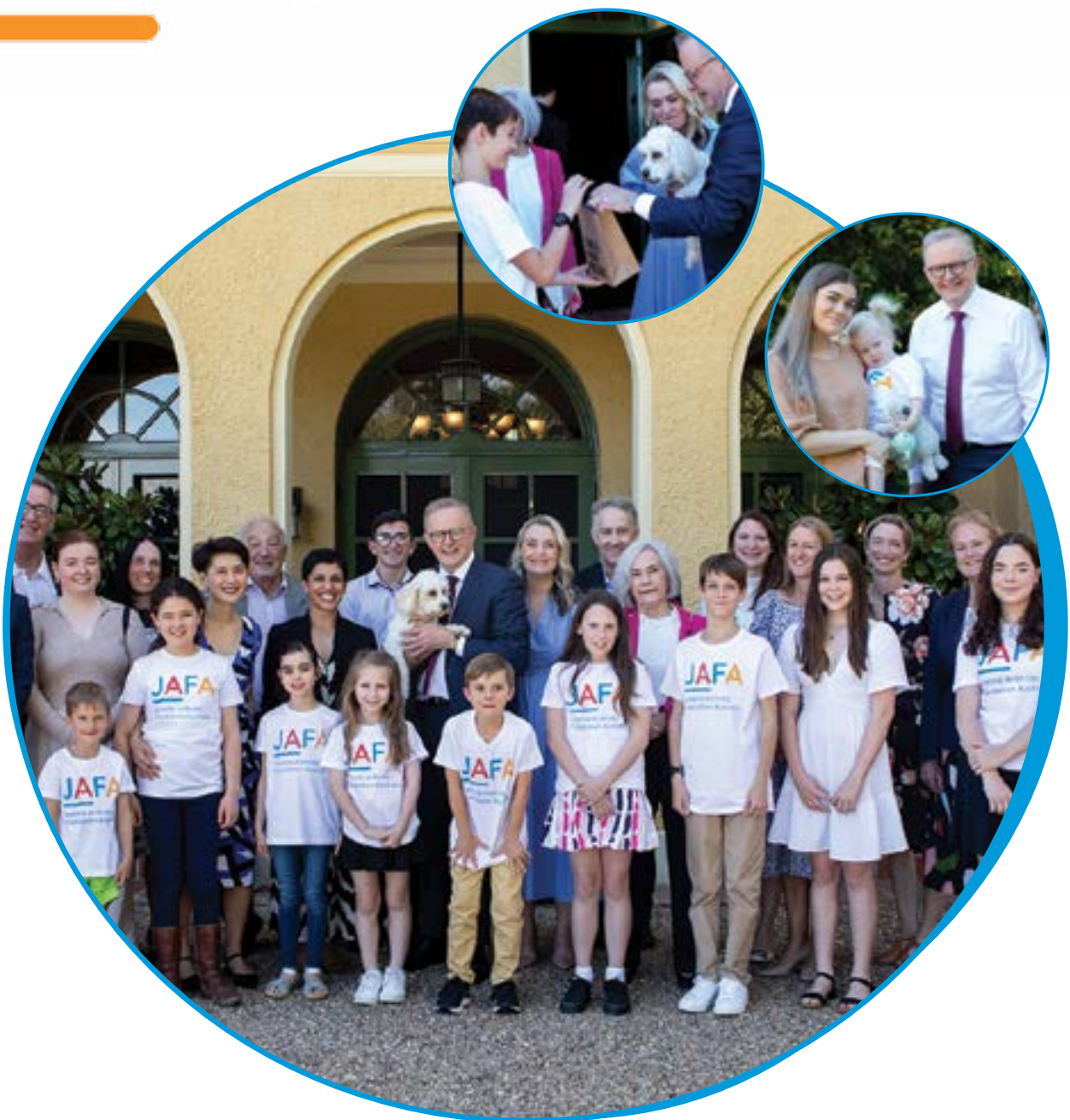


2022: Building Momentum

An annual report on the activities and achievements of the Juvenile Arthritis Foundation Australia in 2022





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From the Chair



Andrew Harrison with daughter Greta Hazel-Harrison, who was diagnosed with JIA at age 6.

As Chair of its Board of Directors since February 2022, I am proud and pleased to present this review of the actions and advocacy undertaken by the Juvenile Arthritis Foundation Australia (JAFA) in the past year.

In 2022, JAFA has continued to shine a light on the disparities endured by children and young people with juvenile arthritis and other childhood rheumatic diseases and their families. These include severely limited access to services and support that are commonplace for children with comparable chronic diseases, and which impact especially unfairly on those living in rural and regional Australia.

