

## Brighton & Sussex Network

### WELCOME BACK

Due to the pandemic and the restrictions this put on our in-person activities, it's been a while since our last newsletter and normal activities. We're though excited to announce that we are now planning a return to our activities and need your support to do this! Before that, lets catchup on what's happened over the last few years.

### NAME UPDATE

We have dropped the 'West' from our name to show we cover the whole of Sussex and are now known as **Brighton & Sussex Network**.

### 2019

During mid-November 2019, we held our big event ON THE ROAD: BRIGHTON at the Brighton Amex stadium, over 200 people attended the day and was a great success. The feedback received was very positive. You can see some of the pictures on our Facebook page <https://bit.ly/BROTR2019> On the day we received £90 in donations.

We would like to say a huge thank you to the Royal Sussex County Hospital, The Royal Alexandra Children's Hospital, Crohn's & Colitis UK staff and our Local Network volunteers without whom the event would not have been possible.

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Early November 2019 Heather & Jenny Jeffrey held a concert at the All-Saints Church, Findon Valley, Worthing. The concert raised an amazing £640, this was split between 2 charities and we received a £320 donation.

December 2019 Dorit Oliver Wolff & Steyning Grammar School raised £827.50



## 2020

January 2020, two of our volunteers (Paul and Sue) attended Head office and were shortlisted for Volunteer Awards 2019. They made it to the final 10 out of over 1000 volunteers nationally, and although they didn't win, they made it to the final 3 for the Stronger Together category.

Thank you to all of our amazing Network Volunteers, this award wouldn't have been possible without you too, so this is for all of us!



Early February 2020, everyone at Shutterly Fabulous dug deep for a Fabulous bring and buy sale. The staff raided their homes looking for donations and unwanted Christmas presents! There were cushions, clothes, books, jewellery and a whole lot more. Some staff even went the extra mile to bake cakes and biscuits to be sold.

On the day, the Shutterly Fabulous gang gave generously - as this was a cause close to everybody's hearts. We are thrilled that they raised a fabulous £205 on the day.



## 2021

May/June 2021 and the Brighton & Sussex medical School raised £74.54 at their Brighton fringe festival event.

## 2022

March 2022 and the IBD Team from St Richards Hospital, Chichester held an information evening and raffle. Around 80 people attended and an amazing £280 was raised.

April 2022 the Local Network volunteers were out in force to cheer on everybody running the Brighton marathon for Crohn's & Colitis UK. We were stationed around the half way mark, with the weather being nice it was a great day cheering, thanks to all who attended and everybody who ran the marathon. Check out our pictures on Facebook. <https://bit.ly/2022MARATHON>





## 2019 - AN ULTRA HIKER WITH CROHN'S

Sarah is one of our Local Network volunteers who has Crohn's and was diagnosed when she was 19 years old. She hikes and is inspired by the It Takes Guts campaign and this is her story:

I was 50 this year and to celebrate I decided to walk 2 Ultra 50k Walks to raise money for Crohn's & Colitis UK, and I managed to raise over £1600 in total.

The first walk on the Jurassic coast in June was brilliant, went like clockwork. The second in September on The North Downs reminded me that I suffer with Crohn's Disease.

I was camping the night before and the night after the North Downs walk. The weather was biblical at times with rain and wind. Luckily, I managed to get the tent up the night before the walk with no rain and had a good night's sleep.

Up at 4.45am to catch the bus to the start at 5.30am where I ate sandwiches and took my medication. At the start line I had a cup of tea, but I could not go to the toilet. I tried, I jogged around, and I had a second cup of tea but with no Success. This worried me as I always go for a poo in the morning. What would happen if I needed to go on the middle of the walk? Normally when I am hiking, I can find a bush, I was armed with my trowel to dig a hole, my baby wipes and my dog bag to pack out my waste, but there were hundreds of us, I was not alone as I normally am when out in the countryside.

The first stop was after 11km and I so wanted to have a poo so I could stop worrying but no, my body would not comply. At lunch time at 26km I produced a lot of wind but still nothing. The ¾ stop at 38km was much of the same. By this point I was not enjoying the walk any longer. It was not the tiredness. It was the worry about going to the toilet.

The hiker in front of me was setting a pace for me to follow and I was setting a pace for the hiker behind. Normally you would keep this steady but I kept speeding up, this is because I needed to pass wind and it was rather smelly at this point, I did not want to suffocate the person behind me. I was being erratic in my speed which was not good for the person following. Then I got cramp in my inner thigh, I could not stand up, 3 runners stopped to help me. All this time the thoughts going through my head was "Please I don't need to go to the toilet now" I could not put weight on my leg and these guys stayed with me for a good 15 minutes, holding me up, ruining their timings.

Finally, I was ready to move on, my heroes went on their way and because of the cramp I had to slow down. After 11 hours I made it to the finish line, I my dinner, drank rehydration drinks and still I had not gone to the toilet, by this time my stomach was swollen and my gas levels were worrying.

I got on the coach to take me back to the camp site, it had started to rain. We had to wait a good 20 minutes for the coach to fill up plus the 10-minute journey all while I could not release wind. I thought I was going to explode. Back at the camp site and still could not go, by this time the rain was coming down in sheets.

