Submission
No 450

INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

Organisation:	Juvenile Arthritis Foundation Australia
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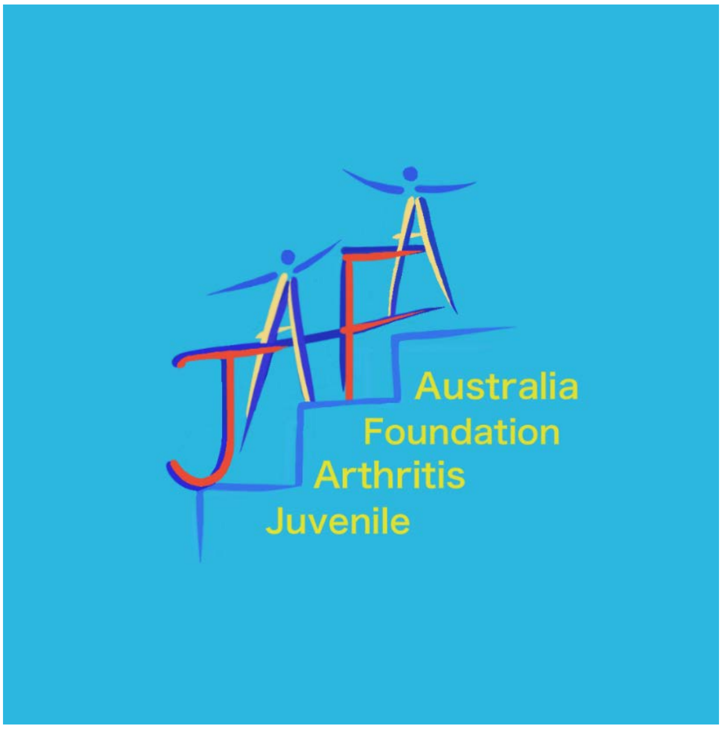
Juvenile Arthritis Foundation Australia submission to the inquiry into Health Outcomes and Hosptial Services in Rural, Regional and Remote New South Wales



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ABN: 99 637 927 952 **WEBSITE:** https://www.jafa.org.au/

Juvenile Arthritis Foundation Australia Submission to the Health Inquiry into Health Outcomes and Access to Health and Hospital Services in Rural, Regional and Remote NSW.

The Juvenile Arthritis Foundation Australia thanks the Committee for the opportunity to make a submission on behalf of children suffering from much neglected and underserved childhood rheumatic diseases, of which Juvenile Arthritis is the commonest form. The challenges in accessing services that are experienced by these children and their families living in regional, rural and remote areas is a major contributor to increasing the risk of poorer outcomes, permanent disability, stress and anxiety, and financial hardship.

About Juvenile Arthritis (JA)

JA is a serious, painful, incurable and debilitating autoimmune disease which occurs in children under the age of 16 years and can start as early as 12 months of age. With an estimated prevalence of 1-2 per thousand, there are at least 3,000 children and another 3,000 young people affected in NSW, making it a common chronic childhood disease.

The prevalence of JA is similar to other serious childhood diseases such as juvenile diabetes and around 6 times more common than cystic fibrosis. JA affects the joints and can cause an inflammatory eye disease called uveitis. It has the potential to result in permanent joint deformities and loss of vision if not diagnosed early and treated effectively. The majority of children with JA suffer pain on a daily basis that restricts them from active participation in school/learning, sport, play and social life. Awareness of JA in Australia is so low that on average it takes 10 months from the onset of symptoms to diagnosis and can sometimes take much longer. Consequently, some children already have irreversible joint damage and permanent loss of vision by the time they are diagnosed. The Australian Institute of Health & Welfare (AIHW) estimates that there are many thousands of people in Australia whose arthritis started as JA and extended into adulthood and 1 in 3 of these people has a severe disability.

The treatment of JA requires specialist care to manage complex treatments including non-biological and biological disease-modifying antirheumatic drugs (DMARDs) in addition to NSAIDs, analgesics, steroids and intra-articular steroid injections.

JA is a neglected disease in Australia with specialist services falling well short of other more recognised childhood diseases and the Australian paediatric workforce lags well behind international service benchmarks and therefore fails to provide the level of care to children with rheumatic diseases comparable to other developed health economies worldwide (Cox A, Piper S, Singh-Grewal D. Pediatric rheumatology consultant workforce in Australia and New Zealand: the current state of play and challenges for the future. International Journal of Rheumatic Diseases 2017; 20: 647–653).

About the Juvenile Arthritis Foundation Australia (JAFA)

JAFA was established in September 2019 in response to the urgent need for a national voice dedicated exclusively to representing and addressing the needs of children and young people with juvenile arthritis and their families and carers. JAFA's primary aims are to raise awareness of juvenile arthritis, lobby for optimal and accessible health care and support for children with JA, and foster research into the causes, treatment, care, and a possible cure for JA – www.jafa.org.au. JAFA is committed to ensuring children with JA can access the health services they need to live as active, happy, and pain-free childhoods as possible thus enabling them full social and educational participation leading to productive, disability-free lives as adults.

