CROHN'S & FIGHTING COLITIS UK BOWEL DISEASE

INFLAMMATORY

NEWSLETTER

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South West London & Croydon Network

QUIZZES, WALKING AND CHOCOLATE **BROWNIÉS!**

What do quizzes, chocolate brownies and walking have in common?

By Angela Rolle

Quizzes, chocolate brownies and walking have all featured in South West London & Croydon Network's activities and fundraising. These have ranged from a workplace quiz raising £430 to chocolate brownies being sold on World IBD Day and 2 members doing the 5k and 10k WALK IT London raising in excess of £600.00.

We were invited to participate in an awareness raising event at St Helier Hospital. This was the hospital's first IBD event. We had a stand with information which interested visitors and staff alike. We have shared information and various events in our respective areas. The year ended with Crohn's and Colitis

Awareness Week from 1-7 December where we promoted activities at our workplaces. This included a week of raising awareness with colleagues and baking cakes and cookies at a college. Staff and students enjoyed eating different recipes each day and donated generously for the charity. We started the first of our Alphabet Dining Clubs (ADC) in January 2018. Using the alphabet from A to Z, a restaurant is chosen according to the alphabet, the restaurant's name or its cuisine. The ADC is held every two months. It's a good way for people with Crohn's and Colitis to meet others in a relaxed environment for a meal or just join in with a drink.



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A FIRST FOR ST HELIER HOSPITAL

We were invited to have a stand at an IBD Open Day at St Helier Hospital on Saturday 12th May. This was the first event of its type held at the hospital. This information day attracted staff, patients and those who had a family member or friend with the disease. We had many visitors to our stand and interest from people who were at different stages of having Crohn's or Colitis. The programme included presentations from doctors and a range of different stands by healthcare professionals. Local MP Tom brake also attended. It was an enjoyable event for our network meeting enthusiastic medical professionals and patients. We made some good contacts and have kept in touch.

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

WORLD IBD DAY VS. THE ROYAL WEDDING AND OTHER EVENTS!

The World IBD Day event on Saturday 19th May went well at Croydon University Hospital, despite being held on a Saturday which was quieter than the previous year and with fewer visitors than on a week day. There was also competition from other events - i.e. Royal Wedding, Cup Final (football) and good weather! However, there was a steady stream of interested visitors at our stands and the cakes were a big attraction! We made £361.00 including £150 from the raffle by Dee Braim - IBD Nurse Specialist.

MEMBERS ENJOY WALK IT LONDON

WALK IT London was a fun event at Coram Fields (near Russell Square) on Saturday 9th June, with thousands of people either doing the 10K or 5K walk. Two member of the team participated. Bex did 10K and was one the first walkers (or in Bex's case runners!) past the finish line at Coram Fields, and Angela did the 5K. Both were surprised to receive a medal when they finished.





'QUICK WINS' WORKS IN SOUTH WEST LONDON & CROYDON

As we know fundraising can take many forms from large-scale events such as sky dives to marathons.

Our network participates in international events such as World IBD Day and national events such as WALK IT London. However, we also focus on 'Quick Wins'. These are small-scale activities and events which can highlight our network in the community and have a significant impact.

We have held activities ranging from a football tournament and bake sale to medical and educational events at one of the local hospitals - Croydon University Hospital. Also, we were chosen 3 times by Waitrose Community Matters scheme, and were awarded over £1000.

COMMUNITY MATJERS

UK'S FIRST PREDICTIVE TEST FOR CROHN'S AND COLITIS

PREDICTSURE IBD™, A NEW SIMPLE TEST COULD ENABLE PERSONALISED TREATMENT OF CROHN'S AND COLITIS.

Scientists at the University of Cambridge have developed a new test that can reliably predict the future course of Crohn's Disease or Ulcerative **Colitis**, transforming treatments for people with the conditions and paving the way for a personalised approach. In the latest study, published in the Journal Gut, researchers at the Department of Medicine, University of Cambridge, worked with 69 people with Crohn's to see whether it was possible test by looking at whole blood samples alongside CD8 T-cells and using widely-available technology.

