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LAUNCH OF NATIONAL REGISTER OF JUVENILE ARTHRITIS

Australia's first national Juvenile Arthritis Registry (AJAR) has today been launched at an event in Parliament House in Canberra, representing an important milestone for children with the painful and disabling condition.

The registry is a partnership between Juvenile Arthritis Foundation Australia (Jafa), the Australian Paediatric Rheumatology Group and the Australian Arthritis and Autoimmune Biobank (A3BC)

Its establishment fulfils a key objective to gather accurate information about juvenile arthritis and to have a dynamic national registry, in line with other conditions such as childhood diabetes and cystic fibrosis. The registry will provide accurate information to inform efforts to secure improved services for children and young adults with JA and childhood rheumatic diseases.

Speaking at the launch, Jafa co-founder and director Professor Stephen Colagiuri AO said, "As well as leading paediatric rheumatologists, many parents have supported the registry project by providing comment and advice on the data to be collected and the consent process and ensuring meaningful consumer input into the registry. One of Jafa's contributions will be to facilitate and support self-enrolment through its social networks and continue to press for long term funding."

The registry was launched by Assistant Minister for Health Ged Kearney, Dr Mike Freeland MP and Anne Webster MP, with many parliamentary friends of arthritis in attendance.

The registry was a recommendation of last year's parliamentary inquiry into juvenile arthritis and is a significant platform to advance the work being undertaken by Jafa to fill serious gaps in diagnosis, care and treatment of children with the disease.

Media Contact: Felicity Moffatt 0418677701

Available for interview:

A/Prof Ruth Colagiuri, Mobile: 0408 648 235 Email: ruth.colagiuri@jafa.org.au

For more information: jafa.org.au

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

About Jafa

The Juvenile Arthritis Foundation Australia (Jafa) is the primary organisation for children and young people with arthritis. Jafa is a registered charity, founded in 2019 by Associate 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 and carers.

Jafa aims to

- Raise awareness of juvenile arthritis 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 arthritis and their families and carers
- Influence and partner with funders to invest in research into juvenile arthritis and childhood rheumatic diseases

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 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.