# CROHN'S & COLITIS UK

NEWSLETTER OCTOBER 2024 Issue 15

### WELCOME TO OUR AUTUMN 2024 NEWSLETTER

By Helen Thompson

Hello everyone. First of all I wish to apologise for how long it has been but the world and life seemed to be against us recently but that is enough negativity now only positive to move forward.

We are back and are going to be better and stronger than ever with some amazing new members to our team who are already inspiring me & we all can't wait to get started again and be back with a bang and see you all.

We want you all to be involved come and join us.

As always we are all local volunteers affected by Crohn's or Colitis who can totally relate and are looking to help make a difference and support others affected by the conditions including their families throughout Merseyside whilst raising funds and awareness to continue our and the national charities work.

We look forward to meeting you at our upcoming events (keep an eye on your emails and all our socials) and hope to be able to reach out, help and support more of you than ever as we grow as we are stronger together as one.

As a team we are aiming to arrange as many different and special events of varying types and interests as we possibly can and are able to plan and host as best we can.

Thank you for your continued support and as always we hope our latest newsletter finds you all well. Always remember we are here if you need us. Helen

P.S Save the date of 31st May 2025 as you need to be there with us more details coming soon.



# **Mersey Local Network**

## IN THIS ISSUE

Network News	1
Vaccinations	1
New Recruits	2
Liam's Marathon	3
Tash's Boccia Team	3
Invisable Disabilities Campaign	4
Research oppotunities	4
Dates for your diary	5
Contact us	5

### FLU AND COVID - 19 VACCINATIONS

By Laura Darbyshire

As we enter the chilly months, it's vital for individuals with inflammatory bowel disease (IBD) to get vaccinated. Receiving vaccinations, including the COVID-19 booster and flu shot, is crucial due to the increased risks and vulnerabilities these illnesses pose.

If you are planning to get a flu or COVID-19 jab, it is essential to consult healthcare professionals about your ongoing treatments. Staying updated on your vaccinations is key to ensuring optimal protection against these viruses.

Take charge of your health this season and protect yourself by prioritizing vaccinations.

For more information, visit: www.crohnsandcolitisuk.org.uk

### **NEW RECRUITS**

In recent months we have welcomed three new volounteers to the Mersey Network Including Meg, Laura and Liam.

Hi, I'm Meg, I'm 25 and was diagnosed with Crohn's Disease in April 2023, after experiencing blood in my stools, urgency and a positive FIT test. After further research, I learned that other symptoms I experienced for years beforehand such as skin rashes and mouth ulcers, were suprisngly connected to my condition. While I'm still fairly new to the world of IBD and coming to terms with this being a lifelong condition, Crohn's & Colitis UK has been an incredible resource, helping me understand my condition and how to manage it. I'm volunteering to raise awareness about the realities of living with Crohn's—it's not just a bowel condition, but one that can affect the whole body and mind. In my free time, you can find me reading, practicing yoga, or dragging my friends to join me at a garden centre or National Trust site!

find me hiking up mountains, gaming, hanging out with friends or more recently i've taken up bouldering at the local climbing center.

I'm volunteering with Team Mersey to raise awearness of Inflammatory Bowel Disease and to meet new people.

I hope to see you at future events with the Mersey Local Network.

My name is Liam and I am 28 years old. I was diagnosed with IBDU (IBD unclassified) in January of 2022. A flare up of my symptoms led to me being in Whiston Hosptial which ended in me receiving regular intravenous injection of biological medications. Through a holistic approach, I have managed to significantly reduce the inflammation and come off all medications. I love to run and recently ran a marathon for the first time. I am glad to say I am a part of Team Mersey as a volunteer and hope to see you soon at a future event.

Liam recently ran a Marathon for Crohn's & Colitis UK. Read on for more information about how he did.





### Crohn's & Colitis UK Mersey Network

# LIAM'S MARATHON

#### by Liam Kearns

Suffering with Crohns and Colitis has had a massive impact on my life. Being an active person was a big part of my identity and this was taken away from me for some time.

In the spring of this year I managed to get my symptoms under control. I set my self the ambitious goal of running a marathon in 6 months following 2 years of inactivity. This was to prove to myself and others with this condition that you can take back control of your life and do the things you love to do.

6th October 2024 I ran the Chester marathon in a time of 3:48:22 and raised £500 for Crohns & Colitis UK. This is something I couldn't have dreamt of less than a year ago and I am very grateful for the support of my friends, family and colleagues during my health journey.





## TASH'S BOCCIA TEAM

Over the last 2 years, our volunteer Tash has been competing in the Disability Sport of Boccia. Boccia (pronounced bot-cha) is a Paralympic sport with no Olympic equivalent and is similar to bowls.

It is a target ball sport which tests both muscle control and accuracy. Visit our what is boccia webpage for more detailed information. <u>www.</u> <u>bocciaengland.org.uk/</u>

Originally designed for individuals with severe physical disabilities, the game has branched out to include all disabilities. Even able-bodied people can play boccia in a social setting as long as you stick to the rules and stay seated during play. After many hours of training sessions, both early morning and late at night, multiple competitions and long travel days, it has been announced by Boccia England that Tash is currently ranked number 1 in England in her classification.

