

2024: Runs on the Board

A report on the activities and achievements
of the Juvenile Arthritis Foundation Australia in 2024



Five years on...



JAJA is deeply grateful to the dedicated parent volunteers who have supported it since its inception. Without their encouragement and conviction that change is possible, JAJA would not have flourished.

We also acknowledge the courage and resilience of our beautiful JAJA kids and young people. They light up our lives – it is a privilege to engage with them.

And heartfelt thanks to everyone who has supported JAJA in so many and varied ways to help give these remarkable children and young people a chance to live their best possible lives.

With your help, since its incorporation as a children's charity in 2019, JAJA's advocacy has:

2021

Leveraged MRFF grants totalling \$22 million for juvenile arthritis and musculoskeletal research

Seen it named Emerging Not-for-Profit of the Year in the Third Sector Awards

2023

Secured funding from the Australian Government for a two-year juvenile arthritis Early Diagnosis Program

2024

Achieved an investment of \$6.9 million by the NSW Government to expand and enhance NSW Paediatric Rheumatology Workforce and Services

2020

Achieved the first incremental increase in the NSW Paediatric Rheumatology Workforce

2022

Initiated a Parliamentary Inquiry into Childhood Rheumatic Diseases

Led to Prime Minister Albanese hosting a juvenile arthritis afternoon tea at The Lodge



Contents

From the Chair	4
Highlights of 2024	5
Early Diagnosis Program	6
• Announcement and Launch	6
• Call to Action and Communication Strategy	7
• Health Professional Hub	7
• Moving Right Along	7
Tripling the NSW Paediatric Rheumatology Workforce	8
Creating Coalitions of Support	9
• National Stakeholder Forum	9
• Consensus Statement on Reducing Delays in Diagnosis	10
• Priority Medicines Initiative	10
Research: On the Move	11
Celebrating and Supporting Our Young People	12
Out and About	13
• Around the Traps	13
• In the Media	14
• Building Community: Raising Awareness	16
First JAFA Hero Awards	17
Strategic Priorities 2023-2025	18
2025 and Beyond	19
About Juvenile Arthritis	20
About JAFA	21
Board, Patron, Staff and Advisors	22

From the Chair

As Jafa enters its sixth year, I am delighted to present this Report which chronicles the 'runs on the board' made for juvenile idiopathic arthritis (JIA) and related childhood rheumatic diseases (CRDs) in Australia during 2024.

The increasing national recognition and attention to JIA and related CRDs in 2024 and Jafa's growing influence and impact are illustrated by:

- The roll out of Jafa's federally funded national Early Diagnosis Program
- The National Stakeholder Forum and National Consensus to reduce delays in diagnosing JIA
- The release of the Inaugural Report on the Australian Juvenile Arthritis Registry
- Establishing the Priority Medicines Initiative to increase the range of available medications
- The NSW Government's investment in tripling the NSW Paediatric Rheumatology workforce.

I am encouraged by Jafa's increasing focus on engaging directly with children and young people with JIA and CRDs which was demonstrated in 2024 by initiating Young People's Roundtables and the appointment of our first Youth Ambassador. It was also pleasing to witness the remarkable uptake and influence of the results of Jafa's IMPACT Study of the personal burden of these diseases on individuals and families and their direct cost to governments.

Watching Jafa's continued growth in capability, confidence and influence, and its achievements towards improving the lives of children and young people with JIA and CRDs has been rewarding. So, it is fitting to introduce Jafa's 2024 Annual Report by thanking those who made this possible: my fellow directors, Jafa's donors, pro bono supporters, our collaborators, the JIA – CRD community, and Jafa's dedicated and hard-working staff and volunteers. We hope you will continue to support Jafa, in 2025 and beyond, to prosecute its ambitious agenda for making Australia a fairer place for affected individuals and families.

Jafa is also grateful to the federal and state governments, health officials, and individual politicians of all persuasions who are listening to and heeding Jafa's advocacy and supporting policies to bring the diagnosis and care of JIA and CRDs to an equitable level with comparable chronic childhood diseases.

And finally, we sincerely thank Her Excellency, Ms Sam Mostyn AC for her gracious agreement to become Jafa's patron.



Andrew Harrison

Chair, Juvenile Arthritis Foundation Australia
January 2025



Highlights of 2024

In 2024, its fifth year, with the help of its supporters, collaborators, constituents and volunteers, Jafa added several 'runs on the board' taking awareness of JIA and CRDs to new levels; making significant progress on its 2023-2025 Strategic Priorities; and engaging multi-stakeholders in achieving tangible improvements to the lives of young Australians with these diseases.

March 2024

The Hon Mark Butler Minister for Health & Aged Care launches the Early Diagnosis Program, the first stand-alone federal funding for a national JIA program



April 2024

Inaugural Report on the first 300 registrants in the Australian Juvenile Arthritis Registry is released



May 2024

Jafa is allocated a second year of federal funding for the Early Diagnosis Program

July 2024

The NSW Minister for Health & Regional Health, the Hon Ryan Park announces much-needed funding to triple the NSW paediatric rheumatology workforce



October 2024

National Stakeholder Forum and National Consensus on reducing delays in the Diagnosis of Juvenile Arthritis is released



October 2024

Jafa launches Priority Medicines Initiative for Juvenile Arthritis

November 2024

Jafa establishes its online information and education Health Professional Hub



November 2024

JIA's Got Talent: celebrates the courage, resilience and talent of young people with juvenile arthritis and related childhood rheumatic diseases



December 2024

Jafa celebrates 5th Anniversary since incorporation and announces the Governor General, Her Excellency Ms Sam Mostyn AC as its Patron



Early Diagnosis Program

Delays in the diagnosis of JIA averaging around 10 months for the past 25yrs or more have led to untold, and potentially avoidable, pain and disability. Now, with funding from the 2023-24 and 2024-25 federal budgets, and the co-operation of Australia's frontline health professionals, and paediatric rheumatology specialists, JAJA is re-writing a new and better history and diagnosis story for JIA.

