Children are the Future:

Prevent Pain and Disability in Children with Arthritis and Rheumatic Diseases

Juvenile Arthritis Foundation Australia
Pre-budget Submission
2022-2023

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JAFA Juvenile Arthritis Foundation Australia

Context

The Juvenile Arthritis Foundation Australia (JAFA) thanks the Assistant Treasurer for the opportunity to make a Pre-Budget Submission.

JAFA also wishes highlight current contextual matters that impact or relate to its submission ie:

1. The House of Representatives Standing Committee on Health Aged Care and Sport is currently conducting a Parliamentary Inquiry into Childhood Rheumatic Diseases of which juvenile arthritis is a major component.

2. JAFA's 'Early Wins' funding request in this Pre-Budget Submission, has been submitted to the Health Minister, the Hon Greg Hunt, and the Shadow Health Minister, the Hon Mark Butler as JAFA's Pre-Election Proposal 2022 - attached by way of information.

3. COVID-19. As we prepare this submission, JAFA is acutely conscious of the additional impacts of COVID (particularly the current Omicron variant) on the families of children with rheumatic/arthritis diseases. These impacts add mental and emotional stress, additional financial costs and practical difficulties for parents caring for children with COVID and/or having it themselves as they struggle to obtain scarce rapid antigen tests, vaccinations for their 5-11yr olds, make decisions about school attendance for their immune-suppressed child, and cope with reduced or lost income.

JAFA's Pre-Budget submission had been developed in consultation with and on behalf of children, adolescents and young people with juvenile arthritis/rheumatic diseases and their families from all over Australia. It is also informed by

- Consultation with consumer and professional organisations both in Australia and overseas, health care providers, and policy makers
- Published Australian and international standards of care
- Comparisons with specialist paediatric workforce and services in equivalent economies internationally.
- Comparisons with similarly serious and prevalent childhood diseases in Australia.

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The Juvenile Arthritis Foundation Australia requests that:

1. **The Australian Government provides $10 million** over the coming three years to the Juvenile Arthritis Foundation Australia to implement a small but important set of national programs capable of making a measurable difference to children and adolescents with juvenile arthritis and their families:

1.1 An Early Diagnosis Program to reduce pain and disability:	$3million
1.2 A National JA Schools Program for safe, supportive learning environments:	$6million
1.3 A National Registry and Essential Baseline Information:	$1million

Total to be expended in the 2022-23 budget:	**$4 million**

2. The Australian Government provides $750,000 over the coming three years to the Juvenile Arthritis Foundation Australia to build a digital community for parents and carers of children with JA to reduce isolation and stress, and promote self-help via a secure, nationally accessible, digital platform offering peer support, information education.

Total to be expended in the 2022-23 budget:	**$250,000**

3. The Australian Government invests $25 million of the 2022-2023 budget for the Australian Government Department of Health to:

3.1 Negotiate with and incentivise State and Territory Governments to begin upgrading and enhancing their paediatric rheumatology services toward meeting nationally and internationally accepted standards of care and;

2.2 Implement priority recommendations from the Parliamentary Inquiry currently being conducted by the House of Representatives Standing Committee on Health Aged Care and Sport.

Total to be expended in the 2022-23 budget:	**$25 million**

Background

What is juvenile arthritis?

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(1). There are many forms of juvenile arthritis /childhood rheumatic diseases of which juvenile idiopathic arthritis (JIA) accounts for approximately, 80%. Consequently, **the Juvenile Arthritis Foundation (JAFA) refers to them collectively as juvenile arthritis (JA).** Around 1in 4 children with JA will also get uveitis – a serious inflammatory eye disease that can cause loss of vision and is the commonest cause of childhood blindness in developed countries.

All forms of JA have in common the need for specialist paediatric rheumatology services provided by multidisciplinary teams of specialist paediatric doctors, nurses, physiotherapists, occupational therapists, podiatrists, psychologists, dieticians and ophthalmologists who specialise in uveitis.

Why is it a problem?

JA is estimated to affect some 6,000 to 10,000 Australian children aged 1-16yrs(1) making it similarly prevalent to childhood diabetes and epilepsy and six times more common than cystic fibrosis(2). 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(3,4). 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(1) to suicidal ideation(5). 20% of children with 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 out-of-pocket costs and reduced employment, and an as yet unquantified burden on the overall economy.

