



LETTER TO PARLIAMENTARY INQUIRY ON CHILDHOOD RHEUMATIC DISEASES AND JEUVENILE
ARTHRITIS

To the House of Representatives Standing Committee on Health, Aged Care and Sport,

I would like to thank you all for allowing me the opportunity to write to you regarding the Parliament Inquiry of Childhood Rheumatic Diseases and Juvenile Arthritis.

I am writing to you today to thank you for raising the issue of Childhood Rheumatic Diseases and Juvenile Arthritis (CRD/JA). I am not new to this condition as I have suffered with it throughout childhood and adulthood, undiagnosed until the age of 26. At the age of 26 I was diagnosed with Ankylosing Spondylitis. My 10-year-old son has recently been diagnosed with Psoriatic Juvenile Idiopathic Arthritis which has only been diagnosed due to my persistence and understanding of the disease.

I have spent my entire life in pain and discomfort being labelled a hypochondriac for all my ailments and not being able to walk at times, having to train myself how to walk unassisted again. Once diagnosed my life changed and I had absolutely no idea what being normal or some form of that meant until the age of 26. For the first time in my life at the age of 26, I was able to live relatively pain free due to the correct management plan in place by my Rheumatologist and GP. At the age of 19 I was admitted to emergency as my entire lower body wouldn't work and was in excruciating pain (10/10). I was in hospital for 2 weeks without a diagnosis, rather the doctors saying they were going to cut my hip bones and realign them as this must be the cause. I thank God that I was mature enough to know this was not the cause and that they were not to touch me. It would be another 7 years before I had a diagnosis. ***A lack of understanding and knowledge about these conditions amongst our local GPs*** is the reason so many children including myself and son are not being identified, diagnosed and supported.

It is my wish, NO child with CRD/JA should suffer like I did, that they get an early diagnosis, the correct care and support to be able to live a relatively happy and healthy life free from pain and discrimination.

I will now tell you the story of my son and the promise that I made him, to never have to suffer like I did. He is 10 years old and diagnosed with PJIA in October 2021. He was continually suffering with random ailments, as did I and it wasn't until last year that I put them all together and presented a well-documented case to his **Paediatrician** in addition to getting blood tests that confirmed he was positive to the **HLA B27 gene**. Since the age of 5 my son had suffered from ***pain in the legs*** which most people say are growing pains. He would have bouts of ***migraines***, where he had an MRI to check he didn't have a tumour. Following that he continually had issues with his ***stomach, with uncontrollable contractions***, my husband and I took him to a paediatrician who dismissed it as a bacterial infection and did not follow up on anything else even after I explained that I had Ankylosing

Spondylitis and my husband had Ulcerative Colitis. Next, he had issues with his **knees and feet, saying his feet kept collapsing** and that his knees would **disjoint and swell up**. I took him to a **Podiatrist** to check his feet and he had a **dislocated heel** and an inflammatory condition in both heels called **Severs disease**. I had him treated and spend over \$2000 on orthotics. It wasn't until mid-2021 that the final piece of the puzzle appeared, and I figured out what was wrong. The year began with him complaining about his **eyes hurting** and being super red (**uveitis**) and his **hands and his fingers getting stiff** and how hard it was for him to write. I took him to the **Optometrist** and had glasses purchased for him along with him being treated for uveitis. I spoke with his teacher and explained what was happening with his hands and if she could let me know if he has had any issues like this before. She provided him additional support in the classroom. My Son is a very active and sporty child representing his Soccer club at A grade and being a REP player for Canterbury Bulldogs Touch Football Club as well as making the regional team for Athletics and Cross-Country running. He is not your typical sick kid, and he will push through almost any pain. In 2021 one of **his toes became extremely inflamed**, we thought it was dislocated or broken but it was not. We presented to the emergency department, they put him on two separate courses of antibiotics, neither of which helped with this condition. There was no follow up at all and it took months for the swelling to go down. His levels of **energy plummeted**, and he was unable to perform any activity let alone walking from the car to the shops. I knew it was the missing piece of the puzzle and I knew what I was looking at now. I booked an appointment with a new **Paediatrician** as the last one had failed my son. My son was finally heard, and we finally had answers. It is a bittersweet moment finding out your child has a **debilitating disease**, but now we knew what we were looking at and he could finally get the help he desperately needed. I asked for a referral to a **Paediatric Rheumatologist** so that we could get a management plan in place as soon as possible. He has suffered a lot emotionally, mentally and physically but he is one of the lucky ones.

We are so fortunate to have Dr Singh-Grewal so close to where we live to support and manage my sons' condition. Unfortunately for so many families this is not the case to have **adequate access to healthcare professionals** that specialise in these conditions, nor do we have access to **General Practitioners that understand what these conditions can look like**. As you can see it is extremely challenging to get support and to have your child diagnosed. I truly believe the only reason that my son has a diagnosis (after 5 years) is due to my personal experience with the disease and my persistence with journaling all his ailments. My sons Paediatrician did not even offer a referral to see a rheumatologist it was only that I asked that we got the referral, otherwise I fear that we would still have no progress and support dealing with paediatricians that do not have the expertise in this field to no fault of their own of course. Additionally, I provided my sons school and coaches with support documents and information on his condition so that they could understand his needs and support him. Any family going through this hits roadblock after roadblock before getting the help and support they need. Seeing so many specialists is certainly not cheap and the financial strain it has had on our family has been substantial. We are lucky that both my husband and I work fulltime and have private health cover to help with the **additional costs** that treatment and medication incur.

My son is struggling with **mental health issues** including suicidal thoughts as a direct result of this condition, we are trying to manage that as best we can with amazing support from his school. It has had a huge impact on our family. **He struggles daily**, but I refuse to allow this condition to ruin my son and take away those things that he enjoys the most. We are in the process of changing medications due to the horrible side effects that they have. These are things that not many people understand are a direct correlation to this disease.

Our children deserve better, they deserve the best medical care and support we can possibly provide for them. This is something that many of them will suffer from for the rest of their lives and early diagnosis is key to preventing severe issues later in life. We live in a country with amazing medical facilities and practitioners, yet Childhood Rheumatic Diseases and Juvenile Arthritis seem to be a big unknown. I ask you to ensure that our children are looked after by this and future governments and that adequate access to medical support services, mental health support, financial assistance and early diagnosis is available to all no matter what socio-economic status or geographical location our kids are from. **I refer to the Terms of Reference 1-5 and implore you to:**

- 1. Improve early diagnosis which includes education, training and awareness amongst healthcare professionals**
- 2. Improve the support provided to the children and families suffering with these diseases. This includes medical, social, psychological and financial support.**
- 3. Improve access to psychological support services for all children.**
- 4. NDIS support and disability parking for our kids when they are unable to walk.**

Thank you so much for allowing me the opportunity to share my person story and that of my son. We have a long road ahead of us with treatment and management. I truly hope that you can all make a difference in these children's lives for the better and provide them with a future of hope.

Kind Regards