ANNOUNCEMENT AND LAUNCH

Funded as a national program to reduce unacceptable delays in the diagnosis of JIA by supporting health professionals to recognise the signs and symptoms and when to refer, the program is now widely known as the Early Diagnosis Program. It represents the first-ever federal funding of this nature and magnitude for a stand-alone JIA Program and JAJA thanks the Health Minister and the Australian Government for listening to its advocacy about harms of undiagnosed JIA.

JAJA was honoured that the Minister for Health and Aged Care, the Hon Mark Bulter, joined our Parliament House, Canberra event in Juvenile Arthritis Week, March 2024, to announce and launch the Early Diagnosis Program. We also thank the Shadow Minister, the Hon Anne Ruston for her attendance and kind words, and Dr Mike Freeland MP for co-hosting the event on behalf of the Parliamentary Friends of Child and Adolescent Health and Mental Health. JAJA's guests at this landmark occasion included representatives from the professional target groups involved, professional and consumer arthritis organisations and JAJA children and young people from around Australia, proudly escorted by their parents, and looking resplendent in their crisp white JAJA t-shirts.



CALL TO ACTION AND COMMUNICATION STRATEGY



Diagnosing juvenile arthritis

CHILD under 16 years
STIFF, SWOLLEN, SORE JOINTS

SUSPECT JUVENILE IDIOPATHIC ARTHRITIS (JIA)

WHAT SHOULD I DO?

ASK ABOUT:
Morning stiffness
Joints affected
Duration

EXAMINE:
Joints
Movement
Vision

INVESTIGATIONS
There are NO definitive blood or radiology tests for diagnosing JIA.

CONTACT PAEDIATRIC RHEUMATOLOGIST / SERVICE

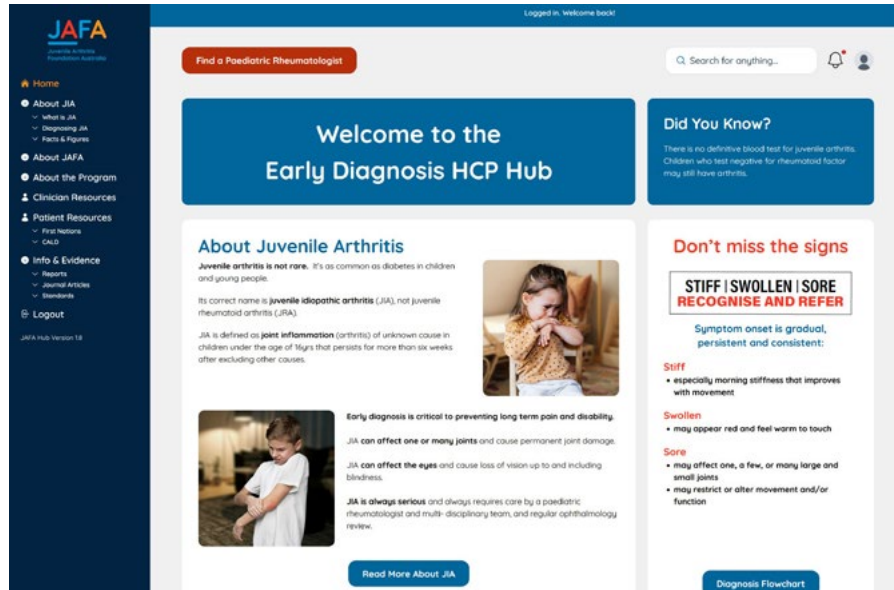
Learn more at jafa.org.au/hcpub

Juvenile arthritis - HCP's program received grant funding from the Australian Government.

After six months of extensive baseline investigations and consultation with the target groups, a nationwide communication strategy based on the call to action: *Don't Miss the Signs – Recognise and Refer* was launched in October 2024. As 2024 closes, this message is being rolled out via the Australian medical print and online press, through relevant professional organisations, Primary Health Networks and community action and is already making a difference.

HEALTH PROFESSIONAL HUB

The Early Diagnosis Program Communication Strategy is supported by a dedicated portal or 'Hub' on the JAJFA website. The Hub has been built for general practitioners, pharmacists, community nurses and other community health professionals to provide rapid and easy access to much needed current and credible information and resources for recognising and diagnosing JIA.



Resources include information about signs and symptoms, a diagnostic algorithm, videos, facts and figures, and a 'find a paediatric rheumatologist' function. Early monitoring and evaluation of the Hub shows excellent uptake, auguring well for increased knowledge and understanding of JIA among the target audience of frontline community professionals.

