

Change Lives

Stop Pain and Disability in Children with Arthritis

A proposal from

The Juvenile Arthritis Foundation Australia (JAFA)

JAFA is a registered charity established to voice, advocate for and address the needs of children and adolescents with juvenile arthritis/childhood rheumatic diseases.

 Awareness



 Access



 Evidence



Just \$10million can help change these children's lives

She has the back of a ~~7~~ 70 year old

He ~~can~~ can't run fast

She sleeps ~~9~~ 4 hours a night

She wants to see ~~Disneyland~~

He wants to play ~~sport~~ without pain

They want a fair go at life



What needs to happen to change lives and stop pain and disability?

Much can be done to reduce the impact of juvenile arthritis and stop pain and disability in affected children and young people. Increasingly effective treatments are available and, although it is not yet possible to prevent or cure this painful disease, there is overwhelming evidence that early diagnosis and treatment to induce early remission can vastly improve outcomes and reduce, or even prevent the risk of disability ⁽¹⁾.

Why invest in children with arthritis and rheumatic diseases?

Juvenile arthritis/childhood rheumatic diseases (referred to hereafter as juvenile arthritis) are a group of painful, incurable, inflammatory, autoimmune conditions affecting the joints and eyes and, in some cases, the skin and internal organs ⁽²⁾.

Juvenile arthritis (JA) affects some 6,000 to 10,000 Australian children and adolescents aged 1-16yrs ^(2,3) making it similarly prevalent to diabetes and epilepsy in children and six times more common than cystic fibrosis. Despite this, awareness of JA is so low among health care providers that some children present with permanent joint damage and loss of vision at diagnosis ^(4,5). 80% of children with JA experience pain daily and suffer a high burden of permanent disability, lost educational opportunity and limited participation in social and physical activities. They also suffer mental health impacts ranging from anxiety and depression ^(2,4) to suicidal ideation ⁽⁶⁾. In 50% of children, arthritis continues into adulthood, accounting for thousands of young adults with severe disability ⁽²⁾. 20% of children with oligoarticular JA will also have uveitis – an inflammatory eye disease that causes visual impairment and eventual blindness if not detected and treated.

“80% of children with JA experience pain daily and suffer a high burden of permanent disability, lost educational opportunity and limited participation in social and physical activities. They also suffer mental health impacts ranging from anxiety and depression to suicidal ideation.”

The treatment of JA is highly complex, involving the use of powerful immune-suppressing medications, steroids and anti-inflammatories that can have serious short and long-term side effects. Further, intermittent acute flares of JA are common, requiring medical attention and often hospitalisation. As a result, children with JA require ongoing clinical monitoring and rapid access to specialist multidisciplinary teams. A typical team is made up of paediatric rheumatologists, specialist nurses, physiotherapists, occupational therapists, psychologists, dieticians and social workers, as well as ophthalmologists trained to detect and treat uveitis.

Paediatric rheumatology services in Australia compare unfavourably with benchmarks from similar economies internationally ⁽⁷⁾ and fall well short of published Australian and international standards ^(8,9). Consequently, JA represents a major area of inequality and risk in the Australian health system.

What is Jafa requesting?

Jafa is requesting Federal Government funding of \$10million over the next three years 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:





Awareness

APPROACHES



Primary care

Other health professionals

Community

Politicians & policy makers

What? A National Early Diagnosis Campaign: from 10 months to 10 weeks

Cost? \$3 million over 3 years

'We fought for almost a year to get Archie diagnosed. His GP insisted he just had growing pains. By the time he was diagnosed one leg was quite a bit shorter than the other and he kept tripping over himself.'

Mother of Archie now 8, diagnosed at age 3

Why? To save children from life-long pain and 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^(10,11). For many children the delay is much longer, up to two years or more, thus critically delaying the commencement of effective therapies. Consequently, it is not uncommon for a child to have permanent joint deformities, uneven limb lengths, disfiguring mandibular underdevelopment or significant loss of vision by the time they are diagnosed^(4,5). Decreasing the average delay in diagnosis from 10 months to 10 weeks or less is feasible and would substantially reduce pain and long-term disability and their devastating sequelae.

How? Enhancing general practitioner awareness and skills by:

- Conducting a national communication and consultation campaign to raise awareness among, and engage general practitioners (GPs)
- Developing and implementing a Living Guideline on the diagnosis of juvenile arthritis*
- Liaising with peak GP organisations and leaders to identify opportunities and enablers
- Testing educational interventions in Primary Health Networks in two large and one small state
- Raising awareness among and providing tools and materials to support other health care professionals, consumers and the community in their interactions with GPs.

Enablers: There are published benchmarks and standards

- Standards and benchmarks exist to guide clinical practice and targets for JA
- There are precedents in other childhood disease areas
- Links with health professional activities currently being undertaken by Arthritis Australia
- The Australian Paediatric Rheumatology Group (APRG) will partner with Jafa on GP clinical matters and training
- The Australian Government Department of Health (AGDH) Chronic Conditions Section and Jafa are ideally positioned to lead this program.