Specialist paediatric rheumatology services in rural, regional and remote NSW

NSW Health-funded specialist paediatric rheumatology services are inadequate and lag well behind most other states in Australia and fail to meet basic and safe standards of care.

Paediatric rheumatology services provided by NSW Health are concentrated in the two hospitals that comprise the Sydney Children's Hospitals Network (SCHN) which also provides a service to John Hunter Children's Hospital (JHCH). They can be summarised as follows:

- The current total paediatric rheumatology service provided by NSW Health for the entire state is 22 hours per week which equates to 55% of a one full-time paediatric rheumatologist.
    - SCHN - 18 hours per week
    - John Hunter Children's Hospital – 4 hours per week
    - There is 1 only paediatric rheumatology nurse in NSW
    - There are no specialist paediatric physiotherapists, occupational therapists, psychologists or pain management practitioners
- This allocation is inadequate to provide services to the 6,000 children and young people with rheumatic diseases including juvenile arthritis in NSW.

It should be noted that we are pleased to report that JAFA was informed on January 8, 2021 by Minister Hazzard that funding is being made available for an additional permanent part time paediatric rheumatologist. This will increase the medical paediatric rheumatology workforce in the public sector to 1FTE which is very welcome but will not rectify the shortfall.

A major consequence of this shortfall is the lack of State funded specialist services in rural, regional and remote NSW. In NSW there is one single rural outreach specialist rheumatology clinic in Orange which is held 4 times a year. There are no paediatric rheumatology outreach services funded by NSW Health anywhere in the state since the clinic in Orange is funded by the Federal Government's Medical Specialist Outreach Assistance Program (MSOAP).

Australian Bureau of Statistics data indicate that 3.1 million people live in Regional NSW (38.3% of the NSW population) and 4.9 million (61.7%) live in Greater Sydney (Australian Bureau of Statistics, 3218.0 - Regional Population Growth, Australia, 2017-18, 27 March 2019). Therefore the current situation is that the whole of regional NSW is served by only one specialist paediatric rheumatology clinic (in Orange 4 times per year) and there are no services south/south west of Liverpool, north of Newcastle and west of Sydney (except for the Orange clinic). This means that at least 40% or an estimated 2,4000 children and young people with rheumatic diseases receive no service near to where they live and are forced to either travel long distances or go without specialist care and risk debilitating immediate and long-term consequences.

JAFA's specific responses to the Inquiry Terms of Reference

The following addresses the inquiry's specific terms of reference.

(a) health outcomes for people living in rural, regional and remote NSW;

It is well documented that people living in rural, regional and remote areas have less favourable health outcomes. According to the AIHW, people in remote and rural areas have a significantly reduced life expectancy and poorer outcomes on leading indicators of health as a result of the scarcity of health services. ABS National Health Survey data highlight particular conditions with increased prevalence including arthritis which is higher in inner regional areas (21%) and outer regional and remote areas (20%) compared with major cities (17%).

While there is a lack of specific data on JA and childhood rheumatic diseases, outcomes would be expected to be worse given the limited access to specialist services.

(b) *a comparison of outcomes for patients living in rural, regional and remote NSW compared to other local health districts across metropolitan NSW;*

We are unable to address this because of a lack of comparative data with metropolitan NSW.

(c) *access to health and hospital services in rural, regional and remote NSW including service availability, barriers to access and quality of services;*

As highlighted above, there are no specialist paediatric rheumatology services based in regional NSW and only one outreach specialist clinic for the whole of regional NSW which is held in Orange 4 times per year. There are no services south/south west of Liverpool, north of Newcastle and west of Sydney (except for the Orange clinic). This means that at least 40% of children with rheumatic diseases (an estimated 1,200 children) receive no service near to where they live and are forced to either travel long distances (*see Laura's story at Appendix 1*) or go without specialist care and risk debilitating immediate and long-term consequences.

It should also be noted that there are no paediatric rheumatology specialists located in regional NSW.

As illustrated by the quotes from the JAFA Facebook page at *Appendix 2*, living in rural and regional NSW close to large city such as Canberra does nothing to mitigate the situation as there are no specialist paediatric rheumatologists or paediatric rheumatology nurses in the ACT either public or private. Residents in the surrounding towns of Goulburn, Queanbeyan, Braidwood, Yass, Cooma, Wagga Wagga and surrounds face 6-12 hour round trips to Sydney for routine treatment and no ready access for acute care.

The SCHN and the NSW Ministry of Health have been approached by families living in the Riverina asking for support to provide an outreach service to Wagga Wagga but these requests have been refused repeatedly. A business case has been developed and presented to SCHN but was rejected despite being relatively cost neutral to NSW Health.

