



Leicestershire & Rutland Network

WELCOME TO THE LEICESTERSHIRE & RUTLAND NETWORK

Welcome to the Autumn edition of our Local Network newsletter. It has been a good year so far with us trying to get back to some sort of normality.

We have hosted a few social events and even been out with our awareness stand. Look inside for details on our first Educational Meeting in 2 and a half years! We invite you, your friends and family along to hear a talk aimed at Newly Diagnosed patients.

We look forward to welcoming you through the doors, in real life. We are paying more attention to accessibility and ease of attendance, so the new venue has great toilets, is all on one level and even has somewhere to lock your push bike!

We hope you'll join us for this event and all of the others we will be organising. Keep an eye on our website and social media. We need you to share, like and interact with our posts to help spread the word.

We are here to support you all whether you are newly diagnosed or are a veteran. We can all get

CROHN'S & COLITIS UK

Common symptoms of Crohn's or Colitis

Crohn's Disease and Ulcerative Colitis are chronic (ongoing and life-long) conditions in which symptoms vary from person to person and will range from mild to severe.



Cramping pains
in abdomen



Tiredness and
fatigue



Feeling generally
unwell



Loss of weight
and appetite



Anaemia



Diarrhoea



Mouth ulcers

Crohn's and Colitis can have symptoms that affect the whole body.
For more information, visit www.crohnsandcolitis.org.uk/symptoms



through Crohn's and Colitis together. Talking and sharing really helps.

If you aren't ready to attend an event in real life or maybe the timings just not right, then we have a solution for you. Our virtual social events are going from strength to strength - we have even more coming soon....

Thank you for sticking with us through these turbulent times. I would also like to extend a huge thank you to my Organising Team. These are a bunch of volunteers who give up their precious time to help out and keep us moving forward and supporting you. If you feel like you'd like to join our wonderful team please get in touch. You can be as involved as you want to be. We cater for all ages, skills and abilities.

A final note from me: If you have received this newsletter as a paper copy through the post, please do pass it on to ensure it is being used to its full potential. Or if you would prefer, we can swap this for an electronic version - just let us know your preferences.

We look forward to seeing you in the near future at one of our events. **Ben Rutter, Lead Volunteer**

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INNER WHEEL CLUB DONATION

The Inner Wheel Club of Bourne in Lincolnshire, invited us along to one of their evening meetings to present a cheque for money they had raised for Crohn's & Colitis UK.

The Club usually meets once a month, with fellowship and fundraising high on their agenda. Through various activities they managed to raise an incredible **£407.50**.

To accept the cheque one of our local volunteers headed out to Bourne, Lincs. We love to support you with your endeavours and we do our best to attend your events when and where we can. We are a small team so it is not always possible. So as well as thanking the Inner Wheel, we'd like to thank Helen for going out of her way to meet the fundraising team and transporting our huge, novelty presentation cheque!

If you're interested in the Inner Wheel you can find more information here: www.innerwheel.co.uk

Their programmes include speakers, outings and special projects. Clubs often adopt a local, national or overseas charity, and members enjoy getting involved. Some Clubs work together with their local Rotary Clubs on joint fundraising or community events.



COFFEE SHOP SOCIAL AT JENNOS

Back in July we held a Coffee Shop Social which only seems like 5 minutes ago. The sun was shining and we were in the heights of summer, how quickly do things change?

It was great to see so many new faces as well as the familiar ones. For some, this was their first charity social event since the pandemic. We hope everyone who attended had a good time and found it comforting to sit and chat, in a safe environment with others affected by Crohn's Disease and Ulcerative Colitis.

Jennos Coffee House have been wonderful in letting us use their facilities and allowing us to take over the corner, upstairs. We do realise that upstairs may not be accessible to all who wish to attend these events, so we have been looking into other venues where we can still be separated off from other patrons. We always try to pick a quiet corner, away from others, allowing attendees to speak openly without worrying about "strangers" nearby overhearing.

We will continue to use Jennos but we will ensure that we let you know if there are accessibility requirements. We have found another suitable venue, a few miles away from Jennos that does not have stairs, has free parking and is also a charity itself. So we are looking to trial this venue next and see how well it goes, so look out for our next Coffee Shop Social in the Diary Dates section.



A SAD FAREWELL

Sadly, Cynthia Pywell passed away on the 11th June 2022 aged 91yrs. She is fondly remembered by the Crohn's & Colitis UK Leicestershire and Rutland Network, for her support and hard work on the Organising Committee.