Benefits: A reduction in pain, disability and lifelong dependence

- Earlier remission
- A reduction in permanent joint and eye damage and long-term disability
- Improved mental health outcomes
- Increased school attendance and subsequent education and employment opportunities
- Less parental time off work
- Less impact on family income
- A reduction in dependence on disability and mental health services and pensions.

*This would be in addition and separate to the current Living Guideline for Juvenile Idiopathic Arthritis which targets paediatric rheumatologists and focuses on specialist clinical management of JIA.



Access

APPROACHES

- Safe & supportive learning environments
- Expert multidisciplinary teams
- Effective drugs & therapies
- Emotional & mental health support

What? A National Schools Program

Cost? \$6 million over 3 years

“She got a detention for low attendance. 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 6 year old May Lin

Why? To ensure safe and supportive school environments and that no child with arthritis suffers discrimination or is left behind

Access to education is critically important to optimising health and socioeconomic outcomes over the life-course. During term time, children spend more waking time at school than home. The school environment sets lifelong patterns, not only of learning, but of physical, mental, emotional and social development, and behavioural responses, and is especially critical for children with limitations such as those imposed by JA. There is evidence of widespread active and passive discrimination against schoolchildren with JA⁽⁶⁾. This includes social exclusion, shaming and even punishments for physical limitations, being left behind academically due to disease related school absences and/or failure to identify and address learning and mental health problems. These impacts have serious consequences for long term socio-economic disadvantage, marginalisation, and dependence.

How? Implement a National Schools Program for Juvenile Arthritis

- Consult with families, school staff, peak health and education organisations, health professionals and their relevant organisations (eg APRG and the Australian Paediatric Society), and State and Territory government education departments to identify the issues and develop solutions
- Engage State and Territory health and education departments, principals' associations, and teachers to interpret and define what duty of care legislation means for schools in relation to JA and how that duty of care can best be fully implemented.
- Provide systems-wide information, training, tools, and mechanisms for principals and school staff to acquire and maintain the skills necessary to support children with JA at school.
- Develop and maintain an online portal to consolidate and co-locate messaging, resources, tools and training, and ensure consistent, efficient long-term monitoring and updating of content materials.

Enablers: A current successful precedent exists

- The highly successful Diabetes Australia Schools Program provides an excellent precedent and model for a JA Schools Program.

Benefits: Better outcomes for children, parents, schools and teachers

- Improved school and educational experience for schoolchildren with JA
- Greater engagement of children with JA in all aspects of school life
- Less time off school
- Earlier identification and management of learning and mental health difficulties
- Improved post-school educational and employment opportunities over their life course
- Reduced stress and concerns for parents
- Improved awareness, confidence in dealing with JA, and job satisfaction among teachers
- Reputational enhancement for schools and community satisfaction with schools
- Collateral benefits may include earlier recognition of and referral for JA symptoms



Evidence

APPROACHES

- < Essential baseline information
- The lived experience
- Educational & behavioural
- Administrative data linkage
- Health services/care models
- Clinical & Translational
- Basic laboratory research

What? Essential baseline information

Cost? \$1 million over 3 years

She has joint injections under general anaesthetic in both ankles, wrists, elbows and thumb and multiple times in both knees. The injections aren't lasting very long anymore. I just wish she could have a break. I'm exhausted, I can only imagine how she feels'

Mother of 9 year old Amelia

Why? To understand the burden of juvenile arthritis

Jafa is highly appreciative of the recent MRFF allocation to childhood musculoskeletal conditions. However, there are fundamental gaps in foundational baseline information about JA that are:

- i) unlikely to be addressed by research funded under the MRFF call and/or
- ii) too critical to be left to the chance they might be funded and/or
- iii) would be best overseen/led by Government or overarching organisations rather than located with a specific research group.

For example, there are currently little accurate national data on the prevalence of JA; the physical and mental health impacts; or the cost to families, the health and disability systems and the economy. This information is essential to inform policy and planning and to support and guide future health services and targeted research.

How? Gather vital baseline information via:

- Jafa-APRG National Juvenile Arthritis (minimum dataset) Registry to understand and document baseline and changes to prevalence, distribution and, over time, incidence.....\$450,000
- A national cost of illness (COI) baseline study to assess the cost of JA to families, the health system, and the economy.....\$200,000
- A national survey of the impacts of pain, time off school and social isolation on mental health.....\$200,000
- A comprehensive AIHW report to include new data sources available since the previous comprehensive report in 2008(\$200,000)*
- A national consensus on research priorities for JA, derived systematically to represent a combined perspective from consumers, clinicians, researchers, government and non-government research agencies.....\$135,000

Enablers: Precedents and models exist for Registries and COI studies

- The Jafa-APRG registry represents a co-consumer/clinical model for minimum dataset registries
- The AIHW Chronic Diseases Monitoring Unit is mandated to monitor and report on health data
- Jafa has the capability to commission and manage these projects and there are successful models from other childhood disease areas.