There remains much to be done before equity is achieved for these children and young people. Nonetheless, as illustrated by the March 2022 Report on the Parliamentary Inquiry into Childhood Rheumatic Diseases and the November 2022 Afternoon Tea at The Lodge with Prime Minister Albanese, it is safe to say that as a direct result of JAFA's advocacy, political awareness of these diseases has never been higher. JAFA is deeply grateful for this high-level recognition of the plight of families - children, young people, parents and siblings - who are so heavily impacted by these diseases. The Board is also deeply indebted to its donors, volunteers, expert pro bono advisors and staff, without whose support little would have been achieved. With their help and with its newly developed Strategic Priorities for 2023-2025 to guide it, JAFA will continue to work tirelessly in 2023 and beyond to secure the recognition and resources these children and young people need to live the best possible, pain and disability free lives they deserve.

Andrew Harrison

A handwritten signature in black ink, appearing to read 'A Harrison'.

**Chair, Juvenile Arthritis Foundation Australia
February, 2023.**

Highlights of 2022

When Jafa titled its first Annual Review 2021: A Very Good Year, we wondered what we might call our 2022 Review when its time came - and if we would be able to improve on the achievements of 2021.

But, with the generosity of Jafa's donors, the influence of its friends and allies, the commitment of its volunteers, the expertise of its pro bono advisors, and the ever-expanding Jafa community providing support and encouragement, 2022 has been an even better year. And, while COVID-19 continued to impact heavily on the community throughout 2022, the challenges and limitations it imposed on Jafa seemed somehow more manageable.

During this time Jafa transitioned from a fledgling non-profit to established 'start up' status having enjoyed significant growth in substance, strength, confidence, recognition and influence. Jafa's robust advocacy for children, young people with arthritis or other serious rheumatic conditions and their families throughout 2022 was rewarded with the ultimate 'jewel' in any advocacy crown – afternoon tea with the Prime Minister of Australia. This and other highlights of 2022 are listed below and can be viewed in more detail within this report:

- In the overarching highlight of 2022, the Jafa Board, and 13 children with juvenile arthritis and their parents enjoyed a delightful afternoon tea at *The Lodge, Canberra at the invitation of the Prime Minister, Prime Minister Anthony Albanese on 25 November 2023.*
- March 31 2022, heralded another Jafa-instigated 'first' in the tabling in federal parliament of the recommendations of the Standing Committee on Health Aged Care and Sport's *Parliamentary Inquiry into Childhood Rheumatic Diseases.*

- \$22 million in Medical Research Future Fund (MRFF) consumer driven research grants were leveraged by Jafa and awarded to 11 research groups for research into childhood arthritis, rheumatic, and musculoskeletal diseases in April 2022 by the (then) Health Minister, the Hon Greg Hunt.
- 2022 also saw a significant increase in the paediatric rheumatology workforce based at the Adelaide Women's and Children's Hospital resulting from Jafa's South Australian Pre-Election Campaign 2021-2022.
- Production and release of a short awareness-promoting video entitled '*Never Too Young*' in which having arthritis is articulated by six children in their own words.

Jafa's ongoing national campaign to Change Lives: Stop Pain and Disability in Children with Arthritis continues to serve as an overarching theme for discussions with Health Ministers and their policy advisors, the Australian Government Department of Health, the Medical Research Future Fund, the Australian Institute of Health and Welfare, the Pharmaceutical Benefits Advisory Committee and many others.

These advocacy and policy initiatives are underpinned by Jafa's unwavering dedication to representing and championing the needs of children and adolescents with arthritis and related rheumatic diseases and their families. And as 2022 draws to an end, and we look forward to reporting the highlights of 2023 in 12 months' time.



About Juvenile Arthritis

Juvenile arthritis/childhood rheumatic diseases (referred to as juvenile arthritis) are a group of serious, painful, incurable, debilitating autoimmune conditions affecting an estimated 6,000 to 10,000 children and adolescents in Australia.

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: 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 anesthetics



DID YOU KNOW?

80%

of children with juvenile arthritis experience pain daily. This means lost educational opportunities, limited participation in play and physical activities, social exclusion, mental health impacts.

1 in 5

children with oligoarticular juvenile arthritis develop vision threatening inflammation of the eyes (uveitis). This is a serious threat to vision. It can impair sight permanently and can cause blindness.

Over 30,000

adults in Australia whose arthritis started as juvenile arthritis and 1 in 3 of these people has a severe disability.

225%

shortfall in specialist services compared with optimal resource levels in other developed countries, leaving children with sub-optimal care

10 months

is the average time from the onset of painful symptoms to diagnosis with some children having already developed irreversible joint damage and loss of vision at diagnosis

43% of children

do not have access to essential multidisciplinary care - specialist medical, nursing, physio and occupational therapy, pain management and self-care education services

Lack of accurate data

is impeding improvements in quality of care, health service delivery and research

Building Political Awareness

Jafa is dedicated to meeting the needs of children and young people with arthritis and related rheumatic diseases, and their families and carers. One of the core ways in which Jafa seeks to meet those needs is through high-level political advocacy to achieve positive and permanent changes to health policy, planning and funding. As a result, 2022 brought unprecedented gains in these areas.

