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AUSTRALIA

Standing Committee on Health, Aged Care and Sport

Parliamentary Inquiry into Childhood Rheumatic Disease

February 2022

Executive summary

As a consumer-based organisation, Musculoskeletal Australia welcomes the opportunity to provide input into the Standing Committee on Health, Aged Care and Sport's Inquiry into Childhood Rheumatic Diseases. The views of children with rheumatic diseases, their parents and families have been specifically gathered for the purpose of compiling this submission.

Although many people are unaware that children get arthritis, it is as common as type 1 diabetes for the same age group. In fact, 1 in 800 Australian children aged 0-17 are living with Juvenile Idiopathic Arthritis (JIA).

For many years, Musculoskeletal Australia has been providing information and support and empowering children and families to make informed choices regarding the care and management of these debilitating and painful conditions.

The health, social, educational and economic health impacts on children and adults who develop rheumatic diseases in childhood, their families and the broader community are immense. Sadly, the supports and services currently available to them are lacking, as is knowledge and awareness of these diseases.

Based on the perspectives of Musculoskeletal Australia and the children and families with which it works and supports, the following recommendations are respectfully made to the Standing Committee Health, Aged Care and Sport's Inquiry into Childhood Rheumatic Diseases:

1) That the awareness and knowledge of health professionals regarding childhood rheumatic disease be improved to enable more timely diagnosis, improved management and more wholistic, patient-centred care which acknowledges the social and mental health impacts of these diagnoses
2) That processes be established to improve communication between health professionals, and between health professionals and families to ensure the provision of seamless, high quality care for children and their families
3) That funding be provided to develop more information, supports and programs relevant to the needs of children with rheumatic disease and their families
4) That the availability of, and access to, an interdisciplinary team of medical and health professionals with specialised knowledge of the diagnosis and management of childhood rheumatic disease be greatly increased, regardless of a family's geographic location and financial circumstances
5) That more financial support be provided to families with a child with rheumatic disease, in conjunction with improved and more equitable access to current supports and programs
6) That community information and awareness campaigns be established to increase the awareness and knowledge of childhood rheumatic diseases within the broader community
7) That funding be provided to develop further resources for school teachers and their communities to promote a better understanding of, and support for, the needs of children with rheumatic disease

8) That funding be provided to develop resources to support adolescents at a time when they are transitioning between paediatric and adult health services

9) That more funding be provided for research in all aspects of childhood rheumatic diseases and that national data collection and analysis be undertaken to better understand the prevalence and impact of these conditions on children and their families.

Table of contents

Standing Committee on Health, Aged Care and Sport

Inquiry into Childhood Rheumatic Diseases

1. Introduction

As a consumer-based organisation, Musculoskeletal Australia welcomes the opportunity to provide input into the Standing Committee on Health, Aged Care and Sport's Inquiry into Childhood Rheumatic Diseases.

The views of children with rheumatic diseases, their parents and families have been specifically gathered for the purpose of compiling this submission. Our submission is also based on Musculoskeletal Australia's many years of experience in working with children and their families.

2. About Musculoskeletal Australia

Musculoskeletal Australia is a national, consumer-based organisation, working to support people for better musculoskeletal health. We work on behalf of the 7 million Australians living with conditions such as osteoarthritis, back pain, rheumatoid arthritis, juvenile arthritis, gout, osteoporosis, fibromyalgia and more than 150 different musculoskeletal conditions. Musculoskeletal Australia has been supporting people with arthritis and other musculoskeletal conditions for over 50 years and our vision is that the quality of life of people who have or are at risk of musculoskeletal conditions is improved.

Our focus is on providing information, education, and empathetic support for individuals and families: we care about people and their personal conditions and circumstances. We also undertake policy and advocacy work on behalf of all Australians who have musculoskeletal conditions.

In 2020, we conducted the first and largest national survey of people with musculoskeletal conditions ever undertaken in Australia. The report of the survey, 'Making the invisible visible: Australians share the impact of musculoskeletal conditions on their lives' is based on the responses of 3,453 Australians with musculoskeletal conditions and covers the impact of these conditions on their daily living, social life, mental health, study and work, leisure time and financial circumstances. The report also details what people do to currently manage their conditions and what they need to better manage them. 'Six steps to ease the pain' detailing actions to address the findings of the survey are then defined.

Musculoskeletal Australia works in partnership with other relevant groups, including health professionals, universities, research organisations and government to achieve our aims. Importantly, Musculoskeletal Australia has a Consumer Advisory Committee that supports the Musculoskeletal Australia Board and management on the strategic direction and future planning of our programs and services.

3. Musculoskeletal Australia's work with children and families

Although many people are unaware that children get arthritis, it is as common as type 1 diabetes for the same age group. In fact, 1 in 800 Australian children aged 0-17 are living with Juvenile Idiopathic Arthritis (JIA).[1]

JIA is the most common rheumatic condition in children. If not treated quickly and appropriately, it can seriously affect the growth and development of a child, causing severe joint damage, growth abnormalities and permanent disability. For many, it has a profound affect not only on their health but also on their education and later on, their career prospects, personal relationships, and financial independence.