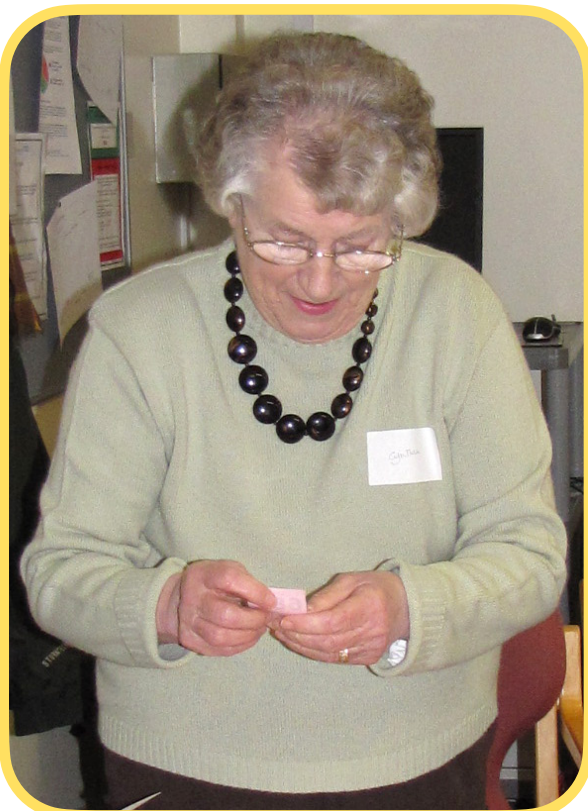


Cynthia was the driving force behind our Local Network back in the early days of the charity. It is a charity that was close to her heart.

In the early years of our Network, Cynthia worked hard to keep our group of volunteers going. At times the Network nearly closed due to not having enough people to form a Committee, but she rallied around and found people to volunteer allowing us to carry on.

Cynthia took on the Chairperson role for many years. She was more than happy to take on various other roles throughout her tenure on the team; making tea, selling raffle tickets at meetings, anything that helped. She was always there offering support to members and colleagues.

She remained an active member of the Organising Team into her late 70s, with ill health eventually forcing her to retire.



Thank you Cynthia for everything you did to support our Network along with the friendship and help you offered to all you met.

GLEN PARVA GALA

What a beautiful day with blue skies and sunshine. It was fantastic to dust off our gazebo and get our banners flying once again.

The Glen Parva Gala was a little smaller than previous years, allowing for a more intimate event. We hosted our awareness stand and invited everyone into our space to chat about the charity and to also speak to a few people that were new to the disease. It is awful to think there are still so many people living with Crohn's and Colitis that haven't found our charity. We feel we connected with quite a few families on this wonderful summers day and helped them realise they are not alone.

To add a bit of fun we hosted a "Hook'a'poo" game. Very similar to "Hook'a'duck" but with a slight difference.... This game as well as our fundraising bucket helped us raise over £54!

There are many local events like this throughout Leicestershire and Rutland. If you know of one local to you, please let us know. We are always looking for more opportunities to crack out the gazebo.

We hope to see you next year at the Glen Parva Gala.



ACCESSING SUPPORT AT ATTRACTIONS AND VENUES

Crohn's & Colitis UK members have told us that it's not always easy accessing the support you need when out and about at attractions and venues. This can be extremely frustrating and cause unnecessary anxiety about visiting certain places.

With this in mind the charity has created a letter that you can give to staff to help explain what it's like living with Crohn's or Colitis and the impact the conditions can have on days out. The letter also suggests ways that staff at attractions and venues can make adjustments to better support people living with Crohn's or Colitis.

This is no guarantee that they will offer any adjustments but can help you decide if you want to attend a venue depending on their response.

FLU VACCINE FOR PEOPLE WITH CROHN'S OR COLITIS

Some people with Crohn's or Colitis are eligible to have the annual flu vaccine free on the NHS. Other people might choose to pay to get it privately.

Some medicines used for Crohn's and Colitis can lower or alter your immune system so it is worth checking with your GP or IBD team to see if you fall into this category.



If your team say you are not eligible to have the flu vaccine on the NHS, you can choose to have it privately. You can get a private flu vaccine from many high-street or supermarket pharmacies. Most offer them from September onwards. It usually costs around £10 to £20.

It may be helpful to talk to your IBD team before you have the vaccine.

www.crohnsandcolitis.org.uk/news-stories/news-items/flu-vaccine



39TH ANNUAL GENERAL MEETING

The Crohn's & Colitis UK AGM took place back in September. If you missed the live event then do not worry, you can re-watch the whole thing, including Consultant Gastroenterologist Professor Miles Parkes' presentation on Predicting Disease Course in IBD, and find out more about the charity plans for the next year.

