

2021: A Very Good Year

The activities and achievements
of the Juvenile Arthritis Foundation
Australia in 2021



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From the Chair

I am delighted to recommend to you this inaugural annual report for Juvenile Arthritis Foundation Australia Limited (JAFA).

The past two years of JAFA's existence has heralded truly significant milestones for children and young people with rheumatic diseases in Australia. As you will read in the pages that follow, JAFA has advocated strongly for the recognition of the burden of these diseases on Australian children and their families and made a strong call to action.

JAFA has highlighted the unacceptable hurdles that exist which restrict access to adequate diagnosis and care, and the unacceptable levels of awareness of these common chronic diseases within Australia.

A dedicated core of volunteers and an increasingly active JAFA community have been central to the successes of JAFA to date, and the Board of JAFA is deeply grateful for the support shown to it. The Board is also grateful to the Federal Government for its response to our call for action, particularly for the current investment in research and the Parliamentary Inquiry into Childhood Rheumatic Diseases.

JAFA believes in creating positive, permanent change and is delighted to report on its achievements and progress over the past year towards achieving its goals. We look forward to consolidating and capitalising on these in 2022 and look forward to the results and recommendations of the Parliamentary Inquiry.

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

Victoria Allen

Chair, Juvenile Arthritis Foundation Australia
February 2022

Highlights of 2021

Notwithstanding the significant challenges and limitations imposed by COVID-19, in 2021, Jafa enjoyed consistent and substantial growth, not only in size but also in its reach, reputation and influence, and was delighted when its efforts were recognised by being named *Emerging Not-for-Profit of the Year* in the 2021 Third Sector Awards.

The rewards of Jafa's advocacy efforts have been considerable and are evidenced in unprecedented political awareness of juvenile arthritis, notably at the Federal level, which has in turn translated into major policy changes and several 'firsts' for juvenile arthritis in Australia that were unimaginable only a few years ago. These include:

- *A Parliamentary Inquiry into Childhood Rheumatic Diseases*: commenced December 2021 – in progress.
- *A Private Members Motion on Juvenile Arthritis* in Federal Parliament, Canberra, calling for attention and action on the plight of children and adolescents with juvenile arthritis: November 29, 2021.
- *Medical Research Future Fund (MRFF)* five year grants for Musculoskeletal Conditions including juvenile arthritis: announced October 14, 2021: applications close February 16, 2022.

In 2021 Jafa consolidated its advocacy efforts in these areas into a comprehensive *National Campaign to Stop Pain and Disability in Kids with Arthritis*. The Campaign was launched in Parliament House Canberra on International WORD Day, March 18 2021 under the auspices of the Parliamentary Friends of Child and Adolescent Health co-chaired by Dr Mike Freeland MP and Dr Katie Allen MP. Since then, the *Stop Pain and Disability* campaign has served as an umbrella for discussions with the Health Minister's Office, the Australian Government Department of Health, the Medical Research Future Fund, the Australian Institute of Health and Welfare, the Pharmaceutical Benefits Scheme and Therapeutic Goods Administration, and as a unifying theme for the Jafa Community and its supporters. It is also the key element of Jafa's Pre- Election Campaign to *Change Lives: Stop Pain and Disability in Children with Arthritis* which seeks funding for earlier diagnosis of juvenile arthritis, a national schools' program and the collection of essential baseline data to determine the extent and impact of JA.



**Emerging Not-for-Profit
of the Year in the 2021
Third Sector Awards.**

JAJA's technical capacity increased greatly in June 2021 when project officer, Ben Laxton joined our very capable CEO, Angela McKay, to expand and implement *KidsConnect*, a secure digital peer-support program for 7-17 year olds, and enhance and upscale JAJA's digital infrastructure and e-communications.

In 2021 Ms McKay also led JAJA through a re-branding process to better express and communicate the essence of JAJA's culture and philosophy of hope underpinned by hard work and effective collaboration.

Underpinning this culture is an unwavering dedication to representing and championing the needs of children and adolescents with arthritis and their families. To this end, and in addition to its popular *KidsConnect* program, JAJA links parents and young people through its online education and information *Symposium Series*; a closed Facebook page which has grown to over 500 members in just two years; an email support group of over 100 people; and online parent meetings on specific issues.

Major policy changes for juvenile arthritis in Australia were implemented.



Re-branding process to better communicate the essence of JAJA's culture.



New programs to address social isolation and ensure access to up-to-date and relevant information.



National Campaign to Stop Pain and Disability in Kids with Arthritis was launched.



