

## Brighton & West Sussex Network

### ON THE ROAD: BRIGHTON MAKING THE INVISIBLE VISIBLE The Amex Stadium, Brighton

Saturday 16th November 2019

Because no one can see it until we say it #ItTakesGuts

This FREE event is for anybody who lives with IBD or knows/care's for somebody with IBD. Suitable for families and individuals.

Registration starts from 9.15am  
Talks start from 10am

At this year's event we will have the following:

- Full programme of talks by various local medical professionals
- Information & advice sessions, with a chance to ask questions
- Exhibition area: Pick up the latest publications and meet staff from Crohn's & Colitis UK
- Activities to keep the whole family entertained
  - Stadium tours
- Complimentary lunch & refreshments

To secure your place you must register here  
<https://otr-brighton.eventbrite.co.uk>

This event is being organised between the Brighton & West Sussex Local Network, Crohn's & Colitis UK Young People & Families, the Royal Sussex County Hospital and The Royal Alexandra Children's Hospital

### IN THIS ISSUE

- |                               |   |
|-------------------------------|---|
| - On The Road: Brighton       | 1 |
| - IBD Standards               |   |
| <br>                          |   |
| - Donation Thanks             | 2 |
| - Brighton Marathon           |   |
| <br>                          |   |
| - What happens at our socials | 3 |
| - Prepay Prescription         |   |
| - Radar Key                   |   |
| <br>                          |   |
| - Dates for your diary        | 4 |
| - Contact Us                  |   |

**CROHN'S & COLITIS UK**  
**SUPPORTING YOU**  
**TO MANAGE YOUR**  
**CONDITION**

## IBD Standards

The IBD Standards are a framework of 59 statements, created by IBD UK that define what should be put in place to deliver high-quality healthcare for people with Crohn's and Colitis.

The IBD Standards define what should be put in place at all stages of the patient journey: pre-diagnosis, newly diagnosed, flare management, surgery, inpatient care and ongoing care, and how the IBD service should be organised to deliver this.

Full details can be found on the website:  
[IBDUK.ORG](http://IBDUK.ORG)

## Have your say about your IBD care

The first UK-wide IBD patient survey will help your local NHS service give you the best possible care. Everyone with IBD should receive safe, consistent, high-quality, personalised care, whatever their age and wherever they live in the UK.

We need your support to make this happen. Complete the IBD patient survey today.



Scan the QR code  
or visit [IBDUK.ORG](http://IBDUK.ORG)

Survey closes on  
23rd September 2019

## DONATION THANKS

December 2018 we had an awareness day at Worthing Hospital where we were informing people about Crohn's and Colitis and raising money. We joined Julia Medcalf, the IBD Nurse. Julia had organised a tombola, sweepstake and cake sale, which raised around £375. We are already planning on doing it again in the winter. If you would like to donate any small gifts for future tombolas please email [bws@networks.crohnsandcolitis.org.uk](mailto:bws@networks.crohnsandcolitis.org.uk)

February 2019 we received a £750 donation from Commercial Square Bonfire Society in memory of Miss J Kenward.

May 2019 we attended the annual Reflections Assembly at Steyning Grammar School Sixth Form, where student Olivia has been raising awareness and fundraising. She raised a total of £261.03

May 2019 the anatomy team from Brighton and Sussex Medical School held an event 'Follow your food' as part of Brighton Fringe and raised a total of £90.45

Waitrose Brighton Community Matters scheme chose us as one of their three charities for May 2019. We received a donation of £300.



July 2019 The Green Man Ale & Cider House in Worthing had its monthly quiz and we were the chosen charity for that month. We received £61.



## VOLUNTEER - CALL TO ACTION

We are looking for volunteers to help to organise events or even help with social media or the newsletter. If you would like to help us with these events or help in any other way please send us an message.

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

## BRIGHTON MARATHON 2019

This year the Brighton Marathon took place on Sunday 14th April 2019

The Local Network were out in force to cheer everybody on including 52 runners supporting Crohn's & Colitis UK.

An estimated £25,000 was raised, so a huge thank you too everybody who took part and donated.

Our cheering post was around the halfway point (mile 13) and had lots of people cheering.





