CROHN'S&COLITISUK

NEWSLETTER

Spring 2023

Issue 4

South Essex Network

WELCOME!

Welcome to the Spring 2023 edition of the Crohn's & Colitis UK South Essex Network newsletter

Hello!

Well, here we all are at the beginning of another year (how did that happen!), and I hope, as always, that this newsletter finds you all happy and extremely healthy

I am delighted to say that our South Essex Network coffee mornings have continued in earnest post covid, and it has been a delight to meet so many new faces at our monthly meet-ups! In this edition I give you some more information about the monthly meetings and where and when we hold them.

There is also some helpful information about the Disney 'Easy Access' card, which is available to Crohn's and Colitis patients of all ages; with details relating to the benefits the card gives you, and how they can be obtained.

We also have a heartwarming article written by one of our committee members, Nicky, explaining the arrangements that were made following the death of her treasured mother-in-law, Lin, to honour her wish to help Crohn's & Colitis UK.

Additionally, as part of our 'meet the team' section, we have a lovely article written by one of our newest

committee members, Tracey, outlining her own IBD journey, and her experiences since joining the South Essex team.

Finally, I'm delighted to announce that Stuart Hill, Lead Pharmacist of Gastroenterology at Queens Hospital, and one of our new Network medical advisors, will be hosting an IBD medication presentation for us all, in June at Hornchurch Library. More info about this great event, including how to reserve free tickets, can be found on page 3!

Wishing you all a very happy and healthy 2023

Best wishes

Diane Costin

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QUEEN'S & KING GEORGE HOSPITALS HELPLINE DETAILS

We have been asked by the Queen's Hospital IBD team to remind patients that the IBD helpline number is an answerphone service, and all messages left will be handled as soon as possible. They also advise that, although there may be a slight delay in returning calls at present, they ask that all patients who require assistance do please call and leave a message, including their name, date of birth and hospital/NHS number, along with their concern or query, and a member of the team will respond as quickly as possible. The IBD helpline contact numbers for both hospitals are below:

Queen's Hospital - 01708 435347

King George Hospital - 0208 970 8161

(3) MONTHLY COFFEE MORNINGS (3)



We are thrilled that our monthly coffee mornings have continued to run successfully since restarting after the covid pandemic last May. We have seen lots of new faces come along to our gatherings at the Hornchurch Fire Station, and are always happy to welcome anybody who would like to pop along for a chat, to ask advice, or just to meet other Crohn's and Colitis patients.



Just a reminder that our coffee mornings are not only here for Crohn's and Colitis patients, but also for family members and friends too! We often have husbands, wives, mums and friends come along, both with patients and on their own, so please don't think twice about attending if you have ever thought about it. We really are a lovely bunch \bigcirc

FREE TICKETS AVAILABLE NOW!

IBD MEDICATION PRESENTATION BY STUART HILL LEAD PHARMACIST OF GASTROENTEROLOGY AT QUEENS HOSPITAL

SATURDAY 17TH JUNE

10.30AM - 11.30AM

HORNCHURCH LIBRARY MEETING ROOM

1ST FLOOR

44 NORTH STREET, HORNCHURCH RM11 1TB

We are absolutely delighted to announce that Stuart Hill, Lead Pharmacist, Gastroenterology at Queens Hospital has kindly offered to host a special IBD medication presentation for us all, at Hornchurch Library in June.

Stuart's talk will cover the various IBD medications that are used for both Crohn's and Colitis patients, and will conclude with a question-and-answer section, to allow for any specific questions patients may have for him

Refreshments will be provided and there is lift access to the 1st Floor of the library

Tickets to this event are free, and can be reserved by registering

Online: https://ccuk-se-education.eventbrite.co.uk

Phone: 01727 734 475

Friends and family are very welcome to attend.

We look forward to seeing lots of you there.

MEET THE TEAM



Each issue we introduce you to a different member of our South Essex committee, highlighting their own personal story with Crohn's or Colitis, and their journey since joining the South Essex Network. This month it is the turn of one of our newest members, Tracey

My name is Tracey Claire and I was diagnosed with Ulcerative Colitis when I was 28. I have been living with Ulcerative Colitis for 18 years, however I only joined the Crohn's & Colitis UK volunteer group recently.

