

WELCOME!

Welcome to the Spring 2022 edition of the Crohn's & Colitis UK South Essex Network newsletter

Hello!

Well, what a two years! I think it is fair to say, none of us were expecting that!

I'd just like to begin this newsletter by saying how much I hope everyone has navigated this pandemic without loss or heartache, and that all of our readers and their families are currently fit and healthy going into 2022. These past few years have been really tough for everyone, especially those who were shielding patients (including my own son), and my sincere wish is that everyone has managed to journey through this unusual time without any illness (both mental or physical).

This third issue of our South Essex newsletter was actually ready to be distributed right back in the Spring of 2020, just before the covid virus hit, and it has sat patiently, waiting to be re-visited ever since the pandemic started. So, now that we are able to arrange distribution again, I have decided to keep some of its original contents intact, rather than lose the information forever, whilst also adding some new, more up-to-date content, to reflect the new times that we find ourselves in. So, this issue is slightly longer than normal - I hope you enjoy it 😊

In this issue we have lots of information on some of the

different ways in which, as a team, we raise funds for Crohn's & Colitis UK, and our South Essex Network; with additional information on how you too can help us with our fundraising efforts. However, there have obviously been some changes to the get-togethers and fundraising possibilities for both Crohn's & Colitis UK and our own Network since the start of the pandemic, and some of these changes are also outlined in this issue too.

There is also a fantastic article written by one of our members, Anthea, exploring the painful problem of injections and what methods can be used when administering them at home, to try to eliminate any issues, along with details relating to the coronavirus guidance and advice currently being provided by Crohn's & Colitis UK on their website, alongside handy links directing you to where to find it.

We also have, as part of our 'meet the team' section, my own personal story this issue, which explores a slightly different perspective; that of a parent of a child with IBD, and how volunteering with my Local Network has helped me enormously since my son's diagnosis 4½ years ago.

Finally, I'd just like to close

South Essex Network

IN THIS ISSUE

Changes to our usual coffee mornings	2
Crohn's & Colitis UK - coronavirus support	3
Asda & Waitrose Community schemes	4
Amazon Smile	5
Collecting used stamps	6
Meet the team	6
Christmas donation	7
Charity cake sale	
PayPal charity donations	
Injections	8
Please offer me a seat	9
Dates for your diary	10

by firstly thanking you all for reading this issue's extra-long introduction (I won't ramble on for quite so long in future issues I promise!), and to remind everyone that if anybody would like to contribute articles (including your own experiences of the covid pandemic as a Crohn's or Colitis patient), or have any ideas or suggestions for topics or information you would like to be included in future issues, then we would love to hear from you! Our contact details are always found on the last page of every newsletter.

Wishing you all a very happy and healthy 2022

Best wishes

Diane Costin

CHANGES TO OUR USUAL COFFEE MORNINGS



Going back 2 years, to pre-pandemic times, our Coffee Mornings at Tescos, Roneo Corner, Romford were always a great chance for people to get together; bringing new visitors to our Network from around the South Essex and East London region, alongside our regular members.

However, with the introduction of the covid lockdowns, and the vulnerable situation many of our members still find themselves in, in-person coffee mornings have now not taken place in our region since February 2020 😞



cont



.... So, to enable our organizing team to continue to get together, we have been holding virtual gatherings online each month instead, which has been a great success, and has allowed team members to come along when free, to discuss their own personal experiences with covid and just re-connect after such a long time apart. These meetings are very relaxed and informal, and allow the team to discuss anything and everything with each other, which is especially important when meeting in person is still not a reality.

Getting together face to face to have a chat and a laugh, and to meet new visitors, who would either like to join the team, or who just want to pop along for more information or support, is something our team has really missed. We are therefore delighted to announce that in person coffee mornings will re-commence on Saturday 14th May 2022, from 10.30am to 12 midday at a new venue - the Community Room at Hornchurch Fire Station. More information can be found in the 'Dates for your Diary' section on the last page. Everyone is very welcome and we really look forward to seeing you!

CROHN'S & COLITIS UK

CROHN'S & COLITIS UK - CORONAVIRUS INFORMATION

Crohn's & Colitis UK have a wealth of information and advice on their website regarding Coronavirus, patient risk levels and the Covid-19 vaccination programme. Information can be found by visiting www.crohnsandcolitis.org.uk/coronavirus

Included on their site is information and articles on everything 'covid', including advice on what to do if you catch coronavirus, the latest government guidance for people who are considered clinically extremely vulnerable, or at high risk and a really useful article entitled 'changes to coronavirus restrictions: what this means for you'.

There is also excellent guidance about the different risk levels and what medications and medical conditions would put you into which clinical risk group; with up-to date advice on the guidelines you should still follow, depending on your risk level, to keep safe.

“

The best thing you can do is to keep taking your medicines and get vaccinated. ”

Prof Charlie Lees, Gastroenterologist

ASDA & WAITROSE COMMUNITY SCHEMES

In December 2019, our Network Lead Volunteer Dave Gregory, visited the Romford Asda store, where he was presented with a cheque for £200 by their Community Colleague Liz, as a donation from their in-store green token scheme.

