



Sun 4th May
Rutland Water
from 10am

BLUEBELL WALK OR CYCLE RIDE

Walk 2, 5 or 9 miles or
Cycle 17 or 25 miles for
Crohn's & Colitis UK. Fun
for all abilities!



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WELCOME TO THE LEICESTERSHIRE & RUTLAND NETWORK

We are excited for 2025! We look forward to seeing you at our in person social events, awareness stands and our big fund-raising event at Rutland Water in May.

This newsletter looks back over the past 6 months, highlighting the great work and effort from our supporters and our volunteers. We will also give you a glimpse into what our volunteers are beavering away on in the background.

The local network of incredible Crohn's & Colitis UK volunteers dedicate their spare time to planning and hosting various events. We are a small team and would love to invite you to join us. If you feel like you can dedicate a few hours of time per month to help with ideas, to help with planning, to be part of an enthusiastic team, then please do get in touch. You don't need experience, we welcome anybody over the age of 18.

If you can't dedicate time to being on the Organising Team then there are more ad-hoc positions available. Visit crohnsandcolitis.org.uk/get-involved/volunteer for more information.

We look forward to speaking to you at one of our events - let's all do 2025 together!

Ben Rutter, Lead Volunteer

Crohn's & Colitis UK Leicestershire & Rutland

BLUEBELL FUNDRAISER 2025

Join us as we return to the shores of Rutland Water for our annual fundraising event, the Bluebell Walk or Ride 2025.

On Sunday 4th May we'll be walking or riding our way around our local, favourite reservoir. Last year we raised over £6000 which was split between the 4 host Networks of Leicestershire & Rutland, Northamptonshire, Nottinghamshire and Lincolnshire. In 2025 we want to smash this and raise even more money to support those affected by Crohn's and Colitis locally in our Network areas.

We pride ourselves on being an inclusive event which is why we allow you to choose your challenge. We have a smaller, short walk taking in



the Bluebells which will be in full bloom (They are gorgeous - a sea of blue throughout the woods!); this is a 2 mile walk. If you want to push a little more then there is a 5 mile walk (which includes the beautiful bluebells) and then for those really wanting to challenge themselves, we have a 9 mile walk which not only takes in the sight of the Bluebells but also the stunning Normanton Church.

All of the walks are on hard ground, so push chairs and wheel chairs etc can navigate them. Be aware the Barnsdale woods can be a little muddy if it's been wet and there is a small up and down hill to get

there.

At each car park there is a toilet block with accessible toilets (remember to bring your Radar key!). At the event village and over in Normanton there is even a Changing Places toilet. Again, these are accessed with a Radar key. For more information on these toilets visit: changing-places.org

If walking is not your vibe then pump up your tyres and bring your bike along (bikes can be rented from Whitwell but this is up to you to organise and we cannot guarantee availability). We invite you to tackle the 17 mile perimeter of the water or if you're feeling particularly feisty, then you can add in the gorgeous peninsula too, making the cycle ride 25 miles long!

There will be basic refreshments available for free on the day but if you wanted some hot food or drink, then the cafe at Sykes Lane, Normanton and Whitwell will be open. Rutland Water is a great place to sit and relax with a picnic, so why not bring a blanket and set up a little picnic in our events village?

love every drop
anglianwater **ANGLIAN WATER SUPPORT**
Anglian Water are supporting the Bluebell Walk or Ride this year.

Need help with your bill?

If you're struggling to pay your bill, Anglian Water has a specially-trained Extra Care Support team who can help you find a way forward with a personalised plan. They can check you're on the right tariff, look at payment plans and point you towards other help and benefits.

Support through the hardest times

Everyone can all benefit from a bit of extra help at some stage. This could be due to age, ill health, disability, mental health problems, financial worries or even language barriers. Registering for the Priority Services Register is free and means they can support you in lots of practical ways. Find out more here.

anglianwater.co.uk/services/extra-support

CROHN'S & COLITIS UK

FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER



crohnsandcolitis.org.uk

@CrohnsColitisUK



#NotYourAverageToilet

Donate

[justgiving.com/
campaign/bluebell2025](https://justgiving.com/campaign/bluebell2025)

BLUEBELL FUNDRAISER 2025

We'll be joined by the Rutland and Stamford Sounds team (rutlandandstamfordsound.co.uk) who will be bringing the music and maybe even getting into the crowds to say "hello" to you and get your song requests.