(d) *patient experience, wait-times and quality of care in rural, regional and remote NSW and how it compares to metropolitan NSW;*

We are unable to address this due to lack of comparative data with metropolitan NSW.

(e) *an analysis of the planning systems and projections that are used by NSW Health in determining the provision of health services that are to be made available to meet the needs of residents living in rural, regional and remote NSW;*

We are not aware of any analysis in relation to childhood rheumatic diseases. It is a relatively neglected condition and was only relatively recently allocated its own budget within the SCHN. Consequently, JA is unlikely to be readily discernible in the NSWH planning metrics.

(f) *an analysis of the capital and recurrent health expenditure in rural, regional and remote NSW in comparison to population growth and relative to metropolitan NSW;*

There is limited health expenditure on childhood rheumatic diseases in metropolitan NSW and no specific funding in rural, regional and remote NSW.

(g) *an examination of the staffing challenges and allocations that exist in rural, regional and remote NSW hospitals and the current strategies and initiatives that NSW Health is undertaking to address them;*

There are no paediatric rheumatology (medical, nursing or allied health) staff located in regional NSW and to our knowledge there are no plans to address this.

(g) the current and future provision of ambulance services in rural, regional and remote NSW;
Not applicable to this submission

(h) the access and availability of oncology treatment in rural, regional and remote NSW;
Not applicable to this submission

(i) the access and availability of palliative care and palliative care services in rural, regional and remote NSW;
Not applicable to this submission

(j) an examination of the impact of health and hospital services in rural, regional and remote NSW on indigenous and culturally and linguistically diverse (CALD) communities;
There are no specific data on childhood rheumatic diseases which address this point

(l) any other related matters.

Summary
Specialist paediatric rheumatology services are limited in metropolitan NSW and virtually non-existent in rural, regional and remote NSW. Affected children living in regional NSW and their families have no option other than to travel long distances to metropolitan-based services to receive essential care. We are not aware of any immediate plans to address this deficiency.

This situation is contrary to NSW Government aspirations. The NSW Government's NSW Rural Health Plan: Towards 2021 published in 2014 states that "*Rural health is a priority for the NSW Government. We want to make sure people in rural areas can access the right care, in the right place, at the right time*". Regrettably this has not been achieved for JA and childhood rheumatic diseases and indeed there has been virtually no change over the past 7 years in moving towards changing the unsatisfactory state of regional services for these children.
https://www.health.nsw.gov.au/rural/Publications/rural-health-plan.pdf

We note NSW Health's commitment to delivering outcomes that matter to patients; is personalised; and invests in wellness (NSW Health Outcomes and Business Plan 2020). We recognise the daunting challenges the health system faces during this unprecedented time and also note that, at this time, it is more important than ever to ensure that the wellness and health care needs of the community are met, especially those in the community with currently unmet needs such as children and young people with JA and rheumatic diseases.

Improving rural, regional and remote services for JA and childhood rheumatic diseases would result in the following benefits:

- earlier diagnosis, improved care and earlier remission of juvenile arthritis
- a reduction in unnecessary, expensive diagnostic tests and other health services prior to diagnosis
- a reduction in joint and vision threatening complications and permanent disability
- a reduction in joint replacements, orthopaedic problems, and chronic pain
- improved school attendance and better career choices / employment opportunities for affected children and reduced adverse long-term social and vocational impacts
- less parental time off work and improved satisfaction with the health system.

Recommendations to improve rural, regional and remote paediatric rheumatology services.

1. **Increase rural, regional and remote local capacity**

   a] Establish two regional paediatric rheumatology centres.
   While there are several options, it would seem logical to base one of these in Newcastle in the Hunter Region which could serve the north western regional area.

   The suggested location for the second service is Wagga Wagga, the largest regional city in NSW. It has 325 bed Referral Hospital, provides paediatric care and community health services and a full range of allied health and support services including physiotheraphy and occupational therapy.

   b] Upskill local health professionals to deliver selected paediatric rheumatology services.
   This could include procedures such as administration of biologic medication infusions and intraarticular joint steroid injections.

   Upskilling of advanced nursing staff could provide a liaison and triaging service with specialist paediatric rheumatology services.

2. **Enhance outreach specialist paediatric rheumatology services.**
   A comprehensive regional outreach service co-ordinated by the SCHN should be developed to provide equitable access to specialist care and obviate the need for long distance travel.

3. **Increase the use of telehealth**
   Telehealth has the capacity to replace a proportion of face-to-face consultation, especially routine review visits. However, providing this service would require an increase in the current staffing levels of paediatric rheumatologists and clinical nurse consultants. This could not be achieved within the current staffing levels. Further, many diagnostic examinations, assessments and procedures (joint examinations, joint injections, fluid removal, infusions) cannot be undertaken remotely.