We were also kindly put forward again for the scheme earlier this year, (with online voting this time around, rather than the use of in-store green tokens, due to the pandemic) and we were delighted to receive another cheque for £200 in recognition of this year's participation.

We would like to take this opportunity to thank Liz and the Romford store for their continued support and kind donations.

Back in 2020, we were also accepted as a chosen charity for the Upminster Waitrose 'Community Matters' scheme. Due to the pandemic, the normal green 'voting' tokens were also no longer distributed to customers, and instead the monthly £1,000 pot was equally distributed between the month's three nominees, with a £333 cheque being gratefully received by the Network in July 2020. Thank you Upminster Waitrose 😊



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!



RAISE MONEY WHILE YOU SHOP 😊

Did you know that you can raise money for Crohn's & Colitis UK every time you shop with Amazon?

AmazonSmile is a website operated by Amazon, with the same products, prices and shopping features as Amazon.co.uk, with the only difference being that every time you shop on AmazonSmile, Amazon will donate 0.5% of the net purchase price of any eligible purchase (excluding VAT, returns and shipping fees) to the chosen charity of your choice.

All you have to do is visit smile.amazon.co.uk, nominate your chosen charity as Crohn's & Colitis UK, then shop as normal!

You can even keep track of how much money your purchases have raised for Crohn's & Colitis UK at any time, along with the total amount that has been raised for the charity nationwide to date.

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

JOIN US 😊

We are always looking for new volunteers for our friendly team and would love to hear from anybody who may be interested in helping within the South Essex Network.

If you think this may be something for you, please fill in the Crohn's & Colitis UK enquiry form to learn more www.crohnsandcolitis.org.uk/volunteering-enquiry-form

MEET THE TEAM

Each issue we will introduce you to a different member of our South Essex Network Committee, highlighting their personal story with Crohn's or Colitis, and the skills and abilities they bring to the team. This month, it is the turn of Diane 😊

Hello! My name is Diane Costin, I am 47 years old and live with my family in Upminster. My son was diagnosed with moderately severe Pancolitis just over 4½ years ago now, at the end of his first year of A'levels, and just after his 17th birthday.

As I'm sure some of you may already know, it is the hardest, scariest, loneliest, most worrying thing in the world to be told your child has been diagnosed with a chronic condition, such as Crohn's or Colitis. I know, personally, that when my son first became ill, I felt a great sense of helplessness, seeing my son go through, and coping with, everything that comes with these diseases, whilst not being able to take the illness away from him.

As a consequence, I decided quite early on to do all I could to raise money for, and raise awareness of, Crohn's & Colitis UK, and on a whim one day I decided to sign up to take part in the Thames Path Ultra Challenge, walking 100km (60 miles) non-stop over 36 hours, to raise money for Crohn's & Colitis UK (for anybody thinking of taking part in this challenge in the future - honestly give it a go - it is really, really tough, but if I can do it, trust me anybody can!)

I also decided to visit a South Essex coffee morning one Saturday, and I am so glad that I did! I was unsure before visiting if I would be the only parent there, but I need not have worried, as there are a range of other family members who come along to meetings, and this has been a great help to me; being able to speak to other parents and discuss with them how their children are also living with Crohn's or Colitis.

I would really like to encourage any other parents who may read this, and may also feel the emotions I went through when first learning about my son's diagnosis, to come along to a coffee morning when they re-start, or to drop us an email to find out about all that being involved with the network has to offer, you won't regret it!

(I am over the moon to say that my son has been in remission for over three years now, graduated from university last year with a 1st Class BSc Computer Science degree, and is now working as a Software Engineer for BNY Mellon; enjoying all that life has to offer 😊)



DID YOU KNOW?

For anybody who would like to help out at events within our network, without the commitment of joining the committee, Crohn's & Colitis UK has created a new role, specifically designed for these volunteers. The role, which is called 'Local Network Event volunteer' would not require attendance at regular meetings, but would allow volunteers to register with Crohn's & Colitis UK to help the Network at events on an ad-hoc basis.

More information about the new role can be found at -

www.crohnsandcolitis.org.uk/get-involved/volunteer/volunteering-roles/local-networks

To make an enquiry about volunteering please complete the following form on the Crohn's & Colitis website

www.crohnsandcolitis.org.uk/volunteer/volunteering-enquiry-form

ST MARY'S HARE PARK SCHOOL & NURSERY CHRISTMAS DONATION

One of our members, Nicky, and her husband both work at St Mary's Hare Park School and Nursery, which is a small independent Catholic school in Gidea Park, and each year the fundraising coordinator there arranges various events, and asks staff to nominate a chosen charity that they would like to support for the event

At Christmas time of last year, as an alternative to sending Christmas cards to each other, each member of staff at the school instead gave a donation to charity and wrote in its place a Christmas note, which was displayed on a 2D Christmas tree in the school staff room. For this event the supported charity was chosen by Nicky's husband; and Crohn's & Colitis UK was his choice! As a consequence, a brilliant £79.50 donation was received last month from the school, and all of the Network would like to thank Nicky, her husband, and all of their co-workers for their wonderful support 😊



CHRISTMAS FAIR - CAKE SALES



During the first two years of the pandemic, Diane C's husband, made and sold cakes at an annual Christmas market, to raise funds for Crohn's & Colitis UK. Stuart's carrot cake, cupcakes and lemon drizzle cake were all a big hit with the customers, and he raised a fantastic £162.50 in combined sales over both events.

