

Leicestershire & Rutland Network

WELCOME TO THE LEICESTERSHIRE & RUTLAND NETWORK

2023 is getting us all excited. We are frantically planning more Educational Meetings, Coffee Shop Socials, Awareness Stands, Virtual Socials and also the return of our Bluebell Walk or Cycle Ride at Rutland.

Be sure to take a look at our diary dates but also, as it is still early in the year, some dates and venues have not been nailed down, so you will have to check our social media or our website. We will do our best to send out emails regarding events too - so if you are a Crohn's & Colitis UK member but don't receive emails from us, please get in touch so we can update your details. Don't worry we won't spam you, we will only ever send you emails regarding upcoming events we think you may be interested in.

We hope to see you in 2023 at one of our many, in person events or even on-line at our virtual socials. We are also trying to reach out to other areas of Leicestershire and Rutland and for this, we could do with your help. If you would like to host a coffee morning, or some other event in your area, let us know. We would be happy to help in whatever way we can. With your help we can spread awareness to all corners of our huge Network!

Inside you will also find an update from our Leicester IBD Nursing Team. Please read this carefully as there have been some updates to the team and the answerphone service. Ben Rutter, Lead Volunteer

CROHN'S & COLITIS UK

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!



**Sun 30th April 2023
at Rutland Water
from 10am**

Register here:

**www.crohnsandcolitis.org.uk/bluebell
"Royal Coronation" Theme**



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2022 LOCAL FUNDRAISING

A huge THANK YOU goes out to all of you who have fundraised and donated throughout 2022! With your help and support we raised: **£3122.53!**

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.

For some ideas, head to: crohnsandcolitis.org.uk/get-involved/fundraise

ROYAL STANDARD PUB COLLECTION TIN

Good news and bad news. The Royal Standard Pub in Charles Street, Leicester, have kindly held a collection tin on their bar for many years. They have directed lots of spare change into these tins over this time including **£8.91** in their most recent tin.



Unfortunately, like many other small businesses, the current management have decided to close their doors for good. This is sad news as we have enjoyed popping in there to collect the tins and we maybe enjoyed sticking around a little too long as well. However, do not despair, the venue has reopened with a whole new look and feel.

www.facebook.com/royalstandard.co.uk

We wish the team all the best with their future and thank them all for their hard work.

If you would like a Collection Tin for your place of work, please get in touch.



RUNNING FOR CROHN'S & COLITIS UK

Bhavna was diagnosed with Ulcerative Colitis 18 years ago. She has been on a long journey over those years, trying to find a balance of diet, medication and lifestyle to regain some control. She was very unwell, constantly looking for the next available toilet wherever she went and coming up with excuses to decline social invitations. This resulted in her becoming housebound and losing all of her self-confidence.



Unfortunately this is a very common story to hear amongst those affected by Crohn's Disease and Ulcerative Colitis.



"I remember when I was first diagnosed and couldn't get on top of things, I felt despair and depressed. Hopefully this will give others hope that you can live a good life with colitis and still achieve great things" Bhavna says

After meeting her husband Leon, a keen runner and with his help and encouragement, she decided to take on a half-marathon. Starting to feel

more confidence and some

normality in life she tried a 10k, and then after finding some passion she later completed the 13.1 miles Derby Ramathon! This led to a string of personal achievements including some that were completed during mild colitis flare ups which made them even more challenging.

50 parkruns, Leicester Big 10k, Virtual London Marathons and even some climbing in Wales, Tenerife and even New Zealand.

Using these achievements Bhavna is sharing her story to help raise funds and awareness for Crohn's & Colitis UK. So far her Just Giving Page has over **£650!** This is incredible.

Head to www.justgiving.com/fundraising/bhavna-story to read more of her story and to send her your words of support.

AN UPDATE ON THE IBD NURSING TEAM BY SHARON GETHINS

The Nursing team are available Monday to Friday. We provide a point of contact for all patients diagnosed with IBD in Leicester and Leicestershire.

The Nursing team: Sharon, Tracey, Jodie, and Kelly.

A typical working week involves the answerphone service which is available Monday to Friday morning. During the afternoons the nursing team are involved in clinics that run from all three Leicester hospital sites and in the Community hospitals too. When not in clinic, the nursing team will be following up on calls, and arranging patient management plans, following discussions with your consultant or other members of the IBD team. The nurses want to ensure the correct plan is in place for you and do their best to provide support.