Afternoon Tea with the Prime Minister

On November 25, 2022, a perfect late autumn day in Canberra, Prime Minister Anthony Albanese, his partner, Ms Jodie Haydon, and their dog Toto welcomed Jafa to The Lodge for afternoon tea. The Jafa Board, CEO, and 13 'children' aged 18 months to 18 years and their parents attended along with Jafa friend and champion, Dr Mike Freeland MP. Guests were treated to a delightful afternoon tea prepared and served by the attentive staff of The Lodge who had kindly ensured a mouth-watering variety of child-friendly treats.

The Prime Minister and Ms Haydon were gracious hosts, mingling and talking with guests and listening solicitously to the children's accounts of their experience of arthritis, and Mr Albanese played a little backyard footie with the boys. The Prime Minister addressed the guests collectively – acknowledging the difficulties facing families with a child with arthritis, thanking Jafa for its advocacy, and noting that the Government is listening.

The purpose of the afternoon tea was to raise awareness of juvenile arthritis. This aim was well-achieved and Jafa sincerely thanks Prime Minister Albanese for his interest and generosity of spirit in taking time out from his onerous political responsibilities to host it. The event was the 'jewel in the crown' of Jafa's advocacy efforts in 2022. It was an honour for Jafa, a welcome acknowledgement of all the families who could not attend and will remain a precious lifelong memory for the children and parents who did attend.







Parliamentary Inquiry Chair and Deputy Chair Trent Zimmerman MP and Dr Mike Freeland MP relaxing with Jo Cassar and son, Daman, after the Inquiry's February 2022 Sydney Hearings

Parliamentary Inquiry into Childhood Rheumatic Diseases

If the jewel of Jafa's political advocacy in 2022, was the Prime Minister's Afternoon Tea, the pinnacle of its policy advocacy was the tabling in the federal parliament, on March 31, 2022 of the recommendations of the Parliamentary Inquiry into Childhood Rheumatic Diseases.

Instigated by Jafa, championed by Dr Mike Freeland MP and conducted by the House of Representatives Standing Committee on Health Aged Care and Sport, the Inquiry commenced on December 3, 2021. The Committee, then chaired by Mr Trent Zimmerman MP and co-chaired by Dr Freeland, received 128 submissions from affected individuals and families, professional and consumer organisations, and conducted two Public Hearings. Based on the findings, the report corroborated the substance of Jafa's advocacy and made 15 clear calls for action.

The 15 recommendations highlighted the urgent need for improved access to multidisciplinary care and outreach services; systematic data collection; and programs to facilitate earlier diagnosis and improve awareness. As testimony to the acute deficiencies in services, the Committee's key recommendation was to triple Australia's paediatric rheumatology workforce by 2030.

Since then, the Government has changed and, as 2022 closes, Jafa is running an ongoing advocacy campaign to encourage the current Minister for Health, the Hon Mark Butler, Assistant Health Minister, the Hon Ged Kearney and their Department to respond to the Inquiry recommendations.

Federal Pre-Election Campaign

Jafa's campaign for the May 2022 federal election entitled Change Lives: Stop Pain and Disability in Children with Arthritis commenced in December 2021. It was predicated on three priority programs derived from extensive consultation with the Jafa community and advisors and the community of professional care givers. The campaign centered on the urgent need to fund:

- **A National Early Diagnosis Campaign** to reduce delays in diagnosis from an average of 10 months to 10 weeks or less and make permanent joint and eye damage at the time of diagnosis history.
- **A National Schools Program** for safe and supportive learning environments to ensure that no child is discriminated against or left behind educationally as a result of their arthritis.
- **A National Registry and Essential Baseline Data Collection** to generate knowledge and understanding about the extent and impact of arthritis on children, their families and the economy, and how best to mitigate this.

The campaign targeted both major political parties and although unsuccessful in so far as neither party committed to funding the proposal, it brought a number of benefits. Most importantly it created unprecedented political awareness among the many federal MPs across Australia who were approached to support the campaign. Side benefits included Jafa constituents experiencing a taste of the power of the patient voice, and the valuable campaign infrastructure and experience gained by Jafa.

State based Political Campaigns to increase Paediatric Rheumatology Services

Three major state-based political campaigns were either completed or commenced in 2022.

- **South Australia (SA)**

JAJFA's first state-based political campaign commenced in September 2021 with a proposal to the then SA Health Minister for \$5million over three years to increase and improve access to paediatric rheumatology services statewide. The JAJFA campaign targeted the sitting (Liberal) Minister for Health and the Opposition with a clear and balanced argument based on the need and potential benefits. No commitment was made by the then Minister for Health. However, a promise to strengthen the paediatric rheumatology workforce was made by the Shadow Minister for Health should his party be elected.

Consequently, following the election of SA's current Labor government in March 2022, the incoming Health Minister, Chris Picton, provided additional funding to the Adelaide Women's and Children's Hospital for two 0.5FTE paediatric rheumatologist positions and an increase in paediatric specialist nurse time. By the end of 2022, these positions were filled placing the SA paediatric rheumatology service in its best-ever position to provide the quality of care its patients need and deserve.

