

## Submission to Parliamentary Enquiry on Childhood Rheumatic Disease

31/1/2022

Dear Mr Zimmerman,

We write as a concerned group of senior doctors in training, near completion of our paediatric rheumatology specialist training. With respect to the terms of reference for the inquiry into childhood rheumatic disease, we write in regard to Term 3: access to medical services, and Term 5: the adequacy and consistency of professional education, training, and awareness among healthcare professionals. We thank the inquiry for the opportunity to contribute to this important matter.

In Australia, there are more than 10,000 children, some as young as two years old, living with chronic debilitating rheumatic diseases (1). Although Juvenile Idiopathic Arthritis (JIA) is as common as childhood Type 1 Diabetes, there are currently the equivalent of only 10 full time consultant paediatric rheumatologists caring for these complex patients across Australia. This serious shortage of paediatric rheumatology specialists is further evidenced by there being no paediatric rheumatology service available to children in the Australian Capital Territory, Northern Territory, or Tasmania. In the vast majority of rural and remote regions, there are no local or specialist outreach services. These patients and their families have to travel to neighbouring states or into capital cities to receive care, placing a significant burden on them as well as the neighbouring public paediatric rheumatology services that are not staffed or funded to provide care for them. Based on international standards of care in paediatric rheumatology, there should be at least 31 consultant paediatric rheumatologists providing care across Australia (2). There is clearly an urgent need to train more paediatric rheumatologists in Australia. There are, however, currently only three Royal Australasian College of Physicians (RACP) accredited training centres within Australia and only one of these three positions has consistent public funding\*.

A keen consideration in addressing term of reference 5 includes the inadequate number of specialist training centres across Australia, and the tenuous nature of funded training positions in paediatric rheumatology. This has not only allowed for dire delays in combating the workforce shortage but also acts as a deterrent for future trainees. Some current trainees have had to wait years prior to being able to commence specialist training due to lack of accredited positions. All the trainees who will complete their training within the next 18 months have had to move either interstate or overseas (often both) to meet training requirements. Adding to the significant upheaval of moving to access specialist training, it can also be difficult to secure funding for overseas placements, and trainees have in the past been forced to take unpaid positions in order to complete requirements. This situation is not the same for adult rheumatology trainees who are able to complete their training within the State or Territory within which they reside as there is an adequate number of training positions.

Government funding to provide an adequate number of training positions in paediatric rheumatology would not only allow for the serious shortage of paediatric rheumatologists to be remedied but it would also allow for increased service capacity at these training centres and beyond. Consultants in

[1] Australian Institute of Health and Welfare, 2008. Juvenile arthritis in Australia. Arthritis series no 7. Cat no PHE 101. Canberra, AIHW

[2] Service NH. NHS Standard Contract: Paediatric Medicine: Rheumatology 2013 [Available from: <https://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-medi-rheum.pdf>].

\*The three accredited training sites are the Royal Children's Hospital Melbourne (charitably funded), Queensland Children's Hospital (publicly funded) and Perth Children's Hospital (intermittent charitable/public funding).

clinics run with trainees in attendance see more patients which reduces waiting lists. Trainees can provide an accessible extra point of care (aside from consultants or specialist nurses) for families in between formal reviews. There are currently very limited outreach clinics for patients from remote regions, and trainees in such a clinic would allow greater numbers to be seen in a shorter time frame. Centres wishing to secure training site accreditation need to meet strict standards set by RACP, including those relating to adequate consultant supervision, education and professional development opportunities. The wider unit can benefit from meeting these standards. For example, new research outcomes and guidelines may be reviewed during education sessions. This prompts units to regularly adjust to new evidence, which ensures the patient cohort receives best-practice treatment. Trainees also contribute to educating the wider community. Sessions delivered to emergency, paediatrician or GP colleagues, as well as allied health, aid communication between units and aim to improve patient care and flow. However in order for further training sites to be accredited, the consultant workforce must be increased to allow appropriate supervision and expertise for training of new specialists.

As current trainees who have gained experience in internationally renowned best-practice multidisciplinary centres, we understand that the modern era of paediatric rheumatology provides great advances in patient care. However, alongside this, there is increasing complexity in treatment options and contemporary therapies that demand highly specialised knowledge and training. With the improved accepted prognostic standards in JIA and other paediatric rheumatic diseases, it is no longer acceptable to have a child with a rheumatic disease be managed solely by a paediatrician or generalist like it may have been 20-30 years ago. Dr Roger Allen, who practiced as a paediatric rheumatologist for 40 years in Melbourne until his recent retirement, recalled how when he was a trainee it was frequent to see children with rheumatic diseases in wheelchairs. This is very much the exception, rather than the expectation, in modern paediatric rheumatology units. This is due to aggressive early intervention and specialist management. The severity of the diseases and their capability to cause destruction and ill health have not changed, and a child who cannot access care will experience this same damage as was seen in the 1980's and 90's.

In specific reference to term of reference 3, in working with young adults with childhood-onset rheumatic disease in Australia, we have directly encountered patients with irreversible joint damage and disability from aggressive arthritis, who suffered as a result of inadequate awareness and delayed access to specialist care. This is a scenario that must be avoided, in the best interests of the patient, their family, and wider society. Conversely, while working abroad, we saw first-hand the improved outcomes that can be achieved with early access to biologic medication and ongoing multidisciplinary team support. We have seen patients who can access new medications through multi-centre research trials and the life-changing results this can provide. We are keen to bring this expertise home to our Australian patients who currently have limited access to specialist care due to the significant shortages of doctors trained in paediatric rheumatology. We want to provide the best quality care that Australian patients deserve. We cannot do this without increased funding for both training positions and consultant positions to provide education and supervision for those completing training.

We write as a group of doctors in training who have a passion for caring for children with rheumatic diseases. We want to be a part of the solution, helping to increase the workforce capacity caring for these children. We have learnt what can be achieved in a well-funded and supported system, with true multidisciplinary input and access to research opportunities that are simply not available anywhere in Australia. It is essential that the Federal Government provide for the future care of children with rheumatic diseases and this requires funding for the creation of a sustainable national training program in the speciality of paediatric rheumatology.

We have listed our recommendations below and would welcome the opportunity to discuss these issues further.

Recommendations
<ul style="list-style-type: none"><li>• Establishment of publicly funded paediatric rheumatology training positions in currently accredited sites</li></ul>
<ul style="list-style-type: none"><li>• Funding to increase the consultant workforce to align with international best practice</li></ul>
<ul style="list-style-type: none"><li>• Funding of multidisciplinary teams (clinical nurse consultant, physiotherapist, occupational therapist, psychologist and social work) in all tertiary paediatric rheumatology services</li></ul>

Kind Regards

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With grateful acknowledgement to Dr Roger Allen MBBS FRACP for his insight