

South West London and Croydon Network FROM WALK IT TO FUNDRAISING SWL&C RAISES FUNDS AGAIN!



By Angela Rolle

It's been a busy time for the network since May 2019. Following our event celebrating World IBD Day on Wednesday 15th May at Croydon University Hospital, we were back at the hospital to participate at an education event on Tuesday 21st May, where we shared information with visitors on IBD. A few of our volunteers have moved from the area which has been a shame, but we have welcomed some new volunteers!

The two smiling faces in the photo above are my friend Yvonne and I at Walk It London on Saturday 8th June. I didn't plan to do the 5k walk as the previous year, but Yvonne was really keen and persuaded me. How could I say no? The added bonus was creating more awareness and raising funds! We had nice, dry weather for the walk and were joined by 1600 other folks! As in 2019 all the participants were in good

spirits, and I enjoyed chatting to people from across London and beyond! A sea of purple brightened up Bloomsbury Square and the surrounding area, and we were each rewarded with a medal (another one to add to my collection!) We passed our target of £200 and raised £531.00. A big thank you to everyone for such fantastic support and donations.

A few of our volunteers have moved from the area which has been a shame, but we have welcomed some new volunteers! There's an article about one of our newest volunteers on page 4 in this newsletter.

Here in South West London and Croydon, it's always good to find out what's happening across London and beyond.

Our socials - ADCs - Alphabet Dining Clubs which we have every two months continue to be popular and as it's advertised on our Facebook page as well as through the main charity's website, new people attend, which is great.

So, if you're reading this and live in or near South West London or Croydon and want to meet people who have Crohn's or Colitis and enjoy trying new restaurants and cuisines, do look out for our next event in south west London during mid-March.

We are a friendly group and who knows, you might want to join our network and volunteer! Enjoy reading our newsletter and maybe see you at our next ADC!

IN THIS ISSUE

Network Volunteer Training	2
Bucket Collection	
SWL& C Scores!	3
Introducing Rihana	4
IBD Awareness Week	

WORLD IBD DAY 2020

It's not too early to start planning for World IBD Day!

For the past couple of years we've collaborated with our IBD Nurse Specialist to have information stands and a cake stall to raise awareness and fundraise.

These events have been well-attended as we've aimed to have them during weekdays when the hospital is busy.

As a network we are already thinking about what we will do this year.

Wish us luck!

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

CROHN'S AND COLITIS BUCKETS

On a sunny Saturday 3rd August we spent an afternoon at Clapham Junction Station (one of the busiest stations in Europe!) doing a bucket collection. We had a stand with information and had some interesting conversations with the public. We all enjoyed ourselves, promoted the charity and our work and raised £217.08. We've discussed doing another bucket collection this year in another part of London. Who knows? Watch this space!



WHAT'S HAPPENING IN EFCCA?

What is EFCCA? This is the European Federation of Crohn's and Ulcerative Colitis Associations. I heard about this organisation some years ago and wrote about my condition - Ulcerative Colitis.

The EFCCA Magazine is an interesting read as it contains some insightful articles from members and research across Europe. These include articles on digestive health in Europe and beyond, Ulcerative Colitis Treatment Guidelines and plans for World IBD Day 2020 (which isn't far away!)

One of the priorities for EFCCA is networking, exchanging information, knowledge and practices, and also collaborating with international IBD organisations.

For more information check out www.efcca.org

CROHN'S AND COLITIS AND TRANSPORT

A recent article on the website explains how important it is that public transport is truly inclusive. People with disabilities, including those with invisible conditions like Crohn's and Colitis have every right to travel as confidently as other passengers.

Many people with disabilities say that they don't feel confident using public transport and 1 in 4 say that negative attitudes from other passengers prevent them from travelling.

Crohn's & Colitis UK is supporting the Department of Transport's new campaign 'It's everyone's journey'. Do read it and share. www.crohnsandcolitis.org.uk

THE POWER OF RESEARCH

Crohn's & Colitis UK is the UK's leading charity supporting research into the conditions. We've been funding life-changing research into the causes, symptoms and treatments of Crohn's and Colitis for over 30 years.

As well as funding ground-breaking research, we connect researchers with patients, and work in partnership to advance the understanding of Crohn's and Colitis. To find out more about our work, please read more about the research at:

www.crohnsandcolitis.org.uk/research

SWL&C SCORES!

On Saturday 5th October, the Southwest London and Croydon Network held our second 5-a-side football tournament to raise awareness of Crohn's and Colitis, raise funds for the charity and have a bit of fun while getting active.

The event was held at the Powerleague in Vauxhall and 4 teams registered, all with a range of abilities. Each team played 4 games in total, including either a 3rd/4th place playoff, or a final for 1st and 2nd place.



The weather stayed dry and we also held a bake sale at the side of the pitch for the gathered supporters, with many of the goods accounting for the intolerances of certain ingredients that can be part of living with the conditions.

With donations on the day, and to the Just Giving Web page, we managed to raise £1,134.71, a fantastic amount, which was in the top 5% of donations to all Just Giving pages in October 2019. Just as important, though, was the fact that we were able to increase awareness of the illnesses while showing that they don't have to stop you from keeping active.

A big thank you to those who donated, and all those who came down to play, watch or support!



