

Parliamentary Committee
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Parliament House
CANBERRA
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Submission to the Parliamentary Inquiry into childhood rheumatic diseases

I would like to sincerely thank each member of this committee for providing me the opportunity to make a submission and for taking the time to consider and reflect upon the information in each of the submissions received.

I knew little of childhood rheumatic diseases until my child was diagnosed with Juvenile Idiopathic Arthritis (JIA) at the age of 2. He is now 7 and I have now learned it is a cruel and debilitating disease which has had a profound impact on every aspect of our lives.

My child's story

My child initially came down with a virus in a childcare setting which led him to becoming ill. Unusually, he began to limp. After subsequent visits to a GP and his deterioration to a point where he was unable to even sit, we were referred for an ultrasound and blood tests and after the results of these processes were analysed, to the Children's Hospital to attend a clinic. At the clinic a specialist and accompanying nurse noted a number of joints were swollen and inflamed and diagnosed JIA.

The clinic was overcrowded, and there was little time for discussion. We left confused and with little knowledge of the condition. This is not a failure of the specific health staff but rather of the sheer volume of patients and limited time and resources available to treat them.

In the 5 years since diagnosis my child has cycled through and failed almost every available treatment from steroids, methotrexate, Humira and Tocilizumab. These treatments have been cruel and traumatising.

From extreme nausea, not eating and the resultant massive weight loss from methotrexate to Humira injections which are particularly painful, it has been a difficult journey. For many months my child was having these injections every two

weeks. When this was not successfully managing his arthritis, we moved to monthly infusions in hospital of Tocilizumab resulting in such a low immunity to illness generally that we were constantly admitted to hospital with infections ranging from croup to pneumonia and on occasions he was very critically ill.

Blood tests have been needed regularly along with joint injections under a general anaesthetic and so the number of injections including insertions of cannulas has been extremely frequent. Up to 6 people would be needed on many occasions to enable these procedures to take place. These events were accompanied by my child screaming, being violent and hysterical. I have been bitten, kicked and punched constantly in the process as his 'safe' person who allowed these painful procedures to be done to him. The resultant mental trauma to my child and myself has been extensive, and on many occasions health staff were brought to tears by the process, which, given how strong and resilient they are, speaks volumes.

Additional to the hospital visits and injections have been regular ophthalmologist appointments due to recurrent bouts of uveitis (inflammation of the eye which, if untreated, can result in loss of sight), visits to occupational therapists, physiotherapists, paediatricians, paediatric rheumatologists, and as a direct result of the extensive medical intervention and trauma, psychologists and more recently psychiatrists. Please keep in mind he is just 7 years old.

Pre-covid he had constantly missed school due to medical appointments and illness and when he was there had to strive to catch up. This has also impacted me, as a single parent, as I try to hold down a full-time job along with maintaining his medical care.

Covid-19 has added an additional layer of complexity to our already complex situation. Given his long history of severe illness he has had to remain isolated until he could be vaccinated, with obvious implications for the fact that I am working full-time with no support. Even with vaccination there are no guarantees as to how he would respond to a Covid-19 infection. There was no priority rollout of the vaccination for high-risk children, and we have felt utterly invisible to the government during this time.

Currently, he has finally received his first vaccination with the second to come shortly in the hope of returning to school if it can be done in a safe environment. Additionally, we are awaiting approval for a new medication which we are hoping will assist his arthritis which is at present not under control. This means currently he is in pain every day. Watching your small child struggle and in pain every day is traumatic and takes a large mental toll. It is a relentless and ongoing struggle. And he is only 7 years old.

Terms of Reference:

1. Research into the causes of childhood rheumatic diseases, including prevalence levels of childhood rheumatic diseases in Australia

At diagnosis no-one could tell me **why** my child developed JIA, **how** he would likely respond to treatment, or **what** the future held for him in either the short or long term. The answer to many questions about his illness throughout the last 5 years has been simply "I'm sorry, we don't know". This fuels fear and anxiety about what the future holds and prevents adequate planning to be in place as, looking ahead, everything is unknown. Will he, given the recurrent uveitis and its consequent treatment, lose his sight, or need cataracts at a young age? What is the impact of that on his future? How can I put strategies in place to prepare for that when no-one can provide the answers needed to do such planning?

