CROHN'S & COLITIS UK

MID & WEST CORNWALL

NEWSLETTER

February 2019

Edition 6

Message From the Editor

A very warm welcome to you all, in particular any new members to the organisation.

FIGHTING

INFLAMMATORY

BOWEL DISEASE

For those unaware, the Mid and West Cornwall Crohn's & Colitis Local Network covers the area from St Austell in the East down to Lands End in the West. The network meets around four or five times a year, and usually have a guest speaker. This maybe a Gastroenterologist, a Surgeon, a Pharmacist or a Dietician. Our resident IBD Specialist Nurse, Jo Sheppard, or one of her team such as Caroline Collins is often present as well.

Since our last Newsletter, one of our Organising Team members, Lucy Brightley, has stood down from her role. On behalf of the team, we would like to thank her for the support she has given us. The team are always looking for help to expand the support it can provide its members. If you would like to get involved and help contribute to the groups activities, please contact us by email at mwc@networks.crohnsandcolitis.org.uk

There was some good news for our Network Co-ordinator, Brian Richards, who was one of seven people nationally to be awarded a 2018 Volunteer Award.



Brian, seen here with his award, was nominated for taking on a key role in order to continue providing a service to people with Crohn's or Colitis in the Mid and West Cornwall area. This involved coordinating regular medical meetings in the Knowledge Spa in Truro.

Brian was presented with his award by Alan Thackrey, Vice-Chair of the Board of Trustees at the Crohn's & Colitis UK head office in Hatfield, Hertfordshire on 24th January. Brian was described as 'Determined, Understanding and Considerate'. Congratulations Brian, long may the good work continue.

Sophie Riley - Newsletter Editor

Meet Your Local Organising Team (OT)

Brian Richards MBE (Network co-ordinator)



I am retired and have had Crohn's / Colitis for nearly 50 years. My main interest is sport, in particular Rugby and Cricket. I originally joined the Organising Team some 20 plus years ago so that I could help provide the support for IBD patients that I would like to have had when first diagnosed at age 15.

Tegen Argo



I have had Crohn's disease for about 8 years, and a permanent lleostomy for over 4 years. I volunteered to join the network, because I think it is very important to raise awareness of IBD, as its an invisible disability and we need more awareness!

Alan Edwards (Social media)



I was diagnosed with Ulcerative Colitis and Proctitis in 2001 and I had a total colectomy in 2010. I joined the Mid & West Cornwall Network in 2017 so that I could assist in raising awareness and help people cope better. I'm still a firm believer that the outdoors is a great healer, so spend as much time out there as possible.

Fundraising Activity

Sarah Gallop recently celebrated her birthday by raising £150 for Crohn's & Colitis UK, through her Facebook page. Many happy returns Sarah, and thank you on behalf of Crohn's & Colitis UK.

Coffee Morning and Raffle

Brian Richards, is seen here with Diane O'Connor, who recently organised a Coffee Morning and raffle at the Lamorna Pottery Bed & Breakfast and Cafe. £200 was raised for the Crohn's & Colitis UK Research Programme.

Thanks are expressed to proprietors Jeremy and Munier for kindly hosting the event, and particularly to Diane for taking the initiative with her fund raising initiative.



Volunteering Opportunities

NHS Research, Development & Innovation in in Cornwall

The NHS in Cornwall is committed to providing the best and most appropriate care using the most up to date knowledge. The RCHT does this by recognising the importance of learning and taking part in research.

The RCHT Research, Development and Innovation Team would be delighted to hear from you if you are interested in taking part in clinical research in Cornwall. This may be within Hospitals, NHS clinics, GP Surgeries and in the community across Cornwall.

If you want to know more about what's involved in taking part in clinical research studies, please click on this website:-

http://www.royalcornwall.nhs.uk/services/research-developmentinnovation/

Public Involvement In Medical Education The group is part of the University of Exeter Medical School, and is looking for people based in Cornwall to attend meetings and to take part in specific educational activities or projects in the area. The purpose of the group is to monitor and challenge where necessary, the training programme and progression of Medical Students from their commencement through to final Graduation.

If you would like more information, please contact the Administrator, Helen Thomas, at <u>PIME@exeter.ac.uk</u> for more information.

Sophie Riley (Newsletter editor)



I decided to join the Mid & West Cornwall Network because I had the time to spare and a desire to put it to good use. Having had some experience in communications and marketing, helping to raise awareness of, and contributing to, the support that is offered locally, seemed like the ideal opportunity to share my experience whilst making a decision.

Sarah Gallop



After multiple surgeries, I am determined to get out and enjoy life with a 'J' pouch as much as possible. I love to spend time with my two children at the beach or exploring the woods.

Chloe Pickering



As someone who works full-time, I need to have flexibility with my volunteering. Crohn's & Colitis UK allows just that with conference calls I can jump on from home and the odd meetup, which is also great for the social aspect. I like to help out and utilise my business skills to assist with fundraising ideas, volunteer recruitment and of course, raising awareness.

Page 2

Crohn's and Colitis UK Mid & West Cornwall Network

Can't Wait Card. As a Crohn's & Colitis UK member, you will also receive a 'Can't Wait' card which can be shown to many local traders and shop owners who may allow you to use their toilet facilities.

Public Toilets. As all IBD patients appreciate, its always sensible to know where the nearest public toilet is. With major cutbacks and toilet closures, Cornwall Council has produced a status list of toilets indicating who is responsible for them. The list was valid as of May 2018, and can be accessed from the website below.

www.cornwall.gov.uk/media/19391562/publictoilets-status

Crohn's & Colitis UK

Social Media

Social media has become very popular, particularly with the younger generation. It is a great way for us to raise awareness with other IBD sufferers. Did you know that there are Facebook and Twitter pages for Crohn's & Colitis UK and for our local network?

Why not check out and like/follow the Charity's and our very own brand new pages out at:

f Crohn's and Colitis UK



CrohnsColitisUK

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 network valuable funds which can be used to benefit all those affected by Inflammatory Bowel Disease.

The Mid & West Cornwall 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.

CONTACT US

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Crohn's & Colitis UK Mid & West Cornwall Group

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 is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

CONTACT US BY:

Telephone: 0300 222 5700*

Mon, Tue, Wed and Fri - 9 am to 5 pm

Thu - 9 am to 1 pm

Email: info@crohnsandcolitis.org.uk

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.