For many years, Musculoskeletal Australia has been providing information and support and empowering children and families to make informed choices regarding the care and management of these debilitating and painful conditions.

Most recently, this has been undertaken via our 'MSK Kids' program. The MSK Kids program includes:

- 'Teen Talk', an online peer support platform for teens living with musculoskeletal conditions. Teen Talk provides a safe space for people between the ages of 13-20 currently living with a musculoskeletal or chronic pain condition (www.msk.org.au/msk-kids-teen-talk)
- comprehensive and freely accessible juvenile arthritis information and resources on our website (https://msk.org.au/msk-kids/) and via our social media channels
- a national Help Line staffed by nurses and by volunteers who are living with musculoskeletal conditions (www.msk.org.au/help-line/)
- webinars to support children with childhood rheumatic disease and their families, providing the latest information on conditions, treatments and living well, delivered by top experts in their fields (www.msk.org.au/msk-kids-videos)
- resources specifically designed for children, including an animated picture book (www.msk.org.au/kids-pain-book)
- school resources for teachers and families to support students with musculoskeletal conditions (www.msk.org.au/school-resources)
- peer support groups for parents and families to help alleviate the isolation and loneliness experienced by many people caring for children with musculoskeletal conditions (www.msk.org.au/peer-support-groups/).
- social media sites for families of children with rheumatic disease, including Facebook and Instagram
- a bi-monthly newsletter for families of children with rheumatic disease

Musculoskeletal Australia has a designated staff member overseeing its MSK Kids program. The staff member in this position has the lived experience of being a parent of a child with rheumatic disease. Having this personal experience is beneficial in being able to communicate with empathy and understanding with children with the disease, their parents and family members.

Musculoskeletal Australia is particularly proud of its most recent initiative, 'Teen Talk – an online support group for young people aged between 13-20 who live with a musculoskeletal condition or chronic pain. We know from experience that teens are a hard group to reach through traditional methods. Too old for days at the zoo or trips to the movies, they easily 'slip between the cracks'. An online support community speaks their language and is a natural progression from the online world in which they are already involved.

Teen Talk runs on our own private server through the online portal 'Discord'. Discord is an instant messaging and digital distribution platform designed for creating communities. The program is free to use. For young people, run by young people! Our server is being administrated by three of our young ambassadors and overseen by Musculoskeletal Australia staff and has proved to be an invaluable resource for children across Australia to connect. As one of our young users said:

> *"What I love most about Teen Talk is being able to access it any time and any place. I love connecting with people from all over Australia. Because of its digital format, Teen Talk doesn't have to stop when we move into lockdown and it's accessible by everyone, having broken down the barrier of location and the struggle that can come with getting out of the house. Teen Talk is anonymous, allowing our group to talk freely and to feel more comfortable in putting ourselves out there."* (Thalia, Teen Talk member, aged 16 years)

One of the young members of Teen Talk, Ollie and his mother, Amelia, provided a video to express their views regarding the value of Teen Talk: www.youtube.com/watch?v=14EhxFNUv-M

Musculoskeletal Australia is looking to further build on our current resources by developing sustainable, engaging and adolescent-focused resources that build essential knowledge and practical skills for adolescents (and their families) to ensure optimal transition of care between paediatric and adult health services, while also addressing broader adolescent health issues.

Prior to establishing the MSK Kids program in 2019, Musculoskeletal Australia conducted annual camps and regular fun days for children and families and also provided a regular newsletter. These events were well attended and much appreciated by parents and kids as they provided opportunities not only for children to come together and meet each other but for parents to meet each other and gain peer support. These events were also attended by a paediatric rheumatologist, who would provide information sessions for the children and the parents. In recent times, these valuable information sessions have been replaced by our series of online webinars for families.

Please see **Appendix One** for some photos from our camps, fun days and other activities over the years.

Musculoskeletal Australia also firmly believes in working with children, their families and other relevant organisations to achieve the best outcomes for children and their families. Musculoskeletal Australia always works to establish partnerships and collaborations with other relevant stakeholders towards this goal.

4. Responses to the Inquiry's Terms of Reference

4.1 Research into the causes of childhood rheumatic disease, including prevalence levels of childhood rheumatic diseases in Australia

Musculoskeletal Australia welcomes the Medical Research Future Fund Grant for chronic musculoskeletal conditions. Further funding is required, however, to develop strategies to support the delivery of care to young people with JIA and other musculoskeletal conditions.

Musculoskeletal Australia funded Curtin University to explore digital health strategies for chronic pain management in young people. This research, led by Professor Helen Slater and Professor Andrew Briggs, found that young Australians with persistent musculoskeletal pain want access to digital health solutions to support their self-care. More specifically, they wanted solutions that are oriented to their needs, are readily accessible, reliable and free.

Key recommendations from these research studies included:

- funding the development of innovative digital technologies to support improved pain care. Bioinformatics for data capture and monitoring could be used to test novel online interventions and align with electronic medical records to capture patient reported outcomes
- enhancing the interoperability of e-health systems across care settings to improve health system efficiencies and patient reported outcomes. This would involve building research partnerships between health services sectors, policy makers, NGOs and universities to drive changes in system operability across health sectors
- seeking cross-sector partnership models. Connecting consumers, researchers, policy makers, health service providers, professional associations, funders and not-for-profit organisations in partnership models to assist in building research capacity. The development, evaluation and iteration of innovative systems requires cross-sector engagement and support and would streamline the implementation of innovative care within current health systems.