- **Victoria**

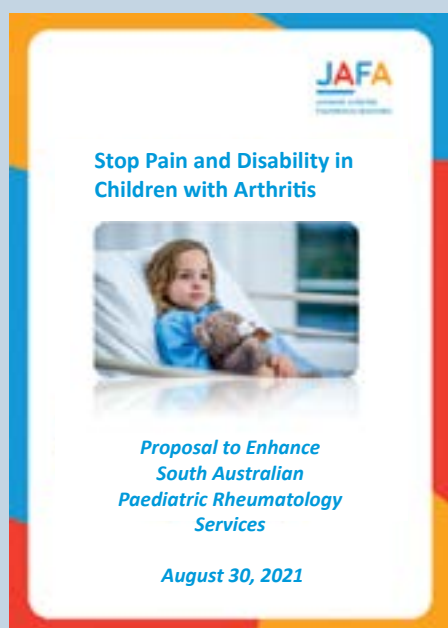
Prior to Victoria's November 2022 state election, JAJFA developed a succinct but detailed proposal arguing the case for modest funding of \$1 million per year to enhance Victorian paediatric rheumatology services at the Royal Children's and Monash Hospitals, and enable them to conduct outreach services to regional Victoria. Although neither party committed to funding the proposal, it will remain a platform for advocacy in 2023 and the campaign enabled JAJFA to begin building a relationship with both the Minister for Health and the Shadow Minister and their senior officers.

- **New South Wales (NSW)**

JAJFA's successful 2019 NSW campaign resulted in the Minister for Health and Medical Research, the Hon Brad Hazzard, increasing public sector paediatric rheumatologist time from 0.5 FTE to 1.1 FTE. Despite this, NSW paediatric rheumatology services remain abysmally poorly resourced compared with other states.

Consequently, in November 2022, JAJFA launched a new campaign for the March 2023 NSW election. JAJFA's NSW pre-election proposal makes a modest ask of \$1.75 million per year to begin redressing the gross underfunding of NSW paediatric rheumatology services and provide equitable access to best practice care for affected children and young people, comparable to that which is available for other similarly serious childhood diseases. As 2022 closes we look forward to continuing the campaign up to the NSW election on March 25, 2023.

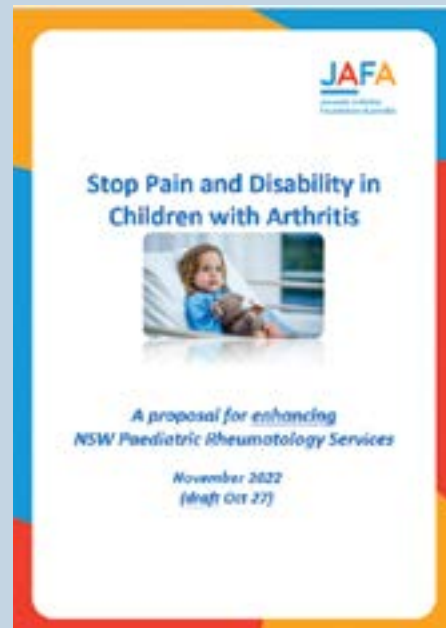
South Australia



Victoria



New South Wales



FIRST ON 



GREG HUNT
FEDERAL HEALTH MINISTER

April 27 2022, (then) Health Minister Greg Hunt, announces \$21.6 Million in Research Grants for Juvenile Arthritis and Childhood Musculoskeletal Conditions.

The Cost of Living with Juvenile Arthritis and Childhood Rheumatic Diseases

A national survey to assess the financial and impact on 0-25yr olds and their families

You can help by completing this anonymous 30-minute questionnaire

The results will be used to advocate for better services and support

JAJA Juvenile Arthritis Foundation Australia



Scan the QR code or use the link below to find out more

www.jafa.org.au/survey



Building Research Momentum

One of JAFAs strongest long-term ambitions is to become a major influencer and funder of Australian research into juvenile arthritis and related childhood rheumatic diseases. We are delighted to report that 2022 was witness to JAFAs first steps towards fulfilling that ambition.

Medical Research Future Fund Grants

In response to JAFAs advocacy to remedy the lack of research into juvenile arthritis and related childhood rheumatic diseases, in April 2022, the (then) Federal Health Minister, the Hon Greg Hunt, announced grants to 11 research groups across Australia for projects on arthritis, rheumatic, and musculoskeletal conditions in children.

Totalling 22 million and framed as ‘consumer driven research into emerging health priorities’, as 2022 draws to a close, JAFAs is delighted to see these ground-breaking MRFF funded projects commencing. Over the ensuing three to five years, they will bring unprecedented knowledge and understanding of what happens to children with arthritis and other rheumatic diseases in the health system and beyond. Areas covered include diagnosis, medications and treatment, hospitalisations, pain management, and data linkage between these and other important aspects of care. The studies will test and inform models and methods for improving clinical care, and both health and health system outcomes.