With this years event being held on the un-official Star Wars day (If you know, you know....)

there will

be a fun Star Wars themed animal hunt through the Barnsdale Woods. If you find them all we'll reward you with a sweet treat.

Daisy Jane's face painting skills will be on hand to help get you in the mood for a fun day of fundraising!

(daisyjanesfacepainting.com)

Young and old are welcome to join in and get their faces made up!

How much do I need to fundraise?

As with any charity event, there are costs involved in making it happen, and your registration fee helps cover these.

To ensure we can continue providing vital support for people living with Crohn's and Colitis, we kindly ask each adult participant to commit to raising a minimum of £50 in sponsorship. Every pound you raise will make a real difference, funding essential services that offer support, information, and hope to those who need it most. We'll be on hand to provide fundraising ideas along the way.

We are also looking for willing volunteers to help out on the day. So if you'd rather help out, please consider joining our friendly volunteering team. No experience necessary. We have roles including marshalling, registration, event set up and more.



Register: www.crohnsandcolitis.org.uk/bluebell

TOILET HERO

Local toilet hero Helen is on a personal mission to get companies/venues to up their toilet game.

Helen wrote to various venues including Mansfield District Council, Nottingham Rock City music venue and even our very own Anglian Water/Rutland Water to highlight the poor toilet services or to help inform them of their shortcomings when it comes to people living with inflammatory bowel disease.

Emails, letters and phone calls all help inspire change. Sometimes these companies have not considered the needs of those with toilet issues. Often accessibility has been compromised, such as Rock City having "Accessible Toilets" which needed to be unlocked/opened by a staff member. As we all know, those affected by a bowel disease do not always have time on their side.

The Changing Places Toilet situated at Whitwell, Rutland Water is accessed via a Radar Key. The local cafe should have a Radar key available for those who have forgotten theirs; however when asked, staff were unsure where this key was.

Without people like Helen, procedures would not be improved. Well done Helen on your toilet mission. Improving lives, one toilet at a time.



An amazing loo at Alicante Airport. Designed for stoma users. Very rare in the UK

NATIONAL TRUST FOOD

Whilst on her mission to improve standards for those with Crohn's and Colitis, Helen found herself struggling to find suitable nourishment at a National Trust venue.

Helen was in a flare so was avoiding difficult to digest foods. She highlighted to the National Trust team that it would be really helpful to have a white bread option. In her email she was polite and did point out that they had a lovely range of sandwiches and rolls but they were all on granary, seeded and brown bread.

The National Trust replied with:

"We always strive to be as inclusive as possible and I am sorry to hear that you are unable to find something available that would suit a low roughage diet or people with the issues you mention.

We are currently in the development phase for our spring and summer menus for next year and I am pleased to say that we are looking at widening our white bread options so hopefully you will see some changes in the not too distant future."

It goes to show, that companies do listen and it is always worth politely highlighting areas of improvement.

SPEAKING OF SELF ADVOCACY

During one of the excellent virtual social events (*see the diary page for more details of virtual social events*) we were discussing self advocacy and how patient's and their family/friends have to push and push to get the care they expect.

As the discussion developed, Crohn's & Colitis UK network volunteer Vicky highlighted a document which had been worked on in Sheffield. This document is called "Take control of your care" and is a toolkit for people with IBD, to help communicate confidently with those involved in patient care.

We recommend having a read of this document: voiceability.org/assets/download/VA74-IBD-Toolkit-v4

Ben, Lead Volunteer

You know how your condition impacts your life. Your IBD team are experts in treating the condition in a wide range of individuals. It's really important to work together. By discussing what is possible, you'll be able to agree a plan that you are both happy with.



L'BORO COFFEE MORNING

Once again Graham and Jane chose Crohn's & Colitis UK as their chosen charity at the Loughborough Baptist Church coffee morning.