About juvenile arthritis

Delivering on important programs

From advocacy to action

Building community

Communicating our message

Juvenile arthritis (JA) and childhood rheumatic diseases 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 JA.



~~Strong~~ **Low to little**
to no awareness

The prevalence of JA is similar to other serious childhood diseases such as juvenile diabetes and around 6 times more common than cystic fibrosis yet there is virtually no political or community awareness among health professionals.

**6,000
to 10,000**

Australian children estimated
to be living with JA



80%

Of children with JA experience
pain on a daily basis

This means lost educational
opportunities and limited
participation in physical activities.

1 in 5

Children with JA develop a serious
inflammation of the eyes (Uveitis).

This is a serious threat to vision
and can cause vision loss and
possible blindness.

30,000

People in Australia whose
JA extended into adulthood.

50% will have active disease
as adults and 1 in 3 has a
severe disability.



Delivering on important programs

From advocacy to action

Building community

Communicating our message

JAFA is committed to delivering quality programs to ensure that families and young people living with juvenile arthritis have ready access to current, relevant and up-to-date information on these conditions, and help children come to terms with their condition through interaction with peers.

Online symposium series for parents, carers and older children

JAFA supports parents, carers and older children to optimise their home/self-management of JA and capacity to navigate the health system by bringing them credible, practical, up-to-date information through its three times yearly online symposia. The symposia provide updates on clinical care, research and topical issues such as COVID-19, along with insights into the role of government health agencies such as the Pharmaceutical Benefits Scheme and the Medical Research Future Fund.

The *JAFA Symposium Series* features presentations by Australia's leading paediatric rheumatologists, uveitis specialists, rheumatology nurses and allied health professionals who share with participants their knowledge and expertise on critical issues and advances in treatment and research. Each Symposium includes a popular 30 minute Q&A with an Expert Panel plus an update from JAFA on new activities, campaigns and services. Over 100 families attend each symposium. Themes for 2021 were:

- Ages and Stages, Schools and Rules, Transition to Adulthood
- Current and Emerging Medicines: Implications for Clinicians, Consumers and the PBS
- Current and Emerging Australian and International Research

Videos of these and previous Symposia are available at: www.jafa.org.au/whats-new-1



Over **100** families attend each symposium.

Delivering on important programs

From advocacy to action

Building community

Communicating our message

KidsConnect

Since its inception, Jafa has been concerned about the social isolation and consequent marginalisation of children with JA that is associated with school absences, illness and physical limitations that prevent participation in sport, the playground and free social interactions with peers. Of equal concern is the geographic isolation of children living in regional and remote Australia.

To address these issues, *KidsConnect*, the brainchild of Jafa supporter and digital communications expert, Dr Shilo McClean, was piloted through Jafa's Facebook group in early 2020. With proof of concept confirmed, Jafa was fortunate to receive a 2021 St George Community grant which enabled the recruitment of an experienced technical officer to upscale and fully implement this inclusive, fun and innovative program.

KidsConnect is a secure online platform where 7-17 year olds with JA can meet and engage with counterparts in a safe digital space through age-appropriate chat and game resources such as Minecraft and Discord, unhampered by distance or physical considerations. At the same time, building peer-relationships to help them navigate the issues relating to mental health, social relationships and self-esteem which often accompany a diagnosis of juvenile arthritis. *KidsConnect* was soft-launched in December 2021 and will be formally launched in March 2022. Parents can register their child's interest by contacting Ben Laxton at: ben.laxton@jafa.org.au.



Safe digital space through age-appropriate chat and game resources, unhampered by distance or physical considerations.



From advocacy to action

Building community

Communicating our message

While Jafa will always provide practical support and advocacy for children and families living with JA, its core advocacy focus is on systemic and sustainable change to ensure optimal access to best practice JA treatments, care and support for all who need them no matter who they are or where they live. The calendar year 2021 was one of strong growth and robust political advocacy by Jafa which was rewarded with a positive and unprecedented political response.

Parliamentary inquiry into childhood rheumatic diseases

The jewel in the crown of Jafa's political advocacy in 2021 was the announcement on December 3, 2021 of a Parliamentary Inquiry into Childhood Rheumatic Diseases. Announced and commenced on the same day, the Inquiry is being conducted by the House of Representatives Standing Committee on Health, Aged Care and Sport. The Committee is chaired by Mr Trent Zimmerman MP and co-chaired by Dr Mike Freeland MP.