JAFAs is proud to have leveraged the Australian Government’s first significant investment in research into these serious and debilitating childhood conditions. We thank the Government for this and for the ability of this investment to grow research capacity within the professional paediatric rheumatology community and related academic researchers. We are also grateful for the focus on consumer driven research and pleased to report that JAFAs consumer representatives are named research investigators on two of the juvenile arthritis projects. And we are heartened by the implications for future similar MRFF investment indicated by the diseases on which this round of grants focus being labelled emerging health priorities.

National Cost of Illness Study

There is currently no comprehensive data available on the costs associated with juvenile arthritis and childhood rheumatic diseases in Australia. As a result,

estimates of the local financial and economic impact of these diseases are usually extrapolated from studies undertaken in other countries – notably the USA.

Generous funding provided in 2022 by investment company Five V Capital and Adrian and Charlotte MacKenzie is enabling JAFAs to address this deficit. To generate much-needed evidence about the extent and nature of the costs of these diseases JAFAs has used this funding to commission a research group from the University of Sydney to undertake this landmark study. The costing study is being led by Professor Natasha Nassar and will focus on:

- Costs to the health system (medications, medical care)
- Out-of-pocket expenses for individuals and families (treatment aids, travel to appointments)
- Lost income for individuals and families due to disease related time off work or inability to work
- Impact on quality of life

The study commenced in November 2022 and is due to report its results in late 2023.

Towards a National Juvenile Arthritis Registry

Disease specific registries are used to determine and provide accurate data on prevalence; age-related, gender, and geographic distribution; incidence; main forms of treatment; and to track changes in disease and treatment patterns over time. Despite being common in other serious childhood diseases, there has been no national registry for juvenile arthritis or related childhood diseases. Consequently, figures quoted on the number of children and young people with these diseases are estimates only.

JAFAs has been working towards addressing this deficiency for some time. To this end it has initiated a three- way partnership to establish the Australian Juvenile Arthritis Registry (AJAR), a minimum dataset registry for 0-25 year olds with arthritis or other rheumatic diseases. The registry partners are JAFAs, the Australian Paediatric Rheumatology Group, and the A3BC biobank. With our partners, we look forward to launching AJAR in Parliament House Canberra in March 2023.

Building Community

Jafa has no formal membership and no fees – people are free to come and go as they please. It is a welcoming community of interest, open to parents, carers, young people, children, grandparents and other close relatives affected by juvenile arthritis and childhood rheumatic diseases. Jafa supports this community with opportunities for peer support, information, education, engagement and unification around common needs.

Online Symposium Series for parents and older children



Jafa supports parents, carers and older children to optimise understanding of the home/self-management of their condition and to navigate the health system by bringing them credible,

practical, up-to-date information. The main mechanism for this is its three times yearly online symposia. The symposia feature leading paediatric rheumatologists, uveitis specialists, specialist nurses and allied health professionals who share their knowledge and expertise on critical issues and advances in treatment and research. Over 100 individuals and families register for each symposium. Videos of previous Symposia are available at: <https://www.jafa.org.au/jafa-symposia-series/>. Themes for the 2022 symposia were:

- Minding Mental Health
- Accessing Benefits: The NDIS and Beyond
- Flares and Scares and Side Effects.

KidsConnect

KidsConnect is an innovative, secure purpose-built online platform where 7-17 year olds with juvenile arthritis and childhood rheumatic diseases can meet and engage with counterparts in a safe digital space via age-appropriate chat and game resources (Minecraft and Discord) unhampered by distance or physical considerations. At the same time, building peer-relationships to help them navigate geographic isolation, and/or the social marginalisation associated with school



absences, illness and physical limitations that prevent participation in sport and the playground. Funded by a St George Community grant in 2021, and brainchild of Jafa supporter and digital communications expert, Dr Shilo McClean, KidsConnect was formally launched in early 2022. Since then it has provided

a much-enjoyed mechanism for bringing together children and adolescents with arthritis and rheumatic diseases in a friendly and inclusive environment. Parents can find more details and/or register their child's interest in joining by contacting kidsconnect@jafa.org.au.

Support for parents

Jafa links parents and families living with juvenile arthritis and childhood rheumatic diseases through its 700 people strong private Facebook group, and through ad hoc parent meetings, in-person events, and email support groups. Jafa staff and volunteers enormously enjoy speaking directly with dozens of its constituents each week.

Speaking Up - Speaking Out

One of the many ways Jafa supports its constituents is by encouraging and providing a conduit for the Jafa Community to use its voice to articulate the needs of their children for health care services and their own needs for support. To this end, Jafa offers tools such as 'Lobbying Packs', letter templates and tips on how to approach local MPs and/or seek local media attention. Jafa also encourages and supports its constituents to respond to relevant public consultations. As a result, over the course of 2022, there has been a noticeable increase in confidence and capacity of our families to speak up and speak out for what they need.