MOVING RIGHT ALONG

As the communication strategy rolls out nationwide, JAJFA is preparing to report on Year 1 of the Early Diagnosis Program and widen its scope in 2025 (Year 2) to include those specialist medical professional groups most likely to see children with JIA symptoms along their pathway to diagnosis. 2025 will also see an intensified focus on reaching First Nations and culturally and linguistically diverse health workers.

Tripling the NSW Paediatric Rheumatology Workforce

Workforce capacity is key to effective care ie ‘the right care in the right place at the right time’. State and territory governments are responsible for providing appropriate numbers, distribution and skills mix in the specialist workforce. In 2024, Jafa’s ongoing advocacy for action to redress the severe under-resourcing of paediatric rheumatology services in NSW was resoundingly rewarded.

In a landmark media release on June 17, 2024, NSW Health Minister, the Hon Ryan Park announced an historic investment of \$6.9 million to enable the NSW paediatric rheumatology workforce to deliver a comprehensive service to children and young people with JIA and related CRDs across the state, saying:

This investment will fund an additional six senior clinicians to deliver improved access to highly specialised care and ongoing monitoring for children with juvenile arthritis in NSW.

Announced on 2GB with (then) Drive Time host Chris O’Keefe who well understands the need due to his own experience of childhood arthritis, and in line with the 2022 (federal) Parliamentary Inquiry into Childhood Rheumatic Diseases, this investment will effectively triple the relevant NSW workforce and enhance access to care for children and young people with JIA and related CRDs across NSW.

Minister Park was generous in his public acknowledgment of the role of Jafa’s advocacy in bringing this largest-ever investment in Australian paediatric rheumatology services to fruition.



Creating Coalitions of Support

Leadership is the power of one harnessing the power of many.

John C Maxwell

The power of one is great but the power of many is greater so, in 2024, Jafa concentrated on nurturing its existing relationships and seeking new allies to create coalitions of support for action on JIA and related CRDs. The result was overwhelmingly positive, and we thank those organisations that are now raising awareness of JIA/CRDs in places Jafa could never have reached working alone.

NATIONAL STAKEHOLDER FORUM

Held in Parliament House Canberra on October 9, 2024, Jafa's National Stakeholder Forum was initially intended as a consultation for the Early Diagnosis Program but the combined energy and intellectual input of the assembled stakeholders quickly evolved it to a larger and broader scope. The 'power of many' was manifest in the diverse wealth and range of innovative ideas and experience generously shared by participants including:

- Parents and young people living with arthritis from around Australia
- Senior personnel from the Australian Government Department of Health and Ageing
- Professional and consumer arthritis organisations and paediatric rheumatologists
- The Royal Australian College of General Practitioners
- The Australian Primary Care Nurses Association
- The Pharmacy Guild and Pharmaceutical Society Australia
- Optometry Australia, Medicines Australia and others.

The invaluable insights and ideas generated by gathering this eclectic mix of stakeholders together is already informing the Early Diagnosis Program and Jafa's over-arching strategy more broadly. Jafa thanks our Parliamentary co-host, Dr Mike Freeland MP, and was honoured that both the Health Minister, the Hon Mark Butler, and the Shadow Health Minister, the Hon Anne Ruston, visited the Forum to address participants and were warmly encouraging of Jafa's advocacy.



CONSENSUS STATEMENT ON REDUCING DELAYS IN DIAGNOSIS

Having invited the Australian Paediatric Rheumatology Group to partner with it in this initiative, Jafa was delighted and proud to release the Consensus Statement on Reducing Delays in the Diagnosis of Juvenile Idiopathic Arthritis at the National Stakeholder Forum on October 9, 2024.

The 18 organisations approached pledged their support for reducing the average time to diagnosis of JIA from 10 months to 10 weeks by 2030 – strong testimony to the unprecedented awareness of JIA among Australian frontline health professional groups. Signatories also included leading arthritis organisations and other peak health alliances. And, as new organisations continue to add their signatures, this living document represents another ‘run on the board’ towards a fairer future for JIA in Australia.

Jafa
Juvenile Arthritis
Foundation Australia

APRG
AUSTRALIAN PAEDIATRIC RHEUMATOLOGY GROUP

Consensus Statement on the Diagnosis of Juvenile Idiopathic Arthritis

Released Australian Parliament House, Canberra - October 9, 2024

We, the undersigned, support the goal of the Juvenile Arthritis Foundation Australia (Jafa) and Australian Paediatric Rheumatology Group (APRG) to reduce current delays in the diagnosis of Juvenile Idiopathic Arthritis from 10 months to 10 weeks by 2030 in order to facilitate early intervention and access to treatment to reduce associated pain, disability, dependence, financial disadvantage, and mental ill health and optimise opportunities for children and young people with Juvenile Idiopathic Arthritis to live their best possible lives.

Arthritis Australia
Australian Multicultural Health Collaborative
Australian Physiotherapy Association
Australian Podiatry Association
Australian Primary Health Care Nurses Association
Australian Rheumatology Association
CreakyJoints Australia
Eczema Support Australia
Medicines Australia
Musculoskeletal Health Australia
Missing School
Occupational Therapy Australia
Optometry Australia
Pharmaceutical Society of Australia
The Pharmacy Guild of Australia
The Royal Australian and New Zealand College of Ophthalmologists
The Royal Australian College of General Practitioners
Zoe's Angels

PRIORITY MEDICINES INITIATIVE

The Priority Medicines Initiative addresses Recommendations 11 and 14 of the Interim Report of the 2022 Parliamentary Inquiry into Childhood Rheumatic Diseases which called for a review and concerted effort to expand the range of effective medications available for JIA/CRDs on the Pharmaceutical Benefits Scheme (PBS). Initiated by Jafa and co-led with the Australian Paediatric Rheumatology Group, the Priority Medicines Initiative was launched in Parliament House, Canberra, in the form of a workshop to review, prioritise and commence a multi-stakeholder dialogue to take the Initiative further.

