

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!



WELCOME TO THE LEICESTERSHIRE & RUTLAND NETWORK

2024 is coming together nicely. Our Network is busy planning in person Educational Meetings, Social Meetings, Fundraising Events and more!

Our biggest event of the year is our Bluebell Walk or Ride at Rutland Water so delve further into this newsletter for more information. We are also looking forward to welcoming back our local IBD experts from the University of Leicester Hospitals Gastroenterology team. They will be delivering some educational meetings, allowing you to hear directly from the experts and ask any questions you may have.

We'll also be welcoming you along to various social events, in-person and online, where you can meet others affected by Crohn's and Colitis and chat in a safe environment.

We hope to visit more areas of our vast Network, bringing our awareness stand to your local fete or gala, so please let us know where your local event is. *Ben Rutter, Lead Volunteer*

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Crohn's & Colitis UK Leicestershire & Rutland EDUCATIONAL MEETING DECEMBER 2023



We held our last Educational Meeting of the year in December at the War Memorial Hall, Glen Parva.

We had a good turnout to see Sharon Gethins (Advanced Care Practitioner in IBD) and Dr Patricia Hooper (Consultant Gastroenterologist) deliver a talk on Crohn's and Ulcerative Colitis treatments.

They started with a brief introduction to both Inflammatory Bowel Diseases and rounded off discussing how each can be treated. Our educational meetings are a little more formal than our social events. Questions were welcome throughout the talk but most were saved for a Q&A session after the 45 minute presentation.

After the talk, we invited all of our guests to have a hot drink and to take part in our raffle with some great prizes on offer, including a Jennos voucher (a local coffee house where we host a few Social Events) and a Shopping Voucher!

We aim to have a minimum of 2 educational meetings a year, so keep an eye on our diary dates page on our website or Facebook Page. We do also email our members with up coming events throughout the year, so make sure you are signed up to Crohn's & Colitis UK as an official member.

We extend heartfelt gratitude to our guest speakers who give up their spare time to join us for a few hours on their day off, and do their very best to answer all questions posed to them.

We also need to thank our volunteers for tirelessly hosting these events, dedicating their spare time to organise and set them up.

If you would like us to put on an educational event with a specific topic, please let us know.

If you know of a suitable venue in your area, please also get in touch as we're always looking to reach all corners of our Network area.

Website: www.crohnsandcolitis.org.uk/lr Email: lr@networks.crohnsandcolitis.org.uk Facebook: @CrohnsColitisukLR X: @CrohnsColitisLR Instagram: CrohnsColitisUK_LR

L'BORO COFFEE MORNING

Our regular supporters, Graham and Jane, chose Crohn's & Colitis UK Leics & Rutland Network to be the charity of choice in their local L'Boro Baptist Church Coffee Morning.

Thanks to this event, they donated a fantastic **£213.85** to the charity. This will help Crohn's & Colitis UK continue their work in supporting you!

We are incredibly lucky to have such great members in our Network who choose to support us. We are always happy to help the event in whatever way we can. We can share some merchandise, branded flags and balloons, bunting as well as publications to hand out.

So please do consider supporting us at your local event. We're happy to attend with an awareness stand if you'd like us to!

Photo: Amber and her mum Fiona at the Coffee Morning.



IBD ADVICE LINE UPDATE AND SURVEY: THE IBD NURSING TEAM

Our local IBD Nursing Team have given us an update on the advice line and would also like to hear your feedback using it. Here is their message:

"We are committed to providing our Crohn's and Colitis patients with the best and safest service possible. As some of you may be aware, we have updated our voicemail facilities on the helpline to accommodate multiple callers to leave messages at the same time. This has meant that there is never an engaged tone when contacting us, something that we know was hugely frustrating before. This has however meant that our clinic slots fill up extremely quickly.

