

MEDIA RELEASE

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## **PEAK BODIES ALIGN IN CONSENSUS STATEMENT ON JUVENILE ARTHRITIS AS NATIONAL STAKEHOLDERS CONVENE ON UNACCEPTABLE DELAYS IN DIAGNOSIS**

In the leadup to World Arthritis Day, 11 key health and allied peak bodies have aligned in a broad-based push to reduce critical delays in diagnosing the painful childhood illness Juvenile Arthritis, signing a consensus statement to be released at a National Stakeholder Forum in Parliament House, Canberra today (9 October).

The Consensus statement supports the goal of the Juvenile Arthritis Foundation of Australia (JAFA) and the Australian Paediatric Rheumatology Group (APRG) to reduce the current dangerous delays in the diagnosis of Juvenile Arthritis from 10 months to 10 weeks by 2030.

Juvenile Arthritis affects between 1 to 4 in every thousand Australian children<sup>1</sup>, about 6, 000 to 10-thousand children, and if not diagnosed promptly can lead to lifelong pain and disability.<sup>2</sup>

Signatories to the consensus statement include peak bodies - the Royal Australian College of GPs, The Pharmacy Guild of Australia, Medicines Australia, the Australian Primary Care Nurses, Optometry Australia, the Australian Physiotherapy Association and others.

The National Stakeholder Forum, to be attended by specialist and frontline health professionals, consumer advocates, Members of Parliament and Departmental officials, will refine and finalise action plans, tools and strategies to support GPs and other community healthcare professionals to recognise and refer juvenile arthritis before children progress to irreversible joint and eye damage and lifelong pain and disability.

The Forum has been convened by JAFA and will see the launch of the first phase of its federally-funded *Health Professional Support - Early Diagnosis Program*. The program will centre on a national communication and information campaign to alert GPs and other community health professionals using red flags and compelling messaging, linked to a comprehensive information hub with approved clinical guidance and professional information.

Jafa founder Prof Ruth Colagiuri said, “JAFA is proud to launch the first phase of this campaign which is set to save countless children who have undiagnosed juvenile arthritis now, or who will get it in the future, from a life of pain and being left behind educationally, socially and economically, and the accompanying mental health and financial impacts. We are very grateful to the Minister for Health and Aged Care, the Hon Mark Butler and the Albanese Government for listening and taking firm action on this previously neglected disease.”

Dr Ben Whitehead, Chair of the APRG said, “Awareness of juvenile arthritis is so low it’s not uncommon for children to have joint deformities or vision loss by the time they are referred to a paediatric rheumatologist. Early diagnosis and prompt referral are critical to getting children with arthritis treated before any damage occurs. The APRG wholeheartedly supports JAFA’s campaign.”

Chair of the RACGP Committee on Child and Youth Health, Dr James Best said, “GPs will welcome the support this Program brings to help them to diagnose this serious but neglected condition earlier.”

#### References

1. Sinnappurajar P, Chaitow J. Juvenile idiopathic arthritis - a new outlook. *Medicine Today* 2023; 24(10): 12-19.
2. AIHW 2023: <https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/juvenile-arthritis>

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**CONSENSUS STATEMENT attached**

**World Arthritis Day is on 12 October 2024**

## **About JAFA**

The Juvenile Arthritis Foundation Australia (JAFA) is the primary organisation for children and young people with juvenile idiopathic arthritis (JIA) and childhood rheumatic diseases (CRDs). JAFA is a registered charity founded in 2019 by Associate Professor Ruth Colagiuri AM and Professor Stephen Colagiuri OA. JAFA's key focus is on political advocacy to increase access to best practice health care and medications for affected children and young people and their families, and research for better treatments and ultimately a cure.

## **About Juvenile Arthritis**

JIA and CRDs are painful, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs. JIA/CRDs are estimated to affect some 6,000 to 10,000 Australian children aged 0-16 years making it similarly prevalent to childhood diabetes and epilepsy. 85% of children with JIA experience daily pain and suffer a high burden of permanent disability, time off school and lost educational opportunities, social and physical marginalisation, isolation, and mental ill health. Up to 20% will also have uveitis - an inflammatory eye disease that causes visual impairment, cataracts, glaucoma, and eventual blindness if not detected and treated early.

The average time from the onset of symptoms to a diagnosis of JIA in Australia is 10 months, with children seeing an average of four to five clinicians and undergoing unnecessary, expensive and painful investigations in the interim. For some children the delay is much longer, critically delaying the commencement of treatment and it is, sadly, not uncommon for a child to have permanent joint and/or loss of vision by the time they are diagnosed.

The treatment of JIA/CRDs immune-modulating medications, steroids and anti-inflammatories which can have serious short and long term side effects. Many children also require ongoing joint injections of corticosteroid injections under general anaesthetic and acute 'flares' of JA requiring medical attention and possible hospitalisation are common. As a result, all children with JA/CRDs require ongoing regular clinical monitoring and rapid access to specialist multidisciplinary teams (MDTs) is essential.