



**Gold Coast Hospital
and Health Service**

PO Box 6021
Parliament House
CANBERRA
Canberra ACT 2600

27th January 2022

Secretariat
The House of Representatives Standing Committee on Health,
Aged Care and Sport Inquiry on Childhood Rheumatic Diseases and Juvenile Arthritis

Dear Committee,

I am writing in support of the submission from Childrens Health Queensland and would like to reinforce the urgent need for increased resourcing and services for children with chronic autoimmune conditions such as Juvenile Idiopathic Arthritis, Systemic Lupus Erythematosus, Juvenile Dermatomyositis, autoinflammatory syndromes and other musculoskeletal diseases in Queensland. I am the Director of Paediatrics for Gold Coast Health. The Gold Coast is one of the fastest growing Australian childhood populations and there are currently over 162 000 children and young people under 18 living in our community with a projected under 18 years population of 180 000 by 2026 and 208 000 by 2036. We have the 6th largest paediatric facility in the country.

The Paediatric Rheumatology service at Gold Coast University Hospital (GCUH) is the only permanent Paediatric Rheumatology service outside a capital city in Australia, providing care close to home for a large number of children with potentially debilitating chronic disease. The Paediatric Rheumatology service at Gold Coast University Hospital began in March 2019 by diverting funding for General Paediatrics and provides care to local young people 18 years and under. The Paediatric Rheumatology service at Gold Coast University currently consists of a Paediatric Rheumatologist one day a fortnight and is supported by the General Paediatric team at GCUH. It has no associated Allied Health or Nursing support.

Since the commencement of Paediatric Rheumatology services at GCUH there has been rapidly increasing demand with ever increasing waitlists. Families and patients are keen for locally delivered, comprehensive care. Long wait lists can result in children developing irreversible complications of untreated rheumatic disease with negative implications for future quality of life and function while awaiting specialist treatment. This is a rapidly developing speciality with substantial advancements having been made in the treatment of childhood rheumatic disease resulting in dramatic changes in lifelong outcomes for these children. With appropriate treatment the rates of significant physical disability have significantly decreased. However, these complex treatments can be prolonged and invasive and may lead to poor psychosocial outcomes for children and their families (i.e. needle phobias, school disengagement, depression and anxiety). Access to Multidisciplinary Team (MDT) management is critical to avoid this, however unfortunately at present this need is unmet in Queensland. Treatments are also labour intensive from the perspective of the health workforce, further straining an already under provisioned service. No longer is outpatient care with a single clinician seen as an appropriate model of care.

Internationally recommended guidelines state that there should be 1.0 Full Time Equivalent (FTE) Paediatric Rheumatologist for every 200,000 children to provide a comprehensive Paediatric Rheumatology service.^{1,2} In Queensland at present the total publicly permanently funded Paediatric Rheumatologist FTE is 1.6 for 1,345,915 children (1 rheumatologist per 841,196 children) and the Gold Coast has 0.1 FTE Paediatric Rheumatologist for 162 000 (one per 1.62 million children).

Multidisciplinary care is the internationally accepted best model of care for children with rheumatic disease. Multidisciplinary care encompasses medical, nursing and allied health practitioners. At this point the Paediatric Rheumatology service at GCUH only has medical staff and nowhere near recommended FTE. This dearth of accessible MDT care means that the only access for allied health support is through the private sector and many of our families are unable to afford private care. Currently children with rheumatic disease do not qualify for the National Disability Insurance Scheme unless they have severe physical disability, which with early comprehensive treatment we are hoping to avoid. As a result, many children do not get care they need including Physiotherapy, Occupational Therapy and Psychology services. Improving access to MDT care in the community could be facilitated by improving the access for children with rheumatic disease to the National Disability Insurance Scheme and ensuring that a Statewide/National approach to the planning and development of funded paediatric rheumatology services occurs to ensure services are prioritised, multidisciplinary, equitable, integrated and patient focused. Funding models mean that resources for this cohort compete with acute care and adult care requirements and are not seen as a priority at state or national level.

Fostering the development of innovative models of care with specialist nurses at a Nurse Practitioner/Nurse Navigator/Clinical Nurse level and Allied health practitioners with specialist expertise should also be supported using centralised funding models such as Commonwealth funding, this has been very successful in other disease groups resulting in case managed care. The training of future paediatric rheumatologists also needs significant investment as it is a small speciality with limited training opportunities due to poorly resources services across Australia, including the Gold Coast.

At present the paediatric rheumatology medical workforce is insufficient to meet current demands and this is compounded by the lack of allied health and nursing support, current population projections show that demand is only going to increase. We know that early and appropriate treatment for this range of conditions has significantly improved long term outcomes. Urgent resourcing and advocacy is required to provide appropriate Specialist and MDT care for this cohort of children with significant and complex medical needs to allow them to be active members of our community. We need to ensure that the significant advances in treatment and outcomes can be delivered to Australian children not only to improve quality of life for these children but to reduce the inevitable costs of ongoing morbidity and disability to the Australian public of untreated disease.

Thanking You



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1. National Health System United Kingdom (2013) Standard Contract, Paediatric Medicine: Rheumatology. NHS England. Available at <http://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-medi-rheum.pdf>.
2. Duke EM (2007) The Pediatric Rheumatology workforce: a study of the supply and demand for pediatric rheumatologists. Report to Congress. Bureau of Health Professions. Health Resources & Services Administration. US Department of Health & Human Services.

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