

WELCOME!

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

Hello!

Well, unbelievably here we all are, already in the 2nd half of 2023 and, as always, I hope that this newsletter finds you all happy and extremely healthy 😊

Firstly, I must start this introduction by thanking Stuart Hill, Lead Pharmacist for Gastroenterology at Queen's Hospital for giving up one of his Saturday mornings in June, to provide a wonderful IBD medication presentation to us all at Hornchurch library. In this newsletter, not only do we have a full run-down of Stuart's really engaging and informative talk, but we also have another article written by the Queen's & King George Hospitals team, introducing the nursing and pharmaceutical staff, and outlining what their roles are, and where they are based.

As part of our 'meet the team' section, we also have a great article written by one of our newest committee members, Pete, whose wife Tracey has Ulcerative Colitis. Pete explains his own IBD journey, as the husband of an IBD patient, and how he now feels about his decision to join the South Essex team.

Finally, I'm delighted to announce that we have another great event planned

for the South Essex Network. This September we are holding a special screening of the wonderful play 'Room 5', which was written by Crohn's sufferer, and South Essex committee member, Diane Harman. This comedy, which explores the trials and tribulations of living with IBD, was originally performed at the Queens Theatre back in 2013, however, it is now being re-shown on its 10th anniversary; so that it can be enjoyed again by a whole new group of people. More info about this fantastic event, including how to reserve free tickets, can be found on pages 4 and 5!

I hope to see you all in September at the Room 5 screening!

Best wishes

Diane Costin

South Essex Network

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QUEEN'S & KING GEORGE HOSPITALS HELPLINE DETAILS

A reminder for patients, that the IBD helpline number for Queen's and King George Hospitals, is an answerphone service, and all messages left will be handled as soon as possible.

All patients who require assistance should 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 (normally within 24-48 hours). The IBD helpline contact numbers for both hospitals are below:

Queen's Hospital - 01708 435347

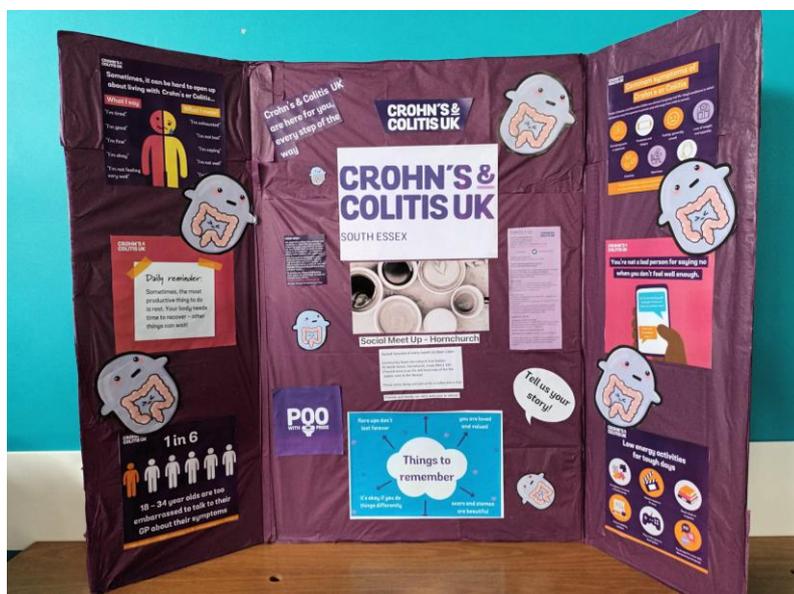
King George Hospital - 0208 970 8161

😊 MONTHLY COFFEE MORNINGS 😊

Once again, we are delighted that our monthly coffee mornings at Hornchurch Fire Station continue to be such a success. We have seen lots of new faces come along to our gatherings again over the last few months, and are always happy to welcome anybody who would like to pop along for a chat, to ask advice, or to meet other Crohn's and Colitis patients.



Just a reminder that our coffee mornings are not only available for 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 😊



IBD MEDICATIONS PRESENTATION - STUART HILL



We were extremely lucky when Stuart Hill, Lead Pharmacist, Gastroenterology at Queen's Hospital, offered to host an IBD Medications presentation for us at Hornchurch library in June. It was a fantastic presentation, and we can't thank Stuart, and Vidya Morgan, Lead IBD CNS, who also came along to speak to patients, enough for giving up their time to come and meet everyone.