For more information on this article please see www.crohnsandcolitis.org.uk

IBD....WORK....AND I

For some people, the idea of talking about their Crohn's or Colitis at work is uncomfortable. I can understand that, and for roughly a year after my colectomy I was one of those people. Not because I was embarrassed, but because I know it's a topic that can make people who are unaffected by IBD feel embarrassed. However, over time I realised that the reason people get embarrassed is *because* it's a topic that isn't often discussed, and one that people don't know much about if they aren't affected by it. I therefore felt that, in my role as a volunteer for Crohn's & Colitis UK, and not long after the two year anniversary of my surgery, I should do something at work for Crohn's and Colitis Awareness Week. I brought in some cakes and treats, and put them on the communal kitchen table along with the Crohn's & Colitis UK balloons and flags I was sent in my Awareness Week Volunteer pack. I also put the information poster on the table beside the treats. I then sent an email to the 40 people in the office inviting them to help themselves on the strict condition that they read the information poster in its entirety before taking any cake! In the email, I also described IBD, and my experiences with it, and explained the purpose of Awareness Week, providing links to the Crohn's & Colitis UK website and giving details on how to donate to the charity. I explained that the 7th of December was "Go Purple" day, and if anyone felt so inclined they could join me in showing support for the charity and those affected by Crohn's or Colitis by wearing something purple.

For the rest of the day, I had colleagues approaching my desk to tell me about a friend or relative they had who also suffers with Crohn's or Colitis, or telling me they had no idea quite what I'd been through and showing support. It was great to have an open discussion about the illnesses with some colleagues that I don't normally interact with on a day-to-day basis. People came out of their way to talk and learn more, and many were very happy to make donations.

The 7th of December happened to be our work Christmas lunch, and I was extremely touched and proud to see several colleagues had come in with something purple on, from a full-on purple shirt and tie combo, to purple tights, to a pair of earrings. I didn't ask for proof from those who assured me their support was being shown by wearing purple garments not readily seen in public...!

*This was written by one of our volunteers

Croydon University Hospital hosts 2nd IBD Evening

Report by Dee Braim, IBD Nurse Specialist (Gastroenterology Department)

The 2nd IBD evening, on the 28th Feb 2019 at CUH was a great success. 70 patients and staff enjoyed six expert presentations delivered by the IBD team and two visiting patients (Victoria & Lorna) who live with IBD. Topics covered included Overview of IBD, Pregnancy, Medication, Extraintestinal Manifestations of IBD and Cognitive behavioral therapy. Victoria and Lorna gave an emotional

Victoria and Lorna gave an emotional heartfelt account of their IBD journey and shared their experiences with a powerful pictorial presentation. They set up **#getyourbellyout** campaign in 2014 to give those with IBD a platform to discuss, support and empower each other globally. Through fund raising events they have raised £77,000 for Crohn's & Colitis UK. Feedback from the evening was excellent, and we hope to run another in 2020.

A big thank you Tillotts pharma, who sponsored the evening and to Anne Kiragu and her staff who arranged the catering and raffle prizes. We raised £144.00p for Crohn's & Colitis UK who work tirelessly to promote awareness for IBD, support research projects and provide patient information booklets. Thank you also to the presenters and volunteers.



DATES FOR YOUR DIARY

NETWORK MEETING I

Wednesday 10th July Venue Keg & Grill pub, South Croydon

NETWORK MEETING II

Wednesday 16th October Venue Keg & Grill pub, South Croydon

NETWORK MEETING III

Wednesday 4th December Venue Keg & Grill pub, South Croydon More information about the events and contact information via the website

LOCAL FUNDRAISING

Charity Collection at Clapham Junction - Saturday 3rd August

Football Tournament and Bake Sale -Saturday 17th August (venue and time tbc)

Future local fundraising activities will be advertised via our Facebook page or website - www.crohnsandcolitis.org.uk

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 Crohn's and Colitis.

CONTACT US

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Crohn's and Colitis UK SW London and Croydon



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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.

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