COLITISUK Leicestershire & Rutland Network

WELCOME TO THE LEICESTERSHIRE & RUTLAND NETWORK



The final throws of Summer are playing out and we feel we are only just getting started. With various illnesses and commitments we as a Network have had to have a bit of time away from organising events and have been a little quiet.... or so it seemed before putting together this newsletter.

Our annual fundraising event at Rutland Water returned, we have had a Coffee Shop Social, there has been fundraising, cake sales and more! I would like to thank the organising team for keeping the wheels on this vehicle and also to all of you, our members, for your ongoing participation and support.

We hope to see much more of you in our virtual events and our in person events. We are deep into the planning of our Educational Meeting in October. For the first time we are looking outside of Leicester for

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venues and meeting places. Please help us with this as much as possible by highlighting possible venues and attending when we set them up. Leicestershire & Rutland covers a vast area and it can be difficult to reach all corners but we want to try.

If we can't get right to your doorstep right now or you're feeling disconnected for whatever reason please take advantage of our Virtual Social Events. These are open to all, for free and we have many different days and times available.

We are always looking for enthusiastic and willing volunteers to join our small team. We meet every month or 2 on Zoom and put our heads together to work out what events to do, how to do them and how best to be there to support you. You can be as involved as much or as little as you'd like to, or are able to. If that's not for you, don't worry, prepare your favourite brew, kick back, and take a peep through this newsletter. When you've finished, pass it on to someone else, leave it for someone at work or at the very least, pop the diary dates in your diary and recycle the rest.

Ben Rutter, Lead Volunteer

Photos on this page were taken at our Annual Fundraising Event at Rutland Water: The Bluebell Walk or Ride 2023. For more about this event and more pictures, dive into this newsletter a little further.

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PATIENT PANEL BAKING

For World IBD Day, back in May, the Peterborough Patient Panel held a Cake Stall in the foyer of Peterborough City Hospital.

In total they raised a delicious $\pounds 288$ with $\pounds 50$ being donated to the Crohn's & Colitis UK Leicestershire & Rutland Network.

In the photo is Pippa, Jacqui and John. Our Local Network volunteer Helen, also helped with the stall along with Vanesha - one of the IBD nurses. The amazing cake was made by Natalie Young, Admin team of Gastroenterology and Hepatology.

The stall helped with profile raising and recruited some new members to the Patient Panel.

If you want to fundraise or maybe set up a Cake and a Cuppa event, make sure you check out our Fundraising Page and send us photos for us to share.

www.crohnsandcolitis.org.uk/cakeandacuppa

Cake & a Cuppa

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Sign up to get your FREE fundraising pack!





A ROYAL THRONE

Helen, one of our wonderful local network volunteers, was invited to the King's Royal Garden party in May in recognition of her volunteering.

She made a point of visiting the accessible toilet facilities to check them out. Here is a covert snap of Helen using the wash basin provided by the King.

She reports "the facilities were well appointed, and there were no queues".

Feel free to share your interesting bathroom pics/selfies with us.

ONE MAN'S JOURNEY UP HIS OWN BACKSIDE

Our regular Coffee Morning Host'ee and all round top bloke Graham, performed his one man show at the Charnwood U3a Science and Technology group at Loughborough Bowls Club earlier this year.

His talk "Crohn's Disease and Ulcerative Colitis, One Man's Journey Up His Own Backside" was performed to a private event. He received loads of positive feedback and if you've ever been around Graham, you'll understand why!

We will let you know when he decides to talk again as we think you'd really enjoy what he has to say.

What have you been up to raising funds and/or awareness for Crohn's & Colitis UK? If you would like help putting information together or need some branding to give your event some pizzazz, then hit us up. We'd love to hear from you and help out in anyway we can.



AN UPDATE FROM THE IBD NURSING TEAM BY SHARON GETHINS

We have had some really exciting developments to our IBD service over the last few weeks. The biggest impact has been on our Advice Line service.

After listening to your feedback, we have upgraded the voicemail system to allow multiple messages to be left at one time. This has hugely increased our accessibility and we've already had great feedback from patients that have been able to leave a message straight away, so no more dreaded engaged tones!!

The Advice Line opening times remain the same, **9:30am-11:30am**, but in instances where the calls out number our clinic slot capacity, the system will automatically switch off so that we can manage the enquiries safely. Your calls will also be followed up by a text to confirm receipt of your message and a time frame of when you will be



called back by one of our nursing team. We may also text you if we have any questions regarding medication or blood/stool sample tests.

Our team is growing with new Nurses joining the team. During these next few months, please bear with us whilst our new team members settle in and get to grips with all this Crohn's and Colitis.

