

Bristol, Bath & North Somerset Network

Welcome to our first newsletter since September 2019! Welcome to new members who have joined since then, and apologies for not reaching out to you sooner. The Covid pandemic has meant that no local in person charity fundraising, social or medical educational meetings have been permitted since early 2020 so we have had very little to tell you about. Nevertheless, we are very pleased to let you know that, after a period with the network's Lead Volunteer role vacant (but very ably covered in the interim by Beth Tasker – thanks very much, Beth!), we now have a new Lead Volunteer, Claire Sunshine, who introduces herself below.



MEET THE NEW LEAD VOLUNTEER

Hi, I'm Claire Sunshine, the new Lead Volunteer for Bristol, Bath and North Somerset. I live in Weston-super-Mare with my husband and 9 year old daughter. I work full-time at the Environment Agency in Emergency Planning. I have Fistulising Perianal Crohn's Disease (don't Google it and if you do, don't say I didn't warn you!). I was pretty sick from 2012-2014 but thanks to the wonder drugs Infliximab and Humira (not at the same time) I am much better now. I credit my amazing IBD nurse Aileen with saving me from Crohn's despair and will always advocate for the IBD nurse service. I stopped taking Humira in October 2019 and, fingers crossed, so far so good. At the time when I was ill, there was no local network so in 2014 when I was getting better, I started volunteering and helped get the network established. Seven years on and with more experience I feel ready to take on this new challenge. I have big shoes to fill! Tony did a sterling job over the last few years and he has set up a great team, so I'll be doing my best to build on his great work.

CORONAVIRUS—COVID-19 INFORMATION

The charity has an excellent webpage which is regularly updated to reflect the latest advice crohnsandcolitis.org.uk/news/coronavirus-covid-19-advice—no doubt many of you will have found this page already. It is especially useful for those of you who are taking immunosuppressive treatments.

HAVE YOU OPTED IN?

Are you receiving the regular Crohn's & Colitis UK e-newsletter and other national news?

You can opt in at crohnsandcolitis.org.uk/news/newsletter.

NETWORK VOLUNTEERS NEEDED!

Our (normally!) busy Network needs a volunteer to take the lead in organising fundraising events when such activities are once again permitted. No previous experience is necessary and you'll be volunteering with a great, supportive group.

Once the network's activities are properly up and running again we will also need more volunteers to help generally with fundraising, social and medical meetings.

If you are interested or would like to know more about what is involved in these roles, please fill in the [enquiry form](#). It would be great to have teams ready and waiting to get all our activities back on track as soon as it is permitted and safe to do so.

PATIENT INVOLVEMENT IN RESEARCH

Get involved in the IBD Public and Patient Involvement in Research Day on 6th November 2021 (10am - 2pm). It's your opportunity to have your say in the future of research in ulcerative colitis and Crohn's disease. It's a free virtual event and you can register online on the Crohn's & Colitis UK website.

www.crohnsandcolitis.org.uk/ppi-day

**Virtual IBD Patient and Public
Involvement in Research Day**

**Have your say in the future of
Crohn's and Colitis research!**

Saturday 6th November 2021

FUNDRAISING (2019–2021)

TONY'S LEJOG CYCLE RIDE

Volunteer Tony Walmsley raised a magnificent £2,605.63 for Crohn's & Colitis UK by cycling from Lands End to John O'Groats in the summer of 2019. Tony cycled unsupported and on his own for most of the epic 911 mile journey which he completed in just twelve days. Challenges included strong headwinds in the Highlands of Scotland, a broken spoke, loose front wheel bearings and some very busy A roads. Crossing the Scottish border into Gretna Green only to be told that he was just half way through his quest must have been tough, too!

Tony, who is a former lead volunteer for our Network, said "I was diagnosed with Ulcerative Colitis ten years ago. I am a keen cyclist and chose to complete this challenge to prove to myself that life can continue as normal whilst living with this disease. I also wanted to use the ride to raise awareness of, and funds for, this charity." In 2018, Tony was given a national award from Crohn's & Colitis UK for his work in supporting people affected by the disease.

Tony has been bowled over by the support he has received from both friends and complete strangers in achieving his aim.



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Crohn's & Colitis UK's Bath & North Somerset Network are now registered with easyfundraising, which means you can help us for FREE. Over 4,000 shops and sites will donate to us when you use easyfundraising to shop with them—at no

extra cost to yourself! All you need to do is sign up and remember to use easyfundraising whenever you shop online. It's easy and completely FREE! These donations really mount up, so please sign up to support us at [easyfundraising.org.uk/causes/cacuk/](https://www.easyfundraising.org.uk/causes/cacuk/)

You can also support Crohn's & Colitis UK nationally with Amazon Smile:

Go to smile.amazon.co.uk and use your usual Amazon login details as normal

In the 'Pick your own charitable organisation' box—search for Crohn's and Colitis UK

Press the 'Select' button to choose Crohn's & Colitis UK as your preferred charity

Whenever you shop, make sure you shop at smile.amazon.co.uk to ensure that 0.5% of eligible purchases are donated to Crohn's & Colitis UK!