INTRODUCING RIHANA

Hi, my name is Rihana and I'm 19 years old. I'm a first year student at university, I study psychology and I have Crohn's Disease. I found out I had Crohn's in June 2019, after being hospitalised for 2 months. When I say it wasn't great, it really wasn't, I was really scared. I knew I was sick, I'd known for 2 years prior to my hospitalisation I was sick, I kept telling my GP I was sick for a really long time and nothing seemed to be working. I wasn't eating, I barely slept, I couldn't keep anything in me, I was tired and I had lost so much weight it wasn't pretty, so I had all the basic signs but it wasn't noticed despite my countless attempts. I got rushed into Croydon University Hospital and it was as if my prayers were answered because someone was finally doing something to help me after I had really been going through it for 2 years. I was immediately admitted, I was put on IV steroids, antibiotics, and biologics within the next few weeks, everything was tried to try and get me under control, and nothing worked. The doctors tried three times and nothing worked.

I just remember my heart breaking when the steroids and biologic didn't work on the final try, screaming and crying to my mum, because I knew what came next. Surgery. Practically my whole colon was removed, and I now have a stoma. It all happened so quickly because I was slowly dying and if I was left in that position any longer I wouldn't know if I'd be here today.

So after 2 months of amazing care in hospital I finally got to go home. But whilst I was there, there was really nice doctor who had UC and she told me about Crohn's & Colitis UK. I think I knew then and there that I wanted to join, I wanted to help anyone that was like me, I didn't want anyone to ever have to get to a life or death position like I was in and anything I could do to help prevent that I would. But in all honesty I also joined Crohn's & Colitis UK because I was confused, I didn't know what Crohn's was, I didn't know what a life with a stoma was either, I needed help in understanding it, and what better way to understand it than meeting people in the same position as me, talking about what I've been through and raising awareness about something that is actually so common but not many people know about.

So I recently became a volunteer at Crohn's & Colitis UK in South West London and Croydon and honestly it's one of the best decisions I've ever made, and I am so so happy to be helping and learning along the way and I plan to for a long long time.

Rihana ☺

IBD AWARENESS WEEK AT CROYDON UNIVERSITY HOSPITAL

On Wednesday 4th and Thursday 5th December from 11am to 1pm, Croydon University Hospital and Crohn's & Colitis South West London and Croydon Network held a joint IBD Awareness event. This was collaboration with Dee Braim, IBD Nurse Specialist. Dee organised the event and involved her colleagues, together with a raffle that raised £403.74. We had a stand and tables with information. Being a busy hospital we had a lot of interest from patients and visitors, from asking what is Crohn's and Colitis to talking about their health conditions. Many people also donated money as they had friends or family members who had the condition.



Dee Braim, IBD Nurse Specialist at Croydon University Hospital with a trolley full of raffle prizes!

IT'S ALL PURPLE AT FAIRFIELD SCHOOL OF BUSINESS!

Crohn's and Colitis IBD Awareness Week was a perfect opportunity for network members to spread the word about IBD.

At my workplace - Fairfield School of Business in Croydon, I sent emails to students as well as reminders on our staff (unofficial) WhatsApp group chat about the event. I also had a display of information leaflets and some freebies - e.g. bracelets in the reception area and in my office - Student Support to encourage staff and students to wear in support.

Many students were interested about Crohn's and Colitis, and told me of friends or family members who had the condition. One of the students told me she'd advertise the event on social media which was great!



Angela and colleagues support Crohn's and Colitis Awareness Week at Fairfield School of Business, Croydon - 1st-7th December 2019

WHAT'S NEXT FOR SOUTH WEST LONDON & CROYDON NETWORK?

Now we're two months into 2020 what's next on the calendar of events for our network?

We have regular activities which we aim to organise each year. These include educational talks, fundraising and awareness raising. We are aware that there are many people with Crohn's and Colitis who live in South West London, Croydon (and surrounding areas of Croydon) who don't know we exist. We want to reach out and promote what we do as much as possible, so our plans will include more collaborations or partnerships. Sharing information with the other community networks in London is vital, so do get in touch if you can help with this.

CALLING FOR VOLUNTEERS!

We always need more volunteers, as more volunteers means organising more activities which create more awareness and hopefully much-needed funds for support and research for the charity.

We are a friendly group of volunteers who have Crohn's and Colitis. Our ages range from late teens to over 60. We're from different backgrounds. We're supportive of each other and believe that what we do can make a difference. So if you live near Croydon or in South West London, please contact Volunteer Enquiries on: 01727 734475.

We look forward to meeting you!

DATES FOR YOUR DIARY

In response to the coronavirus (COVID-19) situation currently affecting the UK the charity has taken the decision to cancel all Local Network events from 16th March until at least the end of April.

Please check the website for the latest information:

www.crohnsandcolitis.org.uk/coronavirus

LOCAL FUNDRAISING

Please contact the network for more information.

OTHER LOCAL EVENTS

Talk IBD is a group for people who have IBD. Meetings are held in the Neuro Seminar Room next to John Parker Lecture Theatre, ground floor of Atkinson Morley Wing at St George's Hospital from 7.00 - 9.00pm.

Meeting dates for this year are: March 9th, 15th June, 14th September and 30th November.

For more information please contact Simon Prager on: 020 8677 0526

Email: simon.prager@gmail.com

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

CROHN'S & COLITIS UK

SOUTH WEST LONDON CROYDON NETWORK

Lead Volunteer: Angela Roll

Email: swlc@networks.crohnsandcolitis.org.uk

Website: www.crohnsandcolitis.org.uk/xxxx



Crohn's & Colitis UK South West London and Croydon Network



CrohnsColitisSL

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
- 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 Crohn's or Colitis and understands what you are going through

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.*

The South West London and Croydon 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.