The video can be found here: crohnsandcolitis.org.uk/info-support/become-a-member/connect-now/september-2022/agm-2022-round-up

Jackie Craissati provided a summary of the 2021 Annual Report, highlights included:

The charity advocated for patients who needed faster access to surgeries and endoscopies in hospital. Campaigns to encourage more accessible toilets and better workplace understanding were undertaken. IBD UK (chaired by Crohn's & Colitis UK) published a national report on IBD and the performance of services against IBD standards. The charity restarted its grant giving and funded a total of £318k of research grants.

Head over to our website for more information on the great work achieved and our future plans.

EDUCATIONAL MEETING



If you are new to our Network you may never have heard about our Educational Meetings. Our last one would have been way back in 2019. Can you remember that far back? Things were simpler....all we were arguing about was Brexit.

Educational Meetings are a little more formal than our Coffee Shop Socials. We invite our local IBD/ Gastro Team along to deliver a talk on an IBD related topic. The talks generally last around 30-40 mins, then we have a question and answer session, before we fire up the tea pot and dish out the biscuits ready for an hour of relaxed chat. Sometimes the guest speaker will stick around for a while and be open to smaller discussions.

At the end of November (See the Diary Date section for more details) we'll be hosting an Educational Meeting where Gastroenterology Consultant, Dr Hooper and IBD Specialist Nurse, Sharon Gethins, will be talking on our chosen topic: **Newly Diagnosed: A beginners guide to 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.

CROHN'S & COLITIS UK

Everyday things that can be hard with a chronic illness



Getting washed and dressed



Socialising with friends and family



Doing chores and errands

**Be proud of yourself.
Simple achievements deserve recognition too.**

VOLUNTEER WITH US

Are you looking for a new challenge? We have volunteering roles to suit all abilities and skills.

Networks have four main volunteer roles: Lead Volunteer, Finance Volunteer, Awareness Volunteers and Medical Advisors. We also have Local Network Event Volunteers who support events on an Ad Hoc basis.

Volunteering is flexible. Whatever your interests, experience or skills, there are many ways to give your time. Typically teams meet 6 times a year to plan activities and individuals might spend 2-4 hours per week volunteering.

crohnsandcolitis.org.uk/get-involved/volunteer/volunteering-roles/local-networks

Volunteer to help out. Volunteer to get more involved. Volunteer to meet new friends. Volunteer to help support others.



DATES FOR YOUR DIARY

COFFEE SHOP SOCIAL

Date/time: Friday 28th October, 11am-1pm

Venue: The Salvation Army Cafe, Ladysmith Rd, Wigston LE18 4UZ

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!

This venue is all on one level with easy access for those with limited mobility. Toilet facilities are good. There is free on site parking and a bike park area with a canopy. www.crohnsandcolitis.org.uk/lr



VIRTUAL SOCIAL EVENT - WALES AND WEST MIDLANDS

Date/time: Tuesday, 8th November, 6.30pm-8pm **Venue:** Online - Zoom

Our Lead Volunteer, Ben, will be the host for this event. So if you want to see a familiar face and talk to others affected by Crohn's or Colitis, then sign up.

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

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/virtual-social/virtual-social-event-wales-and-west-midlands

EDUCATIONAL MEETING - A BEGINNERS GUIDE TO CROHN'S & COLITIS

Date/time: Saturday 26th November, 1pm-4pm

Venue: Glen Parva War Memorial Hall, Dorothy Ave, Glen Parva, Leicester LE2 9JD

Gastroenterology Consultant, Dr Hooper and IBD Specialist Nurse, Sharon Gethins, will be talking on our chosen topic: **Newly Diagnosed: A beginners guide to 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.



L'BORO BAPTIST CHURCH

COFFEE MORNING

Date/time: Saturday 19th November 10-12pm

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

Loughborough Baptist Church have chosen Crohn's & Colitis UK once again to be their "Good Cause" for this event. So they will be raising awareness of our charity and Crohn's Disease and Colitis. Pop in for a brew.

If you can't make this event they host a coffee morning every Saturday from 10-12noon raising funds for a wide range of good 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, or other event, please get in touch.



BLUEBELL WALK OR RIDE 2023

Date/time: TBC (Usually the first Bank Holiday Weekend of May)

Venue: Whitwell Car Park, Rutland Water, North shore

It has been a while since we hosted our Bluebell Walk & Ride at Rutland Water. In 2023 we are hoping to return to the Rutland Water shores for a walking and bike riding event in real life!