Research must be done to provide us with the foundation for this planning.

The first priority is to find out exactly who is currently impacted and to co-ordinate that information to better inform the critical decisions around funding and resources. Tracking the outcomes and medical intervention needed in current cases will be vitally important to this process.

Additionally, we need to know why it is occurring, what are the triggers, what works in treating it and eventually, how we can prevent children in the future from suffering from it in an acute way through a better understanding of managing it.

Recommendation 1: Provide adequate funding to enable a comprehensive understanding of current cases, effective treatments and outcomes and ensure this information is readily available to those who are impacted by childhood rheumatic diseases.

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

As mentioned earlier, the impacts are extensive and currently not able to be planned for given the little knowledge or funding of research in this area.

Health Impact

The health impacts for my child have been most severe. As a direct result of the medical intervention needed to treat him, he has developed Post Traumatic Stress Disorder (PTSD) and Oppositional Defiance Disorder (ODD) along with being diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), the symptoms of which may also be attributed to the medical intervention he has experienced.

His compounded trauma is now such that we are under the care of both a psychologist and a psychiatrist. His anxiety is such that he cannot be alone for a moment – he must be able to see me at all times. His mental distress and physical pain are so extreme that he has threatened on a number of occasions to end his life. He has often said he is better off dead than living with this disease. All sharp objects in my home are hidden, all windows locked. It is heart-breaking and he is only 7 years old.

This disease has also had a health impact on me. It is a full-time role just managing my child's health however I must also maintain full-time paid employment to ensure I cover the many financial costs associated. I am traumatised from having to hold him down and try to comfort him through the many invasive procedures he has been through.

I bear the brunt of his now complex and difficult behaviour on a daily basis as a direct result of these interventions, and I am constantly in a battle to address medical issues where access to the specialist who can assist is extremely rare given their workload, the case is too complex for GPs to assist and there is no one to turn to for the responses I need.

I am beyond exhausted and can't imagine what his future will look like given I am in the trenches every day. My long-term goals are weekly at present. Watching a small child live with pain every day takes a huge toll and I can see no light at the end of the tunnel at present. The care my child requires has impacted my ability to spend time with my older children and with my friends. Given he has needed to be isolated during the Covid-19 pandemic, this means so have I. In the time where I most need support it has had to be removed and I feel completely on my own.

Social Impact

My child is an extreme extrovert who loves children and to play and interact with them. When at school this was often difficult as the most common 'game' for his peers was to run around chasing each other. On a good day, after a short period of time, my child can no longer continue to participate due to fatigue. On a bad day, he is confined to a wheelchair or sitting watching others play.

Due to illness and his susceptibility to illness he has missed out on many opportunities to socialise. Covid-19 has made it almost impossible. On many occasions he has been in foetal position on the floor sobbing that he wants to be able to participate like other children. It is very distressing. He would greatly benefit from knowing other peers who have the same condition and from the general public having some awareness of this disease and its implications for those who suffer from it.

Educational Impact

Educationally, although he is a bright child, he has missed many days of school due to illness and medical appointments. He is constantly playing catchup when he returns to school and as a result always feel he is behind and not good enough.

Due to the damage the arthritis has done to his fingers, he finds it difficult to write – a real frustration to a bright mind who wants his voice heard. Often the medications he is on have an impact on his ability to learn due to drowsiness. Fatigue due to the arthritis compounds this issue.

Teachers know little about JIA and as a result we have at times struggled to help teachers understand how one day a child can be running around and the next they can be in a wheelchair. The random nature of good and bad arthritis days makes planning difficult. With no accessible knowledge-base for educators to fall back on, the job of trying to navigate these issues again falls to parents or carers.

Economic Impact

The personal economic impact of JIA has been profound. The government-funded clinics are so overcrowded and short-staffed that they are plagued with time delays. When it is finally your 'turn' there is little time to discuss the issues in enough depth given their complexity vs the time constraints.

Additionally, putting an immune-suppressed child into an overcrowded clinic has often resulted for us in a three-week illness which impacts not only his health but my ability to work fulltime. As a result, I have had to see specialists privately at great personal financial cost.

