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MEDIA RELEASE

PRIME MINISTER RECOGNISES CHILDREN WITH JUVENILE ARTHRITIS WITH AFTERNOON TEA AT THE LODGE

Jafa welcomes the Prime Minister's support to raise awareness of juvenile arthritis, a debilitating but under-recognised childhood disease

Children living with Juvenile Arthritis, a painful and potentially disabling rheumatic condition, have travelled from around Australia to join Prime Minister Anthony Albanese and MPs for an afternoon tea at The Lodge, in Canberra.

The event is being regarded as significant progress in efforts by the Juvenile Arthritis Foundation Australia (Jafa) to raise awareness of the disease and increase specialist services to treat it.

Mr Albanese invited a group of 13 children, their parents and Jafa representatives to his Canberra residence, The Lodge, to hear first-hand how children are living with daily pain, struggling to keep up at school and having difficulty accessing the medical care they need.

"Jafa is delighted that the Prime Minister has today provided vital recognition of juvenile arthritis (JA) which affects up to 10,000 children in Australia but is virtually unrecognised," said Jafa's Chair Andrew Harrison. "For these children to be able to speak directly to Mr Albanese about living with juvenile arthritis is a huge step forward in the work we have been doing and goes a long way to helping put JA on the map. We are sincerely grateful to have the opportunity to engage with the highest level of political leadership with the aim of working together to help these children."

Jafa's founder, Associate Professor Ruth Colagiuri, said, "A diagnosis of juvenile arthritis can occur as early as 12 months of age and can mean a lifetime of pain and disability. Much of this burden could be avoided by earlier diagnosis and referral to specialist paediatric rheumatology services. This would ensure that no child remains undiagnosed until they develop disabling joint complications and loss of vision."

Dr Ben Whitehead, Chair of the Australian Paediatric Rheumatology Group said, "Australian services for children with arthritis fall well below paediatric rheumatology standards in other equivalent countries, and below Australian standards for other serious chronic childhood diseases so it's heartening to see the Prime Minister helping to raise awareness of the plight of these children."

In March this year, a landmark Parliamentary Inquiry into Childhood Rheumatic Diseases made 15 recommendations to the federal parliament including tripling the paediatric rheumatology workforce by 2030. The current shortage of specialist services means that many families must travel long distances to attend appointments. For example, there is currently no specialist rheumatologist in the ACT or Tasmania and, even in the major states, services for children with JA are limited.

Among the children Prime Minister Albanese met at The Lodge were:

Dannock: Tasmania

His parents noticed 10 yr old Harry was having trouble holding a knife and fork, his teacher noticed his handwriting was deteriorating, and his Karate teacher couldn't get him to clench his fist properly. His GP thought he might have juvenile arthritis and gave him a referral to a specialist. But there are no paediatric rheumatologists in Tasmania and after nearly eight months of being unwell and in pain, Harry was finally seen by a (adult) rheumatologist and put on treatment for his arthritis. He was also found to have uveitis, an inflammatory eye disease that occurs in about 20% of children with arthritis and which can cause loss of vision if not diagnosed and treated early.

Addison Sharp: Queensland

At age 16 and in Year 11, Addison has just had what usually only happens to older people and sometimes professional athletes – a knee replacement. In fact, her first knee replacement only a few months ago was unsuccessful and had to be redone. Since then, she has also had surgery on her jaw. Addison's mother says it took four years from Addison's first symptoms until she was diagnosed at the age of 6. That represents four years of missed medical treatment and care. Addison wants to be a paediatric rheumatologist but, in addition to her constant pain, these surgeries represent precious time away from school and study.

Willah aged 18 months: Regional Victoria

Aged 18 months, Willah started limping and crying when she stood. After an X-ray at the local hospital her parents told to monitor the swelling in her knee and ankles. Three weeks later, after more tests and physio and GP visits, Willah was referred back to the hospital where she had an (unnecessary) ankle operation which revealed no infection or injury. Willah was then referred to a Melbourne children's hospital where she was diagnosed with juvenile arthritis and treated with corticosteroid injections into her joints. She is now on strong medications daily, monthly blood tests and three-monthly eye checks. Like many families in regional Australia, Willah's parents have to make long, frequent and expensive trips to Melbourne for the specialist care their little girl needs.

"Children with juvenile arthritis deserve better" said Professor Colagiuri. "It's time to bring resources for this painful disease up to the same level as other similarly serious and prevalent childhood conditions. We sincerely thank the Prime Minister and Dr Mike Freeland MP for their foresight in recognising this and for helping to boost the visibility of these children."

JAFA is the primary organisation representing children with juvenile arthritis and their families in Australia and was named Emerging Non-profit of the Year in the 2021 Third Sector Awards.

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Link to Parliamentary Inquiry Report into Childhood Rheumatic Diseases:

https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/024921/toc_pdf/InquiryintochildhoodrheumaticdiseasesInterimreport.pdf;fileType=application%2Fpdf

Download video clips of children living with juvenile arthritis:

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

<https://youcanchangeachildslife.org.au/>

About Jafa

The Juvenile Arthritis Foundation Australia (Jafa) is a registered charity, established in 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 childhood rheumatic diseases which aims to:

- Raise awareness of juvenile arthritis (JA) among health professionals, politicians and governments, the education sector, the broader community, and potential funders.
- Lobby governments to provide optimal and accessible health care and support for children, adolescents and young people with juvenile arthritis and their families and carers.
- Influence and partner with government and private funders to invest in research into the causes, treatment, care, and a possible cure for juvenile arthritis.

Background

Juvenile arthritis (JA) and childhood rheumatic diseases (CRDs) are painful, incurable, inflammatory, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs. JA/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. 80% of children with JA 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. 20% of children with oligoarticular JA will also have uveitis - an inflammatory eye disease that causes visual impairment, cataracts, glaucoma, and eventual blindness if not detected early and treated JA carries a financial burden to families through additional costs and reduced employment.

In 50% of affected children, arthritis continues into adulthood accounting for tens of thousands of adults with severe disability. The average time from the onset of symptoms to a diagnosis of JA 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 thus critically delaying the commencement of treatment. It is not uncommon for a child to have permanent joint deformities, uneven limb lengths, disfiguring mandibular under-development and/or significant loss of vision by the time they are diagnosed.

The treatment of JA/CRDs aims to avert damage to joints, eyes, skin and organs by driving the inflammatory process into early remission through the use of powerful immuno-modulating medications, steroids and anti-inflammatories. These drugs can have serious side effects - lethargy, nausea, weight and hair loss, stomach ulcers, impaired growth and increased risk of infections. Many children also require ongoing joint injections of corticosteroid injections under general anaesthetic and acute 'flares' of JA requiring medical attention and 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.

Paediatric rheumatology services in Australia compare poorly with those in equivalent economies internationally, and with services for similarly serious and prevalent chronic childhood conditions within Australia and fall well short of published Australian and international standards. Consequently, JA/CRDs represent a major area of inequality and risk in the Australian health system.