The workshop was co-hosted by Dr Mike Freelander MP, in his capacity as Chair of the House of Representatives Standing Committee on Health, Aged Care and Sport, and attended by some 40 consumers (including young people), paediatric rheumatologists, representatives of the PBS bureaucracy, the Pharmaceutical Benefits Scheme Advisory Committee, the Therapeutic Goods Administration, Medicines Australia and relevant pharmaceutical companies. This was the first time these stakeholder groups had been brought together for such a purpose. The energy and good will were palpable, the discussion fruitful, and follow up action will be ongoing throughout 2025.

Research: On the Move

Fostering and leveraging funds for Australian researchers to find better ways of treating and caring for JIA and CRDs and, ultimately, a means of prevention and cure is one of JAJA's enduring long-term ambitions. While JAJA understands this journey will be long and arduous, and will require strong support from both government and private funders, the journey has indeed begun.

Australian Juvenile Arthritis Registry (AJAR) Inaugural Report

AJAR's Inaugural Report on the first 300 registrants was released during Juvenile Arthritis Week in March 2024. Launched in 2023, this JAJA-initiated minimum dataset national registry collects essential data on young Australians with JIA and related CRDs aged 0-24yrs to support health policy, planning and research and operates under a three-way partnership between JAJA, the Australian Paediatric Rheumatology Group and the A3BC Arthritis and Auto-immune BioBank. <https://bit.ly/40oCKQk>.



The Impact of JAJA's IMPACT Study

JAJA's IMPACT Study was the first comprehensive Australian study of the mental, physical and financial costs of JIA and related CRDs <https://bit.ly/3TRszAR>. Released in November 2023, the results of this much needed research were immediately taken up and used across multiple stakeholder groups. The widespread influence of this study was recognised in November 2024 by a Makers & Shapers Award from the Faculty of Medicine and Health at the University of Sydney.

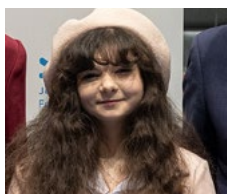
Emerging Australian Research

JAJA is delighted to be involved in JIA KidsLink, a five year, national, University of Sydney led research project to determine what happens to children with JIA in the health system and beyond by linking de-identified data on hospital admissions, medical and pharmaceutical services, education, mental health and disability. JIA Kids Link is one of several JIA projects in a round of Medical Research Futures Fund grants leveraged by JAJA under the previous federal Government in 2022. Another is the A3BC Kids CHAMPION Study which is exploring the potential of personalised approaches to JIA remission and coming off biologics.

We are also super-excited to witness and engage in the growing pockets of JIA research that are emerging around Australia and the increasing interest of academics, clinicians and families to become involved in research into JIA and related CRDs.

Celebrating and Supporting Our Young People

JAJA is unwavering in its dedication to improving the lives of children and young people with JIA and related CRDs but, until recently has engaged predominantly with parents. In 2024, we sought to engage much more directly with children and young people, continuing existing supports but more proactively seeking their perspectives and insights – a rewarding experience indeed.



First Youth Ambassador: announced October 2024

JAJA warmly welcomes 19-year-old Dayna Matchewson, who was diagnosed with JIA aged three. We thank Dayna and her mother Christina for their positive, open and pro-active approach and the wonderful contribution they are already making to awareness of JIA.

Kids Roundtables

In 2024 JAJA initiated in person and virtual Roundtables to engage with 10-20 year olds to hear their thoughts and perspectives first-hand. We were humbled by their maturity, resilience and humour in discussing the challenges of life with JIA-CRDs. JAJA is using the insights gained to guide its efforts to promote awareness and understanding. The Roundtables will be expanded in 2025.

KidsConnect

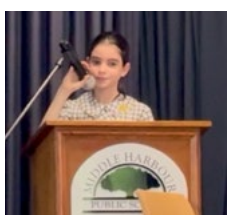


Under the expert guidance of JAJA's Digital Lead, Ben Laxton, this popular, purpose-built, secure online playing field continues to grow and flourish and provide a source of fun and a sense of belonging for 7-17 year olds who may be geographically or socially isolated or who just want to hang out with others who understand. Inquiries to: ben.laxton@jafa.org.au

Online Symposium Celebrating Our Inspiring Young People



After five years of online symposia for parents, JAJA focused its November 2024 symposium on Celebrating Our Young People: Celebrating 2024. This featured a champion skier; an actor/singer/songwriter, a cellist, a mountain biker, and a painter and finalist in the 2024 Young Archies. It was a privilege talking with these amazing young people about how they pursue their dreams despite the constraints of their condition. We thank them for sharing their inspiring stories. Visit www.jafa.org.au/jias-got-talent-celebrating-our-young-people/



Little things (and little people) are the big things: emerging advocates

JAJA is increasingly noticing children engaging in its awareness and fundraising activities and Harriette's story, although not an isolated one, illustrates this. As a result of her advocacy, Harriette, now aged 10 was invited to address her school assembly to explain juvenile arthritis to mark World Arthritis Day. She is pictured opposite, delivering her speech which she spent many hours preparing (unaided) using the JAJA website.