The scope of the Inquiry includes prevalence, impacts, workforce adequacy, access to services and treatments. Submissions closed February 4, 2022 and can be tracked at: https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases.

As we prepare this report, there have been a remarkable 119 high quality submissions. Jafa looks forward to the outputs and recommendations from the Inquiry which we believe will change the trajectory of juvenile arthritis in Australia for ever more. Jafa sincerely thanks Mr Zimmerman MP and Dr Freeland MP and the Committee members for their compassion and foresight in holding the Inquiry, and thanks the Minister for Health, the Hon Greg Hunt MP, for his leadership in authorising it.

From advocacy to action

Building community

Communicating our message

Juvenile arthritis private members' motion: Federal Parliament November 2021

Throughout 2021, Jafa advocated strongly to position juvenile arthritis on the Federal political agenda. One of the key rewards of these efforts was the Private Members Motion (PMM) on JA proposed by Dr Mike Freelander MP (Macarthur) and seconded by Mr John Alexander MP (Bennelong). The PMM advocated for support for earlier diagnosis, access to effective interventions and services, and a national registry and vital baseline data collection. Following Dr Freelander's compelling introduction, MPs John Alexander, Emma Mc Bride, Tony Zappia and Andrew Leigh spoke eloquently about the need for awareness and investment in services and support to improve the lives of children and young people with arthritis. A video of the discussion can be seen at: https://www.youtube.com/watch?v=CEpaz69DD_U

The PMM was a milestone in the history of juvenile arthritis in Australia and heralded a new era of political attention and action to address the plight of children and young people with JA and their families, and added to the rapidly building momentum for a Parliamentary Inquiry.

The PMM was a milestone in the history of juvenile arthritis in Australia.



Medical research future fund grants

Since its inception and supported by parents, grandparents, clinicians, friends and allies, Jafa has advocated the Federal Government for funding to accelerate research to achieve better outcomes for Australian children and young people with arthritis and rheumatic diseases. These efforts were rewarded by the announcement, on October

14, 2021 by Minister Hunt, of a new grant opportunity targeting Chronic Musculoskeletal Conditions in Children and Adolescents with funding up to \$20 million over four years from 2022. Jafa welcomed the announcement enthusiastically, not only because of the much-needed research investment but also because of the accompanying 'label' of 'emerging health priorities' and 'consumer-driven research' which heralds a welcome shift in federal health and research policy. The grants are for musculoskeletal conditions affecting children and adolescents including juvenile idiopathic arthritis, juvenile systemic lupus erythematosus, back and hip conditions, muscular dystrophies and musculoskeletal pain. Applications close on February 16, 2022 and Jafa looks forward to seeing the outcomes of the grant review process in mid-2022.

WORD day celebration March 18, 2021 parliament house Canberra

Jafa celebrated international **W**orld **Y**oung **R**heumatic **D**iseases (WORD) Day 2021 with an event in Parliament House, Canberra, for MPs and guests to raise political awareness of the burden of juvenile arthritis on the children who have it, their families and the broader community.



The event was kindly sponsored by the Parliamentary Friends of Child and Adolescent Health: co-chaired by Dr Mike Frelander MP (Macarthur) and Dr Katie Allen MP (Higgins). Despite COVID limitations, the event brought together MPs, parents and children, senior paediatric rheumatologists, Federal Health Department representatives and the Jafa Board to acknowledge the impact of arthritis on children and families, the need for accurate information to describe the burden, and to look forward to finding future solutions.

National campaign to stop pain and disability in kids with arthritis

During its WORD Day event In Parliament House, Canberra on 18 March 2021, Jafa launched its national political campaign to *Stop Pain and Disability in Kids with Arthritis*. The approach is based on policy and systems change to enable children with juvenile arthritis to live their best lives possible. The three central tenets of the campaign are about achieving:

- Questions in the NSW Parliament posed
- The right drugs at the right time
- Research for better treatments, prevention and a cure.

This three-year campaign seeks access to best practice standards of clinical care delivered by specialist, multidisciplinary paediatric rheumatology teams for all who need them, no matter who they are or where they live. It also means access to effective medications to prevent arthritis-related joint and eye damage. And a research investment equal to the impact of juvenile arthritis on children and young adults, their families, society and the economy.

The Parliamentary Inquiry and Private Members Motion on juvenile arthritis outlined above and the MRFF grants announced on October 14, 2021 are direct results of the political advocacy undertaken through Jafa's National Campaign to *Stop Pain and Disability in Kids with Arthritis*.

