CROHN'S & COLITIS UK

FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER

NEWSLETTER

Mid-Essex Network

Our latest edition of the Mid-Essex magazine, and our biggest most action packed yet!

ACTION PACKED NEWSLETTER

By Sarah-Jayne Smith

Welcome to the latest edition of your Mid-Essex Crohn's & Colitis UK Newsletter.

WHAT IS IN STORE

In this letter you will find out about fundraising and local events your Mid-Essex Crohn's & Colitis UK team have been attending and organizing in the local area. From charity events, medical meetings and education days to training and awareness.

We have two wonderful articles written my Organising Team member Fran who recently took on the 3 peaks challenge and writes a splendid report on the Southend Medical meeting earlier this year. Fran has her own blog where you can read lots more from her and personal battle and journey living with the disease. (see page 6)

We would love to hear from our readers and members; if you have stories to share, celebrations to announce and fundraising you have completed please let us know. If you would like to be featured in an upcoming Newsletter or just share a little of your personal story and IBD experience positively please get in touch so we can share with all our members and in turn help us to create a local network celebrating all our members.

Happy reading everyone!

IN THIS ISSUE

WORLD IBD DAY

To promote IBD awareness this year the organising team once more took to Chelmsford High Street Wearing the Crohn's & Colitis UK tee shirts we handed out flyers to people passing in the street and had the Information sheets and booklets available in the Saracens Head along with refreshments and cakes
It was great to hear people that had heard of Crohn's & Colitis UK and to be able to reach out to those that wanted a bit more information and support
Having handed out 200 flyers and chatted with everyone that joined us we certainly feel that we had a successful day. We were able to promote the national charity and our own network and events too.

VOLUNTEER TRAINING DAY

On the 21st September some our organising team members went along to a training day. Here is Team member Sally’s write up of the experience. -

By Sally Newman-Russell

Two of the organising team went to a training day in London It was a great event meeting the Volunteer Development Officers from Head Office and networking with other groups too. The organising team took the opportunity to learn from the other groups and share the good things our network does with them.

‘IT WAS REALLY ENERGISING FOR THE ORGANISING TEAM TO MEET OTHER TEAMS’

It was really energising for the Organising Team to meet other teams. We picked up some ideas that you will find in upcoming events in 2020 as well as simple fundraising ideas and awareness raising suggestions.

NEW TEAM MEMBER

A little information about our new volunteer organising team member Samantha….

‘My name is Samantha and I joined the Mid Essex Network earlier this year. I am not a sufferer of an Inflammatory Bowel Disease and my knowledge of the illnesses before joining the group was limited. I was apprehensive at first, I knew that most of those in the group either had the disease themselves or knew someone who suffered. I was worried that my lack of knowledge and experience would impact my ability to get involved and help. Looking back now, I don't know why I was so worried! From my first meeting I was made to feel included and my ideas and point of view were welcomed. I volunteered because the work of the charity interested me and I was eager to develop my understanding of the difficulties that some people can face when living which such life-altering diseases. I work during the week so I can only offer a limited amount of time but they were very open and flexible to allow me to volunteer around my commitments. I have enjoyed my time with the group so far and I am excited to see what the future holds!

FRAN'S THREE PEAK CHALLENGE.

A MEMOIR OF MY JOURNEY

By Fran

'It was June 28th and I was one of the insane people meeting at Fort William train station at 8am to take part in the Three Peak Challenge, climbing the highest mountains across England, Scotland and Wales. We were all checked in and given a number, which we were now known as – very SAS: Who Dares Wins. Then Steve, one of the leaders, gave a speech and it was at that point I started really wondering what the hell I'd let myself in for. I have an invisible illness, am I completely stupid? It sounded utterly petrifying and it was. No amount of training can prepare you mentally and physically for what was ahead.

Ben Nevis, the tallest mountain in the UK at 1,345m, was first. The leader explained the first hour will be the hardest then you'd find your pace. He wasn't kidding. In that hour I had a constant battle with that negative voice inside my head and it was winning. My face felt like it was on fire as blood rushed around my body and I was struggling to breathe. I felt like I was actually going to die right there and then. I passed people sitting on some rocks and felt a pang of jealousy as we were told it would make it harder if we stopped. I felt like he was lying to us.
The path was built from thick man-made rocks, so you had to concentrate and find flat and shorter stones to walk on. The bigger they were, the harder it was on your legs. Once that hour was up, I managed my breathing and I was used to the ache.

