

Nottinghamshire Network

A WARM WELCOME

Hi my name is Lynn Baker I have been the Lead Volunteer for the Nottinghamshire Network for just over a year, but have been part of the organizing team for much longer.

Over the years I have received support from other people in the Network and now my own health is more stable would like to support others.

In this newsletter we have a couple of articles from volunteers, one from a new volunteer and one from a veteran!

If you have any spare time to give in any capacity please do contact volunteering@crohnsandcolitis.org.uk. We are always looking for people that can help us both on a regular basis and for one off events

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A NEW VOLUNTEER'S VIEW

My name's Annisha, I'm 26 years old and have been volunteering with Crohn's & Colitis UK since the beginning of this year. I decided to get involved as I wanted to get behind a health-related cause after dealing with my own health problems last year. Crohn's & Colitis UK stood out as a charity to support as they do such vast and varied work to help a great cause. Whether its giving advice to those diagnosed, supporting their families, raising awareness to the general public or funding much-needed research, they make sure they cover all bases in order to work towards improving the lives of those living with Crohn's and Colitis. I'm excited to get involved and am hoping that on top of helping a great cause, I can learn new skills and meet new people along the way too. I'm also hoping I can help the charity by bringing my own skills to the table, mostly by helping them communicate with the general public and reach a wider audience.



A VOLUNTEER'S STORY

I used to think that my diagnosis of "Crohn's colitis" was because the doctors were not sure exactly what form of IBD I had. This was probably because I had four failed colonoscopies - 3 if you don't count the time I fainted in the waiting room and never made it to the operating room. I am fairly sure it was not because of the injection they gave me - after all I have had loads of needles stuck into me over the years. In fact it was one of these that started off the process that lead to my diagnosis.

I used to be a regular blood donor and would only miss the occasional session when I was streaming with cold. The last time I went down, they did the usual blood drop test and told me to go away - my blood did not have enough iron in it. They told me to visit my GP who confirmed I was anaemic and then tried to work out why. After about a year of being tested prodded and poked, they decided what the problem was and started treatment.

Up to that point I had not felt particularly ill - but the first stuff they gave me caused diarrhoea, as did the second. And then the pain started so I was given something to ease it which gave me constipation and I ended up in hospital with a "nil by mouth" notice over the bed

Then I was put onto wonderful steroids and the pain was eased. And I could not stop taking them - or rather it took lots of goes at tapering them off before we did it slowly

enough for me to stop completely. So that first Christmas after being diagnosed was really difficult - the pain, the steroids, not being able to eat the best meal of the year!

But how do you cope with this strange illness? So I looked to Crohn's & Colitis UK (it was known as NACC back then) and joined the local group; it was a great help - people who understand what you are going through. Sadly the people who were running it ran out of energy (as happens with IBD) and the group closed down. A few years later NACC asked members in Nottingham if they would help set up a new group and I have been treasurer ever since, trying to give back the support I received when I needed it and keep in touch with the friends made through the group.

I was diagnosed over 20 years ago and the worst time really was the beginning. Since then I have been lucky that azathioprine has continued to keep symptoms at bay. There were bad patches - usually in April once the silly season for my line of work was over and I could stop and realise how tired I was then I worked out how to organise my work better and stopped having such problems.

So does Crohn's hold me back? I have probably retired earlier because of it - I was getting tired and worried I would miss something important in my work. But I have found lots to keep me very busy including learning new skills (including driving a minibus, singing in a choir and replacing fence posts).



**CROHN'S &
COLITIS UK**

**FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER**

Leicestershire & Rutland, Lincolnshire Central,
Northamptonshire and Nottinghamshire local Networks

BLUEBELL WALK & CYCLE RIDE

Rutland Water

Sunday 5th May 2019

to start from Whitwell Car Park on the North Shore
of Rutland Water (off the A606) 10am - 12noon

**2 mile / 5 mile / 9 mile Walk
17 or 25 mile Cycle Ride**



This year's theme is
"Woodland Creatures"
(Optional Fancy Dress)

**To take part call 07434 731970
or visit www.crohnsandcolitis.org.uk/bluebell**

RIO RUNS WITH ROBIN HOOD!

My name is Rio and I was diagnosed with Crohn's Disease in October 2015, over a year from my symptoms being dismissed by the GP. Luckily for me I knew what symptoms to look for as two of my family members have Crohn's disease, however that also means I know just how hard and debilitating the disease can be. Since being diagnosed I have had several treatments including steroids, immunosuppressants and cytotoxic drugs. Unfortunately I am still trying to find a medication that suits me due to the detrimental effects they have had on my body.