In 50% of affected children, arthritis continues into adulthood and is estimated to account for tens of thousands of young adults with severe disability(1). Adults whose arthritis began in childhood suffer an increased burden of both physical and mental health impacts compared with their counterparts whose arthritis started in adulthood. The impact includes:

- Lifelong pain and disability
- Joint damage/deformities often requiring joint replacement in people in their 20s and 30s
- Loss of vision up to and including blindness
- Mental health problems due to intractable pain, constant medical interventions and social stigma
- Reduced income due to inability to work and dependence on unemployment / disability pensions.

Social and geographic isolation and the daily demands of the care of JA are a source of stress and mental health problems for parents and siblings as well as for the affected child. Geographic isolation plays a considerable role for families in rural and remote Australia. However, many parents even in major cities, have never met another family with JA and report feeling alone, anxious, and isolated.

Why invest in children with arthritis?

There are three compelling reasons to invest in children with juvenile arthritis:

1. **Humanitarian grounds to relieve childhood suffering as shown in this 3 minute video** https://youcanchangeachildslife.org.au/, **along with the need to educate, inform, connect, and alleviate isolation and stress among parents and carers of children and adolescents with arthritis.**

2. **Juvenile arthritis currently represents a major area of inequality and risk in the Australian health system and a significant economic burden of lost productivity and dependence**
Reducing pain and averting disability from JA requires aggressive treatment with potent autoimmune suppressing drugs often used in the treatment of cancer in adults), steroids and anti-inflammatories. All these drugs can have serious side effects (nausea, vomiting, hair loss, stomach ulcers, stunted growth) and must be carefully balanced to preserve normal growth and development. The paediatric rheumatology workforce in Australia lags dangerously behind international comparators from equally developed economies(6). Waiting times are long, public clinics are unacceptably overcrowded and access to advice between clinic visits is severely limited.

   In around 50% of all children arthritis continues into adulthood bringing with it a high burden of need for health services (including joint replacements), permanent disability (joint deformity, loss of vision), mental ill health**(1)**, and associated dependence on pensions, disability services, and lost productivity through inability to work full time or at all.

3. There are solutions?

There is ample evidence that access to early diagnosis and treatment to induce early remission can vastly improve outcomes and reduce, or even prevent disability(7). These **solutions do not require expensive, high-tech equipment. Rather, they rely on a well skilled and accessible specialist multidisciplinary paediatric rheumatology workforce** delivering best practice care, and supporting primary-care physicians and relevant non-rheumatology health professionals to provide general care and services. Best practice care to optimise outcomes also relies on the availability of accurate and current data to inform policy and practice and provide feedback on progress.

Early wins that would begin to have an impact within 12 months:

- A national JA early diagnosis program
- A national JA schools program
- A national JA registry and essential baseline information

Build digital communities to connect parents and carers, bridge isolation and provide peer support.

Turning the tide: mid to longer term wins can be accelerated by the Australian Government investing in negotiating and incentivising State and Territory Governments to bring their paediatric rheumatology services into line with nationally and internationally recommended standards.

Children are the future, it's time to stop pain and disability in children with arthritis

Budget Request 1: Early Wins

The Juvenile Arthritis Foundation Australia requests that:

The Australian Government provides $10 million over the coming three years to the Juvenile Arthritis Foundation Australia to implement a small but important set of national programs capable of making a measurable difference to children and adolescents with juvenile arthritis and their families:

1.1 An Early Diagnosis Program to reduce pain and disability:	$3 million
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Total to be expended in the 2022-23 budget:	**$4 million**

Why?

Late diagnosis: 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(8,9). For many children the delay is much longer thus critically delaying the commencement of effective therapies. As a result, 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(3,12). **Working with general practitioners to decrease the average delay in diagnosis from 10 months to 10 weeks or less is feasible,** as indicated in the UK NHS standards for referral to specialist paediatric rheumatology services (10) **and would substantially reduce pain and long-term disability and their devastating consequences**.

Low awareness of JA and discrimination in schools: Access to education is critically important to optimising health and socioeconomic outcomes over the life-course. Many children with JA experience excessive time out of school due to pain, illness, appointments and treatments and side effects. There is evidence of widespread active and passive discrimination against schoolchildren with JA(5). This includes social exclusion, stigma, shaming and even punishments for physical limitations, being left behind academically due to disease related school absences and/or failure of schools to identify and address learning and mental health problems. Thesis consigns many children to avoidable lifelong socio-economic disadvantage, marginalisation, and dependence**.** **A National Schools Program for safe and supportive learning environments for children with JA is eminently feasible as illustrated by the highly successful Diabetes Australia Schools Program** which provides an excellent precedent and model.

