

JAFA

Juvenile Arthritis Foundation of Australia

Purpose

The Juvenile Arthritis Foundation of Australia (JAFA) has been established to provide a national voice dedicated exclusively to representing and addressing the needs of children, adolescents and young people with *juvenile arthritis and childhood rheumatic diseases* (hereafter referred to collectively as Juvenile Arthritis) and their families and carers.

How?

JAFA's primary aims are to:

1. Raise awareness of Juvenile Arthritis (JA) among health professionals, politicians and governments, the education sector, the broader community, and potential funders
2. Lobby governments to provide optimal and accessible health care and support for children, adolescents and young people with JA and their families and carers
3. Influence and partner with funders to invest in research into the causes, treatment, care, and a possible cure for JA.

Why?

Because *kids with JA deserve better*

- JA is a serious, painful, incurable and debilitating autoimmune disease
- It is one of the commonest childhood diseases affecting some 6,000 children in Australia
- There are thousands of people in Australia whose arthritis started as JA and extended into adulthood and 1 in 3 of these people have a severe disability
- The prevalence of JA is similar to other serious childhood diseases such as juvenile diabetes yet there is virtually no political or community awareness of JA, and little awareness among health professionals
- Services for JA in Australia lag well behind other serious childhood diseases with similarly complex treatment and care requirements.
- Government investment in JA services and research is sadly lacking. Consequently,
 - on average it takes 10 months from the onset of symptoms to diagnosis
 - some children already have irreversible joint damage and loss of vision at diagnosis
 - once diagnosed access to specialist medical, nursing, physio and occupational therapy, pain management and self-care education services is very limited
- The various arthritis consumer organisations run certain services for affected children and their families but with 4 million adults vs 6,000 children with arthritis their efforts are understandably largely devoted to their adult constituents.

Who?

JAFAs founders are Ruth and Stephen Colagiuri. When their 7yr old granddaughter was diagnosed they were shocked by the lack of services and support for children with JA and their families. They think *kids with JA deserve better* so they have started JAFAs to turn the present situation around.

Ruth and Stephen are professors of public health and medicine respectively. They have worked in diabetes and chronic diseases in various facets of the health and university systems over a professional lifetime, and have been involved in many disease specific not-for-profit organisations.

The response to JAFAs has been overwhelmingly positive. It is increasingly engaging with and being assisted by parents and young people affected by JA as well as paediatric rheumatologists and uveitis ophthalmologists and is being advised by expert 'friends'.

Minter Ellison, one of Australia's most highly regarded law firms, is assisting JAFAs with legal and governance issues on a pro bono basis.

How do we know it will work?

JAFAs is using the highly successful JDRF as its role model. JA and diabetes are (currently) incurable, auto-immune conditions that have many similarities. Services for, and awareness of JA today are no better today than services for juvenile diabetes were 40 years ago. Ruth and Stephen have seen JDRF evolve from a parent support /advocacy group in the late 70s early 80s to the eminently effective organisation it is today. JDRF was, and remains, the defining factor in achieving the current excellent level of investment in juvenile diabetes services and research. Further, it has exercised remarkable influence on education policy to raise awareness and skills among teachers, enabling them to support children in managing their diabetes in the classroom and under exam conditions. In time JAFAs can achieve the same for kids and young people with JA.

When?

The answer is now.

What is JAFAs doing now?

Minter Ellison is currently taking JAFAs through the legal and practice requirements to become a fully-fledged not-for-profit organisation with deductible gift recipient and tax exempt status, and a licence to raise funds. This is expected to be completed by mid-March 2020. Meanwhile, JAFAs is:

- i) Building a solid grass roots base of families friends and allies using social media
- iii) Creating a public presence and brand recognition to facilitate lobbying and fund raising
- iv) Developing a suitable governance mechanism, structure and infrastructure to underpin points i) to iii) above and position JAFAs to successfully pursue its primary aims
- v) Lobbying State & Territory Governments to increase and improve JA services.

Who can help?

Everyone can do something to help build JAFAs into an innovative and effective organisation and give kids with JA the best possible chance for a healthy, happy and fulfilling life. Contributions can be large or small from volunteering time and skills to donations or just spreading the word among family and friends and on social media to raise awareness of JA and get the JAFAs brand recognised.

Please contact Ruth on 0408 648 235 or ruth@jafa.net.au to enquire or offer suggestions.