From advocacy to action

Building community

Communicating our message

Federal pre-election campaign

Encouraged by its successful advocacy throughout 2021, JAJA Launched its Pre-Election Campaign for the forthcoming 2022 federal election in late November 2021 and looks forward to pursuing this in the first quarter of 2022.

NSW campaign to increase paediatric rheumatology services

In January 2021, the NSW Minister for Health & Medical Research, the Hon Brad Hazzard, announced an additional 0.5FTE paediatric rheumatologist position for the Sydney Children's Hospital Network to bring the total paediatric rheumatology positions in the public system from 0.55FTE to 1.1FTE. This resulted from a year-long campaign by JAJA, and parents in the NSW JAJA community, consisting of:

- Briefings, submissions and meetings
- Questions in the NSW Parliament posed by Independent MP Alex Greenwich on behalf of JAJA
- Letters to local Members of Parliament from parents
- Supporting publicity in local media

Despite this 100% increase, the NSW paediatric rheumatology workforce remains inadequate to look after the thousands of children, adolescents and young people in NSW with arthritis. The next step will be a campaign for an additional paediatric rheumatology nurse.

South Australian campaign to increase paediatric rheumatology services

Following consultation with the SA JAJA community and clinicians, in September 2021, JAJA submitted a proposal to SA Health Minister Wade making the case for increasing paediatric rheumatology services. The proposal was supported by Arthritis Australia and SA families and state-based MPs. Although there is as yet no formal response from Minister Wade, as we enter 2022, JAJA is aware that some improvements have been made and looks forward to hearing further details.

Building community

Communicating our message

In the past two years, much of JAJA's energy and attention has been dedicated to community building to address the previously lacking 'community of interest' around JA. This resulted in significant growth, reach and influence in 2021 and a palpable sense of a vibrant, supportive JAJA Community. It is largely due to this sense and reality of community that JAJA is increasingly able to communicate its message effectively.

JAJA has no formal membership and no fees and individuals are free to come and go as they please. It is a 'broad church' open to parents, carers, young people and children affected by juvenile arthritis and childhood rheumatic diseases.

Grandparents and other close relatives are welcome. The professional paediatric rheumatology community of specialist doctors, nurses, physiotherapists, occupational therapists and other allied health care providers are considered close and valued friends and mentors.

Social Media

Community building for change is a core focus of JAJA's five year three point strategic plan developed in 2020. From the outset, community building has been predicated on interpersonal communication and consultation with parents and young people; JAJA's online Symposia Series, events such as WORD Day; programs such as KidsConnect; and JAJA's various advocacy campaigns.

Community building also relies heavily on social media and support groups eg:

- A closed *Facebook group* of parents, carers and young people commenced in February 2020 and now numbers over 500 participants
- An Email Support Network which includes over 100 people
- Several hundred others are registered with JAJA and join in for explicit purposes, conversations, activities or events.

Building community

Communicating our message

Virtual Parent Meetings

Canvassing needs, perspectives and opinions is an integral component of JAJA's community building. JAJA was formally established December 2019 and prior to and including that time its community building was predicated on face-to-face parent meetings.

With the advent of COVID-19 in early 2020 these meetings moved online and now take the form of:

- Scheduled meetings held back-to-back with JAJA's Online Symposia. These meetings tend to focus on themes raised by the symposia eg research priorities or particular areas on which JAJA wishes to consult, and usually number around 50 people.
- Ad hoc issue-specific meetings of 4-10 people to i) discuss and provide mentoring and support eg around submissions to the Parliamentary Inquiry or ii) mobilise the community eg around JAJA's Pre-Election campaign.



Communicating our message

JAJFA's technical capacity was strengthened in June 2021 when project officer, Ben Laxton, joined JAJFA's CEO, Angela McKay, to expand and upscale JAJFA's digital infrastructure and e-communications. This has resulted in a number of enhancements including:

Customer relations

The selection and installation of a comprehensive CRM in 2021 is facilitating JAJFA's capacity to communicate news, events, alerts and notifications to the JAJFA Community, supporters and donors. Work on populating the CRM will continue in 2022.

Branding

With the expert help of Wills Brand Design in 2021, CEO Angela McKay led JAJFA through a re-branding exercise to implement a 'brand' new look that better expresses and communicates the essence of JAJFA's culture and philosophy of hope underpinned by hard work and effective collaboration.

Website

The JAJFA website is currently being upgraded to reflect the new JAJFA brand and enhance its navigability and capacity to better reflect JAJFA's culture, philosophy and advocacy.