Harriette's effort was rewarded by donations totaling over \$300 and considerably increased awareness of JIA among her school's teachers, students and parents.

While the financial benefit of this exercise was welcome, the 'power of one', especially a small 'one', to change attitudes is invaluable and a good model for growing effective future advocates.

Out and About

JAJA was fortunate, in 2024, to enjoy wider and more personal interaction with the JAJA community of individuals and families living with JIA and CRDs, closer relations with the professional rheumatology community, and making new friends among an ever-widening circle of other relevant professional organisations.

AROUND THE TRAPS

New Zealand



Attending the May 2024 Australian Rheumatology Association Annual Scientific Meeting in Christchurch offered a wonderful opportunity to network with registrants who visited JAJA's stand in the Trade Hall, listen to researchers presenting the results of its IMPACT Study and swapping experiences with its other arthritis non-profit staff.

Canberra



JAJA very much appreciated attending Medicines Australia's annual PharmAus event in Parliament House as invited guests and stall holders, enjoying the opportunity to mix and meet new and renew existing acquaintances with pharmaceutical company representatives, politicians and their staffers, and other guests.

Fremantle

JAJA's Founders were pleased to be invited to speak at the Australian Paediatric Rheumatology Group's (APRG) Annual Spring Meeting in Fremantle in October 2024 about progress with the Early Diagnosis Program and took this opportunity to seek APRG members input and advice on next steps.

Perth



The October trip to Fremantle offered a welcome opportunity to visit Perth and meet with the local highly skilled and dedicated paediatric rheumatology team and to meet face-to-face for the first time with some of our JAJA families, and Arthritis WA.

Adelaide



An invitation in November 2024 to speak in a session of the Royal Australian College of Ophthalmologists Annual Meeting to raise awareness of uveitis (eye inflammation associated with JIA) was an unexpected honour. It also enabled JAJA's founders a rare and very welcome opportunity to meet and strategise with the Adelaide Women's and Children's Hospital paediatric rheumatology team.

IN THE MEDIA

Juvenile Arthritis Week

AFA's Juvenile Arthritis Week 2024 events (March 17-24), which included a fabulous event in Parliament House both offered unprecedented media opportunities to spread the word about JIA and related CRDs in the mainstream and medical press. We are conscious that it can be very emotional for parents and children to talk publicly about their personal experience of these intrusive diseases and sincerely thank them for their generosity in sharing their stories in this way.



Pharmacy Daily

Wed 20th Mar 2024



Dispensary Corner

IN A tale that smells more like a sour lemon than a sweet vanilla breeze, a US woman found herself in a sticky situation after a Bath & Body Works air freshener allegedly went kaboom in her car.

Kyndal Chandler took to TikTok to share her misadventure, complete with a hospital visit and a hefty ER bill.

In the viral video, Chandler can be seen nursing her eyes and showing off what appears to be a bleach-splattered car roof, courtesy of the explosive freshener fiasco.

With over 42 million views, Chandler's plight has struck a chord with fellow drivers, sparking a wave of sympathy

JA program to shorten diagnosis delays

THE Minister for Health and Aged Care, Mark Butler, today announced that the Australian Government is set to tackle the protracted delays in diagnosing Juvenile Arthritis (JA), a painful autoimmune disease affecting many children.

The newly unveiled program aims to arm pharmacists, general practitioners and other health professionals with critical clinical guidance and information from the peak Australian Paediatric Rheumatology Group.

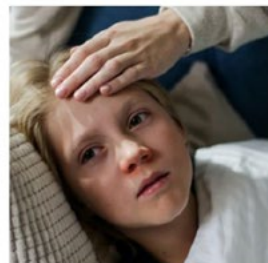
This initiative is designed to enhance awareness of JA's symptoms and diagnostic criteria, significantly reducing the time it takes to identify the condition and begin effective treatment.

Labelled as "unacceptable" by health experts, these delays have

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remained unchanged for over two decades, impacting up to 10,000 Australian families.

Currently, the journey to a JA diagnosis stretches an average of 10-11 months, a period that hasn't seen improvement in more than 20 years.

Butler said, "this delay not only exacerbates the daily suffering

of young Australians but also heightens the risk of permanent joint deformities, loss of vision, and lifelong dependence".

The program, titled 'Juvenile Arthritis: Early Diagnosis - Early Intervention Changing Children's Lives,' emerges in the wake of vigorous advocacy by the Juvenile Arthritis Foundation Australia and is a principal recommendation from a recent Parliamentary Inquiry into Childhood Rheumatic Diseases.

Dr Ben Whitehead, Chair of the Australian Paediatric Rheumatology Group, highlighted the low awareness and common misconceptions surrounding JA, emphasising that many believe "kids don't get arthritis".

This program seeks to dispel such myths and ensure early and accurate diagnosis. *JG*



Juvenile arthritis program aims to reduce delayed diagnoses

Advocates have welcomed the \$800,000 initiative, but warned a lack of specialist access means GPs have a major role to play.



An estimated 18,500-30,100 Australians aged under 24 are impacted by juvenile arthritis.