Whilst we appreciate this may seem like there are few clinic slots available, in reality we are dealing with more patients than ever before. In November and December alone, we spoke to

1318 patients, 88% of which were all called back on



the same day. Calls are triaged in order of priority with patients experiencing Flare up's of their symptoms called first.

We are constantly seeking patient feedback to shape our service and we are extremely proud that our recent patient satisfaction survey has come back with a 92% satisfaction rating. We would love to hear from those of you who have been in touch with the advice line, and hear about your experience. If you would like to participate in this survey, please follow the link below:

www.surveymonkey.com/r/QH7BFNP

If you do need to contact the IBD helpline, the number is **0116 258 4352** and is available Mon-Fri. Please call at 9:30am sharp to ensure you can get a clinic slot, as once the slots are filled the service will close until the next working day at 9:30am."



DONATION IN MEMORIAL

Your donation in memory will help fund vital research, improve care, and provide better information and support for those in need.

A donation has been made by the friends and family of Praveshkumar Kanjibhai Patel (*Pictured on the left*) who passed away on 6th January 2023 at the age of 61 after a period of illness with Crohn's Disease and pancreatitis.

The family hope this gift will enrich the lives of others living with inflammatory bowel disease.

In total £335 was collected and donated to Crohn's & Colitis UK.

Thank you to Praveshkumar's friends and family and please accept our sincerest condolences.

For more information about Donation in Memorial please visit <u>www.crohnsandcolitis.org.uk/get-involved/donate/in-memory</u>.

Alternatively, you can also send a cheque made payable to 'Crohn's & Colitis UK' to: Crohn's & Colitis UK, 1 Bishops Square, Hatfield Business Park, Hertfordshire, AL10 9NE

BLUEBELL WALK OR RIDE 2024 AT RUTLAND WATER

Dust off those walking shoes and pump up those tyres, it's nearly time for our 34th annual fundraising event at Rutland Water.

On Sunday 5th May we'll be back on the shores of Rutland Water to raise money, awareness and heart rates with challenges to suit all abilities.

We pride ourselves on providing an inclusive event whether you want to meander through the bluebells or push yourself to the limit on a 25 mile bike ride.

We have varying course lengths including 2, 5 and 9 miles walks as well as a 17 and 25 mile cycle ride. All of the challenges take part on Rutland Water's perimeter path which is suitable for pushchairs and walking sticks. Well

behaved dogs are welcome as long as they are on a leash at all times. Bring a picnic to keep yourself fuelled. Take your time and make a day of it. There are benches along the way allowing for breaks or just

Tickets are £10 per adult with under 18s going free. This ticket price is something we thought long and hard about but in these difficult times our costs to host such an event have increased hugely over the

hard about but in these difficult times our costs to host such an event have increased hugely over the past 34 years. Your ticket price goes towards all of the essential costs. However we still rely on you fundraising before the event, ask friends, family and colleagues to donate towards your challenge. We hope you understand why we ask this but appreciate times are hard for all. Let's make 2024 the best year yet and raise plenty of money and awareness for Crohn's & Colitis UK.

Share your Just Giving Pages with us on social media and we'll highlight as many as we can!

If you would rather help out than take part, please sign up to be a volunteer. We have roles to suit all abilities from marshalling to registration. You can join us for the day or just dedicate a couple of hours in the morning or afternoon, whatever works for you.

To sign up to the walk or cycle ride: www.crohnsandcolitis.org.uk/bluebell

To sign up as a volunteer, scroll to the bottom of the Bluebell Walk or Ride web page.

Get your friends and family involved. The more the merrier.

to take in the scenery. Our toilet game is raised this year too, with the usual selection of toilets nearby and a new set of <u>Changing-Places.org</u> toilets at Whitwell and Normanton.

Joining us again this year will be the fantastic <u>DaisyJanesFacepainting.com</u> who will be decorating the faces of our young participants and also those young at heart.

To add to the fun we have devised a Treasure Hunt. Each participant will be given a map with some tricky clues to decipher. If the code is cracked a treasure can be collected back at the Events Village. So bring along your best code cracking family member and keep your eyes peeled on the day!





