Juvenile Arthritis Research (UK registered charity no. 1091620)

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**P R E S S R E L E A S E – For immediate release**

School Toolkit launched by Juvenile Arthritis Research to recognise and support children with arthritis in school.

**Children get arthritis, too**

Every week, 20 families in the UK are told that their child has a condition most have never heard of – Juvenile Idiopathic Arthritis (JIA). Many of these will have been in pain for weeks, months or even years waiting for a diagnosis. And from that point, it is a diagnosis that will remain with them for the rest of their lives.

**Why schools matter**

Research\* has shown that teachers and school staff can be amongst the first to notice that something is wrong with a child. Knowing the signs and symptoms of JIA and being able to signpost to the correct services, could help a child receive that vital prompt diagnosis.

Without prompt diagnosis and treatment, JIA can cause permanent damage to joints and long-term disability. It could even lead to the loss of eye sight through JIA-related uveitis.

For those already diagnosed, schools play an instrumental role in enabling a child with JIA to live a full life and fulfil their potential at school. The newly launched School Toolkit from Juvenile Arthritis Research, available free of charge to schools and educational settings in the UK, enables staff to confidently support children with JIA in their setting.

**How can I get my free School Toolkit?**

Educational settings in the UK can request a free School Toolkit from [www.jarproject.org/toolkit](http://www.jarproject.org/toolkit).

“Wow - it's fantastic, the student presentation is particularly impressive with how it
translates all the key information in a child friendly manner.” *Miss Crawley, Woodlands School*

\* Rapley T, May C, Smith N, Foster HE. 'Snakes & Ladders': factors influencing access to appropriate care for children and young people with
 suspected juvenile idiopathic arthritis - a qualitative study. Pediatr Rheumatol Online J. 2021;19(1):43.

**Further information:**

**What is Juvenile Idiopathic Arthritis?**

Juvenile Idiopathic Arthritis (also called JIA) is an autoimmune disease. This means the body’s natural defences (called the immune system) which are designed to fight off viruses, bacteria and infection get confused and start to attack joints. This causes pain, discomfort, fatigue, and reduced mobility.

Across the UK, around 15,000 children and young people under the age of 16 have been diagnosed with JIA – that’s around 1 in every 1,000.

Without adequate and prompt treatment, JIA can lead to other health conditions as well as permanent disability and long-term health implications. Some children with JIA develop uveitis, which is inflammation inside their eye. If this isn’t treated promptly, children could lose their sight.

At the moment there is no cure for Juvenile Idiopathic Arthritis. All existing treatments reduce the symptoms of JIA, but are not a cure. Whilst these treatments have beneficial effects in reducing pain and inflammation, and provide some protection against long-term joint damage, they come with their own side-effects and can take their toll emotionally too for children taking these medications.

**Low awareness causes delays**

One of the big challenges is that awareness of the condition is low. If you haven’t heard of a disease, it’s much harder to get a diagnosis. We know of some families that have had to wait for over 5 years for a diagnosis, because neither they nor their doctors recognised the symptoms. That’s five years of pain, discomfort, and of not knowing what’s wrong.

JIA is often an invisible disease – you may even know someone who has it, but don’t necessarily realise. It’s also variable – many children with arthritis appear ‘fine’ one day, but struggle the next as their joints become more inflamed again.

**The key symptoms**

If a child can no longer do something that they could before then it could be because their joints are stiff or in pain. Perhaps they cannot sit on the floor anymore, or struggle to hold a pencil. They may be limping or struggling to chew food. JIA can affect any joint. It can also affect multiple joints. If you have any concerns ask your GP if it could be Juvenile Idiopathic Arthritis and ask for a referral to a paediatric rheumatologist (these are the doctors who specialise in children’s joint conditions) and an ophthalmologist (specialist eye doctor to check for inflammation inside the eye). The sooner a child is diagnosed, the earlier treatment can start. The good news is that with prompt diagnosis and treatment, many children will go on to lead full and active lives.

**About Juvenile Arthritis Research**

Juvenile Arthritis Research is a charity making a difference to the lives of those affected by juvenile idiopathic arthritis. They are a parent-led charity with direct experience of JIA, and are run entirely by volunteers. Their vision is a world where no child has to suffer from arthritis and their core aims include research to find a cure for JIA, raising awareness that children and young people get arthritis and providing support to children and their families affected by JIA.

You can find out more about Juvenile Idiopathic Arthritis in their booklet, My JIA, available as a free download from [www.jarproject.org/myjia](http://www.jarproject.org/myjia). If your child has JIA, please visit [www.jarproject.org/hope](http://www.jarproject.org/hope) to find our online support pages and to request a support pack to be sent to you.

You can read about children with JIA at [www.jarproject.org/stories](http://www.jarproject.org/stories).

Schools can request a free School Toolkit to enable them to confidently support children with JIA and to recognise the signs and symptoms of JIA at [www.jarproject.org/toolkit](http://www.jarproject.org/toolkit).