Karen, a lady from Wales who had completed the London Marathon and had only done a half marathon the weekend before, turned into my guardian angel. Her friend had stormed ahead so she was pulling me through, and I did the same for her. She'd reach in Burt the backpack and pass me my water and gave me peanut butter to suck out of a pouch. I spoke words of encouragement when she was struggling. She declared this was a lot harder than the marathon. We reached a mountain leader named Ice who asked my name then said, "You're gonna be trouble, you're the vocal one" I laughed, I clearly found my voice again.

> 'I WALKED BACK TO THE COACH WITH A BIG SMILE'

I struggled once again when there was more of an incline, thanks to my lower back pain – one of my Crohn's side affect. We stopped at each turn to regroup and the leader asked if I was okay. I told him I had Crohn's. "Wow! Bloody well done you! That's even more fantastic you're doing this." He was right, it bloody was.

We reached the summit, but cloud blocked any view. One picture later and we were pacing back down. I thought it would be easier going back but it was hard for different reasons. As we were against the clock, we walked at a speed and you had to concentrate harder on certain sections because of hundreds of stones were in place of a path - death trap, one slight slip the wrong way and…
So many almost lost their footing, like a girl named Tara. She was sitting on the ground with a sprained ankle, crying because she was also raising money for a charity and now knew she had to spend the rest of the time sitting in the coach while we all finished the challenge.

The weather had turned ugly. The thunder made such a noise as it bolted through the sky, so much so that it felt too close for comfort, then the heavens opened. The rocky path became slippery and I fell.

"Are you okay?" I heard above my head. I was but the guide wasn't having any of it and told everyone else to carry on while he waited with me then walked beside me to the end. "Well done! You did it in 5 hours and 26 minutes," one of the staff explained as I climbed over the fence back to the car park. I walked back to the coach with a big smile.

We didn't reach Scarfell Pike until nightfall. We got off the minibus, put our backpacks on and topped up our water bottles. Muscles ached and most of us had just woken up but we needed to be alert instantly. After a headcount, we started following the path up and it wasn't as rocky as Ben Nevis but this one I was the most nervous about. Steve had told us how hard it was. Yes, Scafell Pike was the smallest of all three mountains, but it was by far the most challenging. My lower back had started to once again play up because of the incline at the bottom of Scafell Pike. Soon the gap between me and everyone else was getting wider.

"Is that Fran?" Adam, one of the leaders asked when I said something.

"Yes. I'm the last one aren't I?"

"What was that? Sorry I didn't hear."

But I couldn't repeat it. I was already crying and was trying to catch my breath. Adam tried to comfort me and told me about a man who'd climbed lots of mountains but knew when to listen to his body and turn back. We got to the river and this was the point of no return. It was carry on and complete no matter what, or wait with Steve and go back down with him. I looked ahead and there was the vertical staircase he'd told us about. The torches were lighting the way, shining just how steep the staircase was. I knew my back wouldn't have been able to hack it. Karen pulled back with me, she very sweetly said, "Look, we did Ben Nevis together and we will go on to do Snowdon." We sat on a rock and waited half an hour to see if anyone else would pull out. I was disappointed but I knew I had Crohn's Disease and I had to listen to my body now more than I ever had. The way back was pitch black and completely silent apart from our footsteps and voices. Steve asked us to stop for a minute. "Listen," he said and the silence was breath-taking. We made our way across the field as bats flew over our heads and back to the 'sick' minibus where we explained to those there why we were back, then I rested my head on my backpack I've named Burt and slowly fell asleep. I was woken by the sound of the driver shutting the door. I sat up and head torches were flashing outside the van. Once the first group got back we were given porridge made with water, drenched in honey and topped with cranberries. I ate mine talking to Atara, aka Wonder Woman, who'd smashed Ben Nevis and now Scarfell Pike. She said this one was her favourite as she'd completed a lot of training on stairs at Box Hill in Surrey and 5-10k runs 3 times a week. But everyone else said it was the worst. Liz was as pale as a ghost and Louise said it virtually killed her.

'WE HAD JUST 4 HOURS TO COMPLETE SNOWDON'

From the Lake District, we travelled across to Wales to reach Snowdon, at around 9am, five hours behind schedule because of injuries and delays so now we had just four hours to complete Snowdon. And I was determined to do just that.

The first half hour was a steep road leading up then it flattened out. My back was hurting me and once again as I saw others hike past me, but because this was the last mountain, everyone was a lot slower and quieter. I was telling myself just to put one foot in front of the other as that's all it takes. I did it. The hardest part was over and the view was stunning. I was almost halfway, talking to Louise when another leader explained that because the group was running so behind we will not reach the summit and the other leader won't be able to get everyone else to it on his own, while he is at the back with us. We had no choice but to turn back.