A landmark \$800,000 program will aim to dramatically reduce delays in the diagnosis of juvenile arthritis that are currently placing many children at risk of permanent disability.

Senator Anne Ruston's post

Senator Anne Ruston • 20 March 2024

More than 6,000 children across Australia suffer from the devastating and debilitating impact of juvenile arthritis.

That is why the launch today of Juvenile Arthritis Foundation Australia's national program focused on early diagnosis is so important.

We want all Australian children to enjoy a healthy life, which makes early diagnosis and treatment absolutely critical.



Dr Mike Freeland MP's post

Dr Mike Freeland MP • 20 March 2024

What a way to wrap up another busy week in Parliament: by announcing Federal funding to support over 30,000 Australian children living with juvenile arthritis!

This funding will provide health professionals with the resources and education they need to diagnose and provide care for these children.

A special thanks to the wonderful work of the Juvenile Arthritis Foundation Australia and to the Federal Minister for Health, Mark Butler MP, for their tireless work.



honey | latest

Royals Honey Loves

localagentfinder


FINDING THE RIGHT AGENT IS CRUCIAL

COMPARE FEES PERFORMANCE REVIEWS

Nine / 9Honey / Latest

Laura burst into tears every time her own mum hugged her: 'You really start to doubt yourself'

By Maddison Leach | 10 months ago



BUILDING COMMUNITY: RAISING AWARENESS

Jafa is grateful to the volunteer community fundraisers and the many people who supported them as they ran, rode, walked, and held awareness and gold coin donation days in schools across the country and “lit up Christmas”. Their contribution to Jafa is invaluable.

By participating in these events and spreading the word to their networks, community members raised awareness of JIA and CRD’s with hundreds of people across the country and, in the process, raising much needed funds that assist Jafa to continue to operate.

Jafa teams were seen at the City 2 Surf, Sydney; Sunshine Coast Marathon; The Lumary City to Bay Run; and individual cyclists Bay Ride and one mammoth Brisbane to Sydney Ride.

Every picture tells a story: celebrating community fundraisers and their supporters



Building community is about connections, shared experiences and support. As the Jafa community continues to grow there is nothing quite like coming together with other families experiencing JIA and CRD’s.



We salute the Family Hangout hosts and thank all the families who came together in locations around the country for Juvenile Arthritis Week in March and World Arthritis Day October 12.

First Jafa Hero Awards

Jafa has many things to be grateful for and many, many people to thank for the varied and unique ways in which they support our efforts to ensure that children and young people with JIA and related CRDs have the best possible chance of living their best possible lives. You are all heroes and we sincerely thank you for your wonderful support.

In 2024 we singled out two people who have made truly outstanding contributions to improving the lives of children and young people with these diseases to receive our first-ever Jafa Hero Awards. They are:



Dr Mike Freeland MP for his unwavering support and dedication to championing the cause of young Australians with JIA-CRDs since day one, and his tireless work on the 2022 (federal) Parliamentary Inquiry into Childhood Rheumatic Diseases – and beyond.



The NSW Minister for Health and Regional Health, the Hon Ryan Park for listening to Jafa’s advocacy and acting promptly and decisively to triple the NSW paediatric rheumatology workforce to provide children and young people across NSW access to the specialist care they need and deserve.

Strategic Priorities 2023-2025

JAJA's strong commitment to strategic planning has served it well, taking it from a fledgling NFP in 2019 to a nationally and internationally recognised influence in JIA and CRDs today. Reflecting on progress in 2024 highlights some truly exciting developments and remaining challenges.

JAJA STRATEGIC PRIORITIES 2023-2025

Priority 1

Juvenile arthritis is diagnosed within 10 weeks and referred to care by paediatric rheumatology teams.

Priority 2

Affordable best practice treatment, care and support is accessible to all children and young people with arthritis.

Priority 3

A prioritised and diverse consumer driven research agenda for juvenile arthritis is under way and funded.

Priority 4

All levels of government and the community are aware of juvenile arthritis and its financial & economic burden.

Priority 5

JAJA is an effective, respected, well-resourced, sustainable organisation optimally serving children and young people with arthritis and related rheumatic diseases and their families.

With its federally funded Early Diagnosis Program commencing in March 2024, JAJA's pursuit of its Strategic Priorities 2023-2025 is nowhere more apparent than in Priority 1. Unprecedented advances have already been made in this area and the publicly declared support of 18 key health organisations and alliances for reducing delays in diagnosis augers well for continued gains.

The 'pot of gold' for *Priority 2* was the NSW Budget commitment tripling the NSW paediatric rheumatology workforce. This was a direct result of JAJA's advocacy and a welcome affirmation that targeted, persistent but respectful advocacy to State and Territory governments to take up the call for equitable access to best practice care for affected individuals can be effective.

Priority 3 was bolstered in 2024 by the widespread uptake of the results of JAJA's 2023 IMPACT Study assessing the personal burden of JIA and CRDs which earned a University of Sydney Makers & Shakers Award, and by the release of the Inaugural Report on the first 300 registrants in the JAJA-initiated Australian Juvenile Arthritis Registry.

JAJA's consistent efforts on *Priority 4* have resulted in political recognition of JIA and CRDs reaching new levels. In 2024 three JAJA events held in Parliament House Canberra, attended by both the Health Minister, The Hon Mark Butler, and Shadow Health Minister, the Hon Senator Anne Ruston both of whom are warmly encouraging of JAJA's advocacy. These advances were crowned in 2024 by Her Excellency, Ms Sam Moystyn AC, consenting to become JAJA's patron.

