

# True story

His daughter's arthritis diagnosis five years ago led to **Stephen Wombwell** starting an annual Christmas Fair to raise funds for the Leeds Paediatric Rheumatology Department

At the end of the summer holidays in 2013, my daughter Nonie had a fall down some stairs and both knees swelled up. She was five years old at the time, and after a few weeks the swelling hadn't gone subsided. The stiffness in her legs was particularly bad in the mornings and receded during the day. Some mornings were so bad that we had to put her in a bath to get her going.

Fairly quickly our GP referred Nonie to York Paediatrics who diagnosed juvenile idiopathic arthritis (JIA) and referred us to the specialist team at Leeds General Infirmary.

The first course of treatment was large dose ibuprofen while we waited for the small operation during which Nonie was put under general anaesthetic and given an MRI. Following confirmation of JIA in her ankles, knees and jaw, Nonie was put under general anaesthetic again and given steroid injections into the affected areas to kick start the process of reducing the inflammation and preventing any further long-lasting damage.

She then went onto methotrexate for several months but this caused havoc with her liver function. After repeated pauses to prevent liver damage and more blood tests than I can remember (every two weeks at one point) it was decided to stop this and move Nonie onto etanercept (twice weekly injections done by us) and then adalimumab (once

fortnightly injection, still done by me).

Nonie still suffers from JIA. She came off her meds in February 2018 but within eight weeks the swelling and stiffness returned and she had her third operation with steroid injections. Apart from a bit of stiffness and aching, she is remarkably well. She participates in all sports at school and swims like a fish. She has learnt that sometimes her legs are going to hurt and she just has to grit her teeth and get on with it; in no way does the JIA hold her back.

*“Apart from a bit of stiffness and aching, Nonie is remarkably well. She participates in all sports at school and swims like a fish”*

It has been important that Nonie carries on playing sports even if her legs hurt as she needed to build up muscle to help control the hyper mobility.



**Nonie Wombwell was five years old when she was diagnosed with juvenile idiopathic arthritis**

A diagnosis of JIA is not the end of the world as the disease is usually controllable. Our doctors have all been amazing but we haven't been afraid to say our piece. We were told lots of anecdotal stories about methotrexate when our daughter was on it. We didn't like it and asked about alternatives and had her medicine changed.

There is no noticeable difference between Nonie and any of her classmates. Initially the diagnosis of JIA came as a surprise as I, like many others I suspect, thought arthritis only occurred in adults. There was the usual cry of “why poor Nonie” and “life is so unfair” which was fairly quashed as we realised that JIA is manageable and in the clinics we have seen children with significantly worse outcomes than Nonie's. JIA is now something we just deal with and don't let it interrupt life. **AD**

## Newburgh Priory Christmas Fair

The Newburgh Priory Christmas Fair in North Yorkshire supports juvenile arthritis via the Leeds Paediatric Rheumatology Department Supporting Juvenile Chronic Arthritis Trust Fund Number 3T12.

For three days, over 20 carefully selected small businesses from across the UK will exhibit and a series of events will take place. This is a wonderful opportunity to enjoy one of Yorkshire's seldom seen country houses whilst supporting juvenile arthritis.

### Where?

Newburgh Priory, Coxwold, York YO61 4AS

### When?

- Thursday 29 November 5pm–9pm: shopping, drinks and carols from the Ampleforth College Choir, £10 (purchase in advance).
- Friday 30 November, 10am–5pm: shopping £5 (purchase on the door) plus a talk by Ed Kluz at 11am (tickets £15,



purchase in advance) and Manor Garden Wreath Making Workshop at 2.30pm (tickets £40, purchase in advance).

- Saturday 1 December, 10am–5pm: shopping £5 (purchase on the door) plus The Gingerbread House Workshop at 11am

(tickets £15 for children and £30 for adults, purchase in advance).

**For tickets and further information please contact fair organiser Georgie Pridden [georgie@pridden.com](mailto:georgie@pridden.com).**