



Australian
Rheumatology
Association

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Via email: Health.Reps@aph.gov.au

To Whom It May Concern

Re: Parliamentary Inquiry into Childhood Rheumatic Diseases

The Australian Rheumatology Association (ARA) welcomes the Parliamentary Inquiry into childhood rheumatic diseases.

The ARA is an association of rheumatologists and allied health professionals in Australia. It is the peak professional body for the management of musculoskeletal and related inflammatory conditions.

Musculoskeletal, inflammatory and connective tissues diseases (MSK conditions) are the largest cause of disability globally, and in Australia. MSK conditions outranked all communicable and non-communicable causes of disability in Australia, as of June 2019 (AIHW data).

The Australian Paediatric Rheumatology Group (APRG) is a group within the ARA. Paediatric rheumatologists treat children and young people (<18 years). However, due to the shortage of specialist paediatric rheumatologists some adult rheumatologists are required to care for children and some have undertaken additional training to facilitate this. Given the increasing complexity and specialisation of paediatric rheumatology unfortunately the number of adult rheumatologists willing and skilled to treat children is declining.

Juvenile arthritis and other childhood rheumatic diseases affect 6,000 -10,000 children across Australia. Many of these diseases extend into adulthood with 1 in 3 identified as having severe disability, including joint deformities and vision loss, because they are diagnosed too late or children can't access the care and treatment needed to control their disease. Hence any potential to optimise treatment early in disease and improve outcomes would be in keeping with the best interest of the individual patient, their family and the extended Australian community.

Children with rheumatic diseases can also experience stigma and isolation resulting from their physical and social limitations and miss significant school time through illness and the demands of treatment, such as infusions of steroids and strong immune-suppressing medications.

We have addressed the individual terms of reference of the inquiry below.

Terms of reference

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

The ARA welcome the announcement of the \$20 million MRFF grant for research into childhood rheumatic diseases. Research is essential to improve patient outcomes. It would be prudent to ensure that any research into childhood rheumatic diseases is done within Australia as part of an international team, similar to what occurs with adult rheumatology.

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 ARA recommends the provision of adequate and equitable services for the management of childhood rheumatic diseases. A multidisciplinary team (MDT) approach, with psychosocial supports in place is considered best practice. The impact of childhood rheumatic disease is underestimated and access to optimal care can help to minimise these impacts. Adults who have had rheumatic disease since childhood often have more severe disease, disability and reduced quality of life. If we can improve the care of paediatric patients with rheumatic disease this will improve the outcomes for these patients as adults.

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

There is an extreme shortage of paediatric rheumatologists in Australia. Currently there are only 20 paediatric rheumatologists in Australia which are appointed in positions which, due to other commitments such as University appointments and family responsibilities, equates to less than 10 full time equivalents being available in public hospitals. According to published data on recommended staffing this would be considered to be <33% of that required for a first world country. Australia also has a very significant undersupply of MDTs for childhood rheumatic diseases. This disadvantages children with rheumatic disease in terms of optimal care and results in poorer outcomes.

Paediatric rheumatologists by themselves cannot provide effective care and thus attention to the provision of expert nursing, allied health and community supports needs to be given. Without a collaborative MDT, world class care cannot be guaranteed. Thus, we advise that these teams be established in all Australian states and territories and funded on an ongoing basis.

Adult rheumatologists may have to see paediatric patients due to the shortage in paediatric rheumatologists. The ARA have been made aware of a situation where an adult rheumatologist who has been providing services to paediatric patients as part of her practice for decades has notified the local public hospital of her retirement 6 months in advance to ensure there is no interruption of treatment for these vulnerable paediatric patients. Unfortunately, the impact on service provision has not been identified as a priority and funding has still not been put in place to ensure continuation of this vital and valuable service, nearly 7 months later. This will necessitate children and families driving long distances to access care in an adjacent state.

The ARA also bring to the inquiry's attention to absence of a well-established transition process for paediatric patients moving into adult care (>18 years), despite this being acknowledged as global best practice. This results in high rates of drop out of care and poorer outcomes for patients. We recommend that specific funding be allocated to support coordinated transition services which would necessitate funding of positions not only in paediatric rheumatology but also adult services to facilitate a smooth process.

