# CROHN'S & COLITIS UK

MID & WEST CORNWALL

# **NEWS**LETTER

October 2018

Edition 5

#### Message From the Editor

A very warm welcome to you all, and I hope you enjoyed the fabulous summer. Hopefully the fine weather has indirectly helped your general health and well-being, and has set you up for the long winter months ahead.

FIGHTING

INFLAMMATORY

BOWEL DISEASE TOGETHER

Dani St Leger has taken the decision to stand down from the Organising Team. We would like to take this opportunity to thank her for her support of the team.

The next Medical meeting, will be held once again in The Knowledge Spa (Room G02), at The Royal Cornwall Hospital in Truro on Monday 15<sup>th</sup> October from 6:00pm to 7:45pm. Our guest speaker will be Andy Pothecary, a Pharmacist based at Treliske. His presentation is entitled 'Switching to Biosimilar drugs in IBD', and would be of particular interest to anyone currently using or considering the option of using one of the new range of biologic drug.

Sophie Riley Newsletter Editor



### Public Involvement in Medical Education

# Shaping the education of future healthcare professionals and scientists

The Public Involvement in Medical Education group (PIME) is made up of members of the public. Their involvement in the education of healthcare professionals and scientists helps ensure that curricula are innovative, authentic and person-centered.

- The PIME group are involved in: selecting which applicants are character to the
- chosen to study, supporting the teaching and
- assessment of students, developing the curricula and
- engaging with the local Community

Reasonable reimbursement of travel costs.

experiences.

term commitments.

You do not need any background

in education or healthcare. We are looking for people from all walks of life and with different life

For more information or to express your interest please contact us at: PIME@exeten.ac.uk or PIME, Exeter Medical School Building, St Luke's Campus, Heavitree Road,Exeter, EX1 2LU

medicine.exeter.ac.uk

Meet Your Local Organising Team (OT)

Brian Richards (Network co-ordinator)



I am retired and have had Crohn's/Colitis for 48 years. My main interest is sport, in particular Rugby and Cricket. I originally joined the Organising Team so that I could help provide the support for IBD patients that I would like to have had when first diagnosed at age 15.

#### Lucy Brightley



I am a mother of five, am a keen cyclist and walker. I have lived with Crohn's for 18 years. My guilty pleasure is Clash of Clans and McVities digestives.

#### 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.



Exeter, but in order to make sure our graduates are well prepared for the demands of modern healthcore, we need input fram members of the public too." Professor Jean McEwan,

"Being able to influence the education of future healthcare

professionals by providing a public perspective is rewarding, rewarding, engaging and fun." Mis Chris King, PIME Steering Group Member

## Sophie Riley (Newsletter editor) Page 2

#### Local IBD Helpline Information

#### Feeling Unwell?

If you are currently registered with an IBD Consultant within the RCHT, and are having problems with your IBD, you can always contact the local IBD Dedicated Helpline on:-

#### 01872 252 178

#### or email

rch-tr.IBDnurse@nhs.net

One of the IBD Specialist or Support Nurses will normally get back to you within two working days.

You can discuss your problem with them, and alterations can sometimes be made to your treatment. If necessary, an urgent appointment can be arranged for you.

#### RCHT website -Gastroenterology Pages

#### Did you know?

Don't forget, the RCHT IBD website now provides dedicated Gastro enterology pages.

This can be accessed by logging onto the RCHT website, then click on 'Our Services' then 'G' for 'Gastroenterology'.

This takes you to two options, either the Gastro or Gastro surgery pages.

#### Stress Free Outdoors at Helston Old Cattle Market

We joined Stress Free Outdoors at Helston's Old Cattle Market Health, Nutrition and Fitness Fair in January.



This was a great day, surrounded with exceptional ideas and businesses, sharing information, knowledge and awareness of Inflammatory Bowel Disease in Cornwall. It also promoted the available support not only for individuals with IBD, but families and friends too. There is another already planned for later this year so keep an eye out for one of our volunteers. Alan Edwards

#### Research & Development.

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

The RCHT Research, Development & Innovation Team would be delighted to hear from you if you are interested in taking part in clinical research in Cornwall.



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.

#### Tegen Argo



I have had Crohn's disease for about 7 years, and a permanent lleostomy for well over 3 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!

#### 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 and Colitis UK allows just that with conference calls I can jump on from home and the odd meet-up, 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. 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 and 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 and 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:



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 and Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.

# CONTACT US

#### MID & WEST CORNWALL NETWORK

Co-ordinator: Brian Richards MBE Helpline: 0300 222 5700\*

Website: www.crohnsandcolitis.org.uk/mwc Email: mwc@networks.crohnsandcolitis.org.uk

Crohn's and Colitis UK Mid & West Cornwall Group



Crohn's and 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.