

Our latest edition of the Mid-Essex newsletter, read on to find out what we have planned for you this year!

Mid-Essex Network

HELLO THERE!

By Samantha Merrett

In this newsletter you will find out about fundraising and local events your Mid Essex Crohn's & Colitis UK team have planned for 2020. These vary from fundraising events, medical meetings and education days.

We have an article about the Volunteer Awards Day and a wonderful piece of artwork by Jodi, an 18 year old Crohn's disease sufferer.

We would love to hear from our reader and members alike; if you have a story to share, celebrations to announce or if you have any fundraising you would love to tell us about, please do let us know.

Happy reading everyone!

A CAUSE FOR ART...

By Cherrise Chand

Hi there! My name is Jodi and I was diagnosed 2.5 years ago, aged 15, with Crohn's disease. This came as a massive shock as I had always been so healthy! Once I had managed to 'get my head round it', I decided that I wanted to do something to raise awareness of this awful, invisible disease!

Attention!

In response to the coronavirus situation currently affecting the UK, the charity has decided to cancel all Local Network events from 16th March until at least the end of April.

So in my first year at College studying for my Level 3 in Art and Design, I decided to dedicate my final project on my Crohn's disease.

I developed my art work through the following process: I screen printed a bowel onto a hospital gown, and then hand painted ulcers onto it; I super imposed a photo of my face (from when I had been in a full flare up) onto a photo of me wearing the gown; I added words through 'photo shop' that described how I felt when I was very ill. The photo was taken in the medical room at College in black and white so I stood out!

The aim of my art work is to raise awareness of this disease by bringing the 'inside' 'out', so everyone could get an insight into what Crohn's can do to you!

The main message that I want to get across is that not every disability is visible, and people are going through their own struggles, even if you can't see it!

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I'm pleased to say that I gained a 'Distinction' for my art work, but above all I am proud that I have created a piece of art that highlights the struggles the people affected by Crohn's and Colitis live with!



VOLUNTEER AWARDS DAY 2020



By Christine Critchell

On Thursday 30th January 2020 both Sally and myself were invited to the Volunteer Awards day at Crohn's & Colitis UK's Head Office in Hatfield. We learnt that they have 1,000 volunteers and out of those nominated for the awards they whittled it down to the final 10! So as you can imagine, we felt privileged to be there!

We met up with the other 8 volunteers, some we knew and some we didn't, so it was nice to hear of others stories in different areas from as far afield as Brighton, Yorkshire and Scotland. Mark explained the itinerary for the day, we also heard from some of the management team and we participated in different workshops where we looked at ease of using different websites pertaining to Crohn's and Colitis.

After lunch, we had an interesting workshop on employment or working rights, where we looked at various scenarios and publications from other charities to see which we preferred for both content and layout.

We then had a fun session with props! We were split into groups

and asked to grab a prop (a Crohn's & Colitis UK tee shirt, a purple wig, sombrero etc.) that would help us think of something memorable we had done for the charity.

Then to the awards ceremony, we were very surprised to see the room full of the staff at Head Office to watch us being presented with our certificates and awards. We were split into categories where I came runner up in the 'Across the Board' volunteer for my work on the Parent to Parent helpline over the last 6 years and helping on our local network committee and also helping the Publications team to update some of their booklets, particularly the one for parents.



Sally was a very well deserved winner of her category, Trailblazer, when a new feedback process was announced, Sally requested some forms before they had even been launched and promptly returned with feedback that has helped Head Office iron out the kinks. Another example of Sally being ahead of her game was her approach in contacting GPs. Improving contact and access to GPs and their patients was something that the volunteering team had wanted to do for a long time and Sally independently sourced a full list of contacts throughout the UK which she provided to Head Office along with what could be done with the list to assist network volunteers.

"Sally's proactive approach really helps shape priorities, it's incredibly supportive and an asset to Networks across the country. Well done Sally!"