Spreading the World

Throughout 2022, Jafa worked enthusiastically to crystallise, frame and refine its messaging and extend its reach and influence. This effort was rewarded with unprecedented political and community awareness of juvenile arthritis and related childhood rheumatic diseases; growing recognition of the Jafa brand; and a pleasing growth in demand for Jafa's input / or representation from both government, non-government and private stakeholders.

Expanding Networks - International Recognition

As a result of Jafa's remarkable political advocacy achievements, it is arousing growing interest from other countries. During 2022 Jafa increasingly engaged with the Paediatric Global Musculoskeletal Task Force and became a member of the European Network for Childhood Arthritis and Autoinflammatory diseases (ENCA). Jafa values these relationships highly for the rich friendship, broadened perspectives, and encouragement they bring to all involved.

Jafa's First Formal Appeal

Jafa's reputation and brand recognition in Australia is also growing rapidly. In June 2022 Jafa undertook its first formal public appeal backed by a clear call to action to 'change lives and stop pain and disability in kids with arthritis'. This successful appeal was supported by a suite of purpose-designed tools including a video and social media tiles. In addition to raising funds to support Jafa programs, the Appeal raised considerable awareness of the plight of children and young people with arthritis, and simultaneously added to Jafa's capacity to conduct such campaigns.

Never Too Young Promotional Video

Thanks to a grant from MinterEllison, Jafa was able to commission Tom Phillips (Beckwith Productions in conjunction with Daybreak Films) to produce a short promotional video. Never Too Young is designed to dispel the commonly held belief that children don't get arthritis. This sensitively produced video features six children articulating their experience of life with arthritis and is a valuable tool in Jafa's awareness armament.

Social Media

Assisted by its pro bono communications advisor, and media advisor, and its expert staff, in 2022, Jafa's social media capacity grew exponentially in both quality and reach, and now includes an increasing presence on Instagram and LinkedIn as well as Twitter. Additionally, Jafa's private Facebook group is now complemented by a public Facebook page www.facebook.com/jafa4kidsarthritis/

Website

In line with Jafa's late 2021 rebranding exercise, in 2022 the Jafa website www.jafa.org.au was transformed from an amateur site to an attractive, easily navigated, professionally presented website that carries a wealth of resources and information, and which reflects Jafa's warm and open culture and philosophy.

Media and Publicity

Jafa is very fortunate to have the pro bono support of expert media and publicity advisor, Felicity Moffat. Working with the CEO and Board, Felicity has been instrumental in obtaining media coverage of key Jafa events and advocacy since its inception. This has included radio and TV interviews and coverage in industry publications. Additionally, throughout 2022, the Jafa community of parents has increasingly used its voice to raise awareness through local media coverage on topical issues in juvenile arthritis and related childhood rheumatic diseases through human interest interviews and stories, and special events such as the November 2022 afternoon tea with Prime Minister Anthony Albanese.



Building Momentum

Jafa is strongly committed to strategic planning to focus its energy and guide its efforts. To this end, Jafa has clearly articulated its purpose, aspirations and directions from the outset and will continue to do so into the foreseeable future through its new strategic priorities.

Jafa's original strategic plan was developed in August 2020. This three-point plan served Jafa well, successfully guiding it to progress from fledgling to start-up status, and assisting it to win the Third Sector Emerging Not-For-Profit Award for 2021 in recognition of its growing impact and influence. However, by mid-2022, the Board acknowledged that Jafa had reached a critical point in its evolution where a new plan was required to support Jafa to meet the emerging challenges, capitalise on past gains, and continue to build momentum to improve the lives of its constituents. As a result, the Board determined to develop a new three-year strategy to take Jafa to the next level and equip it optimally to:

- Effectively represent, champion and address the needs and interests of children and young people with arthritis and related rheumatic diseases.
- Meet the rapidly emerging challenges of a new and ever-changing political, socio-economic and policy environment.

To facilitate this, a three month strategic planning process was undertaken with the assistance of the Social Impact Hub. The planning process included extensive consultation with Jafa's key advisors and volunteers, its constituents, and the professional paediatric rheumatology community, and resulted in identification of five strategic priorities for 2023-2025.

Strategic Priorities for 2023-25

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:

Jafa is an effective, respected, well-resourced, sustainable organisation serving children and young people with arthritis and their families.