I got in my tent, changed and fell into a deep sleep. About 2 hours later 2 things woke me up. The cramp had returned and I really needed to go the toilet. It was raining cats and dogs. I ran/limped across the field to the toilets - for nothing to happen.



Finally, at 5am I decided to pack up, there was a gap in the torrential rain and it was only a light shower at this point. I was half way through packing up my tent when I felt that familiar rumble in my guts, I just made it across the field in time.

I did not know you could fill a portaloop up, it must have taken 10 flushes for me to empty the bowl, I am so sorry for the person who used that cubical afterwards. I do hope that being out in the fresh air helped the aroma I left.

By the time I returned to my half packed up tent, even the inner tent was soaking wet as I had had to abandon it in my rush to get to the portaloop's. I carried on packing up, left the site and was on the first train home by 7.04am.

I would do this all again. The reason I am writing this is to share my experience. When I was really ill, people who ran marathons, jump out of planes and generally managed to raise money for the charity by doing keep fit things, really wound me up as I thought I would never be able to do anything like that. Now I do that kind of keep fit stuff, the sense of achievement and raising money for the charity, will always inspire me to do it all over again. But it's not always easy.

Sarah

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## CALL TO ACTION

We are looking for volunteers to help us raise awareness, organise events, post on social media, contribute to our newsletter, fundraise and many other activities. If you are interested in finding out more, please get in touch.

Email: [bws@networks.crohnsandcolitis.org.uk](mailto:bws@networks.crohnsandcolitis.org.uk)  
or complete the online form at <https://bit.ly/BR-VOL>

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## GET INVOLVED - PATIENT PANELS

### What is a Patient Panel?

A Patient Panel is a forum for patients who use the local services to provide the hospital team with feedback and suggestions for improvements. IBD Patient Panels normally meet regularly every 3 months to discuss topics of care within the local area.

Patient panels gives the IBD service an opportunity to listen, understand and respond to the needs of the patients and careers, their perceptions and also their expectations. This allows for continuous improvement and transformation within the service. The key to these improvements is communication and understanding.

- Suggest developments and service improvements.
- Help to support the case for new resources, like a new team member.
- Help to shape ideas for redesigning services, new developments and research.
- Inform and empower other patients, families, careers and young people.
- Give the IBD team feedback on what works in the service and what could be better.

### How do I get involved or find out more info?

#### Royal Sussex County Hospital and Princess Royal Hospital

Are starting up a new Patient Panel and looking for patients to join, the first virtual meeting is scheduled for 13th June 2022 from 6.30pm to 7.30pm.

To register your interest or find out more  
Email: [brightonibdpanel@gmail.com](mailto:brightonibdpanel@gmail.com)

#### Worthing Hospital

Have an established Patient Panel and are looking for more patients to join the panel.  
The next virtual meeting is scheduled for 15th June 2022 from 7pm to 8pm.

To register your interest or find out more  
Email: [worthingibdpanel@gmail.com](mailto:worthingibdpanel@gmail.com)

## DATES FOR YOUR DIARY

### VIRTUAL SOCIALS EVENTS

Crohn's & Colitis UK are offering people the chance to chat, share experiences and potentially learn from others at a virtual social event with other people from across the UK.

Upcoming dates and registration details are here:

<https://crohnsandcolitis.org.uk/vse>

### LOCAL FUNDRAISING

Thank you to all our amazing fundraisers who have raised funds for the Local Network and national charity. Please let us know of any fundraising events in Brighton & Sussex area and we'll advertise them on Facebook, Twitter and in the newsletter.

### DONATIONS

Thanks to our local members and supporters who have given us cheques, cash collections and books of stamps to help with the running of the Local Network. Cheques for the Local Network funds should be made out to 'Crohn's & Colitis UK' and sent to Brighton & Sussex Network, Crohn's & Colitis UK, First Floor, Helios Court, 1 Bishop Square, Hatfield Business Park, Hatfield, AL10 9NE.

*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](mailto:networks@crohnsandcolitis.org.uk).*

*This will save the network valuable funds which can be used to benefit all those affected by Crohn's & Colitis.*

*The Brighton & Sussex 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

**CROHN'S & COLITIS UK**

### BRIGHTON & SUSSEX NETWORK

Lead Volunteer: Paul Webster

Email: [bws@networks.crohnsandcolitis.org.uk](mailto:bws@networks.crohnsandcolitis.org.uk)

Website: [www.crohnsandcolitis.org.uk/bws](http://www.crohnsandcolitis.org.uk/bws)



[Crohn's & Colitis UK, Brighton & Sussex Network](#)



[CrohnsColitisBR](#)

### GENERAL ENQUIRIES

Crohn's & Colitis UK

1 Bishops Square, Hatfield Business Park, AL10 9NE

[www.crohnsandcolitis.org.uk/contact](http://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

### CONTACT US BY:

**Telephone: 0300 222 5700\***

Monday to Friday - 9am to 5pm

Email: [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)

Live Chat: [www.crohnsandcolitis.org.uk/livechat](http://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.*