A final note to add is that we are looking at having a web page that patients can access. This is a difficult



COFFEE SHOP SOCIAL AT JENNOS

Our last Coffee Shop social feels like a life time ago. Summer was just beginning, nights were getting lighter, weather was promising all sorts of delights and we returned to our regular spot at Jennos Coffee House at Everards Meadow at Fosse Park.

What an incredible turnout. Loads of new faces and plenty of familiar ones too!

We understand it can be daunting to attend for the first time but please don't let this hold you back. Even if you just sit down for 1 minute, please come and see us at our next one. You might not feel like you "need" to talk to others but maybe they need to hear from you!

Jennos have been incredible over the years in supporting our little meetings there. Please show them some love if you're in the area (They have x4 venues now including one at the Tigers Stadium). Jennos have provided us with a £20 Gift Card to raffle at our educational meeting in October.

Please let us know if you'd like us to visit your area. As these are social events, maybe you could join us as a volunteer and we can help you host an event closer to you?

These are social events, so you don't need to be the expert. All you need to do is dedicate a couple of hours of your day. It doesn't have to be a Coffee Shop Social, you could do a Pub & Pint or a Walk & Talk or a Chip Shop & Chatter. Basically, anything you think is fun/interesting, we can turn into a social. We just want our members to meet and have a lovely time.

task to set up but we are excited to bring this to you as soon as we can.

L'BORO COFFEE MORNING

Thank you to Graham and Jane who chose Crohn's & Colitis UK Leicestershire & Rutland Network as their charity to support at their recent Coffee Morning hosted at the L'boro Baptist Church.

With games, cakes and coffee they raised $\pounds 260!$

So a huge well done and thank you to them once again for their continuing support.

Please get in touch if you'd like to host a coffee morning, or any other social event. We are more than happy to support you in anyway we can.



BLUEBELL WALK OR CYCLE RIDE 2023

What an incredible day we had. 2023 saw us return to the shores of Rutland Water for our annual fundraising event. An event we have been hosting for well over 30 years!

It was beautiful to see so many people join us for a walk or bike ride. As our event is a very relaxed affair, participants could do anything from a short 2 mile walk (less if they wanted to) up to a 25 mile bike ride.

Our planned routes took in the beautiful Bluebells in Barnsdale Woods as well as the gorgeous shores of Rutland Reservoir.

> Our talented face painters decorated the faces of the young, and young at heart! Many participants embraced the "Royal" Theme, including some of our 4 legged friends. Thank you to everyone for putting so much effort in, you really helped boost the already great atmosphere.







Together you helped us raise a staggering amount for Crohn's & Colitis UK. Our final tally comes in at: £7388!!

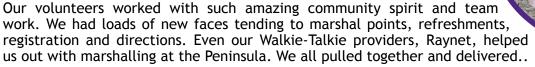




CROHN'S& COLITIS UK

BLUEBELL WALK OR CYCLE RIDE 2023 CONT...

We extend a huge THANK YOU to all those who fundraised, volunteered, donated and took part. We can't wait to start organising next year's event which we believe will be even bigger and better in 2024!



We will be back in May next year and want you to be involved. Either as a participant or volunteer. So keep your peepers peeled and look out for more information to come in the new year.









DATES FOR YOUR DIARY

EDUCATIONAL MEETING/CAKE & A CUPPA

Date/time: Saturday 7th Oct 1pm-4pm

Venue: Gorse Covert Community Centre, Maxwell Dr, Loughborough LE11 4RZ (Via Morrisons Car Park)

It has been some time since our last Educational Meeting. We have secured a a date and a venue! For this event we have scouted the wider area, trying to move us away from a

Leicester'centric venue. The Gorse Covert Community Centre

have allowed us to hire a room and coffee bar for the day over in Loughborough. Parking & attendance is free but we are asking you to book your spot with a ticket. Refreshments available at a reasonable price.

The first half of the event will be a traditional Educational Event where we have a guest speaker join us to talk on a topic. We have chosen the topic: A Guide To Crohn's & Colitis. This will give us an insight into both diseases, their symptoms and treatments. One of our local Specialist IBD Team Members will present for 30-45 minutes with 15-30 minutes at the end for questions and answers.

The first half is a formal event to begin with a presentation followed by questions and answers.

The second half will become a social event. We encourage our attendees to have a chat to others. Share stories, make friends and relax. Our Specialist IBD Team Speaker generally sticks around and will be willing to answer more generic questions you may have.