Looking to 2023

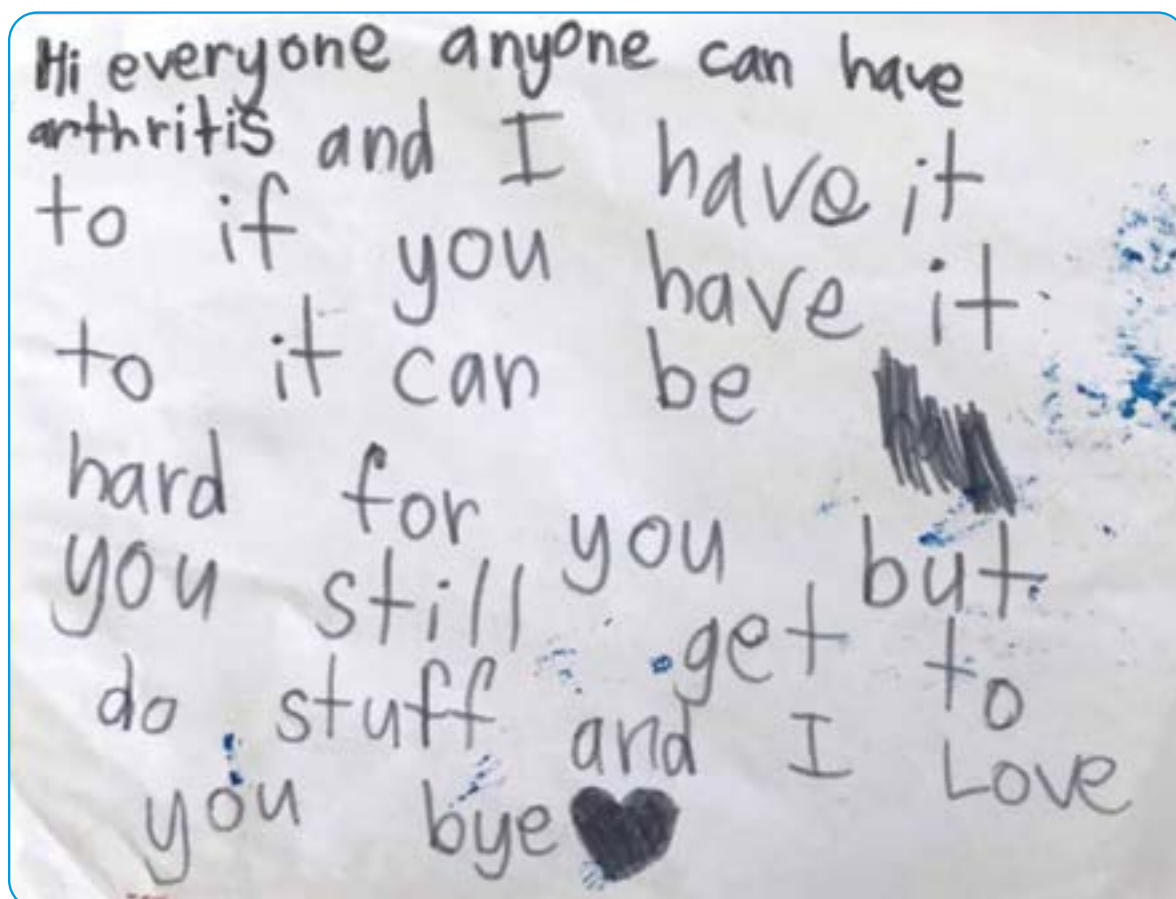
The considerable gains made in 2022 are evidenced in unprecedented political awareness of juvenile arthritis, notably at the Federal level, and crowned by the November 25 Afternoon Tea at The Lodge with Prime Minister Albanese. These gains are also reflected in major policy changes and 'firsts' for juvenile arthritis and childhood rheumatic diseases in Australia that were unimaginable only a few years ago eg the Parliamentary Inquiry and the Medical Research Futures Funds Grants among others. Most importantly, affected families are finding their voice and advocating for their children's needs as never before.

The Jafa Board thanks its CEO, staff, advisors, donors, volunteers, and the broader Jafa community for their commitment and generous support in 2022.

With Jafa's new Strategic Priorities to guide it, we look towards 2023 with energy and enthusiasm for consolidating the gains of 2022 and growing the momentum for 2023 and beyond. In addition to whatever other opportunities 2023 may bring, planning is already well underway for three more historic 'firsts' for Jafa and for the trajectory of juvenile arthritis and childhood rheumatic diseases in Australia:

- Holding Australia's First Juvenile Arthritis Week, March 18-25, 2023
- Launching the Australian Juvenile Arthritis Registry, March 21, 2023
- Releasing the results of Jafa's National Cost of illness Study, late 2023

A message from Nylah aged 6



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. 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, adolescents and young people with arthritis and related rheumatic diseases and their families and carers.

JAFA provides direct services to children and adolescents with juvenile arthritis and related rheumatic 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. Since 2020 JAFA has been guided by a three point - three year strategic plan which has served it admirably. From 2023 this will be replaced a new set of Strategic Priorities developed in late 2022 to ensure JAFA is fit for the challenges of the short-term future while simultaneously positioning itself for optimal longer-term impact and effectiveness. JAFA has ensured exemplary governance, compliance and strategic capability through a highly credible Board which is generously supported pro bono by MinterEllison.

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 of Directors



ANDREW HARRISON, BEC MBA (CHAIR)

Andrew is an experienced company director and corporate adviser. He is non-executive chairman of ASX-listed WiseTech Global Limited and has held executive roles and non-executive directorships with public and private companies. He has served as CFO of Seven Group Limited and Landis & Gyr and has 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 Chartered Accountant and a member of the Australian Institute of Company Directors. Andrew has a child with arthritis.