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

4.2.1 Health impacts as reported by children and families

It is the experience of the families and children associated with Musculoskeletal Australia that they experience many of the symptoms and impacts as outlined below.

The physical impacts of having a childhood rheumatic disease are widespread and commonly experienced. With the majority of the diseases being of an inflammatory nature, joint pain, stiffness and swelling were identified as ongoing and common features. Joint pain, stiffness and swelling can affect mobility and range of movement and can also be experienced in conjunction with fever and skin rash. If not well managed, deterioration of the joints over time may require replacement or other surgery.

Generally feeling unwell, and their children's greater susceptibility to infections and viruses (as a result of the lower immunity caused by medications) are a constant concern for parents. Dealing with frequent infections due to lowered immunity and the increased time it takes to recover, results in further absences from school, sport and other social activities. In addition, other medication side-effects reported by parents included nausea, hair loss and weight gain.

Fatigue and brain fog were also raised as common symptoms and, as one parents stated:

> *'Both my children miss large amounts of school due to pain, fatigue and brain fog associated with their condition. Both are good students and work extra hard to catch up on missed classes, however the impact on their mental health, knowing they are always falling behind, takes a huge toll.'* Kelly, Mother of two teenagers with JIA and third teenager awaiting diagnosis.

Parents spoke of their children's increased mood and behaviour changes and their concern at the increased risk of depression and anxiety, as well as the overall mental health and wellbeing impacts. Anxiety around medication and needle phobia are common. The mental health side of having childhood rheumatic diseases often is not fully acknowledged as evidenced by the following:

> *'As fantastic as it is that there's growing recognition of the physical toll that JA puts on a young person, it's essential to consider the psychological and social impact of JA on young people (and on their incredible families). The transition from primary to high school was challenging for me. I believe I would've had a much easier time if I'd had access to peer support and targeted mental health support.'* Jenny, diagnosed with JIA 30 years ago at age 10.

Concerns about the future health impacts of their children's conditions and their treatment were raised by parents. These included concerns about potential vision complications (uveitis); potential organ involvement/failure (e.g., Systemic Juvenile Idiopathic Arthritis or SJIA); the increased risk of skin cancer from medications and how high-dose steroids might affect their height and bone health.

The issue of their children's pain is a major concern for parents. For parents of children with amplified pain conditions, the 'trauma' can be even greater.

> *'A couple of months after my son was diagnosed with JIA, he was also diagnosed with AMPS or Amplified Musculoskeletal Pain Syndrome. This was even worse than the arthritis in many ways as I didn't feel there was a clear treatment plan and despite seeing a pain specialist, I felt he was just given a lot of pain killers and then we were very much left to our own devices. The drugs had bad side-effects and did little to control the pain. I remember being in the kitchen and hearing him moaning in pain down the hall in his bedroom. All I could do was turn the music up to drown out the noise as the tears rolled down my face. I felt so helpless.'* Buffy, Mother of son diagnosed at 13 with JIA and AMPS.

And for children with rheumatic disease themselves:

> *‘People assume that I'm healthy because I'm always smiling but I'm constantly in so much pain.’* Kookie, age 16, member of MSK’s Teen Talk.
>
> *‘Living with pain is extremely difficult, particularly when sometimes it can come on all at once but there is nothing you can do to completely alleviate it. You’re stuck in a circle of “I want to do this activity, but I know that it will affect my body so I can’t do it” and therefore you miss out on many things that your friends and/or family are doing.’* Steph, age 15, member of MSK’s Teen Talk.

Please see **Appendix Two** for some photos that several families requested we share. These photos show some of the physical impacts of childhood rheumatic diseases.

4.2.2 Social impacts as reported by children and families

As childhood rheumatic diseases are commonly ‘invisible illnesses’ that is, they often have no external physical signs, it can mean that there is judgement, misunderstanding and criticism from peers, teachers, sport coaches and extended family members. More broadly, there is a lack of awareness of these conditions in society and even amongst many healthcare professionals. For people who were diagnosed with a childhood rheumatic disease, they reported that there can also be a lack of understanding from employers. This is exemplified by the following quotes:

> *‘A largely invisible disease, it is difficult to others to grasp what is going on, and often don’t make considerations for their abilities as they are not “obviously” impaired, and the level of impairment changes from day to day depending on pain levels and where in their bodies they are having a flare up.’* Kelly, Mother of two teenagers with JIA and third teenager awaiting diagnosis.
>
> *‘You look well when you have Rheumatoid Arthritis, you don’t look sick. In my case I’m quite active, I like wearing makeup, I like doing my hair – I actually look particularly healthy – and it can be really hard to have people, through no fault of their own, understand that you’re facing something challenging. Things like getting a seat on public transport or having a bad day at work with no-one checking in on you, it can be quite isolating.’* Sophie, age 30 but diagnosed at age 19.

