



Time to Move: Taking action on juvenile arthritis

Juvenile Idiopathic Arthritis (JIA) is a painful, autoimmune form of arthritis that affects around 6000 Australian children.

About Juvenile Idiopathic Arthritis

JIA can seriously disrupt the growth and development of a child, causing severe joint damage, growth abnormalities and permanent disability. In addition, complications of the disease and its treatment include serious infections, uveitis which can cause blindness, and heart, skin and lung conditions.

Although poorly recognised, JIA is one of the most common and serious chronic conditions of childhood, and affects as many children as juvenile diabetes.

While JIA resolves in many cases, there is no cure. Around 60% of those diagnosed will continue to have active disease into adulthood, compromising their future health and vocational achievements.

The good news

Dramatic advances in treatment for JIA in the past decade mean that much of the joint damage, deformity and disability it causes can now be prevented.

However, early diagnosis and initiation of specialist, team based care, ideally within 10 weeks of symptom onset, is critical for achieving the best results.

The bad news

Delays in diagnosing JIA in Australia are common. Four in ten children with JIA experience delays of more than six months and one in six wait more than a year to be accurately diagnosed. Nearly half of all children with JIA see four or more health professionals before being correctly diagnosed.

Inadequate public and health practitioner awareness of JIA and limited access to paediatric

rheumatologists for diagnosis and care are key factors leading to these delays.

In addition, limited and inequitable access to specialist treatment services, fragmentation of care, lack of psychosocial support and a heavy financial burden are common problems reported by families trying to cope with the devastating impact of JIA.

What needs to be done

1. Fund paediatric rheumatology training in Australia

Paediatric rheumatologists are in short supply in Australia with none available at all in some states/territories. There are currently only 13 paediatric rheumatologists working 7.6 FTE (full time equivalent), less than half of what is needed just to meet clinical need. Three paediatric rheumatologists plan to retire in the next five years.

Limited access to paediatric rheumatologists is a major contributor to delays in diagnosis and appropriate care for children with JIA and other

Dedicated funding of \$720,000 over six years to train three paediatric rheumatologists will help to retain current clinical capacity. Additional funding would allow more to be trained, addressing current shortages and freeing up capacity for teaching and research.

musculoskeletal conditions managed by these specialists.

There is no dedicated funding for paediatric rheumatology training in Australia.

Those who wish to take up the specialty need to go overseas or source their own funding for training.

Because there are so few paediatric rheumatologists most have little time to pursue research or provide education and training in the field for other health professionals, impeding improvements in quality of care.

2. Expand public paediatric rheumatology services

Team-based care is the 'gold standard' for managing JIA, but is rarely delivered.

In 2011, Australia-wide, public funding for specialist health care professionals in paediatric rheumatology consisted of just 2.7 FTE for nursing, 1.15 for physiotherapy, 0.85 for occupational therapy and 0.5 for psychology.

Appropriate skills among health care professionals in community based private practice are also extremely limited, while the cost of these services is a significant barrier to access.

A program to train and employ 3 paediatric rheumatology nurses in Australia would cost \$1.2 million over 3 years.

In particular, paediatric rheumatology nurses can provide much needed education,

psychosocial support and care co-ordination for children and young people with JIA and their families, especially in areas with limited access to specialist services.

3. Develop JIA information and educational materials for health care professionals

Lack of exposure to paediatric rheumatology in training programs for doctors, nurses and allied health professionals has been identified as a major contributor to delayed diagnosis for JIA and other musculoskeletal conditions.

Developing information and educational materials for health care professionals is essential to support early diagnosis and urgent referral to specialist care and to enhance team based care for children and young people with JIA.

4. Develop comprehensive JIA consumer resources

Developing enhanced, tailored information resources and tools will assist children and families to better understand and manage JIA and to navigate their way around available services and supports. Priority resources for development include:

- Comprehensive, age-appropriate information and education resources and programs for parents and families of newly diagnosed children so that they understand and can manage the condition
- Resources for schools and childcare centres so that there is greater peer and community support for children struggling to integrate with their friends and school environment
- Age appropriate information and resources for adolescents with JIA so that they can be supported during these often difficult, transitional years.

For example, a recently developed program to teach children to manage pain due to arthritis (as well as other conditions) would cost \$350,000 to roll out across the country.

5. Fund research into a cure

Research is essential to develop better treatments and hopefully find a cure for JIA. JIA, however, receives only minimal research funding in Australia.

Only one NHMRC research funding grant has ever been awarded for JIA research.

Despite limited funding, important work to build a biobank to support research into the causes of JIA has begun, with funding from Arthritis Australia. The biobank holds biological samples and detailed clinical and environmental data and is the only one in the world collecting such comprehensive information on children with JIA.

Additional funding of \$5 million over 5 years would support research to prevent, better treat and hopefully cure JIA.

This biobank will underpin wide-ranging research to understand the causes of this complex disease. Already,

it has helped to identify a new gene for JIA and is assisting with other research projects on autoimmune conditions nationally and internationally.