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MEDIA RELEASE

RESEARCH FUNDING WELCOMED AS A START FOR HELPING CHILDREN WITH PAINFUL, UNDER-RECOGNISED JUVENILE ARTHRITIS

The Juvenile Arthritis Foundation Australia (Jafa) has welcomed the announcement of government research funding but has called for the immediate funding of vital medical care and support services for children with juvenile arthritis.

Health Minister Greg Hunt has announced an unprecedented \$21 million from the Medical Research Future Fund (MRFF) for 11 projects aiming at reducing pain and improving health outcomes for children with rheumatic and musculo-skeletal conditions - including \$5 million for juvenile arthritis. Several Jafa families were present as the announcement was made in Melbourne.

Jafa Chair Andrew Harrison said, "This very welcome research funding is vital to reducing pain and disability from these diseases. Jafa sincerely thanks the government for this funding allocation which will provide important evidence to guide more targeted and effective treatments over time.

Government funding is also urgently needed for immediate implementation of the recently released recommendations of a bipartisan Parliamentary Inquiry which identified alarming gaps in the care and treatment of juvenile arthritis – a largely neglected auto-immune disease affecting 6,000 to 10,000 Australian children".

The Parliamentary Inquiry which heard from over 130 families and organisations concluded:

"There is a chronic shortage of medical staff to treat these diseases, and on a per capita basis Australia has a third as many specialist doctors as the UK, and a quarter as many specialist nurses. Best practice care requires a multidisciplinary team that also includes physiotherapists, psychologists, and other allied health professionals, but we heard that such teams are basically non-existent in Australia.

These problems are compounded in regional and rural areas, where specialist care is confined to a few occasional clinics. The Committee heard of patients from places like Bourke, having to travel days for treatment every few months. In Tasmania and the territories, there is no specialist care at all.

Revolutionary new drugs have become available for these conditions in the past few years, but access is hindered by outdated PBS restrictions and the commercial challenges for drug companies servicing such a small market size in Australia."

Jafa founder A/Prof Ruth Colagiuri said, "These kids and their families have suffered enough. This landmark research funding is an excellent start in giving them a fairer go at life. And, as we approach the federal election, we have a perfectly timed blueprint delivered by a bipartisan Parliamentary Committee (March 31, 2021) to guide both Parties to commit to the ongoing action required. Jafa estimates that the cost of providing crucial solutions to longstanding problems affecting these children is insignificant in budgetary terms.

The call is supported by specialist doctors represented by the Australian Paediatric Rheumatology Group.

APRG Chair Dr Ben Whitehead said, “The APRG is delighted to see this much-needed research funding released. In addition, an urgent injection of resources is needed to bring care for Australian children with juvenile arthritis and rheumatic diseases to an internationally recognised standard and deliver a sustainable care path into the future to help these children live their best possible lives.”

Led by MPs Mr Trent Zimmerman and Dr Mike Freeland, the Inquiry’s recommendations aim to tackle persistent structural problems related to insufficient funding for specialist workforce capability and training. Specific recommendations include:

- Funding and training programs to triple the Australian paediatric rheumatology workforce to approach that of other developed countries by 2030;
- Establish a ‘hub and spoke’ model with outreach clinics for rural, regional and remote areas to ensure equitable care can be provided to all children with rheumatic disease in Australia;
- Better access to life-changing biologic medications.

Jafa is the primary body representing children with juvenile arthritis and their families in Australia and worked to initiate the Parliamentary Inquiry and access the first significant research funding for this painful, potentially disabling auto immune disease.

Ends

The Committee’s report can be seen here:

[Inquiry into childhood rheumatic diseases: Interim report – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases/Interim_report)

Jafa’s submission to the Parliamentary Inquiry (#102, and #102.1) can be found here:

https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases/Submissions

Families, Jafa representative and Paediatric Rheumatologists are available for interview

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Download video clip of children living with juvenile arthritis:

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

For more information: jafa.org.au

About Jafa

The Juvenile Arthritis Foundation Australia (Jafa) is a registered charity, established in response to the urgent need for a national voice dedicated exclusively to representing and addressing the needs of children and young people with arthritis and rheumatic diseases. It 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 these debilitating diseases 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.

About Juvenile Arthritis/Childhood Rheumatic Diseases

Juvenile arthritis (JA) and childhood rheumatic diseases (CRDs) are a group of 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 primarily prevalent to childhood diabetes and epilepsy and six times more common than cystic fibrosis. Despite this, awareness of JA is so low among health professionals that some children present with permanent joint damage and loss of vision at diagnosis. 80% of children with JA experience daily pain and suffer a high burden of permanent disability, time off school and lost educational opportunity, social and physical marginalisation, isolation, and mental ill health ranging from anxiety and depression to suicidal ideation. 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 many children the delay is much longer, up to two years or more, thus critically delaying the commencement of effective therapies. It is not uncommon for a child to have permanent joint deformities, uneven limb lengths, disfiguring mandibular underdevelopment and or significant loss of vision by the time they are diagnosed.

The treatment of JA/CRDs is highly complex. It aims to avert damage to joints, eyes, skin and organs by driving the inflammatory process into early remission through the use of powerful immunomodulating medications, steroids and anti-inflammatories. These drugs are administered orally, by injection or infusion or a mix of all three. All can have serious short and long-term side effects - lethargy, nausea, weight and hair loss, stomach ulcers, impaired growth and increased risk of infections. Many children also require ongoing joint aspiration and/or corticosteroid injections under general anaesthetic and acute 'flares' of JA requiring medical attention and hospitalisation are common. As a result, ongoing regular clinical monitoring and rapid access to specialist multi-disciplinary 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, falling well short of published Australian and international standards. Consequently, JA/CRDs represent a major area of inequality and risk in the Australian health system.