A child’s social interaction with others can be impacted because of the physical limitations caused by their illness – this can be two-way in that, as one mother reported, children are not invited to attend birthday parties because of their limitations; or children with the disease feel different to their peers and experience a loss of confidence and a level of social anxiety. The side-effects of medications (increased weight, hair loss, acne, mood swings) do not help a child’s social confidence. Several parents also mentioned their children’s inability to take part in activities like swimming lessons, due to risk of infection from immune-suppressing medications.

Families also reported that their children missed classes at school due to ‘always being sick’. Needless to say, regular absences from school also had an impact on the social dynamics within a child’s peer group.

Having a child, or children, with a childhood rheumatic disease also brings about changes to family relationships, especially with siblings. Parents reported that siblings may worry that they are also going to be diagnosed with the condition or feel that their unwell sibling is receiving more attention. Siblings can experience guilt for being ‘healthy’ and may be burdened with more responsibilities both around the home or at school – for example, following up their sibling’s teachers to take work home for their unwell sibling.

It is also extremely physically, mentally and emotionally challenging and distressing for parents of a child with rheumatic disease. As several parents stated:

> *‘We need support to help our children/their siblings & to help ourselves. Therefore, we need to be validated for our roles as carers, to feel a strong sense and be resilient through the adversity in order to help our children/their siblings to thrive both emotionally & practically. This journey is, in our case, lifelong and more sustainable support services like Teen Talk & Kalparrin are vital in facilitating this on at a holistic level.’* Amelia, Mother of son aged 14 but diagnosed at 2 with lupus.

> *‘It’s been hard on our other kids, and their relationship with each other, as so much focus, time, and emotional energy necessarily gets expended on helping our JIA-affected child. Her flares and joint pain lead to sleep disruption, loss of appetite, loss of weight, and additional corresponding behavioural issues such as next-level anger, irritability, fatigue, all-round crankiness, and at times, jealousy about why she has arthritis when her other siblings don’t.’* Anonymous, Mother of a child aged 5 with JIA, diagnosed at age 2.

The toll on parents’ relationship is also great as detailed by a mother:

> ‘*It’s been hard on our marriage. Having a child with a painful and, at times, debilitating chronic disease adds pressure to family dynamics, no matter how capable the parents are or how solid their marriage may be. Navigating COVID with an immune-suppressed young child, who for the majority of the pandemic was not old enough to be eligible for a COVID vaccine, was difficult. My husband and I had to constantly negotiate our respective and different risk tolerances regarding our family’s exposure to COVID (for example, could he go to the office to work, should our other non-JIA child still go to kindy, can we ask our extended family to take rapid antigen tests before meeting for Christmas?). We were one of those ‘vulnerable’ families that had to lockdown more than the average family, as we shielded our child from COVID.*’ Anonymous, Mother of a child aged 5 with JIA, diagnosed at age 2.

4.2.3 Educational impacts as reported by children and families

Having a childhood rheumatic disease can result in increased absences from school due to pain and feeling unwell. Additionally, absences can result from the need to attend a range of appointments with various health professionals, such as the rheumatologist, psychologist, pain specialist, physiotherapist, ophthalmologist, podiatrist, occupational therapist and dietitian.

Even when a child is at school, their ability to participate in activities such as school sporting events, concerts and school camps can be limited, especially when they are experiencing pain and flares. Children can also experience difficulty with basic tasks such as the ability to hold a pen or pencil for a period of time, sitting cross-legged on the floor, opening their lunchbox, tying their school shoes and reaching high or low lockers. Also, accessing classrooms on upper stories (going up and down stairs) and managing the weight of their schoolbag can also prove challenging.

Children and young people with childhood rheumatic disease can also experience judgement from other students when using special equipment (e.g. a laptop when others are doing written work) or gaining special consideration or allowances around exams (e.g. extra time). This further exacerbates the social isolation and issues children can experience. Teachers' lack of knowledge and awareness regarding childhood rheumatic disease can result in the needs of children not being met, as indicated by the following:

> *'Even teachers have told me that I don't need the accommodations that I do. I had to fight with my primary school for four years for them to put a piece of wood at the door so I could get into my classroom without assistance.'* Thalia, age 16 and diagnosed with osteoarthritis at age 5.

Apart from their ability to participate, parents and children report that their children's ability to perform well at school is also impacted. Due to the pain, fatigue and brain fog they can often experience, parents report that their children experience difficulty when writing an essay or doing exams and tests such as NAPLAN. Children's completion of homework can also be impacted as many of them need to rest when they come home, thereby limiting the time to complete homework.

Parents commented that children's school reports note days absent, which can be disheartening for students who have no control over their illness and its impact. Also, school reports often reflect a child's limitations because they are assessed against a school curriculum and what are standardised achievements.

Parents also expressed concern regarding their children performing at a lower level than their potential in the Victorian Certificate of Education/Higher School Certificate, thus limiting their options for further study. For those with children of an older age, parents' concerns related to the increased risk of their children dropping out of school or university due to their ill-health and associated difficulties.

4.2.4 Economic impacts as reported by children and families

The financial costs for families with a child with a rheumatic disease are extensive.