RUTH COLAGIURI AM (FOUNDER)

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



STEPHEN COLAGIURI AO (CO-FOUNDER)

Stephen is Professor of Metabolic Health in the Faculty of Medicine and Health, Solutions Domain Leader, Charles Perkins Centre and Co-Director of the World Health Organisation (WHO) Collaborating Centre for physical activity, nutrition and obesity at the University of Sydney. He is a medical specialist in diabetes and has worked in the public and private health systems and universities. Stephen is a former President of the Australian Diabetes Society and former Vice President of the International Diabetes Federation. He is an advisor to WHO and has sat on numerous national and international health advisory committees. Stephen has a grandchild with arthritis.



TANYA DMITRONOW (DIRECTOR)

Tanya recently returned to Australia with her husband and three children after nearly twenty years in New York and London. She was a partner at a leading New York law firm where she specialised in shareholder litigation, regulatory investigations and corporate governance. Tanya advised some of the largest 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 her young child with arthritis.



EMILY SHERIDEN (DIRECTOR)

Emily has a combined Arts/Law Honours degree from the University of Melbourne. During her time as a lawyer Emily worked primarily in the area of commercial litigation, while also providing practical advice to a range of clients comprising small, medium, publicly listed and multinational companies. Her interests in philanthropy and public advocacy led to her involvement with the Australian Red Cross Society of Women Leaders for a number of years. Emily lives in Melbourne with her family and has a daughter with juvenile idiopathic arthritis.

Staff



ANGELA MCKAY (CEO)

Angela McKay joined JAFA in late 2020. Angela has over 20 years senior leadership experience spanning both the private and not-for-profit sectors. She has a wealth of experience in the area of disease-specific non-profits for children having spent 8yrs as COO of the Juvenile Diabetes Foundation Australia prior to joining JAFA.



BEN LAXTON (DIGITAL PROJECT LEAD)

Ben Laxton joined JAFA in June 2021, bringing with him extensive experience and expertise in digital technology and communication in the private sector, the public health system and health non-profits.

DONORS

JAFA is grateful for the generosity of all its donors and is particularly appreciative of the very generous donation from Five V Capital and the MacKenzie family which is funding JAFA's current study to measure the financial burden and impact of juvenile arthritis and childhood rheumatic diseases across Australia. We also acknowledge the generous financial grant provided by MinterEllison to enable the production of JAFA's promotional video, 'Never Too Young'.

PRO BONO SUPPORT

JAFA is grateful for the very valuable pro bono contribution of:

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

MEDICAL AND SCIENTIFIC ADVISORY PANEL

JAFA is fortunate to have access to continuing advice and guidance on medical and scientific matters from four of Australia's most prominent and highly respected paediatric rheumatology clinicians and researchers, and an ophthalmologist in the field of uveitis:

- **Dr Jeffrey Chaitow (Chair)**, Head, Paediatric Rheumatology, Sydney Children's Hospitals Network
- **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.

Friends and Allies

Jafa liaises closely with existing national and state based arthritis not-for-profits and has a strong and growing network of highly reputable friends and allies:

- **The Australian Paediatric Rheumatology Group (APRG)**, the professional association of medical, nursing and allied health specialists treating and researching juvenile arthritis. Jafa values its relationship with and the ongoing support of the APRG and its individual members.
- **The Uveitis Special Interest Group (SIG) of the Royal Australia & New Zealand College of Ophthalmologists**, the medical specialists treating juvenile arthritis eye disease. Members of the Uveitis SIG have been unfailingly helpful and supportive of Jafa its attempts to raise awareness of JA and the need for improved access to services.
- **Parliamentary Friends of Child and Adolescent Health and Mental Health** co-chaired by Dr Mike Freeland (Member for Macarthur) and Dr David Gillespie (Member for Lyne) and Dr Monique Ryan (Member for Kooyong).
- **European Network for Childhood Arthritis and Autoinflammatory diseases (ENCA)**. In 2022, with the assistance of Natalie Billiard, ENCA Board Member and co-founder of Australia's Zoe's Angels, Jafa became a member of ENCA.
- **Paediatric Global Musculoskeletal Task Force** is a virtual global community united by its commitment to improving the lives of children and young people with MSK conditions around the world. Jafa mainly engages with the Task Force through its inaugural chair, Victoria Allen, who sits on the Task Force as an observer.

Volunteers

Jafa is entirely grateful to the dedicated band of parent volunteers who have supported it since its inception and without whose energy, input and conviction that change is possible, Jafa would not have flourished.



Jafa's First Advocacy Champion

In February 2022, Victoria Allen, a former market leading merger and acquisitions lawyer and partner at MinterEllison, stepped down from her role as Jafa's inaugural chair. Fortunately, Victoria has remained actively engaged in her new role as Jafa's first Advocacy Champion and continues to work closely with the Board and CEO to support Jafa's advocacy.

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

