

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

**ABOUT:** The Inquiry into childhood rheumatic diseases.

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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 these diseases and we are hopeful that by hearing our story, and the stories of others, that children suffering from these diseases can access the care and treatment that they deserve.

My daughter is 13 and has polyarticular psoriatic juvenile idiopathic arthritis (PsJIA). Her condition affects her joints and skin. She has been unwell since she was two but was only officially diagnosed with PsJIA at age 9. By this time the swelling and range of motion in her joints was so restricted that she couldn't climb a set of stairs, couldn't pick up a toy off the floor, could not manage a family shopping trip and could no longer sit on the floor or participate in physical activity at school. She was crying every day in pain. This disease also affects her digestive tract. We are currently battling ulcers in her oesophagus, erosions in her duodenum, daily nausea, reflux and stomach pain. In Term 4, 2021 her school attendance was less than 50%.

Arthritis is a very misleading term. This is not the worn-out knees and hips of older age. I watch my daughter struggle in so many ways every single day. I have watched her friendships fall to pieces, her mental health decline and her self-esteem fall through the floor. She describes herself as 'broken'. When it was suggested that she may benefit from some counselling her reply was 'Great, so now I'm crazy as well as broken'. My daughter was dux of her Year 7 cohort last year and is beginning study at a selective high school this year. She should be looking forward to an amazing future career and yet, despite treatment, there are days where she cannot get out of bed until lunchtime. I worry terribly for her future and know that she is just one of the many young people battling this much misunderstood illness.

Please find further details of our experience with JIA under the inquiry's Terms of Reference as listed below. My recommendations are shown in bold at the end of each Term of Reference.

## Terms of Reference

### *2. The health, social, educational and economic health impacts on children and adults who developed rheumatic diseases in childhood, their families and the broader community*

- My daughter's arthritis has not responded to treatment as well as expected. This has resulted in five years of daily pain and fatigue and constant worry about the damage that poorly controlled JIA is doing to her joints.
- She has been unable to participate in community sport with her peers, is often too tired for playdates and sleepovers and becomes fatigued and overwhelmed quickly in social gatherings. This has had a huge impact on social relationships, leading to feelings of difference and inadequacy and anxiety about being away from home.
- She has missed 20-50% of each school term between Year 4 and Year 7. She is very academic, and I am constantly trying to 'fill in the gaps' from school absenteeism at home. This will become more challenging as she moves into the upper years of high school. We have NDIS funding, and it is very frustrating that we cannot use funds to pay for academic tuition. The NDIS will not fund a tutor as education is the responsibility of the school and the education system. However, the school cannot provide the education if the student is unable to attend school.
- My daughter's mental health has suffered greatly as a result of JIA. She has daily anger outbursts, cries most days, is anxious and has poor body image and self-esteem. Her younger sister is often on the receiving end of these outbursts and also ends up in tears several times each week. My JIA daughter refuses counselling of any sort as she believes that this is yet another sign of her difference and 'uselessness'. No one ever told us how hard this would be on our family and the mental health impacts slowly worsen as each new JIA symptom or flare occurs.
- We have NDIS funding and access the IPTAAS scheme and are very grateful that this government assistance is available. However there continues to be a financial burden on our family. I have had to drop to part time work to manage my daughter's treatment and appointments. My husband is self-employed and if I have to work, he takes time off without pay. My daughter needs expensive shoes to support her feet, a laptop for when her hands are too sore to write, and these items are not covered by NDIS. We are 45 minutes away from our regional town and whilst NDIS and Medicare cover the cost of her many appointments, the petrol costs add a burden to our family budget.

### **RECOMMENDATIONS:**

**1) Review of NDIS rules around education, allowing for tutoring if illness or disability results in high absences from school.**

**2) Psychology/counselling services linked to rheumatology clinics in order to normalise the mental health impacts of this disease. JIA young people and their families should 'check-in' with the psychologist at each rheumatology check-up. Families should be told how hard this can be and this would be a pro-active approach instead of waiting for mental health issues to arise. Arthur House in QLD is a private practice that runs an amazing interdisciplinary clinic, incorporating a variety of allied health devices with rheumatology.**

*3. Access to medical services, including diagnosis, treatment and ongoing management and support including patient information, with a focus on rural and remote communities.*

- My family lives in a rural community on the North Coast of NSW. We are 6 hours from Sydney and 45 minutes from our regional centre. We only have GP services in our small town. My daughter currently receives care from a GP, paediatric rheumatologist, paediatric gastroenterologist, ophthalmologist, orthotist and physiotherapist all of which, apart from the GP involve travel.
- We bounced backwards and forwards to the GP for fifteen months with various sore, swollen joints and reduced movement. We were told it was 'growing pains' and then after a scan of her knee revealed swelling, we were told she must have injured it, although we knew that she hadn't. We were finally referred to a local paediatrician. The paediatrician diagnosed JIA immediately. We were advised to see a paediatric rheumatologist privately as there was a lengthy waitlist for the public clinic at the children's hospital and by then my daughter was unable to walk up stairs. We saw the rheumatologist privately in Sydney within three weeks. My daughter was finally diagnosed with severe polyarticular JIA and had over 40 joints involved by this time
- JIA is not rare, there are more than enough JIA children on the NSW North Coast to offer regular outreach clinics, but unfortunately this is not available. We have completed the 1200km round trip to Sydney between 4 and 10 times a year in the last five years, depending on the treatment required. Juvenile diabetes has a similar occurrence rate as JIA. In contrast, our local regional hospital has a permanent diabetes service that offers management, education, counselling, and referrals to allied health specialists as needed. Travelling 70km every few months instead of 1200km would be life changing for our family.
- Access to public allied health services in regional areas is limited with lengthy wait times. We see a physiotherapist privately who recommended hydrotherapy at our regional hospital. We waited 15 months for an appointment with the public hospital physio. We had a 20-minute appointment and were approved for hydrotherapy and could access the pool immediately. We have been referred to the Children's Complex Pain unit at Newcastle, but again have now been waiting for twelve months for an appointment. This is not the service's fault; they have been in touch and are just working their way through their referrals. There is roughly a three month wait time for private psychology services in our area. Our physio would like us to see an occupational therapist. I have contacted three, but all say they do not have experience with JIA and cannot help us.