WHAT'S NEW FOR THE IBD TEAM

We are delighted to share with you all that the team is expanding.

We are being joined by Lauren who will support the team in the day to day running of the service and all that involves supporting IBD patients.

Also joining the Nursing team: Julie and Claire who will be working part time and Femi and Nafida full time. Once they are all in post there will be a phase of teaching and supporting our new team so this will take time, please continue to bear with the team. This is an exciting time which will allow the team to implement new ways of providing support to you all.

THE IBD ANSWERPHONE SERVICE - 0116 2584352

This service continues to be very busy. Calls can vary from 5-10-minutes whereas others can sometimes take longer than 20mins. We know it can be difficult and frustrating to get in contact with the team.

The Answerphone Service is available in the mornings between the hours of 9.30-11.30 and we do listen to each message left. We do ask you listen carefully to the message on the answerphone.

We aim to prioritise calls. If someone is having a flare up then we return their call, before we would call back another patient with blood results.

How to help the Nursing team when calling the messaging service:

- Please speak clearly
- Leave your Full name
- Have your Hospital number or NHS number?
- Leave your telephone / contact number
- What is the reason for your call: E.G Flare up, Blood results, medications?
- Keep the message very simple as the nursing team will speak with you to find out more.



If you need to be reminded or want to change your appointment then it is best to call the outpatients department: 0116 2585894/2587526.

If you need to change any contact details, then call the outpatients department: 0116 2585894/2587526 or the Secretaries: 0116 2586630. The IBD Nursing team cannot do these.

Daily reminder:

Sometimes, the most productive thing to do is rest. Your body needs time to recover – other things can wait!

BLUEBELL WALK OR CYCLE RIDE 2023 RETURNS!

In 2023 we are bringing our Bluebell Walk or Ride back to Rutland Water! Following a break since 2019 our big fundraiser will be back on 30th April in aid of Crohn's & Colitis UK Local Networks. We are so excited to be back in person and hope you are too.

We have designed this event to be family friendly so why not bring the whole family for a fun day out amongst the gorgeous bluebells while raising funds and awareness for a great cause? The start time is flexible, allowing you a leisurely start between 10am and 12pm. We have a range of activities to allow those who are able to circumnavigate the reservoir's perimeter on a push bike, and for those who are less mobile or short on time you can tackle one of our walks, ranging from 2 to 9 miles.

The registration village will have music, face painting, merchandise as well some complementary refreshments and even garden games! The route is marshalled with a great local team looking after your safety.



This year's event will have a 'Royal' theme, so dig out your glad rags or pop on your crown and come dressed to impress (not compulsory).

Register your place today and start your fundraising!

Tickets are £12.50 and children (under 18s) free (they do need adding to the register when you sign up).

There are varying course lengths to suit everyone. We have 2, 5 and 9 mile walks available as well as a 17 and 25 mile cycle ride, you choose! We are flexible too, so if you are feeling tired or poorly on the day, you can change your challenge to suit.

Visit: www.crohnsandcolitis.org.uk/bluebell or

Email: fundraising@crohnsandcolitis.org.uk or Call: 01727 734485

We would like to thank the companies involved in supporting this event.

Some kindly donated to the event for free, others provided a discounted rate for their services. They are all wonderful and have been a pleasure to work with.

- PPL PRS Charity & Community Discount Scheme for donating a free license to cover the playing of music: www.pplprs.co.uk
- Morrisons for kindly donating £30 to cover some of the refreshments costs: www.morrisons-corporate.com/morrisons-sustainability/people/charity-and-community
- Anglian Water for providing access to the venue: www.anglianwater.co.uk/
- Rutland Medical Solutions LTD for providing First Aid Cover: www.rutlandmedicalsolutions.co.uk
- Raynet for supplying communications devices to help keep our volunteers connected on the day: www.raynet-uk.net
- Daisy Jane Face painting for providing the face painters: www.daisyjanesfacepainting.com



**CROHN'S &
COLITIS UK**

BLUEBELL WALK OR CYCLE RIDE

**Walk 2, 5 or 9 miles or Cycle 17 or 25 miles
for Crohn's & Colitis UK**



**Sunday 30th April 2023
at Rutland Water from 10am**

**Register here www.crohnsandcolitis.org.uk/bluebell
"Royal Coronation" Theme**

Event organised by Leicestershire & Rutland, Lincolnshire Central, Northamptonshire and Nottinghamshire Local Networks
Registered Charity No. (1117148) England and Wales and (SC038632) Scotland

VOLUNTEER AT THE BLUEBELL WALK OR RIDE

We need your help! Hosting an event the size and scale of the Bluebell Walk or Cycle Ride takes a lot of work. We need at least 35 volunteers to help us with this event with roles ranging from Registration to Marshalling.

