigue and/or medical appointments. This is in addition to the time she has had off school due to COVD lockdowns.

The additional care and support my daughter require is having a significant financial impact on our family. I am self-employed and have had to reduce my work hours in order to attend appointments and to allow for time off school due to illness. As I am self-employed, I do not have sick leave or carers leave and often need to cancel work commitments due to my daughter's ill health. The need to reduce my work hours as well as the increased costs associated with my daughter's care is having a severe financial impact on our family. My daughter is one of three children. The financial and emotional stress that our whole family experiences due to JIA is immense and difficult to measure.

Children with JIA often have long, traumatic journeys towards their diagnosis. GPs are not trained to identify JIA and it is often diagnosed after trips to many different specialists and invasive tests. This often take months or years, particularly for children in rural and regional areas.

My daughter's journey to her diagnosis is considered to be unusual as she was initially seen by a very experienced GP at our local surgery who has previously diagnosed JIA. I have been told on multiple occasions by our regular GP and her colleagues that they would not have recognised JIA in my daughter. In fact, despite seeing a very experienced GP, it took multiple appointments, extensive research of clinical pathways for “unexplained leg pain” on my part, and demanding tests that we were able to obtain a provisional diagnosis after 8 weeks. It was then another 6 weeks that we were able to have the diagnosis confirmed by a paediatric rheumatologist. This was over three months of unexplained pain, joint deterioration, and additional trauma that could have been avoided if services were adequately funded and accessible in a timely manner.

The GP is the gatekeeper to medical services. They are not taught to recognise the obvious symptoms of JIA and are unable to recognise the more subtle signs. When my daughter has a flare up of her JIA and we need to seek medical advice, I need to do research prior to the appointment so I know what symptoms to highlight to the GP and what tests may be required to identify the problem. We regularly encounter a response of “I don’t know, I’ve never seen a child with arthritis before” from GPs at our practice when we need an emergency appointment. This has been a similar response on the occasions when my daughter has presented to our local hospital. My daughter now questions the benefits of seeing our GP because they can “never help and don’t know the answers.” She has developed an intense fear of attending medical appointments as it is rare that we are able to solve the problem and ease her pain without further tests, appointments etc. GPs require additional training in identifying JIA and managing the complex nature of the condition.

Juvenile arthritis services are inadequately funded in Australia, particularly in NSW. In order to obtain timely help families are required to access private services which they must pay out of pocket. The private nature of these services means that services are disjointed, inequitable, and difficult to measure. A parent’s income should not determine the healthcare a child receives.

There is very limited support and information available to families at the time of diagnosis. When my daughter was diagnosed, we were told of the diagnosis and handed a prescription for her medication. There was no follow up, no information provided about her prognosis, and no counselling support available. If a multidisciplinary team was available, families could be provided with the support they need at the time of diagnosis and in the weeks following. Although JIA affects 6000-10000 children in Australia, the initial diagnosis is very isolating and families need support. Without this support families will turn to other sources for information, which can be incorrect, unreliable, and, in some cases, dangerous. It is essential that JIA support services are adequately funded, consistent across health districts, and multidisciplinary to ensure children and their families are provided with the support the need at the time of diagnosis and the months that follow.

The importance of multidisciplinary care for people with chronic diseases has been well established. Currently families are not encouraged to access allied health services to support their child's functional capacity, limit their pain and improve their quality of life. As an allied health professional, I am aware of the value that multidisciplinary teams can provide in holistic patient care. We have sought out allied health support, however, due to the severe shortage of services in our local area, these supports have been infrequent and disjointed. We have the added challenge of finding therapists who are able to manage JIA and effects of chronic pain in children.

There is limited professional education, awareness and training of healthcare professionals in identifying, treating and supporting children with JIA. Although we have built a good team around my daughter, I have needed to source information and resources for many in the team supporting my daughter.

There is very limited awareness in the community about Juvenile Idiopathic Arthritis. JIA is an invisible, unpredictable and fluctuating disease. My daughter can be bedridden in the morning and running around by the afternoon, appearing seemingly fine. We can make plans only to have to cancel them at the last minute due to fatigue, pain or a flare up of arthritis. The lack of awareness in the community has proven to be a significant barrier for my daughter accessing support and understanding in our community.

As a parent I am needing to constantly advocate for my daughter. I am also needing to teach my daughter to advocate for herself, much more than a 7-year-old should ever need to. This creates immeasurable stress and is exhausting. The invisible and fluctuating nature of the disease has proven to be a barrier in my daughter receiving support at school. My daughter has been fortunate to have had two very compassionate school teachers since her diagnosis who will accommodate her needs in the classroom whenever possible. I know this is not always the case with some teachers.

We have experienced multiple barriers when advocating for additional support at school, particularly in regards to accessibility. For example, the school my daughter attends has many stairs to the classrooms, playground etc. I have been informed by the school that in order to have my daughter's class moved to an available, accessible classroom, and to have permission to use the lift, I need to have an occupational therapist and physiotherapist assess the site and document the difficulty my daughter has with managing stairs on days when she is in pain and/or exhausted. These assessments will need to be privately funded and will cost close to $1000 in total. Funding should be available for schools to complete assessments determining a child's level of need and support needs. It should not need to be funded by families in order for the child to be able to attend school safely, and with as minimal pain as possible. My daughter has a right to an education, it should not be further impacted by accessibility issues.

Despite her multiple needs, we have been told that my daughter will unlikely qualify for the NDIS as she is not yet 'disabled enough' by the condition. However, in order to prevent my daughter to maintain current levels of function I am required to spend thousands of dollars each year on various allied health supports, medication and equipment. If not, she would become 'disabled enough' to be eligible for the NDIS. Due to her JIA we have had to purchase the following equipment since her diagnosis:

- accessible the taps in our bathroom and pay for a plumber to install them
- purchase specialised pencils, pencil grips and scissors
- heat packs to manage pain
- supportive shoes
- orthotics
- crutches
- wrist and ankle braces
- supportive chair
- an iPad in order for her to be able to complete work at school
- medications.

We currently have the choice to spend approximately $1900 on a functional assessment in the hope of gaining access to the NDIS, which is unlikely, or to direct that money towards medication, therapies, medical appointments, and equipment to support my daughter. The impacts of JIA are well documented. Services would be more equitable if JIA was moved to "List A – conditions which are likely to meet the disability requirements in section 24 of the NDIS Act." JIA does not discriminate based on a family's income and nor should the services a child can access.

My recommendations to the committee:

- A widespread education campaign for GPs, health professionals, teachers, and the broader community is funded to increase awareness of JIA.
- Skilled multidisciplinary teams including a psychologist, nurse, occupational therapist, and physiotherapist are funded in order to provide support to children with JIA. This will help to maintain function, support mental health, and improve outcomes for children

with JIA. These teams should be funded across all health districts and not limited to the children's hospitals in each state.

- Research is funded to identify the true prevalence of JIA in the community. This will allow funding for health services to be directed appropriately.
- JIA is added to "List A – conditions which are likely to meet the disability requirements in section 24 of the NDIS Act."
- Research is conducted to improve the outcomes of children with JIA, to reduce their pain, and to ultimately find a cure for the disease.
- Services are adequately funded so support can be gained in a timely manner. Any delay in getting support means more pain, additional stress, and ongoing joint deterioration.
- Family support services are funded to provide counselling as required at the time of diagnosis and as the disease progresses.

Thankyou for taking the time to read my submission. Please contact me should you require further information.

Gemma Haskell