Parents report that they have costs related to the purchase of medications, having appointments with a range of health professionals such as a rheumatologist, GP, psychologist, pain specialist, physiotherapist, ophthalmologist, podiatrist, occupational therapist, dietitian and the purchase of aids and equipment (e.g. supportive shoes, back brace, pen grips, heat packs, laptop, wheelchair, stand up desk etc.). There can also be costs associated with making adjustments to the home environment (e.g. grab rails, widening doorways for wheelchair access, walk in shower etc) to accommodate the needs of their children.

As one parent stated:

> *'Having a child with scleroderma meant a whole lot of costs I hadn't expected. In addition to the medication for treatment, there was also medication that wasn't listed on the PBS that would cost $100 at a time. There were also the expenses of car parking at the hospital for appointments (easily $30 each time), time off work to attend appointments or look after a child unwell at home. Extra aids to keep her hands warm, extra electricity costs to keep the house warmer or cooler, and gap fees for allied health such as physio, OT, psychology.'* Penny, Mother of a child diagnosed with scleroderma at age 7.

The economic impact can also be in the form of loss of income if a parent needs to stop or reduce work to care for their child. There can also be loss of income for young adults who were diagnosed with rheumatic disease at a younger age and are now having to manage their work and their condition at an older age. They may need to part-time or work in a setting that best accommodates their health needs and this may not always be their preferred choice or financially optimal. Interruptions to tertiary studies for young people at university, TAFE, etc due to periods of illness can also have short and longer-term financial implications.

Juvenile arthritis and Stills Disease come within 'List B' of Australia's National Disability Insurance Scheme (NDIS) which covers 'permanent conditions for which functional capacity is variable and further assessment of functional capacity is generally required'. Given the rheumatic diseases usually result in periods of relative wellness and other periods of debilitating illness and physical disability and pain, parents report that this can create problems when applying for NDIS support. If a child is assessed during one of the 'better times' they are unlikely to qualify for support. There are other rare conditions (such as scleroderma) for which children and families don't qualify for support, as they don't 'tick the boxes'.

> *"We have not yet applied for NDIS funding, however I have been assured it will be very difficult to get. We are paying for physiotherapy, podiatry, orthotics, psychology, knee braces, ankle braces, strapping tape, medications, etc, so quite a financial strain. We also installed a large spa to provide some relief from pain and give the children the ability to do basic hydrotherapy … We also pay for uber transport daily to get*

> *them home from school as public transport is not an option given the walking distance and pain they endure. These costs add up significantly, and little financial relief is available."* Kelly, Mother of two teenagers with JIA and third teenager awaiting diagnosis.

And yet another perspective from a parent:

> *'My daughter has transitioned to adult this year and definitely not the same as a children's hospital experience where we were spoilt. I worry about her future if we cannot pay allied health/swim/gym/ other appointments and have no private health insurance for her. I worry that there is no support now to keep her well and only if she becomes unwell, can she access NDIS. Why can't she access this now to prevent deterioration? Seems illogical.'* Chris, Father of a child with JIA diagnosed at age 7.

With many paediatric rheumatologists being only based in major cities, children and families living in regional and remote areas must travel hours to reach the closest rheumatologist and often incur additional costs for overnight accommodation. For other families wishing to take a family holiday and travel, travel insurance is more expensive for their child with rheumatic disease.

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

According to the children and families that have contributed to this submission, there are numerous challenges when to comes to accessing medical services, including diagnosis, treatment and ongoing management and support.

General practitioners (GPs) are often the first 'port of call', however, many of them do not have the knowledge, awareness and experience with children with rheumatic diseases. This can often lead to conditions being undiagnosed for lengthy periods with this delay resulting in further complications and deterioration. There is also a lack of paediatric rheumatologists across Australia, but particularly in the Australian Capital Territory, Tasmania, many parts of Queensland and the Northern Territory, which further exacerbates the situation of not gaining timely diagnoses.

Having to see multiple health professionals before gaining a diagnosis can also be costly in terms of time, money and physical and emotional wellbeing.

> *'My six-year old daughter broke her femur in a terrible school ground accident. After months of recovery, the femur bone repaired itself, however, she was seemed to still be struggling to walk and I noticed her hands were blowing up. After visiting GP after GP and getting absolutely nowhere, it wasn't until we were at the final visit to our orthopaedic surgeon I shared my concerns and he directed us to a paediatric physiotherapist. This paediatric physiotherapist recognised her arthritic condition straight away and diagnosed her to have polyarticular juvenile arthritis in over 40 of her joints. He immediately got us to Monash Children's rheumatology.'* Eliana, Mother of a child with JIA diagnosed at age 2.

And from a young person with rheumatic disease:

> *'It took over 8 years to get any diagnosis at all ... Because of this, I really would love more awareness to doctors and the public that young people get sick too.'* Max, diagnosed with JIA aged 12.

It is also vital to develop age and developmentally appropriate resources and programs to support children and young people living with rheumatic disease and their families. This is particularly important as many young people in their mid-to-late adolescence 'drop off the radar' and lose a connection with any medical provider when transitioning from paediatric to adult health services. This can lead to serious and preventable illness-related complications and a higher risk of disability, pain and chronic diseases later in life. Adolescents and their families require support in the management of their musculoskeletal conditions to engender a willingness to engage in ongoing health support and treatment.