## WHAT HAPPENS AT OUR SOCIALS

We meet monthly in Worthing, Hove and Haywards Heath. See last page for more details.

Our social events are relaxed events where we can talk about anything that interests us, from Crohn's and Colitis, to what we did on our holidays or local news stories.

We are here if you need us or just want to talk to like-minded people. We regularly have between 6 and 16 people turning up to each event. All meetings have toilet facilities nearby. New people are always welcome and feel free to bring a friend/partner.

If you require further info then please send us a message.

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

## PRESCRIPTION PREPAYMENT CERTIFICATE

### DID YOU KNOW YOU CAN SAVE MONEY WITH A PRESCRIPTION PREPAYMENT CERTIFICATE (PPC)?

If you know you'll have to pay for a lot of NHS prescriptions it may be cheaper to buy a prescription prepayment certificate (PPC).

A PPC covers you for all of your own NHS prescriptions, including dental prescriptions, no matter how many items you need. There are two PPC options to choose from:

- A 3-month PPC costs £29.10 and could save you money if you need more than three prescribed items in three months
- A 12-month PPC costs £104.00 and could save you money if you need more than 12 prescribed items in a year

The quickest way to buy your PPC is online <https://apps.nhsbsa.nhs.uk/ppcwebsales/>. If you prefer talking to someone, you can call the PPC order line on 0300 330 1341.

You can apply by post as well. Just pick up a form from your local GP surgery or pharmacy.

## RADAR NKS KEY

If you have a health condition or disability, finding an accessible toilet that's clean, tidy and available for you to use can be a challenge.

The National Key Scheme (NKS) offers disabled people independent access to locked public toilets around the country.

Under the scheme, special locks are installed on public disabled toilet doors to give disabled people priority access.

Local authorities have adopted the scheme and 'Radar toilets' can now be found in shopping centres, pubs, shops, bus/train stations and other locations nationwide.

Current members can request a key from the membership team [membership@crohnsandcolitis.org.uk](mailto:membership@crohnsandcolitis.org.uk) or 01727 734465. New members should get a key on sign-up.



The easiest way to keep up to date with all the latest info and events is to follow us on [Facebook](https://www.facebook.com/Crohns.Colitis.Brighton.West.Sussex) - <https://www.facebook.com/Crohns.Colitis.Brighton.West.Sussex>

**CROHN'S & COLITIS UK**  
**SUPPORTING YOU TO MANAGE YOUR CONDITION**

## DATES FOR YOUR DIARY

### SOCIAL MEETING WORTHING

First Saturday of each month @10:30am  
The Lido Café, Marine Parade, Worthing,  
BN11 3PX.

### SOCIAL MEETING HOVE

Second Thursday of each month @6:30pm  
Modelo Lounge, 143/145 Church Road,  
Hove, BN3 2AE.

(oct is 1 week later due to venue refurb  
so will be 17th oct)

### SOCIAL MEETING HAYWARDS HEATH

Second Saturday of each month @10am  
Café Elvira, Borde Hill Gardens,  
Balcolmbe Road, Haywards Heath,  
RH16 1XP.

**CROHN'S &  
COLITIS UK**

## CONTACT US

### BRIGHTON & WEST SUSSEX NETWORK

Chairperson: Paul Webster

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

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



[Crohn's & Colitis UK, Brighton & West Sussex  
Network](https://www.facebook.com/Crohn's-Colitis-UK-Brighton-West-Sussex-Network)



[@CrohnsColitisBR](https://twitter.com/CrohnsColitisBR)

### Crohn's & Colitis UK

First Floor, Helios Court, 1 Bishop Square,  
Hatfield Business Park, Hatfield, AL10 9NE

[enquiries@crohnsandcolitis.org.uk](mailto:enquiries@crohnsandcolitis.org.uk)  
[www.crohnsandcolitis.org.uk](http://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\*

Monday, Tuesday, Wednesday and Friday - 9 am to 5 pm  
Thursday - 9 am to 1 pm

Email: [info@crohnsandcolitis.org.uk](mailto: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.*

## 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 & West Sussex 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 & West 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, 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 Inflammatory Bowel Disease.*

*The Brighton & West 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.*