

MEDIA RELEASE

FIRST COMMONWEALTH FUNDING TO SUPPORT EARLIER DIAGNOSIS OF CHILDREN WITH DEBILITATING JUVENILE ARTHRITIS

- **Health Minister announces first-of-its-kind investment, signalling Australia’s commitment to changing the lives of children with undiagnosed juvenile arthritis (JA).**
- **New national program commences as children with arthritis come together in a roundtable at Parliament House to share ideas to accelerate time to diagnosis for others.**

Parliament House, Canberra / 20 March, 2024 – Minister for Health and Aged Care, the Hon Mark Butler today announces the first major federal government investment in a nationwide program to shorten unacceptable delays in diagnosing juvenile arthritis (JA) – a painful, incurable and debilitating childhood autoimmune disease affecting up to 10,000 Australian families.^{1,2}

The program will support GPs and other health professionals to promptly identify this serious and common but under-recognised disease when children first present with symptoms.

The average 10-11 months it takes to diagnose JA hasn’t changed in over 20 years,³ yet reducing this time opens a crucial window of opportunity for young Australians and their families to access the urgent specialist care needed to treat debilitating daily pain¹ and prevent permanent joint deformities, loss of vision and lifelong dependence.^{4,5}

The program *‘Juvenile Arthritis: Early Diagnosis – Early Intervention Changing Children’s Lives’* follows strong advocacy from Juvenile Arthritis Foundation Australia (Jafa), and is a key recommendation of a recent Parliamentary Inquiry into Childhood Rheumatic Diseases.⁶

Jafa founder Professor Ruth Colagiuri said, "An average of a year is a long time for kids to have painful and damaging inflammation gnawing at their joints and eyes while awaiting diagnosis of JA. This program is exactly what is needed to reduce these disabling delays and help transform kids’ lives from chronic disease to chronic health."

"Jafa thanks the Albanese Government for listening to our concerns and funding this program to raise health professional awareness and save future generations of kids with undiagnosed JA from lifelong pain and disability."

The program launches today in Parliament House at an event co-hosted by Dr Mike Freeland MP and Jafa, attended by 80 guests including families and more than 20 children living with JA, MPs and representatives from leading health professional organisations.

Extensive consultation with children and families affected by JA, leading health professionals and peak bodies, health policy experts and Health Department officials will inform the program. This commences today with a roundtable bringing children and adolescents together to share their own experience of being diagnosed with JA and their ideas and insights about how this could be improved for others.

see many families who have faced an unacceptably long and frustrating road to diagnosis of JA, often with unnecessary expensive and painful investigations, and we can learn a lot from their experience. With the right support and medications available today, we can stop this disease in its tracks and help kids to live the lives they choose.”

The program will deliver clear clinical guidance and information for Australian GPs and other health professionals to raise awareness of JA symptoms and diagnostic criteria with the aim of reducing dangerous delays in identifying JA and commencing effective treatment.

Dr Ben Whitehead, Chair of the Australian Paediatric Rheumatology Group, said, “Despite the condition being widespread, there is low awareness of JA amongst front line health professionals and within the general community. In addition, there is a common misconception that ‘kids don’t get arthritis’ and the first signs of painful or swollen joints can often be dismissed as growing pains.”

“Sadly, this means I often see families too late when they’re already suffering with daily pain and risking permanent damage to joints which could be prevented with early detection and treatments. The new program is a welcome intervention to help us prevent grave yet familiar situations for children with JA, including daily pain and permanent disability.”

The program follows results of the 2023 nationwide IMPACT study commissioned by Jafa and carried out by senior researchers at the University of Sydney, which revealed the urgent need for more timely diagnosis and the widespread impact that JA has on affected children and families in Australia.¹

Many families, young people and children living with JA experience mental and emotional distress, social isolation, poor quality of life, missed education and career opportunities, high financial costs and long term socio-economic disadvantage.¹ JA doesn’t end with childhood – half of all children diagnosed go on to have arthritis into adulthood.⁷ JA is often thought to be a rare disease but is one of the most common chronic diseases affecting young Australians, and is similar in prevalence to childhood diabetes and epilepsy.^{8,9} Families of children with undiagnosed JA face an especially complex journey to diagnosis, which can often be delayed due to multiple referrals, unnecessary, painful and invasive surgeries and medical investigations, incorrect diagnoses and limited specialist availability.¹⁰

For more information about JA, including resources for health professionals and families, visit <https://www.jafa.org.au/>

To hear from children living with JA, visit: <https://www.youtube.com/watch?v=5X7xbnAM5f4>

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About Jafa

The Juvenile Arthritis Foundation Australia (Jafa) is the primary organisation for children and young people with arthritis. Jafa is a registered charity, co-founded in 2019 by Professor Ruth Colagiuri AM and Professor Stephen Colagiuri AO 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 Arthritis (JA) and Childhood Rheumatic Diseases (CRD)

JA and CRDs are painful, incurable, inflammatory, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs. In Australia, there are approximately 6,000 to 10,000 children aged 0-16 years and up to 30,000 children and young people aged 0-24 years who are currently diagnosed with JA.² Further still, many more children remain undiagnosed and live in avoidable pain. If not diagnosed early and treated effectively, JA can cause permanent disability in the form of joint deformity and loss of vision. Other CRDs are less common but equally serious.

References

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