While JAJA has rapidly become highly credible and respected in its sphere and the primary 'go to' organisation for JIA and related CRDs, it remains under-resourced. Despite significant success with grant funding, a lack of discretionary funding impedes progress in vital areas such as research and the provision of essential information, education and support for families – a challenge we will work hard to overcome in 2025 and beyond to fully achieve *Priority 5*.

2025 and Beyond

In 2025 Jafa will continue to be guided by its Strategic Priorities for 2023-2025 which articulate its core purpose and aspirations. Implicit in this is robust advocacy for an equitable health policy and practice environment to support children and young people with JIA and related CRDs to meet the challenges of their condition and live their best possible lives.

The future is unpredictable, but Jafa is well equipped to adapt and meet future needs and will work tirelessly to consolidate the remarkable gains made thus far and pursue its mission. In practical terms this means:

- Expanding the national Early Diagnosis Program to include the medical specialists most likely to see a child with arthritis on their way to diagnosis eg: general pediatricians, orthopaedic surgeons, sports doctors and ophthalmologists
- Fostering research by leveraging funding and initiating support to strengthen Australia's capacity to address the many deficiencies in our knowledge and understanding of JIA and CRDs and how to improve their treatment, care and outcomes
- Conducting concerted political advocacy campaigns around federal, state and territory elections
- Increasing the range of effective medications available on the PBS for JIA and CRDs
- Growing its influence and capacity for change by nurturing its current and highly valued partnerships and collaborations and building new strategic relationships
- Amplifying the consumer voice – especially the voice of young people – and seeking opportunities for the JIA-CRD community to participate actively and on equal terms in matters that affect them.

The Jafa Board and staff look forward with confidence, energy and enthusiasm to developing a new three-year strategy in 2025 to prepare and position Jafa to meet the challenges of 2026 and beyond and make Australia a better, safer place for children and young people with JIA and CRDs.

About Juvenile Arthritis

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. Juvenile idiopathic arthritis (JIA) accounts for approximately 80% of all CRDs with the remaining 20% made up of less common conditions such as systemic lupus erythematosus, chronic relapsing multifocal osteomyelitis and juvenile dermatomyositis.

JIA affects an estimated 6,000 to 10,000 children aged 0-16 years and up to 30,000 people aged 0-24 years making it one of the most common chronic diseases affecting young Australians.

Awareness of JIA among health professionals is so low that some children already have permanent joint damage and loss of vision at the time of diagnosis. Eighty five percent of children experience regular ongoing pain and many suffer a high burden of permanent disability, lost educational opportunity, social marginalisation, and mental ill health.

The treatment of JIA and CRDs is highly complex and involves the use of powerful immune-suppressants, steroids and anti-inflammatory medications, all of which can have serious short and long- term side effects. Many children also require frequent joint aspirations and /or steroid injections into affected joints under general anaesthetic. Many suffer unpredictable acute 'flares' of their disease.

Consequently, access to specialist multi-disciplinary paediatric rheumatology teams for clinical care and monitoring, self-care education and behavioural and psychosocial support, are essential for all children and young people with JIA and CRDs.

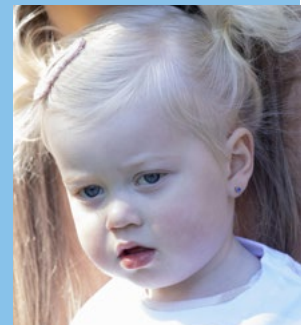
How does it feel?

PAIN

- Daily, often severe
- Many joints affected: ankles, knees, elbows, wrists, neck, jaw, fingers, toes, eye discomfort
- Disturbed/not enough sleep
- Lonely, depressing
- Prevents play and learning

DISABILITY

- Joint damage and deformities
- Loss of vision
- Can damage internal organs
- Reduces normal function: sitting, standing, walking, writing
- Prevents normal childhood eg: play, sport, family activities, socialising

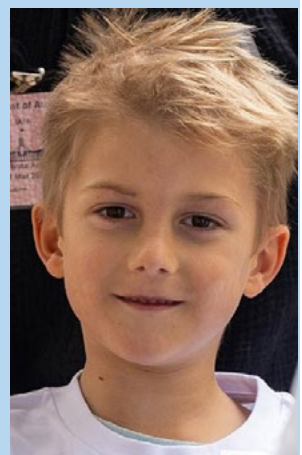


CONSTANT BATTLE

- Unpredictable flares eg: fine at breakfast – can't walk by lunch time
- Finding the right medication/s
- Time out and travel for appointments
- Additional impact on family budget
- Social exclusion and stigma
- Mental and emotional toll of pain, medical interventions and social isolation

NO CURE

- No cure or prevention
- Treatment aims to reduce pain, maximise mobility and prevent disability
- Involves steroids, immune suppressants, and anti- inflammatories
- Significant serious side-effects.
- Constant medical interventions
- Unpleasant tests and treatments eg: injections, infusions, general anaesthetics



About Jafa

The Juvenile Arthritis Foundation Australia (Jafa) is the primary organisation representing children with juvenile arthritis and related rheumatic diseases and their families in Australia and was named *Emerging Not-for-Profit of the Year* in the 2021 Third Sector Awards

Jafa is a fully registered national charity with DRG1 status founded in 2019 in response to the urgent need for a national voice dedicated exclusively to representing and addressing the needs of children, adolescents and young people with arthritis and related rheumatic diseases and their families.