"It's been a rollercoaster of a journey to get the point where I am in the sport now. From starting off in Para-Swimming, now to Boccia, I've always had a dedicated work ethic. Having Crohn's has come with it's challenges during competitions and traveling, but accepting that the Crohn's is a part of me has been a huge help in developing my sporting abilities"

### Crohn's & Colitis UK Mersey Network

# NOT EVERY DISABILITY IS VISIBLE CAMPAIGN

#### By Meg Pepper

For many living with invisible conditions like Crohn's disease and Ulcerative Colitis, using a public toilet can become a source of stress and anxiety. Crohn's & Colitis UK's "Not Every Disability is Visible" campaign aims to change that by raising awareness about the urgent bathroom needs of people with IBD. The campaign encourages businesses to update accessible toilet signage, making it clear that these facilities aren't just for those with visible disabilities, but also for people with urgent, unpredictable and invisible needs.

People with invisible conditions like mine face constant judgment when using accessible toilets. Crohn's & Colitis UK's "Not Every Disability is Visible" campaign is helping change this by advocating for updated signage that clarifies accessible toilets are also for people with invisible illnesses, not just visible disabilities.

I remember one experience that sticks with me. I was at a shopping centre, and the accessible toilet didn't have any signage explaining that it could be used by people with hidden conditions. As I went in, I could hear someone outside questioning why I was using it, saying that I "don't look disabled." It made me feel frustrated, and incredibly self-conscious, as if I had to prove my need to be there. Moments like these add unnecessary stress to an already difficult condition.



Thanks to this campaign, over 25 major UK businesses, including M&S and Tesco, have adopted the new signage. This not only helps reduce stigma but also fosters greater empathy for people living with invisible disabilities. It's a small but powerful step toward making public spaces more inclusive, allowing us to live with less anxiety and more understanding.

With the campaign's continued success, I hope more public places will adopt this initiative, so people with invisible conditions can access the facilities they need—without fear of judgment. To find out more about the campaign or to learn how your business or employer can adopt the new signage, visit <u>https://crohnsandcolitis.org.</u> <u>uk/our-work/campaigns/not-every-disability-isvisible/access-to-toilets</u> and help make public spaces more inclusive.

# **RESEARCH OPPORTUNITIES**

By participating in research opportunities you can help shape the future of treatments. Whether it's taking part in clinical trials, surveys, or focus groups, there are various ways to contribute.

You can sign up to receive updates about research opportunities through Crohn's & Colitis UK's website: <u>https://crohnsandcolitis.org.uk/</u> <u>our-work/research-and-evidence/sign-up-to-</u>

#### hear-about-research-opportunities

By signing up, you'll be among the first to hear about new studies and ways you can get involved.

Being part of these initiatives not only provides valuable data for researchers but also ensures that patient voices are central in shaping research outcomes.

# DATES FOR YOUR DIARY

### SOCIAL MEET UP

16 November 2024 13:00 - 16:00 Queens Park Health and Fitness, Boundary Road, St Helens, WA10 2LT

This is an informal social event to meet others affected by Crohn's and Colitis, our local volunteers and learn more about Crohn's & Colitis UK. There is no need to book a place and everyone is free to come and go as they please.

Look out for our volunteers in their purple Crohn's & Colitis UK t-shirts.

Friends and family are very welcome to attend.

### CROHN'S & COLITIS AWARENESS WEEK 2024

1-7 December 2024

December 1st-7th is Crohn's and Colitis Awareness Week and is the perfect opportunity to come together and talk about what it's like to live with Inflammatory Bowel Disease or support someone who does.

Join us at one of our Virtual Social Events:

- Tuesday 3rd December at 6.30pm-8pm <u>Virtual Social Event - Crohn's and</u> <u>Colitis Awareness Week</u>
- Saturday 7th December at 10.30am-12pm <u>Virtual Social Event - Crohn's</u> and Colitis Awareness Week

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 <u>networks@crohnsandcolitis.org.uk</u>

This will save the group valuable funds which can be used to benefit all those affected by Inflammatory Bowel Disease.

# CONTACT US

### **MERSEY NETWORK**

Lead Volounteer: Helen Thompson Website: <u>www.crohnsandcolitis.org.uk/Mersey</u> Email: <u>mersey@networks.crohnsandcolitis.org.uk</u>



Crohn's and Colitis UK Mersey Group



Crohn'scolitisuk\_mersey

### **GENERAL ENQUIRIES**

Crohn's & Colitis UK

1 Bishops Square, Hatfield Business Park AL10 9NE

https://crohnsandcolitis.org.uk/contact

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 is a confidential service providing information and support to anyone affected by Crohn's and Colitis.

They can provide information on a range of subjects including:

- Managing treatment
- Medication
- Diet
  - Test and Diagnosis
- Wellbeing
- Employment
- Disability Benefits
- Help to find support from others living with Crohn's and Colitis

### CONTACT US BY:

Telephone: 0300 222 5700\* Monday to Friday - 9 am to 5 pm

#### Email: <u>helpline@crohnsandcolitis.org.uk</u>

**Web Chat (Live Online):** see our website for details \*Calls to this number are charged at a standard landline rate or may be free if you have an inclusive minutes' package. Calls may be recorded for monitoring and evaluation purposes.

### NEWSLETTER

Editor: Laura Darbyshire Design: Crohn's & Colitis UK

The Mersey 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.