

Committee Secretariat
PO Box 6021
Parliament House
CANBERRA ACT 2600

15th January 2022

To the Standing Committee on Health Aged care and Sport

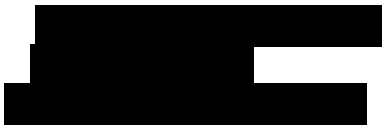
Re: Parliamentary Inquiry into Childhood Rheumatic Diseases

Thank you for the opportunity to raise the following issues about our daughter's arthritis with the Committee. Our key recommendations are:

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1. Increase the number of paediatric rheumatology doctors, nurses and support staff (physiotherapists, occupational therapists etc) in NSW as a matter of urgency.
 2. Implement integrated 'one-stop-shop' public clinics, where all specialists (medical, non-medical and enough of them) required for the holistic management of children with rheumatic diseases/arthritis are available in one appointment.
 3. The above should include the access to psychologists and pain management services at diagnosis and as needed thereafter.
 4. Develop and provide professional development to teachers about rheumatic diseases to ensure they are able to fulfil their duty of care for these children.
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Our daughter is almost 10 years old and had her first arthritis symptoms at the age of 2. Thankfully at the time, she was seen quickly (due to one of her medical grandparents using their contacts to avoid the usual waiting times), did not experience any pain and went into remission. When she was 6 years old, her arthritis flared and now affects both wrists, knees and ankles and her left elbow which was added to the list just before Christmas. This causes her daily pain which is yet to be controlled despite twice weekly injections; missing out on school activities and the inability to participate in everyday activities that other children take for granted.

To control her arthritis, she has previously had joint injections under general anaesthetic into her knees, ankles and wrists on two occasions. She has twice weekly injections of a biologic anti-rheumatic drug (Entercept) that we give her at home and a daily oral anti-inflammatory (Celebrex). These medications do have side effects, some quite serious such as liver damage, requiring regular blood tests which our daughter hates. These procedures and medication result in out of pocket costs. Further, obtaining her medication requires careful management due to the need to order it in advance and gain TGA approval for her paediatric rheumatologist to write the prescription. Further, as she has significant anxiety around her injections, we use a numbing cream one hour prior to her injection, which in a busy household requires thoughtful timing.



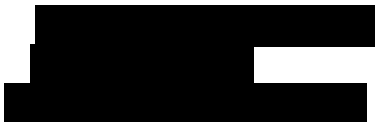
As a result of her anxiety around her pain and injections, compounded by a year with a highly unsympathetic teacher, she was referred to the Macquarie Emotional Health Clinic and attended the 'Cool Kids Program' there. Whilst this was successful in providing her with strategies to manage her worry and in particular reduce the stress and tears that had previously been associated with injections, it required additional time and out of pocket costs.

In addition to the above, she attends 3 monthly appointments with her paediatric rheumatologist and specialist nurse, 6 monthly appointments with the 'eye clinic' to check for uveitis and physiotherapy and occupational therapy appointments as required for her joints and to assist with writing due to the arthritis in her wrists. These appointments are all separate and require separate scheduling, resulting in increased time away from school for our daughter and away from work for her parents who both work full-time.

In fact, due to the time commitments it has not always been possible to prioritise some of these therapies and for some services due to their high demand, her appointments are often rescheduled past the recommended timeframe for clinical review raising issues of clinical risk and safety.

Further, despite all of the specialists being of the highest calibre, there are simply not enough of them, and the wait times at clinics are very lengthy, usually requiring 3-4 hours to attend a clinic. Whilst wonderful, our daughter's paediatric rheumatologist is only funded to provide one clinic per month and in order to continue to see current patients as well as those newly diagnosed, he often has 20 patients to see in a 3-hour clinic. This not only results in long waiting times, but crowded and chaotic clinics that are potentially unsafe. In fact, we recently had a miscommunication about increasing the dose of our daughter's biologic medication, which we give at home by injection twice weekly. This led to her receiving an incorrectly increased dose for the 3 months between clinic visits. While no harm resulted, this illustrates the potential for serious harm when staff are rushed and under resourced and have little time to think, let alone communicate clearly with their patients.