Media and publicity

JAJFA is fortunate to have the pro bono assistance of expert media and publicity advisor, Felicity Moffat. Working with the CEO and Board, Felicity has been instrumental in obtaining media coverage of key JAJFA events and advocacy throughout the year. This has included radio and TV interviews – including with Channel 9 News, as well as coverage in industry publications and, with CEO Angela McKay, was also instrumental in staging JAJFA's WORD Day event and National Campaign Launch in Parliament House, Canberra. Additionally, the JAJFA Community of parents has rallied to use its voice to raise awareness through local media coverage on topical issues in juvenile arthritis via human interest interviews and stories on juvenile arthritis throughout 2021.

Recognition

Third Sector Award

Jafa was honoured to be named Emerging Not-for-Profit in the 2021 Third Sector Awards on November 4, 2021. The Jafa Board wishes to thank its staff, supporters and volunteers for their invaluable contributions to achieving this prestigious award and, most importantly for, their contribution to raising awareness and the unprecedented response from Government that has been achieved in 2021.

It was indeed a very good year.



About JAFA

The Juvenile Arthritis Foundation Australia (JAFA) is the primary organisation representing children with JA 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 (referred to collectively by JAFA as juvenile arthritis) and their families and carers.

JAFA provides direct services to children and adolescents with JA and their families through support groups, regular online symposia on critical management and research issues in JA, and a secure, digital play space, *KidsConnect*, to provide peer support and reduce isolation. However, its core focus is on political advocacy to raise

awareness of JA among high level policy makers in order to effect systemic and sustainable change to improve the lives of children and young people with JA. Implicit in this is connecting the JA community and raising awareness among health professionals and the community.

A three-point, five-year strategic plan developed in 2020 by Directors, key (parent) supporters, and with input from the broader JAFA community guides JAFA's direction and activities. Additionally, JAFA has ensured exemplary governance, compliance and strategic capability through a highly credible Board which is generously supported pro bono by MinterEllison and Deloitte.

Our core focus is on political advocacy to raise awareness of JA among high level policy makers in order to effect systemic and sustainable change to improve the lives of children and young people with JA.



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 their 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



Victoria Allen (Chair), Former Partner M&A, MinterEllison

Victoria is a market leading M&A lawyer specialising in private M&A for financial institutions. She regularly leads the legal teams advising Australia's largest institutions and corporates on structuring and implementing complex and strategic M&A. Victoria has previously held a number of leadership roles within MinterEllison. She has a child with arthritis. Victoria retired from MinterEllison in mid-2021 to concentrate on her role as Jafa's Chair.



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 Colagiuri is Professor of Metabolic Health, Director of the Boden Collaboration of Obesity, Nutrition, Exercise & Eating Disorders, and Solutions Domain Leader at the University of Sydney's Charles Perkins Centre. He is a medical specialist in diabetes and has worked in public and private health systems and universities. He advises the WHO, sits on the Health Minister's National Diabetes Advisory Group and is a V-P of the International Diabetes Federation. Stephen has a granddaughter 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.



Andrew Harrison, BEc MBA (Director)

Andrew is an experienced company director and corporate adviser. He is currently the non-executive chairman of ASX-listed WiseTech Global Limited. Andrew has held executive roles and non-executive directorships with public and private companies and was previously CFO of Seven Group Limited and Landis & Gyr among other senior finance positions, 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.

Staff



Angela McKay, CEO

Angela 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, Project Officer

Ben 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.

Pro bono support

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

Legal and Governance

Garry Beath, MinterEllison, Sydney

External Auditor

Cheryl Kennedy, Deloitte Australia

Media and Publicity

Felicity Moffat, Founder and Principal MD Media

Social media and Digital Technology

Dr Shilo McClean and James Murty, experts in their field and parents of a child with arthritis

Health Policy

Associate Professor Christine Giles, Menzies Centre for Health Policy, The University of Sydney

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 a rising 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 specialists treating and researching juvenile arthritis. Jafa values its relationship with and the ongoing support of the APRG and its individual members and relies heavily on its input to Jafa's policies and positions on clinical health care and research issues.

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 in all its attempts to raise awareness of JA and the need for improved access to medicines and services.

The (Federal) Parliamentary Friends of Child and Adolescent Health co-chaired by Dr Mike Freeland (Member for Macarthur) and Dr Katie Allen (Member for Higgins). The support of the co-chairs has been central to the success of Jafa's efforts to raise political awareness of JA.

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.



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