Sometimes people want to help out rather than participate in the walk or ride as



they'd rather donate their time. We are a friendly bunch and at the end of the day we all feel a great sense of achievement from hosting a fun, safe and rewarding day. It warms our hearts to hear the praise from those taking part. Knowing we all did our part towards it.

If you would like to help, please sign up on the website or contact us for more information.

We do our best to pair you with your preferred partner and also do our best to cater to your abilities.

We send you a detailed description of the role assigned to you and will help you on the day. Some roles require you to be self sufficient including the ability to drive to a different location around Rutland Water.

As we are all volunteers, we are not expecting previous experience, just the enthusiasm to get involved. Your role may be flexible and open to change if we have a need on the day, for example if we have a volunteer call in sick.

Without your help, we would not be able to put on an event like this and raise the awareness or funds expected. Please consider helping... maybe even rope in your workmates and family!



DATES FOR YOUR DIARY

L'BORO BAPTIST CHURCH COFFEE MORNING

Date/time: Saturday 22nd April 10-12pm

Venue: Baptist Church, Baxter Gate, Loughborough LE11 1UJ

Loughborough Baptist Church are hosting a coffee morning in aid of Crohn's & Colitis UK. Pop in for a brew and support this wonderful little event. If you can't make this event they host a coffee morning every Saturday 10-12noon raising funds for a wide range of causes.

**This event is not being hosted by Crohn's & Colitis UK. We are the beneficiary of funds raised. If you would like to host your own coffee morning, please get in touch.*



BLUEBELL WALK OR RIDE 2023

Date/time: Saturday 30th April 10am-4pm

Venue: Whitwell Car Park, Rutland Water, Whitwell, Oakham, LE15 8BL

More details inside this Newsletter. To register as a participant or volunteer please head to: www.crohnsandcolitis.org.uk/bluebell



EDUCATIONAL MEETING

"LIVING WITH CROHN'S & COLITIS"

Date/time: September 2023 - Date TBC, 1pm-4pm

Venue: TBC - Loughborough

Gastroenterology Consultant, Dr Hooper and IBD Specialist Nurse, Sharon Gethins, will be talking on our chosen topic: Living With Crohn's & Colitis.

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. Our venue has free parking, so all you'll need to bring is some loose change if you want to take part in the raffle or buy a pen.

The date & venue are yet to be confirmed. Please look out for an email OR visit our website:

www.crohnsandcolitis.org.uk/lr

COFFEE SHOP SOCIAL AT JENNOS

Date/time: Friday 12th May 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!



VIRTUAL SOCIAL EVENT

PARENTS AND CARERS

Date/time: Wednesday, 3rd May, 6.30pm-8pm

Venue: Online - Zoom

Talk to other parents and carers whose children are affected by Crohn's or Colitis.

These events are free to attend but do require you to sign up via our website.

www.crohnsandcolitis.org.uk/vse



VIRTUAL SOCIAL EVENT EAST OF ENGLAND

Date/time: Wednesday, 29th March, 6.30pm-8pm

Venue: Online - Zoom

If this event doesn't work for you, don't worry. We have a plethora of dates and you are welcome to join in on any one of them (or all of them if you so wish)

www.crohnsandcolitis.org.uk/vse

Crohn's & Colitis UK Leicestershire & Rutland

OUR EDUCATIONAL MEETINGS RETURNED IN NOVEMBER

Late November saw us return to our "In Person" Educational Meetings. This was our first since the pandemic, so we were all a little unsure how well it would be received.

We needn't have worried. We had a great turn out with mostly new faces. We chose the Topic "Newly Diagnosed: A beginners guide to Crohn's & Colitis" and felt like this was a great place to begin after so long away. The feedback we received was all positive. Our guest Speakers, Gastroenterology Consultant, Dr Hooper and IBD Specialist Nurse,

Sharon Gethins, delivered a relaxed and informal presentation. They welcomed questions from the audience and stuck around after the talk to meet one on one with those who needed further information.

