

# Parliamentary inquiry into childhood rheumatic diseases

To the Standing Committee on Health, Aged Care and Sport,

## **Recommendations:**

- 1. Increase the number of paediatric rheumatologists in all states and territories to improve access and reduce patient travel.**
- 2. Increase the number of paediatric nurses to support patients and families.**
- 3. Fund research into non-injectable biologic medication.**
- 4. Include counsellors in multi-disciplinary teams to support children's mental health needs, especially as they head into teenage years and transition to adult treatment.**
- 5. Increase children's access to hydrotherapy pools.**

Thank you for the opportunity to make a submission to this enquiry. This is a personal response based on our family's experiences from the last 10 years when our youngest daughter developed rheumatic symptoms when she was just 3 years old. She was not formally diagnosed with polyarticular Juvenile Idiopathic Arthritis until she was five.

We'd like to make comment relating to the following 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**

- The endless comments we've received that "I didn't know kids could get arthritis" is testament to how little community awareness there is about this condition. It's also a reflection of the tiny funding that flows into promoting awareness, treatment and access to services for children.
- We have no local access to a paediatric specialist and travel interstate for treatment (see Reference 3 below).
- The NDIS system is complicated and word-of-mouth recommendations have been that the outcomes are poor for those who've tried. There is little framework to support families navigate health services for JIA kids. We access services through the health system where possible and cover other services privately.
- Our daughter has missed school for almost every medical appointment she's had. On average every year that's at least two weeks off school just travelling interstate, a week for infusions, and at least another two weeks for blood tests, physio, and other medical appointments. All of this is on top of her time away if she's unwell which has been variable year-to-year. This was absorbed a bit more easily while she was in primary school but the time away has a greater effect in high school and is much harder for her to catch up.
- The same amount of time off work has been needed to take our daughter to appointments, return her to school, and travel interstate. This has had a financial impact as well as a work leave burden for us to manage
- There have been jealousy issues by siblings and perceptions that our daughter who has JIA was getting preferential treatment, particularly when we had to leave our other

small children to travel interstate. This has at times been a layer of tension between our children and yet another area that has needed our time and attention to manage. Introducing sibling programs could help alleviate some of this stressful dynamic for families.

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

- We live in the Canberra, in what is considered a wealthy capital city, and yet there are no paediatric rheumatologists to provide treatment for children with JIA in the ACT. We have travelled to Sydney to visit one of the few paediatric rheumatologists working there since our daughter was five. On average this has been 4-5 trips each year, some years up to six. As stated above, each of these trips have required time off work, time out of school, arranging care for siblings, paying for accommodation, constant driving/wear on vehicles, and a huge organisational mental load. We *need* to have access to specialists locally.
- Each appointment includes a return drive to the Sydney Children's Hospital at Randwick (occasionally at Westmead) to be reviewed by her specialist. Our daughter and her father were involved in a car accident late one night on a return trip from Sydney showing the danger to families that are constantly travelling large distances to access services. Our return journey is always choosing between night driving after a long day or staying in accommodation at further expense and time off work/school.
- While we've had access to The Canberra Hospital for our daughter's monthly infusions, any interventional treatments, such as joint injections, can only be done in Sydney. This extra travel adds significantly to the stress of having your child under general anaesthetics without your partner and support network around you. Returning home to deal with any post-surgical issues remotely is also more complicated and stressful. The ability to have these procedures done locally, again, highlights the need for more specialist services regionally.
- We are also aware that having to access services interstate increases the strain on an already over-stretched team in Sydney. While we see a highly dedicated specialist, Dr Davinder Singh-Grewal, the volume of children he sees means his time with each child is limited. He has shown interest in setting up a remote clinic in Canberra, but we understand that this has been rejected by the ACT health system. There is a dire need to increase the number of trained paediatric rheumatologists in Australia to provide better access for families and ease the workload of these specialists. We are at risk of them burning out under their enormous workload and it's not encouraging for new doctors who may be considering this as a future specialisation.
- The rheumatology nurse in Sydney, Anne Senner, has been equally dedicated and helpful and fills a vital outreach link for families. The help that she has provided to us remotely cannot be overstated and it's laughable that she has had to carry this on her own for so long, only recently receiving a tiny increase in assistance. The health system must start funding these positions adequately.

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

- Our daughter has had to progress through the range of available JIA medications to find a treatment that keeps her swollen joints in check. She says that she particularly

wants to be on a medication that doesn't have to be painful injections, where we don't have to time our holidays around hospital infusions, and one that allows her to function like all her friends who can take their medications as a simple tablet. Funding research into non-injectable biologic medication would be a game-changer for children who grow up knowing the pain of regular injections.

- Having first started on a painful biologic (Humira) when she was in Grade 2, she has developed a huge anxiety around injectable medication. She would sometimes run away after the trauma of having her injection, adding to an already stressful fortnightly ordeal. While we have made attempts to help her manage her injection anxiety, including therapists at our expense, her feelings run deep, and she'll carry this trauma for many years to come.

Providing multi-disciplinary teams that include regular access to counsellors (from initial diagnosis) would help children better cope with their feelings of arthritis, interventional treatments, and medications. This counselling would need to continue throughout their life as they grow up and can better engage with their condition and the health system. Our daughter's anxiety from a young age has meant that her reflex is to now shut down and not engage easily with practitioners. The cost of better services from a young age would have been far less than accessing mental health and other services as she gets older.

- One of the best non-medical treatments that has been recommended to alleviate our daughter's arthritis symptoms is hydrotherapy. Whilst this is considered best practice, our ability to access this has been severely reduced. The sessions we were attending at The Canberra Hospital ceased when they closed the pool and moved it to the University of Canberra. All the new sessions are focussed on older people during the day with little capacity to fit in to a school schedule. The alternate private options require much more travel and cost, and access has been severely hampered in the last couple of years due to Covid restrictions. These pools are another resource that is under-funded and yet have the capacity to improve the daily lives of children significantly.

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

- The endless comments we've received that "I didn't know kids could get arthritis" is testament to how little community awareness there is about this condition. It's also a reflection of the tiny amount of funding that flows into treatment and access of services for children.
- Our daughter's original diagnosis was hampered by this poor understanding of JIA and was delayed by more than a year. This was a critical window as early treatment appears to provide the best outcomes. A local paediatrician had dismissed our initial concerns as being overly precious and told us that "she may not become an Olympic athlete". There is nothing more demeaning than not being believed about the health of your own child and having your parenting ability questioned. We must ensure there is consistent understanding of rheumatic conditions amongst *all* professionals so that early diagnosis is not missed.