**RECOMMENDATIONS:**

**1) Increased funding for public paediatric rheumatology services. This would allow for outreach clinics in regional and rural areas. Outreach clinics should include not just the rheumatologist but a clinical nurse consultant and psychologist, similar to those in place for juvenile diabetes management. This would also reduce waiting times in the public clinics in Sydney.**

**2) Increased funding to public complex pain management services at the tertiary children's hospitals. Timely intervention is of great importance in pain management. Lengthy delays result in a greater financial and emotional costs over time.**

**3) A review of public allied health service waiting list times in rural and remote areas. A fifteen month wait for one twenty-minute appointment is ridiculous.**

*4. Best practice quality of care and availability of treatments, including emerging treatments with a focus on equitable access to effective drugs.*

- Our paediatric rheumatologist is fabulous, and I believe we receive excellent care, but we have had issues with treating our daughter's arthritis.
- My daughter is in the group of children who unfortunately do not respond well to the currently approved JIA drugs. We spent the first 2-3 years of her diagnosis trialling methotrexate, Enbrel, Humira and tocilizumab. Tocilizumab is given by IV infusion and our local large hospital would not manage this treatment for the first few months. This necessitated the 1200km round trip to Sydney every four weeks for four months until the local paediatrician agreed to manage the infusions locally. Finding the right drug once you are a 'non-responder' seems to be a bit of a lottery.
- After jumping through many hoops, our rheumatologist secured supply of an unapproved drug through the Compassionate Supply Program. We are very grateful for this as without it, steroids and their side-effects would be our only option. The drug we take is approved for children with JIA in the USA and Europe. I am pleased that safety is taken into consideration before approval of these drugs, however we seem to be lagging behind other countries in approving their use after trials are completed. Biologic drugs do not just offer pain relief, they are vital in preventing joint damage and destruction and vision damage from uveitis. Our current drug (tofacitinib) is thankfully controlling her arthritis to a satisfactory level at last. We do wonder what next though, if at some stage it stops working.

**RECOMMENDATIONS:**

- 1) Increase funding for paediatric rheumatology services and multidisciplinary clinics so that rheumatologists have greater time to dedicate to their patients.**
- 2) Investigate drugs approved for JIA in the USA and Europe and bring Australian approvals into line with those offered overseas.**
- 3) Continue research into treatment methods that involve targeted and specific drug therapy, reducing the 'lottery' of drug trialling and allowing testing at diagnosis to find the drugs that are most likely to work.**

*5. The adequacy and consistency of professional education, training and awareness amongst healthcare professionals and community awareness of the disease.*

- My daughter had a respected, experienced GP during the time that her joint issues started and yet it took 15 months for her to be diagnosed. JIA it seems, just didn't occur to him as a consideration. An MRI of her knee showed a number of changes very typical to JIA. The radiologist's report noted all of these changes, including synovitis, and yet suggested that there had probably been recent trauma to the knee. Again, JIA didn't seem to be a consideration. I could understand this if JIA was a very rare disease, but 1 in 1000 children have JIA. Our paediatrician diagnosed JIA within five minutes of looking at the swelling in our daughter's joints, he obviously had this in mind based on her symptoms. He ordered blood tests and her inflammatory markers were very high. I often wonder if my daughter's arthritis would have been easier to control had she made it to the specialist earlier.
- My daughter woke with a frozen shoulder one morning. She was unable to move her arm and crying in pain every time she moved it. We were unsure if this was something serious that needed urgent attention. It was the weekend; our regular GP clinic was closed and so we travelled to the GP superclinic 45 minutes away. The GP we saw there asked which joints were affected by arthritis and when we went through them all, he told us that she couldn't possibly have arthritis in that many joints and what did he expect us to do about her arm if she had a chronic disease. My daughter walked out and burst into tears, once again feeling unheard and misunderstood. We saw our regular GP on the Monday who prescribed steroids and short-term pain relief, a scan and physio. It took four months of intensive physio to regain regular movement in her arm and shoulder.
- The regular teachers at my daughter's school have been great at accommodating her needs. Not long after she was diagnosed however, she and a casual teacher and was playing sport. She pulled out early in the game and told the teacher she had to stop because she had arthritis and her knee was hurting. The teacher laughed at her and told her that the was the best excuse she had ever heard for getting out of sport and 'don't you know that kids don't get arthritis'. This single comment meant that for the remainder of her primary school years she had extreme anxiety about having casual teachers and never spoke about having arthritis at school again. There are good resources available for awareness raising in teachers but passing this information on to the wider school community doesn't always seem to happen.

**RECOMMENDATIONS:**

**1) Increased training and awareness raising for GPs and radiologists. If a joint has prolonged swelling or imaging shows synovitis, then JIA should be considered as a possible diagnosis.**

**2) General community awareness raising through media on Juvenile Rheumatic diseases and their impact.**