Crohn's & Colitis UK Leicestershire & Rutland BLUEBELL WALK OR RIDE 2024 AT RUTLAND WATER





We would like to thank:

ASDA for offering to supply some refreshments. Waitrose for offering to supply snacks. Rutland Farm Park for a donation helping us fund some goody bags. PPL PRS for giving us a music license, allowing us to play music in the Events Village. Anglian Water for giving our volunteers free parking on the day of the event. Rutland Medical Solutions for providing first aid support. Raynet for supplying Walkie-Talkies on the day to ensure the volunteers are always in touch with each other.

WE NEED YOUR HELP! VOLUNTEER: BLUEBELL WALK OR RIDE To sign up as a volunteer, scroll to the bottom of the Bluebell Walk or Ride web page:

of the Bluebell Walk or Ride web page: www.crohnsandcolitis.org.uk/bluebell

We need your help at the RUTLAND WATER BLUEBELL WALK OR RIDE event.

All ages and abilities needed to help with a range of roles such as Marshalling, Set up and General Help.

Support, help & guidance will be provided. All we need is YOU!



DATES FOR YOUR DIARY

BLUEBELL WALK OR RIDE AT RUTLAND WATER

Date/time: Sunday 5th May 10am-4pm Venue: Rutland Water, 2 Bull Brig Lane, Whitwell, Oakham, LE15 8BL For more details:

www.crohnsandcolitis.org.uk/bluebell



COFFEE SHOP SOCIAL AT JENNOS Date/time: Friday 5th July 4pm-6pm

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

We return back to one of our favourite coffee houses in July.

Coffee Shop Socials are open to all and are a safe space to talk.

EDUCATIONAL MEETINGS

Date/time: TBC, 1pm-4pm **Venue:** TBC

We are currently planning a minimum of 2 Educational Meetings. We know one will take place in Lutterworth and one other is likely to be in Leicester. We welcome you to contact us with suitable village halls, social spaces, lecture theatres that might be

suitable for us to visit with our informative and interactive educational meetings.

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 an email if you're a member or visit our website:

www.crohnsandcolitis.org.uk/lr

COFFEE SHOP SOCIAL AT JENNOS

Date/time: Friday 5th April 4pm-6pm Venue: Jennos Coffee House, Everards Meadows,

Cooper Way, Leicester, LE19 2AN

These Coffee Shop Socials are open to all. It is a safe space to talk about Crohn's disease and Ulcerative Colitis. It is also a great way to meet new people and to develop some new relationships. We don't just talk bowels, sometimes it's nice just to chat about hobbies/life...anything but bowels!



Biosimilars are predicted to save healthcare systems up to **98 billion EUR** in the next five years across Europe and the US.

VIRTUAL SOCIAL EVENTS

Date/time: Throughout the year

Venue: Online - Zoom Talk to others affected by Crohn's and Colitis or join one of our 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

LOCAL FUNDRAISING & DONATIONS

A huge THANK YOU goes out to all of you who have fundraised and donated! With your generous donations we can continue to support those affected by Crohn's and Colitis, helping people in our Network area and nationally.

Special thanks go to: Praveshkumar Kanjibhai Patel and their Memorial donation: £355. Those who attended our Educational Meeting in October: £46.85. Euston Street Police Station collection tin: £52.19. Loughborough Coffee Morning with Graham and Jane: £213.85. The



Bluebell Walk or Ride 2023: £2623.26. Those who attended our Educational Meeting in December: £35.00. Graham Benskin and their Memorial donation: £389.67. The Grey Friars Lodge for the recent fundraising which made £539.15, that this was kindly matched by Leicestershire and Rutland Freemasons Charity to make a total donation of £1078.30.

With your help and kindness we have raised £4794.12 since our last newsletter only a few months ago.