In early 2018 after buying my first house I had to seriously think about getting life insurance. I felt pretty demoralised at 23 to be declined by several companies. On the back of this and a flare of active Crohn's I decided to do something more positive about my Crohn's so signed up to do the Robin Hood half marathon.

It was important to me to do something for my own personal achievement whilst raising awareness and funds for Crohn's & Colitis UK. I set up a just giving page on May 1st with a target of £500 and a story about my disease. I joined strava and got a decent pair of trainers thinking this was all I needed! I 100% under estimated how difficult this challenge would be. Training was constantly interrupted by pain and flare ups, not to mention the constant fatigue.

Thanks to social media I could share my stories and updates which meant more people were asking about the disease and sharing my stories for others to see.

Finally the day arrived and nerves were getting the better of me but I was determined to see it through. At times I felt like giving up, I honestly felt like I wouldn't make it. But with the support of friends, family and even strangers along the way I managed to complete the course without stopping in a time of 2 hours 47 minutes.

I smashed my target raising a total of £1025 + gift aid. I'm not sure it's something I will ever do again, but for one day I kicked Crohn's butt!



Tickets via DerbyLIVE Box Office | 01332 255 800 | www.derbylive.co.uk

BRASS FOR A CAUSE

Derwent
Brass

DERBY
LIVE

Derwent Brass, presents a A 'Roy Poole' Charity Concert in support of Crohn's and Colitis UK

Derbyshire's Premier Brass Band will perform an evening of top class brass music, from traditional to modern and classical to swing, there will be something for everyone, all in aid of this worthy cause.

**CROHN'S &
COLITIS UK**

APRIL | SATURDAY
13 | 7:30

TICKETS
£7.50*

Venue Address
Landau Forte College
Fox Street, Derby
DE1 2LF

Concert commences 19:30
Theatre opens at 19:00
Unreserved Seating
Licensed Bar | Free Parking

***Tickets**
£7.50 (includes 50p booking fee)
Children (under 16) half price
boxoffice@derby.gov.uk

Available from DerbyLIVE Box Office
Visit: www.derbylive.co.uk
Call: 01332 255800
Sales Centre, Market Place, Derby

Derwent Brass - a registered charity in England and Wales: 1146146
Crohn's and Colitis UK - a registered charity in England & Wales (1117148) and Scotland (SC038632)

DATES FOR YOUR DIARY

TALKING ABOUT

Wednesday April 3rd 7pm - 9pm
Swatch Bar Crowne Plaza Nottingham
 Come along and have a chat with people with similar experiences to you.
 Look out for our Organising Team members sporting their purple t-shirts

TALKING ABOUT

Wednesday June 5th 7pm - 9pm
Swatch Bar Crowne Plaza Nottingham
 Come along and have a chat with people with similar experiences to you.
 Look out for our Organising Team members sporting their purple t-shirts

TALKING ABOUT

Wednesday September 4th 7pm - 9pm
Swatch Bar Crowne Plaza Nottingham
 Come along and have a chat with people with similar experiences to you.
 Look out for our Organising Team members sporting their purple t-shirts

If you have received this newsletter by post and would be happy to receive future editions by email please provide your name, membership number and email address to networks@crohnsandcolitis.org.uk.

This will save the network valuable funds which can be used to benefit all those affected by Crohn's and Colitis.

The Nottinghamshire Network has made every reasonable effort to ensure the content of this newsletter is accurate, but accepts no responsibility for any errors or omission. The views of the contributors do not necessarily reflect the views or policies of Crohn's and Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.

CONTACT US

**CROHN'S &
COLITIS UK**

NOTTINGHAMSHIRE NETWORK

Chairperson: Lynn Baker
 Helpline: 0300 222 5700*
 Website: www.crohnsandcolitis.org.uk/nottinghamshire
 Email: networks@crohnsandcolitis.org.uk



Crohn's and
Colitis UK
Nottinghamshire
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NottsCCUK

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enquiries@crohnsandcolitis.org.uk
www.crohnsandcolitis.org.uk

Charity registered in England Number 1117148 Charity registered in Scotland Number SC038632
 A company limited by guarantee in England: company number 5973370

HELPLINE

Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

CONTACT US BY:

Telephone: 0300 222 5700*
 Mon, Tue, Wed and Fri - 9 am to 5 pm
 Thu - 9 am to 1 pm

Email: info@crohnsandcolitis.org.uk

Web Chat (Live Online): see our [website](http://www.crohnsandcolitis.org.uk) for details

**Calls to this number are charged at a standard landline rate or may be free if you have an inclusive minutes' package. Calls may be recorded for monitoring and evaluation purposes.*