

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

Re: The Parliamentary inquiry into Childhood Rheumatic Diseases.

From: [REDACTED] **I'm a mother of a child with Juvenile Idiopathic Arthritis. I'm a mother of a child with Psoriatic Arthritis.**

Date: 31 January 2022

As a family, we would very much like to thank The House of Representatives Standing Committee on Health, Aged Care and Sport for the opportunity for families of children with childhood rheumatic disease (including Juvenile Arthritis), to share their stories with the committee and for the parliamentary inquiry taking place.

Our son, currently aged 14 years was diagnosed with Juvenile Idiopathic Arthritis (Polyarticular course/ Psoriatic Arthritis), a childhood rheumatic disease aged just 4 years old.

Terms of Reference point 5:

Adequacy and consistency of professional education, training and awareness amongst healthcare professionals and community awareness of the disease, is in our opinion completely lacking.

Our son was born, 2.74kg, healthy and strong, he walked at 11 months and met all his developmental milestones. As a concerned parent of a limping 2 year old, we took our son to two different GP's and an Orthopaedic Surgeon (for a suspected knee tumour), before being referred to a Paediatric Immunologist for a diagnosis of childhood rheumatic disease and then onto a Paediatric Rheumatologist for ongoing care. The process from seeing the first medical practitioner through to diagnosis took nearly 2 years. By the time of diagnosis, our son was aged 4, this unacceptable amount of time before diagnosis meant our son ended up with a leg length difference and damage to his left knee joint, muscle wastage in his thigh muscles from his altered gait and damage to his wrist and thumb joints.

Had the first GP been aware of and considered the possibility of childhood rheumatic disease, our sons outcome and disease journey would have been improved. It would have also been less costly for the government in terms of appointments, treatment and follow up, and the outcome for our son in prevention of joint damage and permanent disability, would have been remarkably improved. Instead, the reality of a delay in diagnosis and having such an aggressive form of childhood rheumatic disease, means our son now faces permanent damage to his joints, life long pain, lack of function/ movement and disability.

Terms of Reference point 2:

Health, social, educational, economic health impacts on children who developed rheumatic diseases, their family and the broader community.

As a Mum, in 2011 when our son was diagnosed with childhood rheumatic disease, he was very unwell and sick, suffering continual pain, I was forced to reduce my working hours to part time to be able to care for our son as his attendance at daycare was sporadic at best. At times I had to work from home to manage both my work and also my sons needs (well before this was an acceptable option in workplaces).

In agony and unable to function, some days our son would be too sore to stand, walk or mobilise , sometimes he resulted to bump shuffling around the house (even as a 6 year old) in order to be able to get where he needed to go. As he started to grow and get heavier, we sometimes needed to use a wheelchair to mobilise our son around the house and in the community as he was too heavy to carry. Given the aggressive and progressive disease journey our son has faced, we were forced to sell our family home and move to a home on a flat block as our son could no longer manage to walk up and down the stairs at our house. The economic impact on our family has been massive given my salary has reduced by 40% whilst we battled on with increasing medical bills. 10 years later, I am still working part time to be able to manage the impact of our sons illness and his needs with childhood rheumatic

disease. This has come at a significant financial cost to our family along with 10years of medical bills - the cost of Paediatric Rheumatologist every quarter for 10 years is quite an expense, on top of theatre and anaesthetist fees for joint injections, Physiotherapy, Occupational therapy, Hydrotherapy, Ophthalmologist, Medication costs and loss of income. These are substantial costs that families with children suffering childhood rheumatic disease end up bearing the brunt of, with virtually no financial support from the government.

The educational impact on our son has been enormous. In year 3 when our sons childhood rheumatic disease was flaring badly and our son wasn't eligible for biologic medication on the PBS, he missed 75 days of school. In summary, that equates to a whole term of missed school. Pain, swelling, fatigue and joint destruction caused our son significant discomfort and could have been prevented if he had been provided with the right drugs at the right time early in his disease journey.

Terms of Reference point 4:

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

Now aged 14, our son has arthritis throughout almost all joints in his body. The PBS has three approved Biologic medications for children with childhood rheumatic disease. Our son is on one of these three and has been for approximately 6 years. However, in the 4 years prior to this, our son was treated with anti-inflammatory medications and Methotrexate. In pre and early primary school, our son was prescribed 20mg per week of Methotrexate when he weighed only <25kg as he was ineligible under the PBS for access to Biologic medication. The treating Paediatric Rheumatologist was outstanding in his management of our sons condition however was heavily constrained by prescribing the best treatment possible at the right time due to the limitations in the PBS eligibility criteria. This resulted in our son sustaining permanent damage to his thumb joints on both hands with the left thumb being an entire centimetre shorter than the right thumb due to damage to the growth plate and is visibly deformed and painful. The painful deformed thumb joint is disabling and having recently seen a specialist hand surgeon, the only treatment on offer to reduce the pain now given the extensive damage to the joint, is a joint fusion which is not ideal when you are a 14 year old boy. This is sadly the reality of children living with JIA who were not deemed eligible on the PBS for the biologic medications when they desperately needed them. Our son is not alone, other children we have met on this journey have also suffered the same fate with arthritis destroying hip and jaw joints from not being prescribed the right medications at the right time.

We note that Adults (18+ years), with the exact same condition as our son have access to approximately a dozen biologic medications that are restricted from the PBS for children (<18years). We request urgent consideration from the government that the same biologic medications which are made available to adults are considered to be (upon Paediatric Rheumatologist guidance and prescribing guidelines) be granted to children with childhood rheumatic disease.

The important thing to understand is children are the future of our country, our son is striving to be an engineer. He's smart, educated and driven and with the right treatment and support he can achieve his life goal. However, a life of pain and joint damage as a child is debilitating, psychologically damaging and devastating for many families. With the right drugs at the right time, our son, along with thousands of other children could quite possibly have vastly improved outcomes and their future could be bright. If however, the government continues to restrict the availability of biologic medications on the PBS and allied health services (physio, OT, hydrotherapy) as they currently are, the disability of our children with childhood rheumatic disease will continue to increase and the eventual cost to the government will be by far greater.

Children are the future of this country, please help us to help them now, so they can have the brightest future possible, to succeed in life and live a life pain free like they deserve.

Should you wish to contact me to discuss the above, my contact details are on page 1 of this submission.

Kind regards

[REDACTED]