

Leeds and District Network

WELCOME FROM THE LEEDS VOLUNTEERS!

Hello, it's lovely to be back!

It's been such a long time since we've published a newsletter due to a number of things, not least a pandemic! Unfortunately precautions due to Covid have prevented us from carrying out our usual activity as a Network, but as we head into the New Year, we hope that we'll be able to return, when safe, to in person Educational Meetings and Social Events.

Our volunteer numbers have diminished a little and we'd love some of you to join the team. No particular skills are needed, just enthusiasm and teamwork. If you're interested, our contact details are on the back page or check out: www.crohnsandcolitis.org.uk/volunteer

In this newsletter, we will reflect on 2021 by sharing some of the incredible fundraising stories from our volunteers as well as a call out for participants to help the University of Leeds with a project.



Some of our Leeds and District Network volunteers!

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FABULOUS FUNDRAISERS!

Skye to London Challenge

Not being able to celebrate her eldest daughter's 30th birthday in March 2021 due to Covid, our Network volunteer Bev and her family planned a trip to the beautiful Isle of Skye in May 2021. Unfortunately their youngest daughter was unable to join due to a flare up of her Crohn's Disease.

Instead, the family decided to turn the trip into a fundraising challenge by walking the equivalent distance between Skye and their daughters flat in London: an incredible 647 miles to be walked between the family of 4 over the next 30 days!

“The miles on Skye were challenging, with lots of steep hills! Despite missing my daughter, we had a lovely holiday and raised £3040 for Crohn's & Colitis UK!”



Christmas Wreath Making

On December 4th, Halifax Tennis Club hosted a Christmas wreath making morning with proceeds going to charity. It took place during Crohn's and Colitis Awareness week and it also fitted with the Craft it at Christmas fundraiser!

Great fun was had by all who attended, everyone loved learning a new skill whilst raising awareness for IBD. An incredible £300 was raised, with £150 each being donated to Crohn's & Colitis UK and Colostomy UK.



If you took part in Craft it at Christmas, or are a keen crafter, we'd love to see photos of what you've made for our next newsletter! Please get in touch at leeds@networks.crohnsandcolitis.org.uk

Rock It @ The Hamlet

A Duke of Edinburgh group at The Hamlet in Wigan have raised money for charity through their Christmas Open Mic event! Over 200 people attended the event, which raised a large sum of money for a few local charities, with a £50 donation to Crohn's & Colitis UK. This charity was chosen as a close family member of one of the organisers has Ulcerative Colitis and volunteers with the Leeds Network.

The Hamlet is a provision for young adults with additional needs and are proud to work with their community. A big thanks to the trainees that organised and set up this wonderful event.



Introducing Research Champion - Emma

Hi, I'm Emma and I was diagnosed with Ulcerative Colitis in 2008. The following year I became a volunteer with the Leeds and District Network, organising information and social events for local people living with Crohn's and Colitis and fundraising for research and local IBD projects. I'll have probably met some of you at our Information Forums and Coffee Mornings.

When I was very unwell with Ulcerative Colitis, some of my questions about treatments and prognosis were met with the answer, "I'm sorry, we don't know, it hasn't been studied yet". I would scour the Connect magazine for information about new research.



In 2017 I was approached by the University of Leeds and Professor of Gastroenterology Alex Ford to join and help design what has become the MODULATE trial. MODULATE is a UK-wide clinical trial funded by NHIR to test the safety and efficacy of four different treatments to help manage ongoing diarrhoea in Ulcerative Colitis patients with 'stable disease' for whom there are currently no treatments at all.

I've been involved in an advisory capacity to help represent the views and experiences of people living with Ulcerative Colitis. We are using the latest technology to run the trial remotely so participants can take part at home to limit hospital visits. The Leeds University site is hoping to open later this month. (For more info go to <https://ctru.leeds.ac.uk/modulate>)

I am very keen to continue contributing to improving research I have found it immensely rewarding to be able to play a small part in the advancement of treatments for patients like myself with IBD. To mark 10 years since my stoma surgery I thought it would be good to take on a new role and it was suggested I might apply to become a Research Champion for Crohn's & Colitis UK. I applied and was delighted to be accepted last Summer. The Research Champion role is to be a bridge between Researchers and people living with Crohn's and Colitis. We attend meetings and share our personal views and experiences, and we try to represent the wider Crohn's and Colitis community to make sure our views are communicated to researchers so that they can tailor their research more specifically to our needs.