"I can see the people in front. I can run up to them and walk with them?" I protested.

"No, you'll be shattered."

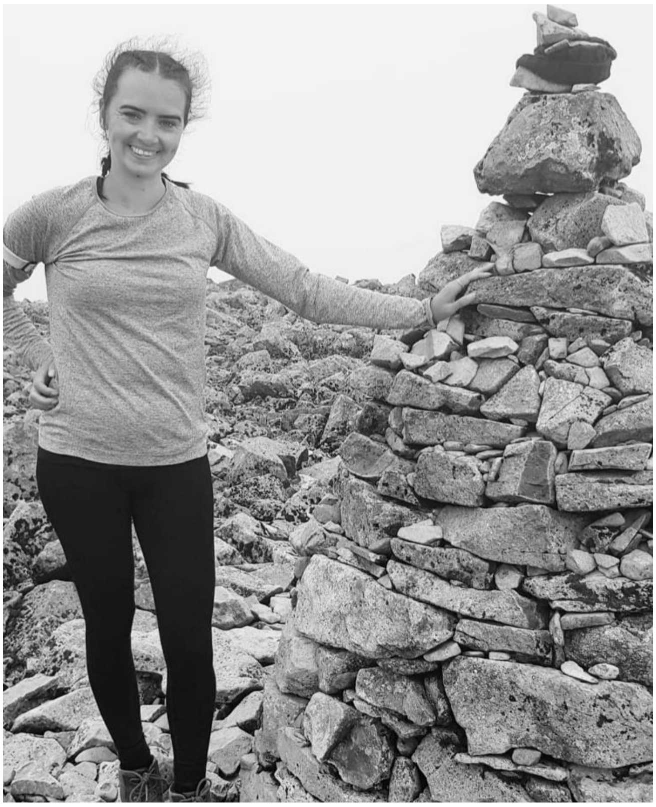
"But I don't want to go back. I can complete this one."

There was no other way but to follow the path back to the minibus. I broke down and the tears fell down my cheeks for as long as that path lasted and more. I hadn't completed the challenge; I'd climbed one mountain but I hadn't signed up to just complete one. I accepted the fact that I didn't do Scafell Pike, but I just couldn't seem to accept Snowdon when I knew I could've done it. After three missed calls, I finally answered the phone to my younger sister. "You have not failed Fran, why do you think that? You're so hard on yourself!"

‘I'M SO PROUD OF MYSELF FOR TRYING SOMETHING I SAID I'D DO.’

It took me days, maybe weeks, to begin to see that I hadn't failed. The Three Peak Challenge is HARD, actually, that's an understatement because I think it's very underestimated. I went into it blind, I wanted to give hope to those first diagnosed with Crohn's Disease, raise money for Crohn's and Colitis UK and after having been through a difficult time, I wanted it to be a personal achievement for me too. I imagined standing at the top of a mountain and finally letting go of everything that's made me cry over the last 10 months. It didn't happen. But it has made me realise a few things.

I believe I have the courage to go and do things, abroad, here or wherever, on my own and be just fine. I know I'm a social person who speaks to new people easily. I know I don't quit easily. So, even though I didn't complete the Three Peak Challenge, I did climb the highest mountain in the UK, hiking above the clouds and I bloody well tried and fought for those with a chronic illness. I now realise sometimes it's not all about reaching the summit, it's about the journey and lessons you learn along the way. I haven't failed in this, or any other thing in my life because I tried and learnt something, so how can that be classed as failing? My family welcomed me home with banners and flowers because they knew I'd done something extraordinary. But your very worst enemy will always be yourself and I was when I was walking down Snowdon in floods of tears. But now I can finally say I'M SO PROUD OF MYSELF for trying something I said I'd do.’ – Fran Flack.



READ MORE FROM FRAN

Fran has a personal blog which douments her journey of having Crohn's disease. To read more visit her blog website at https://underthespotlight1.wordpress.com

QUIZ TIME

A review of the amazing Quiz night had at Beaulieu Community Centre, Chelmsford.

by Sarah-Jayne Smith

We gathered with our bring your own snacks and drinks in the Community Centre, tables filled with teams of friends and family all there to support the charity and have a great and competitive evening.
The space was brilliant and the atmosphere lively. The quiz masters were super; providing a range of questions and themes, adding humour and competition along the way. The event raised over £300 for the Mid-Essex Network and was a brilliant way to bring our members together and raise awareness of the diseases. There was of course always going to be one winning team, and despite my teams excellent attitude and frankly genius answers, it wasn't to be us. We were beaten…by the winners (and a few other teams might I add). The winning team pictured below left with their very luxurious Cadbury Easter Eggs and, let's face it, the satisfaction of being the winners! It was the first time we had held a quiz night, but so successful and fun we will absolutely be doing it again.