Currently we are working behind the scenes to see if it is feasible and how best to plan it. So currently we would say "Pencil in" the 30th April. This is the Sunday before the first bank holiday of May. This is subject to change so keep your eyes on your inbox for further details.

If we do go ahead with this event, we will be asking for volunteers as well as participants.



CHRISTMAS CARD SHOP

Spread some festive cheer this Winter with Crohn's & Colitis UK Christmas cards. With a fantastic range of modern, traditional and funny designs to choose from - there is something to suit the whole family! They are a great way to spread your warm wishes during the festive season and help support people living with Crohn's and Colitis. Your generosity helps us to keep the charity helpline going, campaign for the rights of people living with Crohn's and Colitis and continue to provide support for the most vulnerable people. All cards are 100% recyclable. Browse the full card range:

www.crohnsandcolitisshop.org.uk/



ARE YOU IN? PLEDGES

Supporting the wellbeing of your employees has never been more important. Lead the way in invisible disability inclusion.

Living and working through the pandemic has been challenging for everyone, but for employees with

invisible disabilities and conditions, things have been especially difficult.

Now is the time to lead from the front, to change your workplace for the better by committing to supporting people with invisible conditions.

We've got the tools and resources to help your company be more inclusive.

By signing up to our Silver or Gold pledges we can help you better support people living with invisible conditions - through visual assets, training, and resources.

All the campaign resources are free. You can see a full list of them here.

We don't expect companies to implement all of the pledges straight away, we just ask that you sign up, implement what you can and have a clear plan for considering the rest of the pledges this year. Remember you may already be implementing some or most of the pledges already - this is great. In which case please sign up to make sure you're advertising your commitment to invisible disability both internally and externally. www.noteverydisabilityisvisible.org.uk/pledges

PARENTS & CARERS VIRTUAL SOCIALS

Are you a parent or carer? Do you wish to chat to other parents or carers of children with Crohn's or Colitis?

Crohn's & Colitis UK are offering people the chance to join a virtual social event with other parents and carers from across the UK.

The event will be a chance to chat, share experiences and potentially learn from others. The topics discussed will be down to you, and a trained volunteer will help to lead the meeting, making sure everyone has a chance to speak.

crohnsandcolitis.org.uk/info-support/support-for-you/virtual-social-events



CONTACT US

LEICESTERSHIRE & RUTLAND NETWORK

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Crohn's & Colitis UK

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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

Web Chat (Live Online): see our [website](http://www.crohnsandcolitis.org.uk) for details
 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.



BUFFY THE LIFESAVER

'I faced being single with a stoma and ended up finding true love'. Holly Fleet and her journey of the dating world with "Buffy the Lifesaver".

I was rushed to hospital with severe abdominal pain and bleeding. I suffered with Ulcerative Colitis, which for the past year had taken over my life.

Despite three rounds of Infliximab over five days, my rectal bleeding continued to worsen. I lay in my hospital bed petrified after I was informed I would now need surgery to create a stoma. I didn't know anyone my age (27) with a stoma.

In this time of great emotional stress and fear, I felt as though I needed my partner more than ever. Sadly, our relationship became increasingly strained and we sadly split. I lost my colon and my boyfriend in the space of two months.

I joined the dating app Hinge, and after a couple of weeks I struck up a conversation with my now-boyfriend Callum. I was terrified of telling him about my stoma, I was certain he would no longer be interested in me if I even mentioned it. So I decided to keep it a secret. I completely forgot that in this internet age, everything is easy to find if you just Google a person's name. Callum had stumbled across my Twitter page where I had told my followers all about my chronic illness and surgery.

I felt embarrassed about him discovering this deeply personal fact on social media, but I was relieved that finally, I could actually talk about it.

I told him how my chronic illness had led me to my stoma, affectionately nicknamed Buffy (after my favourite TV show, Buffy the Vampire Slayer) and answered all of his questions about how it works. I reassured him that a stoma does not impact anyone apart from the person who lives with it.

People who have stomas can swim, run marathons, have sex, become mothers and do anything they put their minds to... the only difference is we poo differently from most people!

For me, having a stoma was not the end of my life, it was just the beginning.

To read this story in full:

crohnsandcolitis.org.uk/info-support/become-a-member/connect-now/september-2022/buffy-the-lifesaver

Holly's journey is on her Insta: [@stomababe](https://www.instagram.com/stomababe)

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.

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.

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