There are significant deficiencies in paediatric rheumatology services delivered in regional, rural and remote Australia. The Northern Territory and Tasmania do not have any paediatric rheumatologists. Outreach needs to be provided to regional, rural and remote areas and needs be distributed evenly Australia-wide. Currently the ARA funds paediatric rheumatologists to provide outreach to these communities; in the absence of this there would be no access for these



paediatric patients to specialist rheumatology care. For example, a child with a rheumatic disease who lives in the Mackay region would have to travel nearly 1000kms to be seen at the Queensland Children's Hospital rheumatology clinic if this service was not provided. The ARA requests Federal funding to improve access to regional, rural and remote Australians to paediatric rheumatology care. This is a major issue for some of our most vulnerable and priority populations

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

Current access for biologic agents for paediatric rheumatic disease is limited. Eligibility in terms of conditions and criteria for access should be revised to be in keeping with current best international standards in an evidence-based manner.

Children with rheumatic diseases should have access to tumour necrosis factor inhibitors (TNFis) for the treatment of sacroiliac arthritis and uveitis. This would allow access to TNFis in keeping with international best practice and the recently published Australian Living Guidelines. Currently, children with these conditions can only access these medications through hospitals or self-funding. This has led to inequity of availability of the TNFis for these indications between states and even within states and individual hospitals. PBS listing of the TNFis for these indications would reduce the inequity and ensure access for all paediatric patients who require treatment with a TNFi.

The current Authority forms for biologics in JIA were developed without any input from paediatric rheumatologists. As such they are confusing and time consuming for paediatric rheumatologists to complete. We would recommend a review of the current forms with input sought from the APRG so that they reflect current international best practice.

We request the re-instatement of joint injection item numbers for specialist rheumatologists for rheumatic diseases. A joint injection for a child is a complex process both physically and psychologically and requires significant expertise. This process can take up to 45 minutes and the ARA believe that it should have an item number associated with it. The alternative is for a child to be sent to an interventional radiologist for an ultrasound guided joint injection which is more expensive for the tax payer and may be more distressing for the child and carers, than an injection by a trusted medical specialist.

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

There are only three accredited training sites in Australia for paediatric rheumatology with no dedicated Federal funding for trainees at 2 of these sites. This has resulted in a severe shortage of paediatric rheumatologists and a major issue in succession planning. The APRG have themselves fundraised to be able to provide 4 paediatric rheumatology training positions. However, this is not adequate nor sustainable. We request that the Federal Government provide funding to train paediatric rheumatologists through their 2 years of advanced training, ideally for 20 positions over the next 10 years to overcome the current skills shortage.

The shortage in the paediatric rheumatology workforce has flow on effects for training of other healthcare professionals. Ideally paediatric rheumatologists would educate and support general paediatricians, emergency department physicians, general practitioners, and allied health professionals so that a shared care model would be established, and optimal care could be achieved in primary care. The education and support of these other health professionals would in turn reduce the time to diagnosis and the costs of investigations (blood tests and imaging) and improve patient outcomes. However, the shortage of paediatric rheumatologists means that there is no capacity to train these health professionals. Increasing the paediatric rheumatology workforce is crucial to improve early diagnosis, cost-effectiveness and most importantly patient outcomes.

Similar shortfalls in professional education are also evident amongst allied health professionals involved in the care of children with rheumatic disease. These also require urgent attention as



without a skilled population of paediatric rheumatology specialist allied health practitioners there is no prospect of educating others to manage the large number of children with rheumatic disease.

The current community awareness of childhood rheumatic diseases would seem minimal at best. The ARA advocates for improved funding to increase the community awareness on par with juvenile diabetes.

Thank you again for the opportunity to provide input into this Parliamentary Inquiry.

Yours sincerely

[Redacted signature]

**Professor Catherine Hill MBBS MSc MD FRACP
President**

cc:

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