A fantastic £235 was raised! Thank you to the wonderful duo for continuing their effort in raising money.

If you want to host a coffee morning, or other event, for Crohn's & Colitis UK then please let us know. We'd be happy to help provide branding and maybe even a volunteer. crohnsandcolitis.org.uk/get-involved/fundraise



Picture from April 2024 Coffee Morning

IBD NURSE CONTACT DETAILS

As you may now be aware, the IBD Helpline has been updated to now include an online link.

If you are under the care of the University Hospitals of Leicester you will be given access to a system called "Accurx". You follow the QR code or web address below and answer a few simple questions relating to your query.

The idea is the nursing team will be notified of your request and respond to those with the severest requests first.

This "Accurx" system is only available during the hours 8am-12pm, Mon-Fri. The telephone helpline is still available but as you may know, the slots fill up quickly.

The IBD Helpline/Online Help is there to help you and the many others with IBD in Leicester. The IBD team want to prioritise those in a flare up first. The "Accrux" system allows those requiring less urgent responses, such as admin requests or medication questions, to be dealt with a little later.

The IBD Nursing team understands the frustration and the difficulty in contacting them and they're always doing their best to keep on top of the requests.

If you require urgent help, you're always advised to call 111 or 999 if it's an emergency. For less urgent issues, please keep trying the "Accurx" system or try speaking with your Consultant's secretary or even your GP.

To contact the Adult IBD nursing team call the helpline on 0116 258 4352 and leave a voicemail. Open Mon-Fri (excl bank hols) at 9:30am, slots fill up very quickly and once full it will then re-open the next working day.

Or if you have access to a smart phone/internet use the QR Code or Accurx: accurx.nhs.uk/p/RWEIBD

Currently available Mon-Fri (excl bank hols) between 8am-12pm.

I have a flare-up of my symptoms
Contact us about your symptoms or condition

I have a question about my medication
Contact us about repeat prescriptions, side-effects or anything related to your medication

I have an admin query
Contact us about clinic letters, recent tests, an existing appointment or anything else admin-related

Scan below to contact the IBD Nursing Team at University Hospitals of Leicester:



<https://accurx.nhs.uk/p/RWEIBD>

Please note this is for non urgent requests, for urgent help please call 111 or 999



Picture of the IBD Nursing Team from the Bluebell Walk or Ride 2019

DATES FOR YOUR DIARY

BLUEBELL WALK OR RIDE AT RUTLAND WATER 2025

Date/time: Sunday 4th May 10am-4pm

Venue: Rutland Water, 2 Bull Brig Lane, Whitwell, Oakham, LE15 8BL

We will be returning to Rutland Water for our Annual Fundraising Event and in 2025 we need to make it bigger and better than ever!

So put the date in your diary. We need participants to fundraise and take on the challenges, as well as volunteers to help host the event. See you shore side soon....



CROHN'S & COLITIS UK **BLUEBELL WALK OR CYCLE RIDE**
Sun 4th May 2025 at Rutland Water from 10am

Join our fundraising event and help us raise money to support those affected by Crohn's Disease and Ulcerative Colitis

Walk 2, 5 or 9 miles or Cycle 17 or 25 miles for Crohn's & Colitis UK. Fun for all abilities!

Register here www.crohnsandcolitis.org.uk/bluebell
Themed Treasure Hunt, Face Painting & more On The Day
Organised by Leicestershire & Rutland, Lincolnshire Central, Northamptonshire and Nottinghamshire Local Networks
Registered Charity No. (1117148) England and Wales and (SC038632) Scotland

EDUCATIONAL MEETING

Date/time: TBC, 1pm-4pm

Venue: TBC

We bring along an expert from the world of Inflammatory Bowel Disease to deliver a short talk.

The Educational Events are free to attend and we welcome friends and family too. If you intend on bringing someone under 18 be aware sometimes the topics may stray into areas that may be sensitive.

Make sure you come along to our next one. The dates & venues are yet to be confirmed.