> *"We found the condition extremely hard to diagnose, and it has taken literally years to get to where we are now. We found there are huge gaps in the system for teens, as they are often adult size, but still developing, so it is difficult to know where they fit. We were turned away from the Royal Children's Hospital as my daughter was no longer considered a child, but she was picked up as a pediatric patient at another hospital. So even before diagnosis, we had been displaced and sent from doctor to doctor with no real idea of what direction to go. Telehealth was disastrous for treatment as rheumatology requires physical examination to really know what is going on. It really has been a difficult journey made so much worse by the pandemic."* Kelly, Mother of two teenagers with JIA and third teenager awaiting diagnosis.

A key component of ongoing management of rheumatic conditions is access to allied health. Parents reported that this can be complicated by some GPs often not being aware of the need for other forms of support, the costs involved and the poor communication between the GP and allied health professionals in the process of referral and ongoing treatment.

As previously mentioned, the small number of paediatric rheumatologists and the fact that they are principally based in major cities makes access for children in regional and remote areas more difficult. The number of allied health practitioners in regional areas is also far fewer than in major cities thereby making waiting times longer.

While there is some written information for children and families, none of it is translated in other languages. While the translation and interpreter services through the Australian Government's Translating and Interpreting Service National are available, it is not known to what extent these services are used by culturally and linguistically diverse families with a child with rheumatic disease.

Two other issues raised by parents is that access to a healthcare card is not available for all forms of childhood rheumatic disease and that the continuity of care with paediatric rheumatology services in the public system is particularly under-resourced.

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

It is the view of all children and parents that the early diagnosis of rheumatic conditions and access to affordable, accessible and high-quality treatment and ongoing management throughout Australia is essential.

It is also essential that there is a greater understanding by health professionals of the impacts on quality of life – 'doctors are very good at discussing blood test results, but some of them are not skilled at discussing the effects a condition can have on the child and family's lifestyle.'

A wholistic, patient-centred approach is required and linking children and families in with appropriate allied health supports, especially psychologists with an understanding of the issues faced by children with chronic health conditions, is also highly important:

> *'I developed rheumatoid arthritis at age 12 so it's all I can really remember. Most days I cope with it but over the last few years having anxiety and RA [rheumatoid arthritis] has made it harder to cope with everyday life stresses. I am doing better since seeing a psychologist and starting on anti-depressants and feel able to cope much better. Developing health anxiety was difficult to cope with as I was in constant fear of developing something worse or getting sick. I have found a good GP and psychologist. That has made a big difference.'* Jaya, diagnosed with JIA age 12.

And from another person diagnosed with rheumatic disease at a younger age:

> *'I was diagnosed with psoriatic arthritis when 14 years old - such a tricky age, which impacted me quite profoundly and long-term (e.g. in terms of confidence, self-assurance, etc). Lots of readily available support, especially for teenagers and young adults who contract conditions such as arthritis, is really important, I believe.'* Ahmed, age 14, diagnosed with PsA.

Several parents also mentioned the need for more specialist physiotherapists and improved access to them.

Having a rheumatic disease as a child and having a child with rheumatic disease can be a challenging and often isolating experience for children and their families. Funding and resources are required to provide further supports for children and their families so there are more opportunities to connect with each other — supported children and supported families will result in better health and wellbeing outcomes for all.

Earlier access to biological medications for those with severe disease would be ideal. One parent commented that children start on methotrexate or a traditional disease modifying anti rheumatic drug (DMARD) before they can be shown to have 'failed' that drug and then qualify to start on a biological DMARD. This is because the cost of biologics is so expensive, and the government covers these costs. It would be great if there was a way of testing or assessing which kids are going to need to go onto a biologic so this could happen more quickly.

When discussing best practice quality of care, again the issue of transition between paediatric and adult rheumatology services is highly important.

Given the chronic nature of these conditions, children, adolescents and their families become accustomed to dealing with paediatric health services where health professionals and services are usually found in one convenient location. Once children reach 18 years of age, however, they are generally required to transition to adult health services and providers. It is also in these teen and young adult years that adolescent relationships with parents and health providers change, with a growing need for independence and desire to manage their own health care.

The developmental tasks of late adolescence and early adulthood are sufficiently challenging for young people in good health – having a rheumatic disease further complicates this life-stage transition.[2] Adolescence is also a time when the individual is particularly at risk for loss of medical follow-up and medical complications.[3] A drop-out from specialist care means that young people are more likely to re-present in early adult life with preventable illness-related complications, due to sub-optimal self-management.

Additionally, health service frameworks are often designed for children or adults, but do not appropriately cater for the specific needs of adolescents.[4] Many health services and professionals feel ill-equipped to adequately provide adolescent-oriented care reporting low levels of comfort in dealing with the issues of suicidal risk, sexual health screening, drug use, risk-taking behaviours, and psychiatric complaints.[5] Poorly managed transition can lead to additional long-term costs to health services, preventable co-morbidities and reduced productivity and life expectancy and social costs such as the cost of suffering and distress on carers and families.