BRISTOL BANSHEES GET A DUNKING FOR CHARITY

The Bristol Banshees, a motorcycle club for women, has very kindly raised over £900 for Crohn's & Colitis UK. The charity's fun day this year was held on 27th April 2019 at Barton Hill Rugby Club and all the proceeds were donated to our charity.

The fun day included a medieval fighting competition, a table top display by Crohn's & Colitis UK and, despite the cold weather, a fully operational dunking stool. Several of the Banshees braved the inclement weather and risked hypothermia when accurate throwing in the competition sent them plunging into the icy waters of the dunk tank.

A BIG thank you to the Banshees and also to all the supporters of the event.



CRIBBS CAUSEWAY MALL COLLECTION

Network members spent a day in the Mall at Cribbs Causeway with an information stand and also collecting funds for the charity. £127.95 was raised and the high numbers of people visiting the Mall on a Saturday meant that awareness of our charity was raised. We also had a number of good conversations with people who approached the stand to talk about their own or their family members' experience of Crohn's and Colitis.

ICESCAPE DONATION

Icescape at the Tropicana in Weston-super-Mare very generously donated the proceeds of a skating session on 6th November 2019 in aid of our Network. This resulted in a fantastic donation of £320! Local members also enjoyed a social meeting at the skating rink at the same time. A big thank you to Icescape for their generosity and also to the skaters who attended the session and hence donated their entrance fees to our cause.

FUNDRAISING DURING THE COVID PANDEMIC

Although many of our usual fundraising activities cannot be carried out at the moment, there are other ways to raise money if you would like to do more to help fund the charity's work. More information and suggestions can be found at crohnsandcolitis.org.uk/get-involved.

- April 2020—We received £290 from Waitrose Community Matters in Portishead.
- April 2020—Milly and Harrison's 5 day marathon raised £845.
- May 2020—India King (picture below) raised £895 by climbing the height of Mount Everest (and back down again) on her stairs. 3,871 flights of stairs meant climbing up my stairs at home 775 times (and back down again) to climb Mount StairEverest.
- March 2021—Sarah Hitchings donated £80 from running a small hamper raffle.
- October 2021—Zoey-lea Ryland created a Halloween display in her front garden in Cadbury Heath collecting in aid of [Crohn's & Colitis UK](https://crohnsandcolitis.org.uk) in memory of her mother. Kate went round to visit the scary scene.

Huge thanks to these people for continuing to raise much needed funds at such a difficult time.



RECENT (PRE-PANDEMIC) EVENTS

CHARITY BARN DANCE

Our Barn Dance in April 2019 took place at Hutton Village Hall. About 80 people enjoyed a scrumptious buffet and a fabulous evening of music and calling by the Highly Strung Band. There was much laughter and dancing and we raised £430 for Crohn's & Colitis UK with the same amount raised for the Labrador Trust.



BATH RUH MEDICAL EDUCATION EVENT

Over 60 patients and clinicians attended the Bath RUH Medical Meeting on the 11 Feb 2020.

The IBD clinicians at the hospital are very supportive of Crohn's & Colitis UK and the work we do.

They invited us to bring our table top information stand and give a short presentation covering who we are and the support we are able to give to patients with IBD. A quick show of hands with the audience showed that the charity was well recognised. We are grateful to the hospital and clinicians for the support they give us.

Below: Kate Gibson (volunteer) with Helen Burton (Research Nurse) at Bath RUH Medical Meeting



SOUTHMEAD MEDICAL EDUCATION EVENT

This popular event in late 2019 was attended by 60 people. The four presenters from North Bristol NHS Trust gave interesting and informative talks on Living with IBD, Cancer and IBD, and Surgery and IBD. The presenters also hosted a general IBD question and answer session which was much appreciated by the audience. Cynthia De Gelder, one of our Organising Team volunteers, gave a presentation about Crohn's and Colitis support and the activities of our Local Network.

The Bristol, Bath & North Somerset 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 & Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.

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HELPLINE

Our Helpline Team can provide information on a range of subjects including:

- Managing symptoms
- Medication
- Diet
- Test and diagnosis
- Wellbeing
- Employment
- Disability benefits
- Help to find support from others living with the condition.

We also signpost people to sources of expert advice on disability benefits and options for specialist emotional support.

If you need specific medical advice about your condition, your GP or IBD team will be best placed to help.

For details about IBD services including hospital contact details, advice lines and what to do in an emergency, visit our [find an IBD nurse page](#).

Contact us by:

Phone: 0300 222 5700* (Mon to Fri: 9 am to 5 pm)

Email: helpline@crohnsandcolitis.org.uk

Live Chat: see our [website](#) 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.*

If you have received this newsletter by post and would be happy to receive future issues 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 or Colitis.