Everyone nominated had given so much to the charity in different ways, including a lady called Lorraine who goes into Head Office every week to help with duties such as packing up parcels of tee shirts etc. A young trainee Doctor, James, who also volunteers as a first responder for the London ambulance service and Angus who started the prestigious Prestonfield Spring Ball in Edinburgh where huge proceeds are split between Crohn's & Colitis UK and Edinburgh Children's Hospital charity.

Then after a slice of celebratory cake, we all had our photos taken and said our goodbyes before the journey home.

Thanks to Mark and the team for a great day!

WHAT IS THE PATIENT VOICES NETWORK?

The primary purpose of the Crohn's & Colitis UK Patient Voices Network is to discuss ways local IBD services could be improved. The aim is not to take direct action to improve services, it should be seen as a brainstorm session to make specific plans for improvements that might be able to be made in the future.

The members work closely with the patient engagement team as they network is trusted to give honest, open feedback on service provisions in their local area. Of course, part of this work is to also report back to Head Office on how they do things and what more service users might like to see.

The network is formed of patients, parents and carers.

PATIENT PANEL?

An IBD Patient Panel is a group of people with Crohn's or Colitis, who use the same services in a specific local area and by talking to and working alongside their IBD Healthcare team, will bring a patient perspective that helps improve services for all.

The aim of the patient panel is to ensure that the voice of patients receiving the service are at the heart of the service improvement.

So, you might be wondering, what could I offer? Well...

- Provide feedback on current service provision based on your own personal experiences
- Offer a sounding board for proposals put forward by their IBD healthcare team

- Bring the patient's perspective to the service
- Be proactive in offering suggestions for future service improvements
- Improve clinical practice through the sharing of experiences

Improvement can be achieved through partnership between patients and healthcare professionals, respect in allowing all patients to voice their opinion, team work to make changes happen and leadership to allow patients to lead with their experiences and perspective.

An average panel has 20 members ensuring good representation at each meeting and the meetings are typically held every 6 to 8 weeks when needed.

If you are interested in getting involved or you would like to find out more, get in touch with

patientinv@crohnsandcolitis.org.uk or call 01727 734466.



PATIENT GROUPS SOUTHEND

On the 3rd Wednesday of every month, a meeting takes place in the endoscopy department on the Mezzanine floor in Southend Hospital.

The sessions are aimed at both newly diagnosed and experienced patients under the care of Southend IBD team.

The sessions are an opportunity to share knowledge with each other and provide help and guidance based on past experiences.

Unfortunately, due to the ongoing coronavirus situation these meetings have been cancelled for the foreseeable future but please do check the Mid Essex Facebook page and website for up to date information

www.crohnsandcolitis.org.uk/me

DATES FOR YOUR DIARY

MEDICAL MEETINGS

POSTPONED (until a later date)

Sat 28th March 2020

Harlow Hospital

Venue: Harlow Fire Station, Fourth Avenue, Harlow, Essex, CM20 1DU

Sat 6th June 2020

Southend Hospital

Venue: Education Centre, Southend Hospital SS0 0RY

7th November 2020

Broomfield Hospital

Venue: Medical Academic Unit, Bromfield Hospital, Chelmsford CM1 7ET

SOCIAL EVENTS

Quiz Night

(TBC) September 2020

Venue: Beaulieu Community Centre, Beaulieu Square, Centenary Way, Chelmsford CM1 6AU

World IBD Day

Tuesday 19 May 2020

Wednesday 20 May 2020

More details on activities to follow

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.

The Mid-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.

CONTACT US

CROHN'S & COLITIS UK

Mid-Essex NETWORK

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Group Telephone: 0300 222 5700

Email: me@networks.crohnsandcolitis.org.uk

Website: www.crohnsandcolitis.org.uk/me



@CrohnsColitisME

Facebook.com/ME CCUK

GENERAL ENQUIRIES

Crohn's & Colitis UK

1 Bishops Square, Hatfield Business Park, AL10 9NE

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
- put you in touch with a trained support volunteer who has a personal experience of Crohn's or Colitis and understands what you are going through

CONTACT US BY:

Telephone: 0300 222 5700*

Monday to Friday - 9am to 5pm

Email: helpline@crohnsandcolitis.org.uk

Live Chat: 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.*