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**

**Local charity makes use of disused building to raise awareness of childhood arthritis**

Arthritis is a condition that is most commonly associated with the elderly, yet around 20 children each week are diagnosed with arthritis in the UK.

Juvenile Arthritis Research is a charity based in Tonbridge, Kent, that supports children, young people and families affected by Juvenile Idiopathic Arthritis (JIA). JIA is an autoimmune condition where the body’s natural defences attack the joints causing inflammation, pain and reduced mobility. It can affect children of any age. Once diagnosed, someone with JIA has the condition for life.

The charity was founded 5 years ago by Tonbridge resident Richard Beesley whose wife and daughter both have the condition.

“Before working at Tonbridge & Malling Borough Council, I used to work as a researcher an statistician, so I wanted to go back to my roots in science to help find a cure for JIA,” Richard told us.

The charity soon realised that as well as wanting a cure for the condition, families also lacked information and support.

“We worked together with parents, young people, the medical profession, and even with teachers and schools to develop information resources to support families when a child is diagnosed with JIA.”

Awareness of childhood arthritis is low and this can lead to delays in diagnosis and treatment. The condition can cause permanent joint damage if left untreated, as well as complications with eyesight from JIA-related uveitis (inflammation inside the eye).

“Prompt diagnosis really is vital. The delays are not due to long waiting lists. The delays are happening because of a lack of awareness that children and young people can even get arthritis so we need to increase awareness amongst families, amongst schools, amongst healthcare professionals such as GPs and A&E staff who might be amongst the first medical professionals that a family sees. They need to know that it is ok for them to refer to specialist paediatric rheumatology services if they suspect that it could be JIA.”

To enable communities and health professionals to learn about the signs and symptoms of JIA, Juvenile Arthritis Research have developed an awareness campaign called “ThinkJIA”, the idea being to just “**J**ust th**I**nk and **A**sk” if it could be JIA if a child is experiencing any issues with their joints lasting over 6 weeks.

“GPs will normally rule out other serious conditions but JIA is often overlooked. Often blood tests and X-rays will appear completely normal in JIA so it really is important to refer to paediatric rheumatology where specialists can make a diagnosis. A referral to an eye specialist is also vital because around 1 in 5 children with JIA can develop uveitis which can cause loss of sight if not detected and treated promptly.”

Juvenile Arthritis Research have just moved into new premises in Tonbridge on the site of the old SCI gym on the industrial estate.

“We’ve been welcomed by all the neighbours in the area who are pleased to see the building back in use again. They are particularly excited to know that it is a charity who is making a difference and having a real impact that has moved in. We’re very happy to be there too as it means that we can support even more families in the local area as well as the work we do across the UK.”

New window signage has been installed with thought-provoking yet positive imagery. It features local children, young people and families from the local area who came along to the building for a recent photoshoot. Local photographer Janet Penny from Hushabye Photography donated her time and skills to enable the window signage awareness-raising project to happen.

The images are bright and colourful and feature some of the core messages that families affected by JIA wanted others to know.

Richard told us: “We try to get a balance in all we do between the serious side of raising awareness and showing that living with JIA can bring it’s challenges whilst also giving hope to those diagnosed so that they know that with the right treatment and support, they can still lead full lives.”

As a very small volunteer-run charity, Juvenile Arthritis Research would love to hear from any businesses or funders who are able to offer their skills, services or funding towards their work.

“We’re thrilled to have such a visual presence in Tonbridge with the new building as we hope that it will enable us to continue to strengthen our links with the local community.”

**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).