Final JIA release
Embargoed until Monday March 16 2015

Kid's arthritis – as common as childhood diabetes – and seriously under recognised and resourced.

Arthritis Awareness Week – March 15 – 21, 2015

Kids with painful and disabling arthritis face long delays in diagnosis, and serious shortages of treatment and support services

"We're talking about childhood arthritis – known as juvenile idiopathic arthritis (JIA) and it affects at least 6000 Australian children," says Associate Professor Davinder Singh-Grewal of the University of Sydney.

"Ronan was diagnosed at two, but has been unwell and in pain virtually since he was born," explains his father Scott Milne. "As a baby Ronan was constantly crying and his temperature was always high. The doctors told us it was viral and it took months and months to get the right diagnosis – that it was JIA and his immune system was attacking his joints."

"This is all too common a story," says Franca Marine, National Policy Manager for Arthritis Australia. "We know that the sooner JIA is diagnosed and treated the better, but our research has shown that many children with JIA have their symptoms a long time before they're diagnosed. And during that time the joints can be seriously damaged."

"Arthritis Australia is aiming to raise awareness of this painful disabling condition. We are releasing a five point plan to address 'what needs to be done' about childhood arthritis.

1. **Fund paediatric rheumatology training in Australia**
2. **Expand public paediatric rheumatology services**
3. **Develop JIA information and educational materials for health care professionals**
4. **Develop comprehensive JIA consumer resources**
5. **Fund research into a cure**

Details below.

“In addition to funding for research into a cure, we desperately need to make sure kids and families can get the specialist care and support they need as soon as possible by expanding public paediatric rheumatology services through increased training and information for health care professionals.”

“JIA can look quite different from child to child,” explains Associate Professor Singh-Grewal who is one of Australia’s small band of paediatric rheumatologists (children’s muscle and joint specialists). “That makes it hard for GPs to detect JIA early but, even if they do, it can be hard to get in to see a specialist to start treatment.

“Most states only have one or two paediatric rheumatologists and in some states there are either none at all (Tasmania and NT) or they’re overburdened with long waiting lists. This is all the more tragic because we now have really effective treatments for JIA and the sooner you can start treatment, the more likely you are to control the condition and avoid the severe joint damage it can cause..”

“Ronan is now 6 years of age,” says Scott. “He has nine joints affected and even now we never know what to expect from day to day.”

“I was diagnosed at the age of eight with severe polyarticular juvenile rheumatoid arthritis, which is a form of JIA,” says Anni Grindrod who’s now 22 and working as a graphic designer. “I went from a happy, active and very normal 8 year old to a very sick little girl spending weeks in hospital and in a wheelchair to find a diagnosis and then suitable medical interventions.

“Adolescence was really tough dealing with depression from the chronic pain and loss of mobility.”

Most children with arthritis continue to have the disease into adulthood. Ben Horgan has been living with JIA for over 40 years since he was diagnosed at the age of two.

“When I was four, the doctor told my mother he felt I would be in a wheelchair within a year and would probably never get out of it. He also said that I probably wouldn’t live past my 10th birthday.

“Life has been full of ups and downs since then but, thanks to support from my family and the best medical team we could muster, and by taking charge of my own treatment, I am still here and walking around on my own two feet.”

“This is an invisible condition to most Australians,” claims Arthritis Australia’s Franca Marine. “But it’s all too visible for the kids with JIA and their families.”

“What’s needed,” says Associate Professor Singh-Grewal, “is to fund training for more paediatric rheumatologists and specialist nurses as well as encouraging team based care since so many health professionals have to get involved in what is a very complex condition for these kids who deserve the best care in the world.”

Please support Arthritis Australia’s campaign to raise awareness of juvenile idiopathic arthritis (JIA) for Arthritis Awareness Week, 15-21 March 2015. Just post a photo of yourself as a child or with your favourite childhood possession, such as a toy or balloon, on Facebook or Twitter (#KidsGetArthritisToo).

Background

Juvenile Idiopathic Arthritis

Juvenile Idiopathic Arthritis (JIA) is a painful, autoimmune form of arthritis that affects at least 6000 Australian children. 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 children, 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 Three of the existing specialists 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 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.

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.

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.

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.

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

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 packages 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.

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 will hold biological samples and detailed clinical and environmental data and is the only one in the world collecting such comprehensive information on children with 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 auto-immune conditions nationally and internationally.

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

About Arthritis Australia

Arthritis Australia is the peak arthritis organisation in Australia and is supported by affiliate offices in the ACT, New South Wales, Northern Territory, Queensland, South Australia, Tasmania and Western Australia.

Arthritis Australia provides support and information to people with arthritis as well as their families and friends. The organisation promotes awareness of the challenges facing people with arthritis to the community and to leaders in business, industry, and government. In addition, Arthritis Australia funds research into potential causes and possible cures as well as better ways to live with arthritis.

www.arthritisaustralia.com.au

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