Lack of essential baseline information: There are fundamental gaps in essential baseline information about JA. For example, there is no national registry for JA to understand prevalence and track changes over time despite these being commonplace for other similar childhood diseases (eg diabetes, cystic fibrosis). There is an equally urgent need for baseline surveys to generate current and accurate data on the extent of JA-related disability, mental health impacts, and the cost to families, the health and disability sectors, lost productivity and the broader economy. This information is essential to inform health policy, planning, funding decisions and service development.

Budget Request 2: Digital Communities for Parents

The Juvenile Arthritis Foundation Australia requests that:

The Australian Government provides $750,000 over the coming three years to the Juvenile Arthritis Foundation Australia to build digital communities to reduce isolation and stress among parents and carers of children with JA via *ParentsPeerConnect* - a secure, interactive, national, digital 'village green' offering peer support, real-time chat functions, and providing information and education, tools, tips and resources for the home management of JA.

Total to be expended in the 2022-23 budget:	**$250,000**

Why?

Caring for a child with JA places considerable demands on parents and carers resulting in psychological distress compared with parents whose children without the condition(11) and leads to reduced social interaction and role restrictions. Home management of JA invariably impacts on family dynamics and restricts family activities. Parents of children with JA are more likely to report health problems, family conflict and stressful life events. Mothers are particularly vulnerable experiencing higher levels of stress and depression. Strain on siblings(12) from concern about the possibility of developing JA themselves, troubled relationships with the ill sibling as well as with their parents, resentment about the extent of time and attention spent accommodating the unwell child, and competing for parental attention.

Geographic and social isolation: In countries, such as Australia, with a large landmass and relatively small and unevenly distributed populations, geographical isolation is endemic and has substantial negative impacts on access to health services, disease-specific home care information and education, and peer support as well as financial disadvantage. Consequently, JAFA has received myriads of requests from parents in rural and remote Australia to be put in touch with other JA families. Even in cities, social isolation from peers is a commonly cited deficiency by parents of children with JA, many of whom report never having met another family living with JA.

There are successful precedents. *ParentsPeerConnect* will be modelled on JAFA's successful KidsConnect Program which links 7-17 year olds with JA across Australia in a secure virtual 'playground' via popular interactive digital platforms (Minecraft and Discord). *ParentsPeerConnect* is conceptualised as a digital 'village green' ie a personal network connecting parents and carers of children with JA in communities of interest (eg geographic location, age of child, disease stage, treatment types) providing interaction a peer support with someone who has 'been there'. It will also provide access to education and disseminate information about critical issues in JA care and research via its own youtube channel.

ParentsPeerConnect is eminently scaleable*.* While initially developed to support parents and carers from the time of their child's diagnosis throughout childhood and adolescence, the program it can be easily upscaled to include resources for older teens and young adults with JA.

Budget Request 3: Turning the tide

The Juvenile Arthritis Foundation Australia requests that:

The Australian Federal Government invests $25 million of the 2022-2023 budget for the Australian Government Department of Health to:

3.1 Negotiate with and incentivise State and Territory Governments to upgrade and enhance their paediatric rheumatology services toward meeting nationally and internationally accepted standards of care and;

3.2 Implement priority recommendations from the Parliamentary Inquiry currently being conducted by the Standing Committee on Health Aged Care and Sport.

Total to be expended in the 2022-23 budget:	**$25 million**

Why?

Australian paediatric rheumatology services fall well short of published Australian and international standards (7), comparing poorly with those in equivalent economies internationally(6,10,13); and with services for similarly serious and prevalent chronic childhood conditions within Australia.

There are no specialist paediatric rheumatology services for JA in Tasmania, the ACT or the NT. The NSW public sector has only 1.1FTE paediatric rheumatologist and 1.0 FTE paediatric rheumatology nurse for 3,000 children with JA. The sparse Australian paediatric rheumatology workforce is concentrated in capital cities (with the exception of Hobart, Canberra and Darwin were there are none) and outreach services to regional centres are scarce forcing countless families to travel long distances and incur associated stress, financial costs, and lost income/productivity. NSW and South Australia do not meet the qualified paediatric rheumatologist FTE equivalence required to provide traineeships for new paediatric rheumatologists.