As my journey continues with Ulcerative Colitis, I have started to be more open with my condition and the best thing I have done was join this South Essex committee and online networks. I have found it very helpful, as we can all talk freely about what we are all going through. I would encourage anyone to join a group or network as it really does help to share

your feelings and stories, and to feel that you are not alone.

I am generally healthy and my last flare was 5 years ago. I have now realised that stress is the main factor in my flares. As well as volunteering I work as a civil servant.



VIRTUAL SOCIAL EVENTS

Crohn's & Colitis UK offer people affected by Crohn's and Colitis the opportunity to join a virtual social event with others across the UK. These events are a chance to chat, share experiences and learn from each other. Each event may have a specific topic but the overall discussion will be led by those attending the session.

Anyone who is over 18 and is affected by Crohn's or Colitis can attend these events. Family, friends and colleagues are more than welcome to attend.

Registration opens 3 weeks before each event and you can attend any event, regardless of where in the UK you live

More information, including links to upcoming events can be found at www.crohnsandcolitis.org.uk/vse

IN MEMORIAM - LINDA BARTLETT



My name is Nicky and I am on the committee of the South Essex Network of Crohn's & Colitis UK. I was asked to write this article regarding my mother-in-law, and although it is written with a heavy heart, the outcome is of benefit to others, so that is what has inspired me.

In May 2022 my family suffered a great loss when my mother-in-law passed away after a battle with cancer. Linda Bartlett was a fighter, and throughout her later life she had suffered with some major ailments and illnesses. She was a quiet lady who didn't often voice her wishes, but once she had sadly passed I was speaking to my father-in-law and he told me that Linda had always been very supportive of the work I do to raise funds for Crohn's & Colitis UK, and she was quite insistent that she didn't want a huge selection of flowers at her funeral (although she was a keen gardener) but, instead, any money donated was to go to a charity; and her designated cause was Crohn's & Colitis UK.

I was humbled when I found out, and although it was such a difficult time, I thought that somewhere some good could finally come from an awful situation. Like many families we had had to go through the arrangements, and we stated in her order of service that donations were going to be both collected at the end of the service and also online, so people could choose the best option that suited them.

Through the kind generosity of Linda's family and friends nearly £300 was collected in donations, and along with the South Essex Network committee, I will be able to have a say as to where the funds are allocated, and which areas we would like to help; for example, research.

As hard as it is to think of losing a loved one, if the worst ever happens, I would like to ask you, if this is something that you feel is right for you, to also consider donations to Crohn's & Colitis UK, either through a will, memory donation or as a replacement to funeral flowers, to help to both transform lives today, whilst also providing for a world free from Crohn's and Colitis in the future.

END OF THE AMAZONSMILE SCHEME

For anybody who has been supporting Crohn's & Colitis UK, through the use of the AmazonSmile program, it has been noted that Amazon have recently wound down the scheme, as of early 2023.

Although Crohn's & Colitis UK will no longer be able to benefit from purchases made by supporters, Amazon advise that the charity will still be given a one-off donation to end the scheme, which will be equal to the equivalent of what was earnt by the charity during a 6 month period of 2022.

As of February 2023, the total amount raised for Crohn's & Colitis UK through the AmazonSmile program was £46,661.30

NEW SOUTH ESSEX NETWORK MEDICAL ADVISORS

We are thrilled to announce that Dr Sinha, Consultant Gastroenterologist and Stuart Hill, Lead Pharmacist at Queen's Hospital have both accepted the role of Local Network Medical Advisor to the Crohn's & Colitis UK South Essex Network.

We really appreciate their commitment to our Network and look forward to working with them both in the future, to help support our members, and raise awareness of Crohn's and Colitis within the wider community

COLLECTING USED STAMPS TO RAISE MONEY!

Two of our members, Diane H and Nicky, coordinate and collect used postage stamps to raise money for Crohn's & Colitis UK.

If anybody would like to help us to raise funds this way, we would be very happy to receive any stamp donations you may be able to provide us with ©

For more information, please email us at our network email address se@networks.crohnsandcolitis.org.uk, and one of our team members will get back to you asap

NEWSLETTER DISTRIBUTION

If you have received this newsletter by post, but 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 of those affected by Crohn's and Colitis.