A 'one-stop-shop' clinic, where all specialists (and enough of them) required for the holistic management of our daughter and her condition, are available in one appointment would be of huge benefit. The benefits would include increased quality and effectiveness of care provided, a coordinated care approach, reduced time away from school and work and reduced wait times to see services such as physiotherapy and occupational therapy, which usually have extensive waiting times. In addition, there are currently no public psychological counselling services available for children to support them to adjust to dealing with this chronic disease and help them to navigate the resultant psychological issues, such as isolation, dealing with school and teachers and relationships with other children. Finally, despite their being a public pain management service, there is an approximate 6 month waiting period for a new appointment, which defeats the purpose of helping someone who is in chronic pain. So, both psychology and pain management services should be included in these 'one-stop-shop' clinics.



Our daughter is fortunate, due to seeing her paediatric rheumatologist in the public sector, to have access to the paediatric rheumatology clinical nurse consultant (PRCNC). Unfortunately, there is only one PRCNC for the entire population of NSW, so she is extremely overworked. Despite this, she provides valuable support to parents and children and has even attended our daughter's school to meet with her teachers and provide education about JIA and how they can help her in the classroom. This was extremely important for our daughter in 2020, when she had a teacher who through a lack of understanding, did not support her or meet her needs around JIA. Until this school visit, our daughter had been unable to access her pain management strategies at school and changed from a child who always loved going to school to one who cried everyone morning and eventually refused to go to school. As a primary school teacher myself, education around JIA is lacking for teachers. Even the mention of JIA as a condition is not currently incorporated into any professional learning packages (however other diseases of lower or similar prevalence are included such as juvenile diabetes and epilepsy). Further, no specific rheumatic disease professional development is available to teachers who have a child in their class with one of these conditions and wish to educate themselves further. I strongly believe that this is an area in which our education system is not fulfilling our duty of care to students with a rheumatic condition.

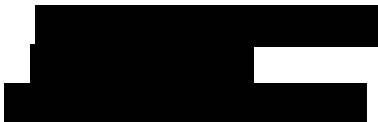
In summary, our daughter recently described herself as 'I look like a normal child on the outside, so people don't understand that I have a disability and pain on the inside.' Her greatest wish is that her pain would go away, she even wrote to Santa when she was 8 saying that she didn't want presents but asking him to take away her arthritis ('I love Christmas it is the best time of the year. One of my wishes is that I want my arthritis to never hurt again.').

Despite what our daughter describes as 'my painful childhood', she is determined not to be different and still participates (when she can) in the activities she loves such as soccer, girl guides, gymnastics, and playing with friends. She is desperate to go skiing again one day.

Our daughter's perspective

She wanted to share with you as part of this submission what it feels like to live with arthritis.

I feel sore all the time and sometimes can't do the things that other kids can do. At home I often wake up stiff in the mornings and it takes me time (especially in winter) to get moving. Having a warm bath helps, but I don't usually have time for that on a school day. I have an older sister and brother who I love playing with, but I am sometimes too sore to even do simple things like a family walk or bike ride. My dad often ends up carrying me on the way home (as I am getting bigger, this is getting harder for him to do).



At school I have trouble participating in sports, games at recess and lunch, writing fast in tests and sitting on the floor for class discussions. This makes feel left out and lonely. Sometimes the teachers are nice and let me do things differently to other students to help my arthritis, but I don't like being different to the other students, so sometimes I don't tell anyone that I am really sore.

The injections I have at home twice a week hurt, and I don't like them. I often get worried about them. I have to wait a long time for my appointments when I go to the clinic which means I miss out on school and play time. I wish my appointments could all be at the same place, so I didn't have to waste so much time.

Thank you again for the opportunity to raise the above issues about our daughter's arthritis with the committee and to make recommendations for change to improve the quality of care provided to our daughter and the thousands of children like her suffering from this painful condition.

Yours sincerely,

A black rectangular redaction box covering the signature.

Kids with JA deserve better.