The presentation, which was held on a Saturday morning, was really well attended, with lots of Crohn's and Colitis patients of all ages, and their families, present.

Stuart gave a really informative talk, outlining the different IBD medications that are used by the Queen's and King George Hospitals team; explaining the varying reasons for using each of them, and the possible side effects of some of these medications. He also gave some really reassuring advice regarding the risks of taking particular IBD medications, and helped to put these slim risks into context, when comparing them to other everyday activities.

Both Stuart and Vidya were happy to chat with attendees, both during the interval and after the presentation had finished, and I know everyone really appreciated their advice, and the reassurance that they gave patients with regard to their own personal IBD journeys.



ROOM 5 10TH ANNIVERSARY SCREENING - IN MEMORY OF LAURA JANE FAVA

Room 5 is a comedy stage play, written to help raise awareness of living with Inflammatory Bowel Disease. It was written by South Essex Network volunteer, Diane Harman, (a Crohn's sufferer herself) and was originally performed at The Queen's Theatre, Hornchurch in September 2013.

As the subject of the bowels is a particularly embarrassing topic, Diane believed that by bringing the idea to the stage, it was the ideal platform to not only educate, but also change public opinion. She therefore based the script on her own experience of living with IBD, and whilst the subject is not funny, she tried to make it capable of presentation to an audience, by introducing humour; whilst still conveying the difficulties and despair associated with these illnesses. She felt that without the humour she could not get her message across, and although it could be viewed as insensitive to some, it was her belief that being a sufferer herself allowed her "poetic licence" to do so!

Her intention was to create an evening of comedy entertainment but with a **SERIOUS MESSAGE**.

Ten years on, the South Essex Network are now taking the opportunity to screen the performance again, for anybody that may not have had the opportunity to see it the first time around. More information, and details of how free tickets to this performance can be reserved, can be found on page 5.

However, this screening will be tinged with sadness, as one of the original cast members, Laura Jane Fava, has sadly passed away since the original performance in 2013.



The mother of 3 children and originally from the East End of London, Laura studied drama at secondary school and trained at Anna Scher Acting School for 2 years. She had been involved in Amateur Dramatics in Havering since 2001, where she enjoyed various roles from farce and comedy to Shakespeare, whereupon she won 2 'Brent' Awards in conjunction with The Brentwood Theatre for 'Best Supporting Actress' in 'An Experiment with an Air Pump' and 'The Prime of Miss Jean Brody'

Laura sadly passed away, after a long battle with multiple brain tumours, on 20th November 2021, aged just 53. As per her wishes, she died in the home that she loved, surrounded by family and love. Laura was so brave and so strong since her first neurosurgery in 2012, until the end of her life. Laura's family were her life, her driving force, her love. Her children were, she said "Her World".

Laura's play ended and the curtains closed for the final time, but there will be a standing ovation for all the wonderful memories that will now forever live in the hearts of her loved ones. Her loss left her family bereft, but they are so proud of her. Laura loved acting and being on stage, and they hope that seeing Laura in this 10-year anniversary screening of Room 5 will bring joy and another standing ovation.

FREE TICKETS AVAILABLE NOW!

ROOM 5 - A COMEDY WITH A SERIOUS MESSAGE

BY DIANE HARMAN

10TH ANNIVERSARY SCREENING

TUESDAY 12TH SEPTEMBER 2023

DOORS OPEN 6.30PM - 7.15PM START

THE SPACE, NEW CITY COLLEGE - ARDLEIGH GREEN CAMPUS

ARDLEIGH GREEN ROAD, HORNCHURCH RM11 2LL

REFRESHMENTS AVAILABLE

FREE ON-SITE PARKING

We are absolutely delighted to announce that there will be a special 10th Anniversary screening of 'Room 5'; a play written by Crohn's sufferer, and South Essex Committee member, Diane Harman.

Synopsis:

A group of people who all suffer with different forms of bowel disease find themselves in Room 5. Due to the embarrassing nature of their illnesses, this is not something they would normally discuss, but one by one they each find themselves sharing their own experiences of living with these diseases, and their quest to find a diagnosis and cure. It soon becomes evident that they each have a story to tell, along with some shocking revelations!

With toilet humour in abundance prepare to both "Laugh Out Loud" and empathise with their situation!

Originally performed at The Queen's Theatre, Hornchurch in September 2013, ten years on the South Essex Network are now taking the opportunity to screen the performance again, for anybody who may not have had the opportunity to see it the first time around.

