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MEDIA RELEASE

Jafa WELCOMES GROUNDBREAKING PARLIAMENTARY REPORT INTO CHILDHOOD RHEUMATIC DISEASES

Wide-ranging inquiry tables recommendations to address the national crisis in the shortfall of specialist services to treat and care for children with Juvenile Arthritis (JA) and Childhood Rheumatic Diseases (CRDs)

Jafa welcomes a landmark report, tabled in parliament today, *which sets out a series of recommendations to support up to 10,000 Australian children living with painful and potentially disabling Juvenile Arthritis.*

The report of the Parliamentary Inquiry into Childhood Rheumatic Diseases represents a line in the sand, giving formal recognition and action points to stop pain and disability in vulnerable young Australians with childhood rheumatic diseases.

Through its persistent advocacy on behalf of affected families, Jafa is proud to have been the instigator of the Inquiry and its important and long overdue national conversation. **Jafa looks forward to the federal, state and territory governments demonstrating their commitment to the Inquiry's recommendations by funding them appropriately at the earliest opportunity.**

Led by MPs Mr Trent Zimmerman and Dr Mike Freeland, the Inquiry has made 15 recommendations. They are necessarily ambitious and comprehensive in scope – tackling, for example, persistent structural problems related to insufficient funding for specialist workforce capability and training. Specific recommendations include:

- Funding to provide training programs to triple the number of paediatric rheumatologists in Australia by 2030;
- Establishment of multidisciplinary centres in major capital cities to support the expansion of allied health for paediatric rheumatology, including specialist nursing services; and
- Establishment of 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.

Dr Ben Whitehead, Chair of the Australian Paediatric Rheumatology Group (APRG), said, "This Parliamentary Inquiry is a long overdue examination of the plight of thousands of children and their families across Australia who are living with Juvenile Arthritis and other rheumatic diseases. This Inquiry has highlighted the severe workforce shortages across the country of the specialised health professionals required to deliver a standard of care comparable with other similar diseases. These shortages particularly affect children and families in rural and remote communities and disproportionately impact Indigenous children.



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“The APRG welcomes the Committee's recommendations released today and urges the Australian Government to invest in implementing the recommendations to make a brighter future for these children and prevent pain and long-term disability now and for the generations to come.”

Jafa Founder A/Prof Ruth Colagiuri said, “Underlying this crisis, has been the lack of community, political, and whole-of-health system visibility into the sheer scale of rheumatic disease prevalence in Australian children – currently estimated at 6,000 to 10,000 children. For too long these insidious diseases have been devastating children and their families, and impacting the national economy in largely untold and unseen ways.

“Because of this, care for these children in Australia compares poorly with those in equivalent economies internationally, and with services for similarly serious and prevalent chronic childhood conditions within Australia. To date, as a nation, we have been failing these children: we fall well-short of published Australian and international standards. Consequently, JA/CRDs represent a major area of inequality and a risk in the Australian health system.

“Children with juvenile arthritis and childhood rheumatic diseases deserve better – it’s time to walk the talk and stop pain and disability from these diseases. These recommendations made by the Standing Committee are a significant milestone in that national awakening and journey.”

Jafa stands ready to continue working collaboratively with all levels of government, and through its strategic partnerships with the APRG, allied health professional associations, and the wider not-for-profit sector, to do its part in delivering real results on the ground for these children and their families.

The Jafa community sincerely thanks the Standing Committee on Health, Aged Care, and Sport, especially Mr Trent Zimmerman (Chair) and Dr Mike Freeland MP (Deputy Chair), for their empathy, rigour, and action towards changing the trajectory of JA/CRDs in Australia. Families with JA/CRDs are expressing new-found hope for their children’s future, and Jafa is excited at the prospect of assisting to make that hope a reality.

Jafa is the primary body representing children with juvenile arthritis and their families in Australia and was named Emerging Nonprofit of the Year in the 2021 Third Sector Awards.

Once tabled, the Committee’s report can be seen here:

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

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 and Paediatric Rheumatologists are available for interview

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Download video clips 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 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 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



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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 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.