Jafa provides direct services to children and adolescents with juvenile arthritis and related diseases and their families through support groups, regular online symposia on critical management and research issues, 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 among high level policy makers in order to effect systemic and sustainable change to improve the lives of children and young people with these diseases. Implicit in this is connecting the affected community and raising awareness among health professionals and the general community.

VISION



Our vision is a world where kids really don't get arthritis.

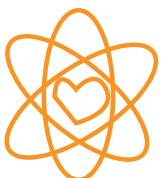
MISSION



Our Mission is to stop pain and disability in children with arthritis through:

- Earlier diagnosis, improved treatment, care and support
- Increased professional, community, and political awareness and advocacy
- Building communities of influence to fund vital research and programs

VALUES



Jafa strives to be an innovative, agile, effective and influential force that is:

- Unwavering in its dedication to meeting the needs of children and young people with arthritis, and rheumatic diseases, families and carers
- Open and transparent in all its dealings
- Strategic, and receptive to ideas and opportunities
- Sensitive to and respectful of diversity and differences
- A supportive collaborator

Board, Patron, Staff and Advisors



ANDREW HARRISON, BEC MBA (CHAIR)

Andrew is an experienced company director and corporate adviser having held non-executive directorships and executive roles with a range of public and private companies. Most recently, Andrew was the former Chair of ASX-listed companies WiseTech Global and Bapcor Limited. He has served as CFO of Seven Group Limited and Landis & Gyr and worked internationally as an investment banker and Chartered Accountant. He holds a BEc from the University of Sydney and an MBA from the Wharton School. He is a member of the Australian Institute of Company Directors. Andrew has a child with arthritis.



ARTI BROWN

Arti has over 20 years of experience in public policy and advocacy, regulatory affairs, governance, risk management and organisational design. Having worked across mining, telecommunications and more recently, finance, Arti currently drives Line 1 Risk Strategy, Governance and Operations as a General Manager at the Commonwealth Bank of Australia. Arti is a graduate of the University of Sydney and is a member of the Australian Institute of Company Directors. Arti has a daughter with Juvenile Arthritis.



RUTH COLAGIURI AM (FOUNDER)

Ruth is an Honorary Associate Professor of the University of Sydney's Leeder Centre for Health Policy, Economics and Data, and School of Public Health. She has worked in clinical care, health policy and health services research in the NSW hospital system, NSW Health Department and academia and led projects and commissioned work for AusAID, the WHO, and the OECD. Ruth is a former vice president of the International Diabetes Federation, Diabetes Australia and served on national and international advisory committees. Ruth has a grandchild with arthritis.



STEPHEN COLAGIURI AO (CO-FOUNDER)

Stephen Colagiuri is Professor Emeritus at the Charles Perkins Centre and Faculty of Medicine and Health at the University of Sydney. He is a medical specialist in diabetes and an active researcher. Stephen has worked in the Australian public and private health systems and university sector. He is an advisor to the WHO. He is a former president of the Australian Diabetes Society and former a vice president of the International Diabetes Federation. Stephen has a grandchild with arthritis.



TANYA DMITRONOW (DIRECTOR)

Tanya recently returned to Australia after nearly twenty years in New York and London. A partner at a leading New York law firm, she specialised in share- holder litigation, regulatory investigations and corporate governance, advising large public companies and board directors in the healthcare, technology and financial services sectors. She graduated from Bond University and New York University where she was a Fulbright Scholar. Tanya has navigated both the US and Australian health systems with young her child with arthritis.

JAJA's Patron



JAJA is honoured to welcome Her Excellency, the Honourable Ms Sam Mostyn AC, Governor General of the Commonwealth of Australia as its Patron. The Governor - General's patronage will be invaluable in raising awareness of juvenile idiopathic arthritis (JIA) and related childhood rheumatic diseases (CRDs) to new levels.

Staff



ANGELA MCKAY, CEO

Angela has over 20 years senior leadership experience spanning the private and not-for-profit sectors and extensive experience in disease-specific non-profits for children having served as COO of the Juvenile Diabetes Research Foundation prior to joining JAJA.



Ben Laxton
Digital Lead



Emma Richards
Program Manager



Gail van Heerden
Program Support



Pip Hooper
Fundraising

MEDICAL AND SCIENTIFIC ADVISORY PANEL

JAJA is fortunate to have access to expert guidance on medical and scientific matters from:

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

SUPPORTERS

JAJA is grateful for the pro bono contributions of:

- **Legal and Governance** – Garry Beath, MinterEllison, Sydney
- **Media and Publicity** – Felicity Moffat, Founder and Principal MD Media
- **Social media and Digital Technology** – Dr Shilo McClean, an expert in her field and mother of a young adult with juvenile onset arthritis
- **Health Policy and Strategy** – Associate Professor Christine Giles, Leeder Centre for Health Policy and Economics and Data, The University of Sydney
- **Communications** – Lisa McDermott, Director EngageComms.

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Jafa has DRG status
and is registered with
the Australian Charities
and Not-for-Profits
Commission (ACNC).



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