Please look out for more details on our website:

www.crohnsandcolitis.org.uk/lr

4X COFFEE SHOP SOCIALS: JENNOS

Date/time: Friday 23rd May, Friday 27th Jun, Friday 25th Jul & Friday 22nd Aug all are 4pm-6pm

Venue: Jennos Coffee House, Everards Meadows, Cooper Way, Leicester, LE19 2AN

Coffee Shop Socials are open to all and a safe space to talk to others affected by Crohn's and Colitis.

CROHN'S & COLITIS UK COFFEE SHOP SOCIAL

Join us for our next social event



Share your photos #CCUKLeics

Venue: Jennos Coffee House, Everards Meadows, John Cooper Way, Leicester LE19 2AN

Registered Charity No. (1117148) England and Wales and (SC038632) Scotland

COFFEE SHOP SOCIAL: BUTTERCUPS

Date/time: Monday 12th May 4pm-6pm

Venue: Buttercups Coffee Shop, Rushfield House, Tilton Road, Billesdon, LE7 9FE

We welcome you to join us for a slice of cake, warm drink and friendly conversation.

CROHN'S & COLITIS UK COFFEE SHOP SOCIAL

Join us for our next social event



Share your photos #CCUKLeics

Venue: Buttercups Coffee Shop, Rushfield House, Tilton Road, Billesdon, LE7 9FE

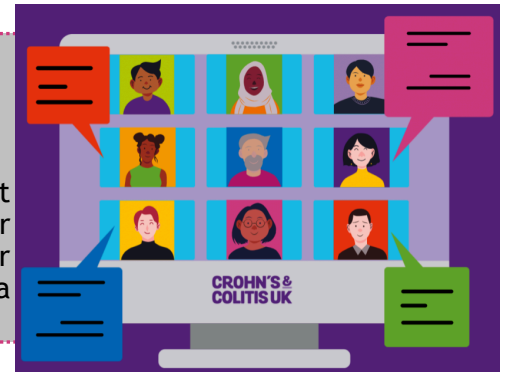
Registered Charity No. (1117148) England and Wales and (SC038632) Scotland

VIRTUAL SOCIAL EVENTS

Date/time: Throughout the year

Venue: Online - Zoom

Talk to others affected by Crohn's and Colitis or join one of the parent and carer events for those whose children are affected by Crohn's or Colitis. You can join in on any of the events. They are friendly and for people aged 18+. They are free to attend but require you to sign up via our website. www.crohnsandcolitis.org.uk/vse



THANK YOU TO SHREE PRAJAPATI ASSOCIATION LEICESTER

The Shree Parajapati Association Leicester (SPAL) selected Crohn's & Colitis UK as their chosen charity for 2024.

SPAL is a non-profit organisation with the aim to improve the quality of life of the local community and promote cultural, social, religious and sporting activities.

They held fundraising events including a sponsored walk around Watermead Country Park as well as inviting the Leicestershire & Rutland Network volunteers to join them at religious events including Navatri.

The SPAL continues to show incredible support for Crohn's & Colitis UK with plenty more fundraising planned for the future. We'll keep you updated on their exciting plans and share the final total raised in 2024 as soon as it's confirmed.



Helen (Our Volunteer) with the SPAL team



Ben (Our Volunteer) at the Navratri Festival along with incredible SPAL team

They chose to support a specific Crohn's & Colitis UK research project: Dr. Venkat Subramanian's project at the University of Leeds, which uses AI to find pre-cancerous and cancerous changes in the bowel. For more information on this research visit: crohnsandcolitis.org.uk/our-work/research-and-evidence/projects-we-have-funded

For more information on SPAL visit: shreeprajapati.org.uk

Using AI to find pre-cancerous and cancerous changes in the bowel



"Bowel cancer is one of the most serious complications of IBD, patients worry about developing it and clinicians devote large proportions of time and resources trying to detect it early, treat it or ideally prevent it."

Dr Venkat Subramanian - University of Leeds
Project cost: £98,691 Project duration: 24 months

People living with Crohn's or Colitis have an increased risk of developing bowel cancer. To help reduce this risk, experts recommend having regular camera tests called colonoscopies which help to look for any pre-cancerous or cancerous changes in the bowel. These tests can take place as often as once every year, to once every five years. The timing depends on whether someone has a higher or lower risk of developing bowel cancer. A new colonoscopy technique using blue dye helps doctors see cancerous changes. But there is still a risk doctors don't find all the changes.