The lack of adequate resources, including patient information/resources, has been identified as a barrier to transitional care for adolescents[6], therefore, the need to provide adolescents and their families with resources to improve their health literacy and ability to navigate the health system, enhance their self-management skills, and psychosocial support in areas such as sexual health and risk-taking behaviours[6] is critical.

Effective transition models and resources have been established for other chronic paediatric conditions, such as cystic fibrosis, yet there is a lack of contemporary, engaging, adolescent-focussed resources to assist adolescents with rheumatic disease and their families transition to adult care services and self-manage their conditions.

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

As evident by many of the comments in previous sections of this submission, improved knowledge and awareness of childhood rheumatic diseases is required by many health professionals, especially GPs. The importance of this cannot be understated as JIA is commonly undiagnosed or misdiagnosed and the physical, social, economic and psychological costs of this are too great for children and families.

Even when attending hospital emergency departments, parents of children with rarer rheumatic diseases report that doctors have little awareness of their conditions. Too many parents commented that they have heard too many doctors and nurses say to their child, ‘You’re too young to have arthritis’ or ‘That’s an old person’s disease.’

This perception is also pervasive in the broader community with many people having no understanding that children could possibly have such diseases.

Health professionals need to adopt a wholistic, patient-centred approach to the management of children with rheumatic diseases given these diseases impact so many aspects of children’s lives and the lives of their families. As one mother stated:

> *‘Just because my child’s bloodwork is in the normal levels doesn’t mean his pain has gone or that he can put on shoes by himself, play more than five minutes of soccer, attend a full day of school, etc.’* Buffy. Mother of son diagnosed at 13 with JIA and AMPS.

Not only do many health professionals require improved awareness of the signs, symptoms and management of childhood rheumatic diseases, school teachers also need access to professional development modules to better understand the needs of these children when they are working with them. It is important that teachers better understand the issues faced by these children in and outside school.

Some parents also suggested that further resources should be available in schools to instruct other children about the issues faced by children with chronic health conditions to promote better understanding of the experiences and lives of these children.

More broadly, increasing community awareness of childhood rheumatic disease will not only improve community understanding, but may also increase knowledge and awareness among parents and families thereby resulting in improved time to diagnosis.

5. Musculoskeletal Australia's recommendations to the Inquiry

Musculoskeletal Australia respectfully makes the following recommendations to the Members of the Inquiry with the aim of addressing the issues raised by children and families within this submission. The recommendations are grouped according to the issues or areas to which they apply.

As Musculoskeletal Australia also endorses the relevant recommendations from the 'National Strategic Action Plan for Arthritis', some of these recommendations have been included here for completeness and for the consideration of the Inquiry's Members. They are appropriately acknowledged within the following list.

Recommendation 1: That the awareness and knowledge of health professionals regarding childhood rheumatic disease be improved to enable more timely diagnosis, improved management and more wholistic, patient-centred care which acknowledges the social and mental health impacts of these diagnoses.

- Improved resources and recognition at GP level to accurately diagnose and accelerate for appropriate treatment with a specialist
- A session (or sessions) with a psychologist or counsellor early on in diagnosis for the child and the family
- An information campaign targeted at GPs and hospital emergency departments on the symptoms of childhood rheumatic disease and corresponding protocols to improve earlier detection and referrals to specialists for more timely diagnosis
- Development of a decision support tool to enhance early diagnosis and referral for children and adults who may require specialist care. This tool should include a guide to key clinical features suggesting inflammatory arthritis, clinical examination, an agreed set of laboratory tests to assist in diagnosis and a checklist of essential information to include in referral letters to rheumatologists to support triage (National Action Plan).

Recommendation 2: That processes be established to improve communication between health professionals, and between health professionals and families to ensure the provision of seamless, high quality care for children and their families.

- Protocols and guidelines for improved communication between health professionals and families be developed within a process involving health professionals, consumer-based organisations and consumers.

Recommendation 3: That funding be provided to develop more information, supports and programs relevant to the needs of children with rheumatic disease and their families.

- Expand peer support programs for people with arthritis to cater for groups with different needs, including children and their families (National Action Plan)
- Expand the reach and coverage of JIA kids camps and programs run by arthritis organisations to cater for more children, different age groups including young adults, and children with other rheumatic conditions (National Action Plan)
- Written resources should be available in at least the 10 most common community languages
- Develop age and developmentally appropriate resources and programs to support children and young people and their families living with JIA. These should include resources suitable for preschool, primary-school and high-school age children, resources and programs for

schools, and transition resources to support children as they move to adulthood (National Action Plan).

Recommendation 4: That the availability of, and access to, an interdisciplinary team of medical and health professionals with specialised knowledge of the diagnosis and management of childhood rheumatic disease be greatly increased, regardless of a family's geographic location and financial circumstances.

- Increased services for rural and remote communities
- Increased funding for more specialist paediatric rheumatologist services - including rheumatologists, rheumatology-trained nurses, psychologists, physiotherapists, occupational therapists and pain specialists with a focus as an urgent first priority on rural, regional, and metro areas currently experiencing the worst short-fall of services
- Provide dedicated funding for paediatric rheumatology training, which is currently unfunded, and expand public funding for paediatric rheumatology consultant, nurse and allied health positions (National Action Plan).

