Running 250 miles to find a cure for juvenile arthritis

Monday 10 September, 2018

Alex Shrimpton (aged 26), a member of Hope Church Tonbridge, is running a phenomenal 250 miles over two weeks to raise awareness of juvenile arthritis, and to raise money to help find a cure for the horrible disease.

From 23 September to 7 October 2018, Alex will be completing an average of 18 miles every day in addition to his job as a carer for which he commutes to Winchester. His run will culminate in the Tonbridge half-marathon on 7 October.

Alex is hoping to raise awareness of juvenile idiopathic arthritis (JIA) – a painful autoimmune disorder that affects around 15,000 children and young people under the age of 16 in the UK. JIA is not the same as either rheumatoid arthritis or osteoarthritis (which are more commonly associated with older people). Without adequate treatment, JIA can lead to other health conditions as the immune system attacks other organs, as well as permanent disability and long-term health implications.

At present, there is no cure for Juvenile Idiopathic Arthritis. All current treatments seek to 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 impinge on long-term health of children taking these medications. In around half of all cases, children go into spontaneous remission. But in the other half, they are confined to taking powerful drugs long-term, with all the side-effects and complications that causes.

Alex will also be raising money for Juvenile Arthritis Research, a charitable project aimed at finding a cure for the disease. With the support and endorsement of leading academic researchers, the JAR project works independently to analyse data and information from a wide range of different scientific disciplines and research fields. By bringing together the disparate sources of information, they believe that they will be able to piece together the clues necessary to fully understand the disorder and develop a cure.

Alex says: “I have chosen to run for Juvenile Arthritis Research, as I am friends with a family who have the bravest little girl, Trinity, who is 6 years old and has had JIA since she was two. Unfortunately, however, she needs ongoing chemotherapy treatment to enable her to walk. Trinity still has a long way to go in her treatment but there are thousands of children left to help. If anyone can help donate I would be most grateful, regardless of how big or small.”

Richard Beesley, the founder of Juvenile Arthritis Research, says: “When Alex told us he wanted to run 250 miles in just two weeks to raise awareness and much-needed funds for our research, I was amazed. Juvenile arthritis is a horrible disease, and there are thousands of children and young people suffering from its effects. We are committed to finding a cure, and are so grateful to Alex for taking on this incredible challenge for us.”

Please help Alex support Juvenile Arthritis Research as they search for a cure for juvenile arthritis - a crippling and painful autoimmune disease. You can give online at www.give.net/Run250. You can also follow his progress on the Juvenile Arthritis Research social media channels.

You can find out more about the project, and support Juvenile Arthritis Research at www.jarproject.org

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NOTES FOR EDITORS:

BACKGROUND INFORMATION ABOUT JIA

In children and young people with juvenile arthritis, the body starts to attack the joints, causing inflammation, pain, discomfort and reduced mobility. If the inflammation cannot be controlled effectively, it leads to joint damage and bone destruction leading to further pain and complications, including permanent disability and long-term health implications. Many children with juvenile arthritis suffer from uveitis, where the immune system attacks the eyes; if not stopped this can lead to permanent vision loss and blindness. Juvenile arthritis is not the same as age-related osteoarthritis, and is a different condition to rheumatoid arthritis.

Juvenile arthritis affects 1 in every 1,000 children under the age of 16. At present, there is no cure.

Thirty years ago, the only medications given to help children with the condition were painkillers. These had variable effects in reducing pain, but were unable to reduce inflammation effectively, and so unable to prevent joint damage. This has resulted in JIA patients, who were children when they developed the disorder, needing joint replacements as young adults.

Nowadays there are a range of new treatments available. The standard treatment is Methotrexate – a chemotherapy drug that works by reducing the immune system. This is often supplemented with other medications (such as painkillers and steroids) when required. However, methotrexate has side-effects and is not always effective. In fact, it is ineffective in treating JIA in around 35% of all patients. Where patients do remain on the drug, they often experience sickness (for which many take anti-sickness medications), hair loss, headache, mouth ulcers, and weakness. Methotrexate is also cytotoxic, and can cause liver damage for which regular blood tests are required.

Where children and young people are unable to take methotrexate, they may move on to ‘biologics’ – the next level of drugs. These work in a variety of ways, but all work to reduce the immune system.

As a result of having their immune system reduced, children and young people on anti-arthritis medications are more likely to contract illnesses. Even relatively simple illnesses can become severe and life-threatening.

ABOUT JUVENILE ARTHRITIS RESEARCH

In January 2018, Richard Beesley founded Juvenile Arthritis Research in order to find a cure for JIA. Richard has a background in biomedical research from the Institute of Child Health, and experience in running clinical trials and research programmes, and has worked in research, project and programme management in a number of public and private sector organisations - most recently in local government. He left his senior role in local government in order to launch the JAR Project. He is entirely committed to this project, having stepped out in faith and put everything on the line to find a cure for the 15,000 children in the UK with JIA and the millions who suffer from the disease globally.

JAR has the support and endorsement, both in terms of their aims and methodology, from the leading research teams in academic research. Their aim is simple – to find the cure for juvenile idiopathic arthritis.

WHAT IS LIFE LIKE FOR A CHILD WITH JIA ?

Trinity is six years old. She was diagnosed with JIA when she was two. For her, JIA looks like this:

Trinity’s experience is not uncommon but, in some ways, she is one of the ‘lucky’ ones as her JIA is currently responding to methotrexate and joint damage is currently being prevented.

All of this is to enable her to live as normal a life as possible. She is not alone. There are thousands of JIA patients across the country, all of them on similar treatment regimens to Trinity. A life of injections and treatment, hoping for remission but planning for a forever without it.

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