DISNEYLAND PARIS EASY ACCESS CARDS



For anybody planning a trip to Disneyland Paris, but who may also be worrying about navigating the long queues that often form at many of the park's rides, we have great news! Disney now provide 'Easy Access' cards for all sufferers of recognized long term chronic diseases, including Crohn's and Ulcerative Colitis. These cards provide simplified (but not immediate) access to their attractions; meaning the days of standing in line for hours on end, worrying about where the nearest toilet may be, are gone.



To obtain an Easy Access card, all you need is a signed, stamped and dated letter from your GP or consultant (dated within 3 months of travel), indicating which chronic disease you have, and the number it is assigned on the Disney Long Term Chronic Diseases list. Then, when you arrive at Disney, you can either take your letter to the concierge desk or reception at your hotel, or to one of the

ticket offices at the entrance to either of the parks, and there you will be provided with an Easy Access photocard and appointment book.

To use your card, you simply visit a member of staff at the main entrance of any attraction, who will check your photocard, and then write a timeslot in your book, indicating when you can come back to the ride, through a separate entrance, bypassing any queues. You can then make the next reservation at another ride after the 1st is over, and so on for the rest of your stay.

Some main points:

- Easy Access card holders can be accompanied by to up 4 people on all rides, who can also enter the ride through the dedicated entrance with the cardholder
- Cards are valid for the entire length of your stay
- The assigned number for Crohn's and Ulcerative Colitis, which needs to be stated on the doctor's letter is '24'

Further details relating to Easy Access Cards, the full list of accepted long term chronic diseases, and additional information regarding accessibility at Disneyland Paris, can all be found at https://www.disneylandparis.com/en-gb/guest-services/accessibility-at-disneylandparis/

YOUR NEWS

We would love to hear from anybody who would like to share their own personal Crohn's or Colitis story with us, so that we may include these accounts in future issues of the newsletter, to inspire and inform fellow sufferers and supporters.

Also, we would be delighted to hear about any fundraising events that you may have taken part in in the past, or plan to in the future, so that we may also highlight these amazing fundraising feats in future issues.

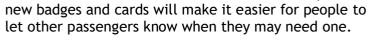
To provide any stories or fundraising news, please do get in touch through our network email address se@networks.crohnsandcolitis.org.uk

We look forward to hearing from you!

PLEASE OFFER ME A SEAT

For anybody who finds it difficult to stand on public transport, you can now request a 'Please offer me a seat' badge and card from TFL.

Devised as a response to the fact that many of their customers, particularly disabled people and those with invisible impairments, conditions or illnesses, often find it difficult to find a seat, TFL hope their





'Please offer me a seat' packs can be sent to any address in the Greater London area, and to South East England. You can order one by filling out the form at https://tfl.gov.uk/transport-accessibility/please-offer-me-a-seat or calling TfL Customer Services on 0343 222 1234.

DATES FOR YOUR DIARY

COFFEE MORNINGS

Community Room Hornchurch Fire Station 42 North Street Hornchurch RM11 1SH

(the entrance is on the left hand side of the fire station, alongside Hornchurch library)

Our informal coffee mornings are held on the 2nd Saturday of every month 10.30am - 12.00 midday

IBD MEDICATION PRESENTATION by STUART HILL

Meeting Room 1st Floor Hornchurch Library 44 North Street Hornchurch RM11 1TB

Saturday 17th June 2023 10.30am -11.30am

QUEEN'S & KING GEORGE HOSPITAL

IBD Helpline:

Queen's Hospital - 01708 435347

King George Hospital - 0208 970 8161

IBD email address:

bhrut.ibdhelp@nhs.net

Blood test booking:

www.swiftqueue.co.uk/bhr.php

CONTACT US

CROHN'S & COLITIS UK

SOUTH ESSEX NETWORK

Lead Volunteer: Dave Gregory

Website: www.crohnsandcolitis.org.uk/se Email: se@networks.crohnsandcolitis.org.uk/se



@CrohnsColitisSE



@crohnscolitisse



Crohn's and Colitis UK - South Essex Group

GENERAL ENQUIRIES

Crohn's & Colitis UK

1 Bishops Square, Hatfield Business Park, AL10 9NE www.crohnsandcolitis.org.uk/contact

Volunteer Enquires: 01727 734 475

Crohn's & Colitis UK - a registered charity in England & Wales (1117148) and Scotland (SC038632). Registered as a company limited by guarantee in England & Wales (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

Live Chat: https://crohnsandcolitis.org.uk/info-support/support-for-you/helpline-service

*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 Essex 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.