Our Volunteers (and their partners in some cases) help dress the room, laying out the publications and

merchandise as well as taking registration and even brewing up some tea and coffee. We extend a huge thank you to Diane, Helen and Diane's husband, Stephen - you folks did a fantastic job of setting up!

We tried a new venue in Glen Parva. The War Memorial Hall has great facilities and is pretty central to our Leicester membership. We hope to return here for more events in the future. However, some recent feedback has highlighted that we do tend to be "Leicester centric" and yet our Local Network covers a huge area. So for our next Educational Meeting we are heading to Loughborough! See our Diary Dates Page for more information.

Please get in touch if you think your local area has a suitable venue or if you have a topic in mind that you think would be ideal for us to discuss.



L'BORO BAPTIST CHURCH COFFEE MORNING IN NOVEMBER



Graham and his wife, Jane, are becoming regular hosts of a coffee morning in Loughborough. Their local church is the chosen venue which is something they have secured themselves. They then decorate using materials provided by us, including flags and balloons as well as hand out some publications to those interested!

They really go all out, even setting up fun games such as "Name the Nutcracker" and taking donations in exchange for cakes. They have raised over £400 with their previous two coffee mornings, which is just fantastic!

Having local members willing to take on these kind of events is so helpful. Our local volunteering team is small and we do our best to

put on events but sometimes we just don't have enough time, plus we are all affected by Crohn's or Colitis ourselves so we can be restricted. If you are inspired by Graham and Jane, then please get in touch. We would happily help you with a fundraising pack and even help you promote the event. This kind of participation is even more critical when we're trying to reach areas of our Network that we just don't know well enough. Finding suitable venues can be tricky, so some local knowledge would be a great help.

Graham and Jane will be back for another Coffee Morning on April 22nd. See the Diary Dates Page for more information.



*The three ladies in the pic with the cakes are (L to R) Lilian Limb, Ann Taylor and Jane North. The young man on the "Guess the name of the Nutcracker" stall is Harry North.

CONTACT US

LEICESTERSHIRE & RUTLAND NETWORK

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 Finance Volunteer: Helen Swift
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 Twitter: @CrohnsColitisLR
 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 and Colitis UK Helpline: visit
www.crohnsandcolitis.org.uk/info-support/support-for-you/helpline-service

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.

EDUCATIONAL MEETING 2023

Our next Educational Meeting is planned for **Sept**
 2023 and will cover Living with Crohn's & Colitis.
 We are looking to venture out over our Network.
 Leicestershire and Rutland is a huge area to cover
 and most of our volunteers are based in Leicester.
 This is why often it looks like we are Leicester
 Centric. However, following recent feedback, we
 want to be better at reaching all areas.

With this in mind we will be bringing our next
 Educational Meeting along to Loughborough. The
 date & venue are yet to be confirmed. Look out for an
 email OR visit: www.crohnsandcolitis.org.uk/lr We
 hope to see you there whether you're a local or just
 fancy a trip out to visit Loughborough.

We need you to come along and make these events
 the best they can be. Audience participation really
 helps with the Question and Answers section (Q&A)
 plus after the educational part, we kick back with a
 cuppa and have a chat. This is a great way to meet
 others affected by Crohn's and Colitis.

We have not been to this venue before but please be
 assured, the toilet facilities are good, we will have
 hot and cold drinks and there is parking for your
 car or even your push bikes if you'd like.

Please get in touch if you think your local area has a
 suitable venue or if you have a topic in mind that
 you think would be ideal for us to discuss.

COFFEE SHOP SOCIAL: JENNOS

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 and
 general life...anything but bowels!

This time we are returning to Jennos Coffee House
 near Fosse Park. Normally we try to sit upstairs, in a
 quiet corner. This allows a little bit of privacy just
 in case the conversation does stray into areas that
 might make the speaker or other patrons
 uncomfortable. HOWEVER, Jennos does not have a
 lift for those with accessibility requirements. So if
 you would like to attend this meeting and have
 difficulty with stairs, please let us know BEFORE the
 event starts. This way, we can make sure we find a
 seat downstairs, in a more suitable location.

Jennos has free parking for up to 3 hours as well as an
 area to securely lock your pushbike. It is easily
 accessible by foot if you are coming from the Glen
 Parva area. It is next to Fosse Park if you fancied a
 little shopping before or after the meet up.

On arrival, grab yourself a drink and head upstairs.
 Your host will be in a purple T-Shirt in front of a
 huge Crohn's & Colitis UK banner.

See diary dates for info

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.