Artificial Intelligence (AI) is a technology that allows computers to think like humans. AI can learn from information, experiences, and mistakes. This research will create an AI programme that identifies pre-cancerous and cancerous changes. This technology will then be used during colonoscopies. This research will also use AI to find people who are at a higher risk of developing cancer. The researchers hope to improve the diagnosis of bowel cancer in people with Crohn's or Colitis. This research could also inform how often someone should have a colonoscopy. For people at lower risk of developing cancer this could mean fewer colonoscopies. And for people at higher risk this could mean improved monitoring.

CONTACT US

LEICESTERSHIRE & RUTLAND NETWORK

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Finance Volunteer: Helen Swift

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Email: lr@networks.crohnsandcolitis.org.uk

Facebook: [@CrohnsColitisUKLR](https://www.facebook.com/CrohnsColitisUKLR)

X: [@CrohnsColitisLR](https://twitter.com/CrohnsColitisLR)

Instagram: [CrohnsColitisUK_LR](https://www.instagram.com/CrohnsColitisUK_LR)

Crohn's & Colitis UK

1 Bishops Square, Hatfield Business Park, AL10 9NE

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 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

Mon-Fri - 9 am to 5 pm

Email: helpline@crohnsandcolitis.org.uk

Crohn's & Colitis UK Helpline: visit

www.crohnsandcolitis.org.uk/helpline

Please contact us via email or tel. 9am to 5pm, Monday to Friday (except English bank holidays).

We aim to respond to 80% of emails within three working days, and 95% within five working days. You may receive a response more quickly if you contact us via social media.

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 charity valuable funds which can be used to benefit all those affected by Crohn's Disease or Colitis.

The Leicestershire & Rutland 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.

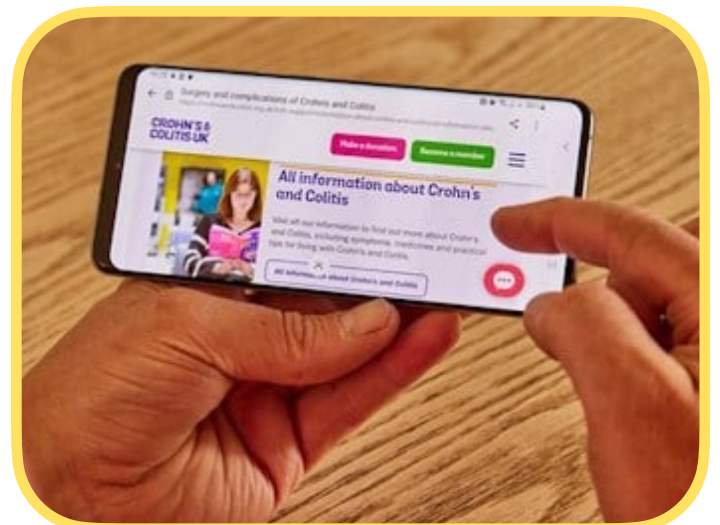
LGBTQIA+ HEALTH WITH CROHN'S OR COLITIS

Crohn's & Colitis UK's new resource on LGBTQIA+ Health With Crohn's and Colitis has now been published.

This information is for members of the LGBTQIA+ community living with Crohn's or Colitis. It is also for friends, family, or people who want to know more about this topic.

These challenges can affect all areas of life, including living with Crohn's or Colitis. This information will help you to:

- Recognise when information about sexuality and gender identity might be shared within your healthcare team.
- Make healthy lifestyle choices when living with Crohn's or Colitis.
- Find out how Crohn's or Colitis can affect sex and relationships
- Be aware of how Crohn's and Colitis can affect treatment for gender dysphoria.



For more information on this research visit: crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/living-with-crohns-or-colitis/lgbtqia-health-with-crohns-or-colitis

GET INVOLVED IN THE NEWSLETTER

We are always looking for interesting, local stories to add to our next newsletter.

If you know of anything, no matter how big or small, that might be worth sharing, please get in touch.