If you fancy taking on a fun challenge, or want to host a coffee morning, or a local walk, or a cake bake, or..... well, anything really.... Get in touch. We'd love to hear your ideas and will do our best to support you in any way we can. Big or small.



GOODBYE TO OUR CEO

Our Chief Executive, Sarah Sleet, is leaving Crohn's & Colitis UK.

Sarah has been with the charity for five years now. Her commitment to driving greater visibility of Crohn's and Colitis has underpinned every part in Crohn's & Colitis UK's work, in striving for the delivery of better diagnosis, care, and lives for all those affected by IBD.

> Sarah was also at the helm when COVID hit and helped to steer the charity through the pandemic.

> > "We provided light and hope

with trusted, up-to-date information and reassurance during a period of horrible uncertainty. Crohn's & Colitis UK emerged from the pandemic with a new structure, a new strategy and increased income and influence, enabling us to do more than ever to make a real difference to the lives of people with Inflammatory Bowel Disease."

Sarah will take up a new post as CEO of Asthma & Lung UK. Meanwhile, Trustees here at Crohn's & Colitis UK are in the process of appointing a new Chief Executive. We wish her all the best and look forward to whoever takes the wheel in her place. Some big boots to fill!

CUT THE CRAP!

3 in 5 young adults do not know that blood in poo, diarrhoea, and stomach pain are key symptoms of Crohn's and Colitis. Through the Cut the Crap campaign Crohn's & Colitis UK have been reaching millions of people to raise awareness of these key symptoms and hundreds of thousands have checked their symptoms through the Symptom Checker.

The more public awareness Crohn's & Colitis UK have of the symptoms and conditions the more ammunition we have to keep driving towards better

diagnosis, better care, and better lives for everyone living with Crohn's and Colitis.

Crohn's & Colitis UK need your help sharing this campaign with your friends and family. We're not asking you to shout from the rooftops (although we won't say no), but three simple ways you can show support:

Share your story, Share our Symptom Checker - <u>crohnsandcolitis.org.uk/symptomchecker</u> and share our advert:

crohnsandcolitis.org.uk/our-work/campaigns/ cut-the-crap

CONTACT US

LEICESTERSHIRE & RUTLAND NETWORK

Lead Volunteer: Ben Rutter Finance Volunteer: Helen Swift Telephone: 0300 222 5700 Website: www.crohnsandcolitis.org.uk/lr

Email: <u>lr@networks.crohnsandcolitis.org.uk</u>

Facebook: <a>@CrohnsColitisukLR

X: <u>@CrohnsColitisLR</u>

Instagram: 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.



YOUNG FUNDRAISERS

Driven. Caring. Dedicated. Ambitious.

If these are words that describe someone you know, nominate them today for the Alex Demain Awards.

The awards first began in 2016 in memory of our exceptional colleague and dear friend, Alex Demain, who sadly passed away in 2015.

The awards honour the achievements of the remarkable supporters, who distinctly meet the values of Ambitious, Compassionate, and Stronger Together, whilst also remembering a great friend.

Nominations our now open for for 2024's Alex Demain Young Fundraiser of the Year Award.

The awards are open to any Crohn's & Colitis UK fundraiser in the UK under the age of 30, who has raised more than £250 since October 2023.

Have you been motivated or inspired by the innovative ways a young person has fundraised for Crohn's & Colitis UK? Maybe you're thinking 'this sounds like me' or 'this sounds like a family member, friend or colleague'.

Crohn's & Colitis UK would love to receive your nomination.

There is a secondary category, the 'Alex Demain Lifetime Awareness Award', to celebrate supporters who have worked tirelessly to raise awareness for Crohn's and Colitis. All nominations will be considered for this award as well.



For more information and details on how to vote:

crohnsandcolitis.org.uk/get-involved/fundraise/alexdemain-awards-nomination

or email: fundraising@crohnsandcolitis.org.uk

Our very own Finlay was nominated a few years ago. Will someone local be our Young Fundraiser of The Year 2024?

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.