CROHN'S & COLITIS UK



NEWSLETTER

APRIL 2023

Issue 1

Milton Keynes & Bedford Network

WE'RE BACK FOR A BUSY 2023!

Welcome to our newsletter where we'll bring you the latest updates from the Local Network.

By Michael Bate

Firstly, welcome to the Milton Keynes & Bedford Network April newsletter, the first one since 2018. The aim is to produce this newsletter twice a year covering what's been happening and what's planned in the future.

Our purpose is to support people affected by Crohn's and Colitis across Milton Keynes & Bedford, to raise awareness of the conditions and raise vital funds for Crohn's & Colitis UK.

UP & RUNNING AGAIN

It's been a busy 6 months, being one of the few Local Networks across the UK who have started in-person events again after the disruption caused by the pandemic.

We've re-started our coffee mornings where it has been fantastic to meet many of you. We've also held awareness stands at Milton Keynes Hospital to raise awareness, and more recently worked with Buckinghamshire University medical students to share a patient's perspective on living with Crohn's and Colitis as part of their education.

VOLUNTEERING

All of this isn't possible without the dedicated group of volunteers so I'll be sharing fact-files to help you put faces and names to our fantastic team, and updating you on some recent changes.



Awareness Stand - Milton Keynes Hospital

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RETURN OF THE MEDICAL MEETING

We are excited to announce this year will see the return of the annual medical meeting between 2pm - 4.30pm on 16 September 2023 at Milton Keynes University Hospital.

The medical meetings offer people a more clinically focused perspective on Crohn's and Colitis with speakers including Gastroenterologist Consultants and the IBD specialist nursing team among others. We are finalising plans so check the Crohn's & Colitis UK website or the network's social channels for more information soon!

It will be a free ticketed event to manage capacity with a suggested donation to the charity instead.

University of Buckingham Medical School

Milton Keynes University Hospital, Fleming Drive, Eaglestone, Milton Keynes, MK6 5LD

MK & BEDFORD COFFEE MORNINGS

We are delighted that our Saturday morning meet-ups have restarted. With the first one since the pandemic having taken place in September 2022.

We've had 7 coffee mornings since then, running them every 3rd Saturday of the month, alternating between John Lewis in Milton Keynes shopping centre and Brewpoint in Bedford.

We know these socials are important for our members and their family and friends to get together informally over a cup of tea or coffee to:

- Share experiences and learn from others
- Build a local community and create friendships

GREAT TURN OUTS

We've been really grateful that 30 people have attended since the first coffee meet-up. It's been lovely to meet you all and hear your personal experiences and journeys.

If you haven't attended one of our coffee mornings yet we'd love to see you at a future one. There's no obligation of course to share anything you don't feel comfortable with or to purchase anything from the venues - feel free to get involved in the conversations or just to listen in.

Friends & family are also very welcome to join us.



March Coffee Morning - Kathy & Sejal (left & second from left)

SEE YOU NEXT TIME?

The dates for the next coffee mornings are below and note we won't be running them over the summer holidays:

Milton Keynes

John Lewis, The Place to Eat Café, 2nd Floor, Milton Keynes Shopping Centre

- 20 May, 10.30am-11.30am
- 23 Sept, 10.30am-11.30am

Bedford

Brewpoint, Cut Throat Lane, Bedford, MK41 7FY

- 15 April, 10.30am-11.30am
- 17 June, 10.30am-11.30am

STAY UP TO DATE

New events are regularly added and are subject to change. The best way to stay up to date with Network activity is by following our social media pages or checking our page on the Crohn's & Colitis UK website for the most up to date information.

You can find all the information in the **Contact Us** section at the end of this Newsletter.

WHERE TO FIND US

If you're ever unsure where to find us on the day then check out our socials where we post pictures of where our volunteers are.

They'll also be wearing purple Crohn's & Colitis UK t-shirts and have purple leaflets, flags and (sometimes!) our Local Network teddy bear mascot complete with a Crohn's & Colitis UK purple t-shirt of it's own!

The photo below shows our fantastic long-time volunteers Anna & Gill modelling what to expect to find when attending our informal coffee morning meet-ups.

If you ever have any questions, feel free to message us on our socials!





Awareness Stand - Abi, Michael & Gill

AWARENESS ACTIVITIES

The Network supported Crohn's and Colitis Awareness Week in December 2022 by hosting an awareness stand between 10am-3pm in Milton Keynes University Hospital, just outside of Costa Coffee.

The purpose was to raise awareness and share information on Crohn's and Colitis and we met lots of people interested in finding more about what the conditions are and the role of the Local Network and Crohn's & Colitis UK.

Our stand was hosted by volunteers Abi, Kathy, Gill & Michael. We also raised nearly £100 in the collection bucket so thanks for everyone's generosity.

IBD TEAM

I'd like to thank the Inflammatory Bowel Disease specialist nursing team at Milton Keynes University Hospital who helped us secure the prime location for our stand, brought lots of fantastic literature and information to showcase and who also hosted the stand on shifts throughout the day too!

We are grateful for our positive relationship with the IBD Nursing Team at MKUH and look forward to working together to continue to raise awareness and run education events in the local area.