The treatment of JA is aggressive and 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 immune-suppressing 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, stunted growth. 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 is critical.

Children are not just small adults nor are adolescents just large children. Each has their own physiological and emotional needs, dictated by their constantly developing bodies and brains, which must be considered and balanced with all treatment/s at all times. Thus, it is essential that providers of clinical care and support for JA have in-depth, specific training in paediatrics as well as in rheumatology.

In their own words quotes from parents and children

‘Every fortnight we have to drag her screaming from under the bed and hold her down while we give her injection - it’s a large dose and it does really hurt her’ (father of 4yr old Mathilda).

‘We fought for almost a year to get Archie diagnosed. His GP insisted it was just growing pains. By the time he was diagnosed one leg was quite a bit shorter than the other and he kept tripping over.’**(mother of Archie now 8, diagnosed at age 3)**

‘She gets a lot of nausea and not just on her medication day. Our paed rheum’s concerned about her nutrition and weight loss. She has uveitis too, so we do the 6 times daily steroid drops as well’ (mother of 8yr old Shani).

‘Mummy, it would be better if I hadn’t been born’ (5yr old Keogh diagnosed aged 1yr).

‘The local hospital won’t do her infusions so we do the 4 hour drive to Brisbane every month. We have family to stay with but it’s still costly and very stressful for her and the whole family and we have to take 2 days off work every time’. (mother of 6yr old Alicia).

‘She had a stomach ulcer from her anti-inflammatories. She’s only 13 and I worry about what the future holds for her’ (mother of 13yr old Erika).

‘He’s in pain all the time. His doctor’s changed meds so many times but nothing seems to help. How am I going to tell him there’s an 8 week wait for the plain clinic?’ (mother of 7yr old Xavier).

Dr Ken, please cut my leg off, just cut it off, I’d be better off without it.’ (15yr old boy with JIA)

She’s had one cataract operation due to her uveitis, but they can’t operate on the other eye and I’m so scared she’ll go blind (mother of 8yr old Tilley).

She got a detention for low attendance at school. How bizarre is that? She was sick and having medical appointments and joint injections. Besides, what 6yr old has any control over whether they go to school or not?’ (mother of 6yr old May Lin)

‘She was only one when she was diagnosed. She has uveitis and we’re worried about her vision. It's so hard to see her go through all that she has to endure. And I can’t work because there’s so much that needs to be done for her (mother of 10yr old Alyanna diagnosed age 1).

‘We used to fly from Alice to Adelaide for his treatment but he’s on strong immune-suppressants and gets every infection going so since COVID we do it by car. It takes the whole week and the driving is really tough on him especially when his joints are so sore’ (mother of 6yr old Toby).

Her teacher doesn’t believe she can’t sit cross-legged on the floor like the other kids. No wonder she’s become so anxious’ (mother of 7yr old Rushika).

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About JAFA

The Juvenile Arthritis Foundation Australia (JAFA) is a fully registered national charity. It was founded in 2019 in response to the urgent need for a national voice dedicated exclusively to voicing, advocating for and addressing the needs of children, adolescents and young people with arthritis and related rheumatic diseases (referred to collectively by JAFA a juvenile arthritis) and their families and carers.

JAFA provides direct services to parents, children and young adults in the form of support groups, regular online symposia on topical management and research issues in JA, and a secure, digital play space, KidsConnect, to provide peer support and reduce isolation. However, its core focus is on political advocacy to raise awareness of JA among high level policy makers in order to effect systemic and sustainable change to improve the lives of children and young people with JA. Implicit in this is connecting the JA community and raising awareness among health professionals and the community.

JAFA is the primary body representing children with JA and their families in Australia and was named Emerging Non-Profit of the Year in the 2021 Third Sector Awards.

JAFA operates to a three point, fine year plan and ensures exemplary governance, compliance and strategic capability through a highly credible Board, an experienced CEO, an expert Medical & Scientific Panel, and the pro bono services of MinterEllison and Deloitte.

Board of Directors

Victoria Allen - Board Chair and Director responsible for Governance and Compliance

Associate Professor Ruth Colagiuri - Founder and Director responsible for Strategy and Policy

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