MAKING CHARITY DONATIONS THROUGH PAYPAL

Did you know that you can make donations to chosen charities, including Crohn's & Colitis UK, through Paypal? Payments can be made either as a one-off donation, or you can even set a particular charity as your 'favourite charity' which allows you to 'conveniently support the charity every time you check out and at other donation opportunities'.

For more information about the scheme, and/or to set Crohn's & Colitis UK as your favourite charity visit www.paypal.com/uk/fundraiser/charity/3191094 for more details

INJECTIONS

We have a really useful and informative report from one of our members, Anthea Shaw, exploring the troublesome issue of injections, and what methods can be used to try to alleviate the pain and bruising that sometimes occurs when administering them at home

Hands up everyone who has had an injection! Most of us have had a flu jab or, as we know in these COVID times, this has meant two, three or sometimes four vaccines, and for some of you this will be the first time you remember having one (the old BCG at school notwithstanding).



Qualified medical staff give these injections, and many of us have repeating hospital visits. Sometimes the stay is for IV fluids (another needle), often with multiple blood tests (more needles) - then if we have surgery, we are sent home with anti-sickness and/or anti-clotting injections to do ourselves, or a family member has to do them for us. For many you will already be familiar with injections, administering them at home daily, weekly, and monthly.

Well, they are not pleasant, are they? And they are often painful, leave bruises or bleed. Lets not also forget that some people have a fear of needles, or are not confident that they should or can do this themselves.

I had the same issue, and having Crohn's Disease for over 20 years I have seen my fair share of needles; from the injections you make up yourself, to the more modern ones that now come as a 'Pen injection', where you can't actually see the needle. Methotrexate, where I was given the needles separately, then the drug, Adalimumab (Humira,) followed by Ustekinumab Sterela, where for both the medication is delivered encased as a pen injection.

The majority of these injections are Subcutaneous (SC) injections, which means that they are injected into the innermost layer of the skin. This, theoretically means that the risk of pain, bruising, bleeding and occasionally infection should be greatly reduced. This assumes of course we are doing this properly.



A nurse showing me how to give myself injections many years ago, told me that I should always gently pinch the skin before injecting. The important thing is to pick an area where muscle is not near the surface; your tummy or upper thigh are common favourites.

Now this instruction is widely given and demonstrated, and I can attest to how effective it is - I don't even know I have just given myself an injection (and yes that includes the pen injection).

Another types of injection which is common, but rarely administered at home due to the risk of bubbles developing in the syringe (the COVID vaccine is one of these), is an Intra Muscular, which is a whole different ball game.

The knack here is to ensure you can 'pinch' the muscle, or just apply directly. Again, these should not hurt if given correctly, as the needles are very thin - I had 4 vaccines and only one stung 😊 cont



I did a bit of research and discovered that there are another 9 or 10 types of injections, used for multiple reasons; from steroid injections for joints (intra-articular) to those given during surgery, which we are completely unaware of.

I am not saying an injection will never be uncomfortable, but if you are one of the many of us suffering from Crohn's Disease or Ulcerative Colitis who have been told that you will need to inject at home, I just wanted to let you know that it is ok, and hopefully reassure you that you can manage this and administer injections in a way that you feel happy with.

Of course you will also always have the option of getting a professional to do this for you, which I know some people choose to do.

PLEASE OFFER ME A SEAT

Did you know that, 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 new badges and cards will make it easier for people to let other passengers know when they may need one.



'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.

CROHN'S & COLITIS UK

VOLUNTEER RECRUITMENT

We are delighted to announce that volunteer recruitment for local networks has now re-started, following the covid pandemic. For more information, or to apply to join your Local Network, please either complete the online enquiry form at www.crohnsandcolitis.org.uk/volunteering-enquiry-form, or contact the volunteering team at volunteering@crohnsandcolitis.org.uk

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, next to the library)

10.30am - 12.00 Midday

Informal coffee mornings will be held on the 2nd Saturday of every month, re-starting on Saturday 14th May 2022.

AWARENESS STANDS

**Queens Hospital Main Foyer
Romford**

Until the current covid situation improves we will naturally not be holding any IBD awareness stands at Queens Hospital.

We will notify you as soon as we are able to re-start these events

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

SOUTH ESSEX NETWORK

Lead Volunteer: Dave Gregory

Website: www.crohnsandcolitis.org.uk/se

Email: se@networks.crohnsandcolitis.org.uk



Crohn's and
Colitis UK –
South Essex
Group



@CrohnsColitisUK

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: www.crohnsandcolitis.org.uk/helpline

**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.