WHAT'S NEXT

It is **World IBD Day** on 19 May 2023 so we have organised two awareness stands again with the help of the IBD specialist nursing teams at Milton Keynes & Bedford:

- Milton Keynes University Hospital, 10am-3pm
- Bedford Hospital, 10am-3pm

If you're in the area, why not pop in and say hello to our volunteering team.

VOLUNTEER FACT-FILE MICHAEL BATE LEAD VOLUNTEER



Hi! I'm Michael, the lead volunteer for the Milton Keynes & Bedford Local Network. I was diagnosed with Crohn's disease in 2018 and after multiple failed steroid and biologic treatments, I finally went into remission in 2020 using a mixture of ustekinumab, azathioprine & octasa medication.

What does Crohn's & Colitis UK mean to me?

"They were a huge help during my diagnosis and a super important source of information to help me understand my Crohn's."

What's your IBD top-tip?

"Listen to your body! Everyone is different and only you know what helps and doesn't."

What's the best thing about being a volunteer?

"Getting to meet other local people with the condition and share experiences."

VOLUNTEERING WITH US

The Local Network cannot do what it does without the help of our fantastic group of volunteers. The volunteering team are broadly split into two volunteering groups; the **Organising Team** and **Event Volunteers.**

- Organising Team volunteers are responsible for putting on events and engaging with their local Crohn's and Colitis community
- Event Volunteers support with events and activities on the day

TEAM UPDATES

There have been some changes to our volunteering team recently with Anna stepping back from the Lead Volunteer role after 10 years and Michael taking that role on. Our Finance Volunteer Kathy also decided to step back after 10 years with Abi joining the Organising Team as new Finance Volunteer. We'd like to thank both Anna & Kathy for their fantastic contributions to the network and look forward to them continuing to support network events. We also welcomed two new volunteers who joined the local network team - Matt and Hope.

INTERESTED?

Volunteering is a great way to meet new people, develop new skills and make a difference to everyone affected by Crohn's and Colitis.

Every volunteering role is crucial to the success of the network and we need your help!

If you're interested in volunteering in any capacity, you can find the different role descriptions on the <u>Crohn's & Colitis website</u> and the <u>volunteering enquiry</u> form.

For more information, visit: www.crohnsandcolitis.org.uk/en <u>quiry-form</u>



VOLUNTEER FACT-FILE ABI FOX FINANCE VOLUNTEER



Hi! I'm Abi, the Network's Finance Volunteer, and I joined the organising team in May 2022. My partner lives with Crohn's Disease and now he's in remission, I wanted to help others affected by the conditions. I also run the Network socials, so if you send us a Facebook or Instagram message, you're likely talking to me!

What is your relationship to Crohn's and Colitis?

"My partner was diagnosed with Crohn's Disease in 2018. At his worst I took on the carer role, so I have seen how debilitating the disease can be."

What's your top IBD tip?

"Lean on your partner, family, friends - when you're ill you're vulnerable and it can be really hard to advocate for yourself, so it's important to have someone who'll fight your corner when you can't."

DATES FOR YOUR DIARY

BEDFORD COFFEE MORNING

15 April, 10.30am-11.30am Brewpoint, Cut Throat Lane, Bedford, MK41 7FY

MK COFFEE MORNING

20 May, 10.30am-11.30am The Place to Eat, 2nd floor, John Lewis, Milton Keynes, MK9 3EP

BEDFORD COFFEE MORNING

17 June, 10.30am-11.30am Brewpoint, Cut Throat Lane, Bedford, MK41 7FY

MEDICAL MEETING

16 September, 2pm-4.30pm University of Buckingham Medical School Milton Keynes University Hospital, Fleming Drive, Eaglestone, Milton Keynes MK6 5LD

MK COFFEE MORNING

23 Sept, 10.30am-11.30am The Place to Eat, 2nd floor, John Lewis, Milton Keynes, MK9 3EP

BEDFORD COFFEE MORNING

21 Oct, 10.30am-11.30am Brewpoint, Cut Throat Lane, Bedford MK41 7FY

STAY UP TO DATE

Our events are hosted by volunteers so sometimes things change. We also add new events regularly.

We recommend you stay up to date by following our socials media pages or checking out the Milton Keynes & Bedford page on the Crohn's & Colitis UK website.

CONTACT US

MILTON KEYNES & BEDFORD NETWORK

Lead Volunteer: Michael Bate Email: mkb@networks.crohnsandcolitis.org.uk Website: www.crohnsandcolitis.org.uk/mkb



Crohn's & Colitis UK Milton Keynes & Bedford

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GENERAL ENQUIRIES

Crohn's & Colitis UK 1 Bishops Square, Hatfield Business Park, AL10 9NE www.crohnsandcolitis.org.uk/contact

Volunteer Enquires: 01727 734 475

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 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

CONTACT US BY:

Telephone: 0300 222 5700* Monday to Friday - 9am to 5pm

Email: helpline@crohnsandcolitis.org.uk

Live Chat: www.crohnsandcolitis.org.uk/livechat *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

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