Benefits: Guidance for policy, planning and future research

Accurate, credible and comprehensive baseline information to:

- Guide health policy, planning and funding decisions for juvenile arthritis
- Provide a baseline for assessing changes over time and the effects of interventions
- Inform and interface with current and planned data linkage and other research initiatives
- Link with and provide entry point to existing biobanks
- Produce a multi-stakeholder consensus on priorities to inform future research

*Note: This cost would be to AGDH and is not part of the requested funds

References

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Policy alignment

The programs outlined in this proposal align with and complement activities relating to children in the National Strategic Arthritis Plan 2019. They also build on successful precedents in other childhood chronic disease areas and link with current or planned research. All have been consulted about widely with young people with JA and parents, medical and non-medical clinicians, and health policy experts. All stand to bring considerable benefits to children and adolescents with arthritis and related rheumatic diseases along with return on investment to the broader community.

About Jafa

The Juvenile Arthritis Foundation Australia (Jafa) is a fully registered national charity with DRG status. It was founded 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 arthritis and related rheumatic diseases (referred to collectively by Jafa a juvenile arthritis) and their families and carers.

While Jafa provides some direct services to children and adolescents with JA and their families, its core focus is on political advocacy and high-level policy to encourage 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 of the plight of these children.

A three-point, five-year strategic plan developed in 2020 by Directors and key (parent) volunteers, with additional input from the Jafa community via surveys and Facebook, guides Jafa's direction and activities. Additionally, Jafa has ensured exemplary governance, compliance and strategic capability through a highly credible Board supported pro bono by MinterEllison and Deloitte.

Board of Directors

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

Victoria recently stepped down from her role as a leading mergers and acquisitions lawyer and partner at MinterEllison to concentrate on Jafa and caring for her 12yr old daughter, diagnosed aged one year.

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

Ruth is a retired public health academic and honorary affiliate of the Menzies Centre for Health Policy and School of Public Health at the University of Sydney. She has a 9yr old granddaughter with JA.

Professor Stephen Colagiuri – Co-Founder and Director responsible for Medical and Research Matters

Stephen is Professor of Metabolic Health and Solutions Domain Leader at the University of Sydney's Charles Perkins Centre. He is a medical specialist in diabetes and has a 9yr old granddaughter with JA.

Tanya Dmitronow – Director responsible for Fundraising and HR

As a New York lawyer, Tanya specialised in shareholder litigation, regulatory investigations and corporate governance in the health, technology and financial-services sectors. She has a 6yr old with JA.

Andrew Harrison – Director responsible for Finance

Andrew is an experienced company director and corporate adviser. He is currently the Chair of WiseTech Global Limited and is also a Chartered Accountant. He has an 18yr old daughter with JA.

CEO

Angela McKay

Angela has over 20 years senior leadership experience spanning both the private and not-for-profit sectors. Prior to joining Jafa Angela spent 8yrs as COO of the Juvenile Diabetes Foundation Australia.

Legal and Governance

Garry Beath, MinterEllison, Sydney

External Auditor

Cheryl Kennedy, Deloitte Australia

Medical and Scientific Advisory Panel

- Dr Jeffrey Chaitow (Chair), Head, Paediatric Rheumatology, Sydney Children's Hospitals Network (SCHN)
- A/Professor Jane Munro, Paediatric Rheumatologist, Royal Children's Hospital, Melbourne
- Professor Davinder Singh-Grewal, Paediatric Rheumatologist, SCHN
- Dr Ben Whitehead, Director Paediatric Rheumatology, Queensland Children's Hospital
- Dr Sophia Zagora, Ophthalmologist and Uveitis Specialist, The University of Sydney

“Mummy, it would be better if I hadn't been born”

5 year old Keogh diagnosed aged 1 year

“She gets a lot of nausea and not just on her dose day. She's hungry but when she eats she feels sick. Her paed rheum's concerned about her weight loss. She has uveitis too, so we do the 6 times daily steroid drops as well.”

Mother of 8 year old Shani

“Every fortnight we have to drag her screaming from under the bed and hold her down while we give her injection.”

Father of 4 year old Mathilda

Dr Ken, please cut my leg off, just cut it off, I'd be better off without it.”

15 year 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 8 year old Tilley

“We used to fly from Alice to Adelaide for his treatment but he's on immune-suppressants and gets every infection going so since COVID we do it by car. It takes up the whole week and the driving is really tough on him especially when his joints are so sore.”

Mother of 6 year old Toby

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JAJA Juvenile Arthritis
Foundation Australia