

MEDIA RELEASE

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**NEW REPORT DETAILS ALARMING HUMAN AND FINANCIAL COST OF COMMON CHILDHOOD ILLNESS
JUVENILE ARTHRITIS**

- **First comprehensive Australian study in juvenile arthritis shows children living in pain, waiting almost a year for a diagnosis and missing school**
- **Significantly lower quality of life compared to other childhood illnesses**
- **Heavy financial burden on families with up to 25 medical appointments per year, families borrowing from relatives**

A landmark report has revealed Australian children with disabling juvenile arthritis and other childhood rheumatic diseases are living in pain, waiting an average 11 -to- 14 months to receive a diagnosis, and missing at 2-3 days of school every month.

A nationwide study commissioned by Juvenile Arthritis Foundation Australia (JAFA) and carried out by senior researchers at the University of Sydney has also found families are increasingly unable to meet the costs of their child's illness which involves around 25 medical appointments and up to 4 hospital admissions per year.

The IMPACT report will today be launched by JAFA at NSW Parliament House, showing the average annual cost for each child with the illness is \$28 - \$35 thousand, with some families borrowing from relatives to pay for treatment.

Despite low awareness, juvenile arthritis is one of the most common chronic childhood diseases affecting an estimated 6,000- to-10,000 children aged 0-16 years and up to 30,000 young Australians aged 0 -24 years.

In response to a national online survey of 233 participants:

- 85% reported pain, 50% said it was moderate to severe pain
- 30% required orthotics/ splints/braces
- 32% had an eye condition (a JIA related condition that can lead to blindness)
- 53% reported a mental health condition

JAFA founder Professor Ruth Colagiuri said, "This report details for the first time the tragic and costly impact of juvenile arthritis in Australia, showing that these children are significantly worse off on a range of markers compared to those with other chronic childhood illnesses. Their quality of life is significantly lower than the Australian norm and lower than for children with comparable diseases."

"To control their disease, the majority of children must take strong immunosuppressant and anti-inflammatory medications which the study showed, carry a heavy burden of side effects (72%). However, it is the lack of access to specialist care across Australia that is a key issue contributing to

poor outcomes and heartache for families. No child should wait almost a year or more to get a diagnosis. This critical delay narrows the window of opportunity for early remission and positive long-term outcomes, causes distress to families and avoidable pain and suffering for the child.”

Dr Ben Whitehead, Chair at Australian Paediatric Rheumatology Group, said, “The serious national lack of paediatric rheumatologists, nursing and allied professionals means it’s likely that, without an investment in the specialist workforce, children will continue in pain and at risk of long term disability and potential blindness. Compounding this is the previously under-recognised financial burden on families, which can make treatment even more difficult to access.”

Jafa Chair Andrew Harrison said, “This study has filled evidence gaps identified by the recent [Parliamentary Inquiry into Childhood Rheumatic Diseases](#) and establishes an important base to inform future national health policy and planning to improve services and support for juvenile arthritis.”

Three key interventions are recommended in the Report:

1. Earlier diagnosis

Reducing time to diagnosis and referral to treatment is central to improving outcomes for these children.

2. Access to paediatric rheumatology services

Improved access to specialist paediatric rheumatology services provided by multi-disciplinary teams (doctors, nurses, physiotherapists, occupational therapists, podiatrists, psychologists, social workers, and ophthalmologists who specialise in uveitis).

3. Financial benefits and supports

While there are a range of financial benefits and supports in place to provide assistance for families, consideration should be given to promoting these schemes to those who need them, reducing inconsistencies and costs associated with applying for them, simplifying application process, and reducing response times.

Jafa thanks the experts who carried out the research and prepared the report:

Professor Natasha Nassar, Dr Diana Bond, Dr Amy Von Huben, Dr Samantha Lain, Faculty of Medicine and Health, Children’s Hospital at Westmead Clinical School Child Population and Translational Health Research, The University of Sydney.

We also thank NSW Health Minister, The Hon Ryan Park for launching the report, and Dr Joe McGirr, Member for Wagga Wagga, for co-hosting today’s event and for supporting the Jafa community.

Our gratitude is extended to Adrian and Charlotte MacKenzie and Five V Capital for their generous donation supporting his important study.

The IMPACT report is available at [Juvenile Arthritis Foundation Australia \(jafa.org.au\)](http://jafa.org.au)



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To download video clips of children living with juvenile arthritis:

<https://www.youtube.com/watch?v=5X7xbnAM5f4>

About Jafa

The Juvenile Arthritis Foundation Australia (Jafa) is the primary organisation for children and young people with arthritis. Jafa is a registered charity, founded in 2019 by Professor Ruth Colagiuri AM in response to the urgent need for a national voice dedicated exclusively to addressing the needs of children and young people with juvenile arthritis and childhood rheumatic diseases and their families

About Juvenile Idiopathic Arthritis(JIA) and Childhood Rheumatic Diseases (CRD)

JIA and CRDs are painful, incurable, inflammatory, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs. JIA is estimated to affect some 6,000 to 10,000 Australian children aged 0-16 years and up to 30,000 children and young people aged 0-24 years and, if not diagnosed early and treated effectively, can cause permanent disability in the form of joint deformity and loss of vision. Other CRDs are less common but equally serious