

NEWSLETTER

MAY 2019

Issue 1

SOUTH WALES Network

WELCOME TO THE ORGANISING TEAM

Hello and welcome to the organizing team for the South Wales Volunteer Network.

By Helen De Saulles

Just a brief introduction to the organizing team!

TEAM MEMBERS

Helen De Saulles is the Lead Volunteer, Zara Evans is the Finance Volunteer and Helen Ludlow is our IBD Nurse Link.

Menna Rees, Kim Sumner, Kate Darby and Laura Houldcroft are all Awareness Volunteers who help organize events and are responsible for our social media accounts (ie Facebook, Twitter and Instagram).

If you would like to be involved with the team or would be willing to help at events then please get in touch with us via social media.



Zara, Kim, Helen DS, Kate, Helen L, Laura

FUNDRAISING

While we run events every year (see Dates for Your Diary) we are very keen to help other people who may also be fund raising.

We can help with publicity and resources, and also can lend a hand or two on the day.

Please get in touch with us via social media, or with head office through their website.

Lastly, we would like to wish you all the best for this year and hopefully we will meet you at some or our events!

FUNDRAISING NEWS

A huge thank you to the following people who raised money for Crohn's and Colitis UK last year:

Dare to Sing Ladies Choir, Aberdare - £1000.00

Ladies Circle, Roath, Cardiff - £1161.00

Raglan Post Office - £42

Many thanks for all your efforts!

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2018 EVENTS

Here are some the events that we were part of last year:

Easter Quiz Night

Educational Meeting - Diet Matters

Royal BakeIt Cake Sale

CCUK Family Day

CCUK Swansea WalkIt



Coco at the Swansea WalkIt

Young at Heart, Bridgend -Talk

Car Boot Sale

Coffee Morning

Christmas Quiz Night

IBD WALES

By Wayne Lewis, Health Services Development Officer for Wales, Crohn's & Colitis UK

IBD Wales was set up in late 2017 and brings together a range of people with a professional and personal interest in IBD and particularly in improving services for any one living with Crohn's and Colitis. Members of the group include surgeons, gastroenterologists (adult and paediatric), IBD Nurses, GP, people with Crohn's and Colitis, Welsh Government etc, with representatives from all parts of Wales.

The group (which is linked to the Welsh Assoc for Gastroenterology and Endoscopy) has developed workstreams related to early diagnosis within primary care, developing new models of IBD Nurse-led care; looking at improving waiting times for elective surgery; linking Welsh Health Boards in with the UK-wide IBD Registry to make better use of the totality of the data being collected across the country; etc

Working in collaboration with health care professionals and people with Crohn's and Colitis has also brought some unexpectedly positive spin offs. For example, Swansea University are working with Patients Know Best to further develop their health care App which is currently in use with Abertawe Bro Morgannwg UHB and soon to be in place with Cardiff and the Vale UHB. As a result of the work of IBD Wales, it has now been agreed that IBD-related info will be included in that App from the point of its roll out. Hopefully Cardiff and the Vale can 'piggy back' on this initial work. Also, and of particular importance, having Welsh Government on the group (and despite giving Anthony, their very capable representative the occasional hard time), has meant that they have heard many of the issues that people face in relation to accessing health care, as well as the positives. Consequently, they are pulling together a meeting all seven Health Boards in early March, chaired by the Deputy Chief Medical Officer, and hopefully this will become the first of a series of meetings focussing on the actual local mechanics of improving services, both locally and nationally.

In May, near to World IBD day, we will also be holding an event at the Senedd where we are planning to have a 'drop-in' session for Assembly Members to come and meet their constituents who have IBD and hear what life is like. We are only just pulling this together at the moment, but if you are interested, we will probably draft a fairly standard letter/email for you to use in inviting your AM to meet with you; I would like to try getting AMs to commit to using the



In Their Shoes App for a couple of days, but need to iron out a few wrinkles before I may (or may not) get the go ahead for this.

As for me, I joined Crohn's & Colitis UK in July of last year as Health Services Development Officer and currently work 3 days a week covering the whole of Wales from my home office base in Ceredigion. By background I am a social worker (no groaning, please) and have a family connection with ulcerative colitis and a personal connection with an inflammatory eye condition with which some of you might be also familiar - uveitis.

I look forward to meeting and working with you all

BENIDORM OR BUST!

Look out for Elijah Sumner who will be driving to Benidorm from 15th May 2019, raising money for Crohn's and Colitis UK.

He and a friend will be driving and maintaining their car for a week as they drive to Benidorm and back.

You can follow Elijah's adventures on his Facebook page and donate via the following website:

uk.virginmoneygiving.com/fundraiser-display

DATES FOR YOUR DIARY

Please follow us on social media for further information.

NETWORK MEETING

22nd May, 6pm, Heath Hospital Social Club All welcome

SWANSEA WALKIT

1st June, Swansea Bay Join us for our annual charity walk - register online via www.crohnsandcolitis.org.uk

OUIZ NIGHT

20th **June, Heath Hospital Social Club** Come and join us for fun and prizes.

NETWORK MEETING

17th July, 6pm, Heath Hospital Social Club All welcome

EDUCATIONAL MEETING

10th Oct, 6.30pm, Heath Hospital Social Club Surgery and IBD. (Mike Davies, Consultant)

NETWORK MEETING

20th Nov, 6pm, Heath Hospital Social Club All welcome

CHRISTMAS QUIZ NIGHT

5th **December, Heath Hospital Social Club** Come and join us for fun and prizes.

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 Inflammatory Bowel Disease.

CONTACT US

SOUTH WALES NETWORK

Lead Volunteer: Helen De Saulles

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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 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.

The South Wales 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.