There are lots of opportunities for people living with Crohn's and Colitis to get involved in research: some studies involve simply completing questionnaires, others you can take part as participants. All studies need patient representation in the design and planning stages too. For all the latest IBD research-related info see the research pages (www.crohnsandcolitis.org.uk/research) on the Crohn's & Colitis UK website and you can follow me on twitter @emmapryde7

Youth Academy Training - Francesca

Our Lead Volunteer, Francesca, has been selected to be part of a 'Leaders for Tomorrow' Youth Academy with EFCCA (*European Federation of Crohn's & Ulcerative Colitis*), for young people who are involved with Inflammatory Bowel Disease organisations across the world.

"I'm really excited to begin the training, to learn more about advocacy for IBD and meet other young people who are as excited about raising awareness as I am!"



Call for Participants - Long Term Health Conditions Project

Do you have some time to spare to chat to the doctors of the future and tell them what it is like to live, or care for someone, with IBD?

The University of Leeds are looking for volunteers for their Long Term Health Conditions Project, which offers first year medical students an opportunity to learn by experience about what is like to have, or to care for someone who has, a chronic illness or disability.

They are offering Crohn's & Colitis UK a small donation as a thank you for the volunteers we help them find.

Each volunteer is paired with two 1st year medical students and will meet together over Zoom on one occasion in February/March.

If you have IBD or care for someone who has IBD and are interested in taking part, please send an email to iandpY1@leeds.ac.uk answering the following questions by Thursday 20th January 2022. If you receive this newsletter after this date, please still get in touch as they might still consider expressions of interest after the deadline.

Name:

Tel. No:

Email:

Support organisation you were contacted through: Crohn's & Colitis Leeds and District Network

Brief details of the condition you or the person you care for, experiences:

Please be aware this opportunity is not organised by Crohn's & Colitis UK. It is the patient's choice to take part.

DATES FOR YOUR DIARY

UNIVERSITY OF LEEDS HEALTH CONDITIONS PROJECT

Deadline for expressions of interest: 20th January

VIRTUAL SOCIAL EVENT - NORTH EAST AND YORKSHIRE

27th January, 6.30pm-8pm

Online

Crohn's & Colitis UK are hosting virtual social events which offer a chance to chat and share experiences. More information about the event and future dates can be found online.

www.crohnsandcolitis.org.uk/virtual-social-events

FUNDRAISING

Skye to London Challenge: £3050

Christmas Wreath Making: £150

Rock It @ The Hamlet: £50

Sergio Russo: £50

Thank you to all of our amazing fundraisers and donators!

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 network valuable funds which can be used to benefit all those affected by Crohn's and Colitis.

CONTACT US

LEEDS AND DISTRICT NETWORK

Lead Volunteer: Francesca Russo

Email: leeds@networks.crohnsandcolitis.org.uk

Website: www.crohnsandcolitis.org.uk/leeds



CrohnsColitisLeeds



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GENERAL ENQUIRIES

Crohn's & Colitis UK

1 Bishops Square, Hatfield Business Park, AL10 9NE

www.crohnsandcolitis.org.uk/contact

Volunteer Enquires: 01727 734 475

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 for anyone affected by Crohn's or Colitis.

Our team can:

- help you understand more about Crohn's or Colitis, diagnosis and treatment options
- provide information to help you to live well with your condition
- be there to listen if you need someone to talk to
- signpost people to sources of expert advice on disability benefits and options for specialist emotional support

CONTACT US BY:

Telephone: 0300 222 5700*

Monday to Friday - 9am to 5pm

Email: helpline@crohnsandcolitis.org.uk

Live Chat: www.crohnsandcolitis.org.uk/livechat

**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.*

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