As his disease has progressed, so has the need for more specialists. The psychiatrist alone is \$420 a visit (with a small percentage refunded by Medicare) and is not funded through NDIS. There have been occasions where I have needed two appointments per week. Again, seeking a private psychiatrist was a direct result of the public system not being able to accommodate his needs in an ongoing way which was essential to his well-being. Resources were only made available for enough time to put a private specialist in place. There have been numerous times where I have had to sacrifice basic living expenses to ensure his medical care is ongoing.

Recommendation 2: Provide adequate funding and resources to ensure there are enough specialists, nurses, and other health professionals with rheumatic disease-specific knowledge to ensure access to timely information to assist patients and their carers. This must be holistic and include mental health

professionals given many of the current treatments for this disease are painful and traumatic.

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

The health, social, educational and economical impacts outlined above make a clear argument for the provision of access to medical services.

Most of my child's treatment has needed to take place in the children's hospital. This has required a 3.5 hour minimum round trip. Additional specialist appointments take place in the CBD. These can vary between bi-weekly, weekly, fortnightly and monthly depending on the severity of symptoms at the time. There are often admissions to hospital.

The time investment for a single parent working full-time is extensive. Between appointments there is currently **no** support for parents. Either make an appointment at a great financial cost (with often extensive waitlists for those services due to the shortage of specialists in this field) and while you wait there is nothing, no-one to ask, no resource to turn to. With a disease that changes day to day this is far from adequate.

Recommendation 3: Provide funding for adequate, accessible and tailored facilities where relevant health services can be reached in an affordable way, taking into consideration that many patients are immune compromised, minimising the financial impact to carers and providing an information resource.

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

As indicated above, current treatments are painful and cause trauma resulting in a need for further health services to assist in mitigating the suffering caused by the treatments themselves. It is a vicious cycle which can only be broken through access to new and emerging treatments. Uniform and consistent information must be compiled and accessed universally so that all associated practitioners are kept up to date with best practice treatment, care and research. This will ensure better outcomes for patients both in terms of medical care and mental health.

Recommendation 4: Provide funding for current and emerging best practice information on treatment and medications to be accessed by all treating health professionals with a focus on reducing the trauma and pain associated with

treatments, particularly for young children.

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

Given the impact to patients and their carers discussed above and the sheer lack of resources currently, it is critical we fund more health professionals with specific knowledge in this field. Given the current reliance on painful and traumatic treatments, it is imperative that we constantly educate and update these professionals so they have access to any training or information which can lessen the burden for patients and carers.

There is currently almost no community awareness of childhood rheumatic disease within Australia. This includes in settings such as childcare centres and in our schools. Teachers require urgent access to current, accurate information on this disease in order for them to adequately fund, support and educate our children with understanding and knowledge of their specific needs.

We should not have to wait for a C-grade celebrity or acclaimed sports person to have a child with rheumatic disease before adequate funding is in place or before community awareness programs are installed.

Recommendation 5: Provide adequate funding for the ongoing training and education of health professionals with rheumatic disease-specific knowledge and ensure access to training for education professionals who work with our children.

Recommendation 6: Provide adequate funding for an ongoing community awareness campaign to assist in early recognition of symptoms and a knowledge base for the community to understand the needs and requirements of those who struggle with childhood rheumatic disease and their carers.

Thank you again for the opportunity to share this information. It is much appreciated. I urge each member of the Committee to seriously consider the lifelong impacts on these children should there be no action taken to adequately fund services for children with childhood rheumatic disease and their parents or carers.

Summary of Recommendations	
Recommendation 1	Provide adequate funding to enable a comprehensive understanding of current cases, effective treatments and outcomes and ensure this information is readily available to those who are impacted by childhood rheumatic diseases
Recommendation 2	Provide adequate funding and resources to ensure there are enough specialists, nurses, and other health professionals with rheumatic disease-specific knowledge to ensure access to timely information to assist patients and their carers. This must be holistic and include mental health professionals given many of the current treatments for this disease are painful and traumatic
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Recommendation 6	Provide adequate funding for an ongoing community awareness campaign to assist in early recognition of symptoms and a knowledge base for the community to understand the needs and requirements of those who struggle with childhood rheumatic disease and their carers