Recommendation 5: That more financial support be provided to families with a child with rheumatic disease, in conjunction with improved and more equitable access to current supports and programs.

- Government to recognise rarer conditions and a process for dealing with those that do not fit "in the box" for support
- Explicit, structured offers of psychological support for parents of children at point of diagnosis, acknowledging the significant impact of the diagnosis on the whole family, and being pointed in the right direction of the range of different mental health services to support the parents on their journey with their JIA child
- Families receive direct financial support to manage the costs of the wide range of medical and other supports required
- Better interface between the NDIA and medical practitioners (GPs, Paediatrician, Rheumatologists), so that medical practitioners are aware and can inform parents that the NDIS may be an option for funding.

Recommendation 6: That community information and awareness campaigns be established to increase the awareness and knowledge of childhood rheumatic diseases within the broader community.

- An approach to a series of community information and awareness campaigns be developed within a process involving government, health professionals, consumer-based organisations and consumers.

Recommendation 7: That funding be provided to develop further resources for school teachers and their communities to promote a better understanding of, and support for, the needs of children with rheumatic disease.

- Funding for secondary school resources to support teachers and students
- Funding for a VCE/HSC survival guide.

Recommendation 8: That funding be provided to support adolescents at a time when they are transitioning between paediatric and adult health services.

- Funding for an app for young people for transition from paediatric to adult care
- Guidelines developed for health professionals and services (with input of young people, their families and consumer-based organisations) to map out a clearer process for managing transition between paediatric and adult rheumatology services

Recommendation 9: That more funding be provided for research in all aspects of childhood rheumatic diseases and that national data collection and analysis be undertaken to better understand the prevalence and impact of these conditions on children and their families.

- Support medical research into JIA, and appropriately fund and approve new and emerging medications for the treatment of JIA and other childhood rheumatic diseases
- Get a national JIA register in place to collect proper data on the number of children affected, so that commensurate medical services (at least per-population) can be allocated to servicing the disease.

6. References

1) Australian Institute of Health and Welfare. Australia’s health 2016. Canberra: AIHW; 2016. *http://www.aihw.gov.au/publication-detail/?id=60129555544*

2) Tucker LB. Cabral DA. ‘Transition of the adolescent patient with rheumatic disease: Issues to consider’. Pediatric Clinics of North America 52. 2005. 641-652

3) Pacaud D, Yale J. ‘Transition from paediatric to adult care services for youth with diabetes’ Paed Child Health 2005, 10(1), 31-34

4) Shaw KL, Southwood JE, McDonagh and on behalf of the British Paediatric Rheumatology Group. ‘Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey’. Rheumatology 43(2):211-219. 2004.

5) Fox A. ‘Physicians as barriers to successful transitional care’, International Journal of Adolescent Medicine and Health 220. 14(1): 3-7

6) Shaw KL. op cit, 211-219.

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Appendix One

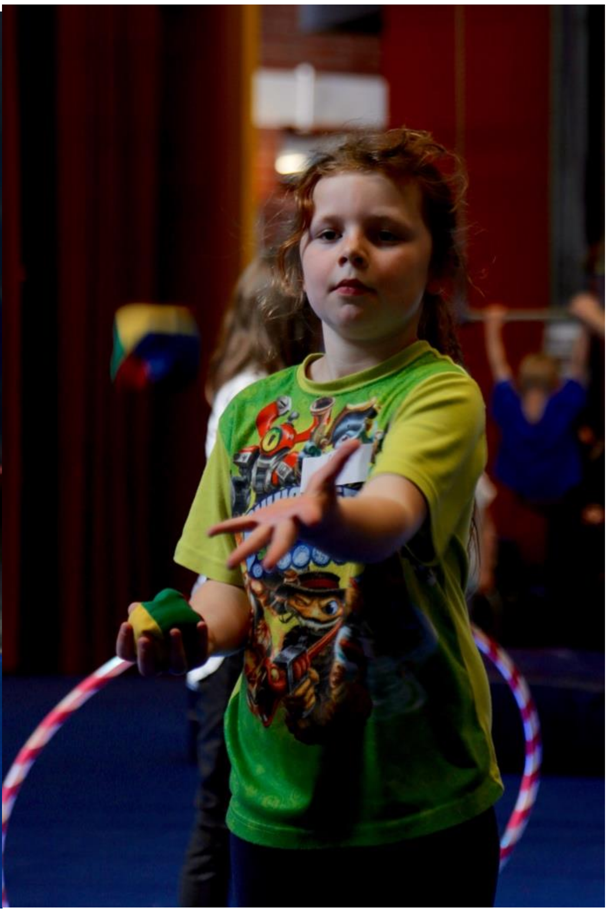
Photos of Musculoskeletal Australia's activities with children and families

Camp Limber Up, 2014

Collingwood Children's Farm 2014

The 'Worst Pain in the World' book launch 2014

Circus Oz, 2015



Kids' Swim Day, 2016

Kids' Bowling Day, 2016

50-year Anniversary Gala Dinner, 2018

Gala Dinner, 2019

MSK Kids launch at Monash Children’s Hospital, 2019

Appendix Two

Photos parents requested be included in this submission