This social aspect will also incorporate a Cake & a Cuppa fundraising event:

www.crohnsandcolitis.org.uk/cakeandacuppa

We will be encouraging you to join in our Cake & Cuppa event by donating money for a slice of cake on the day and\or taking part in our raffle to win some prizes, including a Jennos Gift Card. Feel free to bring along your homemade (or bought) cakes to put on the table. We hope to have a selection of cakes available to eat on the day and to win.

We intend on visiting more areas around our Network in 2024 - bringing our Coffee Shop Socials and Educational Meetings closer to you. If you have a favourite local venue that you think would be ideal for us, please let us know.

This event is FREE but a ticket is required. Get your tickets here (1 required per person): <u>https://ccuk-lr-education.eventbrite.co.uk</u>

Or contact: lr@networks.crohnsandcolitis.org.uk

COFFEE SHOP SOCIAL AT JENNOS

Date/time: Friday, 20th Oct, 4pm-6pm

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

We are returning to Jennos at Fosse Park/Everards Meadow for a Coffee Shop Social Event. These events offer a safe space for us all to sit and talk about Crohn's and Colitis BUT we also cover many other topics. We want to make connections and join people together who wouldn't necessarily normally sit down for a cuppa with one another, allowing us to see we are not alone.

As usual we will be sat upstairs as it tends to be a



VIRTUAL SOCIAL EVENT

EAST OF ENGLAND

Date/time: Wednesday, 11th October, 6.30pm-8pm Venue: Online - Zoom

To fit in with a busy life, these events work around you. We hold them at various times and days throughout the month and they are free to attend. You don't even have to show your face or talk. You can sign up, log in and listen to what others have to say. We believe hearing others really helps, especially if you feel alone, scared or like you can't be open with your friends/family.

We provide a safe space for you to ask questions, discuss poo/bowel disease/surgery/medications/ fatigue etc etc. No judgement only friendly faces.

There is always a Host and Co-Host from the volunteering team to keep things on track and to direct conversation if and when needed.

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

OUR DIARY EETING/CAKE & A CUPPA



WORLD IBD DAY

Doing his bit for World IBD Day on May 19th our Lead Volunteer, Ben, went in for resection surgery. He stayed in the Leicester Royal Infirmary for 5 Days then spent a steady 8 weeks recovering well.

Did you "**Poo with Pride**" on World IBD Day?

We all do it, so what's the embarrassment about? Whether it's in a public toilet, at work, school, or at a new partner's house we have all needed a poo and tried to disguise it.

Wherever you are, whoever you're with, there's no shame in pooing.

Crohn's & Colitis UK's campaign on World IBD Day inspired us to talk about and celebrate our bathroom habits, and for us to share some confessions. Let us know what you did to spread the word or see what others did by searching for #PooWithPride on social media.

Let's work together to flush away the fear and Poo with Pride!

OPEN GARDENS BBQ & STRAWBERRIES

Open gardens are a fun concept. Local people open their gardens to the public and actively encourage strangers to pop round.

In this case, friends of the Network Graham and Jane invited people to their house with the aim of raising awareness and funds for Crohn's & Colitis UK.

> Graham fired up his BBQ and offered hotdogs whilst Jane was serving up strawberries and cream.

> > This little fundraiser raised over

£330! People are very generous with their cash and our hosts were generous with their time.

The only thing they failed to do was take a photo. Remember, we want to hear from you and your fundraising and awareness events. We can offer support with publications, branded balloons and merchandise as well help promote your event. Please get in touch

UPDATED PUBLICATIONS AVAILABLE

Crohn's & Colitis UK regularly review regularly review our information pages to bring you the most up to date guidance and information.

Please find below the latest updates.

Newly diagnosed

Are you newly diagnosed or know someone who is? Getting a diagnosis of Crohn's or Colitis can be overwhelming. But there's lots of information and support out there. See our updated information on being Newly Diagnosed.

Joints

Did you know that Crohn's and Colitis can cause problems with your joints? Joint problems, including some types of arthritis, may affect up to 46 in every 100 people with Crohn's or Colitis. Our joints resource has been updated and includes information on types of joint problems and arthritis and how to treat and manage joint problems. See our updated information on Joints.

www.crohnsandcolitis.org.uk/info-support/become-a-member/connect-now/august-2023/read-all-about-it

CROHN'S& COLITISUK Normal things that can be





recognition too.

CONTACT US LEICESTERSHIRE & RUTLAND NETWORK

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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/supportfor-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.

COLITISUK A person's symptoms are as individual as their finger print



Chronic illnesses affect everyone differently, and their effects can change day to day.

YUYU BOTTLES

Get 15% off any YUYU bottle using our discount code: CROHNSCOLITISUK15

Each time this code is used we get 10% from the sale so you'll also be donating to us at the same time!

www.yuyubottle.com



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.