For a small taster of this fabulous show, the YouTube promo video can be viewed at:

https://www.youtube.com/watch?v=dS_4skoK810

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

Online: <https://ccuk-room5.eventbrite.co.uk>

Phone: 01727 734 475

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, Pete

Hello my name is Peter Bowers. I am 56 years old, and do not have Ulcerative Colitis or Crohn's disease myself; but I have supported friends and family who live with these conditions. My wife Tracey has Ulcerative Colitis and we are both volunteers with the South Essex Network.

It is hard and frustrating to see loved ones suffering from these conditions, as there is nothing you can do to help them, apart from providing comfort and support.

I have experienced the triggers that have caused Tracey's flare-ups, with stress being her main contributor, and she can be in bed for several days when this happens. During a flare-up she suffers with fatigue, loss of appetite, excruciating abdominal pain, and once it is over, with her

immune system being so low, she then suffers with shingles.

We have both found it beneficial to join the committee of the South Essex Network, and to attend the coffee mornings on every 2nd Saturday of every month. The coffee mornings provide an ideal opportunity for everyone attending to seek advice, ask any questions they may have, or just meet up for a chat.

I look forward to continuing to volunteer, and helping wherever I can; providing support to the rest of the committee.

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.

YOUR QUEEN'S & KING GEORGE HOSPITALS IBD TEAM!

For all Queen's and King George Hospital patients, we have a great introduction to the IBD nursing and pharmaceutical staff, that are available at both sites to help you. Some faces you may already know, but here is the current team, with a brief outline from the staff, of all of their main roles and locations 😊



Nursing team, clockwise from back left

Juliet - very experienced member of the team, who has worked at the Trust for many years, providing oversight of most of the service provided from KGH

Zena - primarily based within the infusion clinic at Barking Hospital, administering the likes of infliximab, vedolizumab and ustekinumab infusions

Vidya - our lead IBD nurse

Farhaan - works cross site between Queen's and King George Hospitals, and currently oversees the homecare subcutaneous medications

Christine - currently working elsewhere in the Trust on secondment, and we miss her!

Lynn - recently retired after many years at the Trust, but still doing occasional shifts, including at the infusion clinic

Heide - also working cross site and overseeing homecare, as per Farhaan

These roles are obviously very fluid, with all of the team working across all of the service, covering all aspects as and when required. It's very busy, so everyone is flexible and patients may speak to any of the nursing team when calling the helpline.

The IBD pharmacy team

Stuart - Lead Pharmacist, Gastroenterology

Stuart runs the clinics, for monitoring immunomodulators (azathioprine, mercaptopurine, methotrexate, ciclosporin), or arranging 'shared care' with GPs to manage this where appropriate. He also assists the nursing team, with advice on medications, prescribing where required, and manages the pharmacy side of homecare prescriptions (subcutaneous biologics and the newer JAK inhibitors), managing the medication related guidelines and protocols, etc.

Becky - Hepatology Pharmacist

Becky covers the gastro ward Sunrise A, so may meet some Crohn's and Colitis patients, and understands IBD. She also offers Stuart some support in IBD where required.

NHS PRESCRIPTION PREPAYMENT CERTIFICATE

Although Crohn's & Colitis UK campaign for everyone with Crohn's and Colitis to be exempt from prescription charges, unfortunately the government have no plans at present to change the current exemptions list.

However, according to the NHS, a Prescription Prepayment Certificate (PPC) could save you money if you need more than 3 prescription items in 3 months, or 11 items in 11 months.

The current prescription charge in England is £9.65 per item, however a PPC costs £31.25 for 3 months or £111.60 for 12 months

HOW MUCH YOU COULD SAVE

No. of prescribed medicines required each month	Saving with a 3 month PCC	Saving with a 12 month PCC
2	More than £26	£120
3	More than £55	More than £235
4	More than £84	More than £351

A PPC can be purchased either in person at some pharmacies, or online at

<https://www.nhs.uk/help-nhs-prescription-costs/nhs-prescription-prepayment-certificate-ppc>

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

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

ROOM 5 10th ANNIVERSARY SCREENING

The Space
New City College - Ardleigh Green
Campus
Ardleigh Green Road
Hornchurch RM11 1TB

Tuesday 12th September 2023
Doors open 6.30pm - 7.15pm start

QUEEN'S & KING GEORGE HOSPITALS

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



@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.

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