Save the date for our next Quiz night on 25th April 2020!

HOSPITAL TALK: LET'S TAKE CONTROL OF CROHNS AND COLITIS

ORGANISING TEAM MEMBER FRAN CAPTURES THE INFORMATION AND ESSENCE OF OUR MID-ESSEX NETWORK MEDICAL MEETING AT SOUTHEND HOSPITAL.

By Fran Flack

80 people poured into a tiny room, located in Southend Hospital's education centre. Volunteers served coffee, tea and sugary treats and another was selling raffle tickets. Then we all made our way down the hall and got comfy in the lecture theatre.

Dr Ioannis, one of the hospital's gastro consultants, stepped up and started introducing inflammatory bowel diseases, both Crohn's Disease and Colitis.

"I'll start by asking questions. How much time did it take from symptoms to diagnosis of your disease? How many of you had a diagnosis within 6 months of symptoms?" he asked. A few raised were hands.

"How many of you did it take more than a year?" I raised my hand and this time there were more hands in the air.

"How many of you have missed social activities?" Almost all the hands went up.

There was laughter as everyone agreed that they'd rather a stool test than a colonoscopy.

> "DO YOU THINK IF YOU'RE NOT GETTING SYMPTOMS THEN YOU HAVE CONTROL OF THE DISEASE? NO? OKAY BECAUSE SYMPTOM-FREE DOESN'T MEAN DISEASE-FREE."

"Now let's talk about one of our patients."

Peppa Pig is 25 years old. She's just finished university and has started a new job when she first experienced abdominal pain, bloating and diarrhoea. She visited the GP, who told her not to worry, the tests were normal so she probably had IBS, due to stress. She started bleeding and visited the doctor again. She was put on escitalopram. This was followed by a colonoscopy, a final diagnosis of Colitis and course of steroids. 2 months later, Peppa made an urgent trip to A&E and was once again put on steroids for 3 days via an IV drip and discharged with a plan to start biologics. She once again flared up and after seeing the gastro consultant was put on steroids then started a new treatment. in the 9 months from symptoms to finding a drug that would help, Peppa had lost 15kg, her job and had started anti-depressants.

I used to deny this, but, especially in a flare, Crohn's and Colitis affects so many parts of your life; from functioning at work or school, personal relationships, financially (we still have to pay for our medications) and causing anxiety and depression.

If you don't know much about it, you may think that it's a lot about poo… but there are many additional symptoms; weight loss, rectal abscess, fissure, ulcers, fever, sweats, blood, skin rash, red eyes, kidney stones, arthritis.

Dr Ioannis then showed pictures of what the two diseases look like as "many people don't know what they have. If you don't have symptoms, the inflammation is still there."

Colitis affects the colon, while Crohn's Disease (normally in the small and large intestine) can affect the whole digestive system anywhere from the month to the butt, it's also associated with more complications.

"So, what is our target?" he said. "To bring patients back to their normal symptoms and maintain the remission. Steroids are very good medication to make you feel better so you can go back to work or school but in the long term, they are associated with serve side effects; hypotension, diabetes, osteoporosis. This is why we have the medical treatments to maintain the remission and there are more coming," he reassured us.

What treatments you receive depends on the individual; the frequency of flares, symptoms and severity, response to previous medication, risk factors and extent of disease. He explained that the aim for them is to find the right treatment for someone in the early stages of inflammation. He said, "we need the patients to tell us exactly how the disease is. No one knows their body like you. This is where we are heading now, the patients taking responsibility for their disease. We need to know how often you're going to the toilet, what it's like and how the pain is, then we have a baseline to where we are starting from." That's how we can take control of the disease, while the doctors can educate us with those appointments and talks like this.

EVENTUALLY, HE SAID, WE WILL BE ABLE TO DO THE STOOL AND BLOOD TEST AT HOME AND LET THE HOSPITAL KNOW THE RESULTS. GREAT IDEA, I THOUGHT.

"What are the long-term complications of inflammation?" someone asked. "Cancer. Patients with Crohn's or Colitis are 3-4 times more likely to develop cancer in the future and the risk factor for that is the presence of inflammation and the severity." Err, what!! That's not worrying at all, I whispered.

"8 to 10 years after your disease diagnosis you should enter a cancer surveyors programme. You'll need to have colonoscopies, depending on specific risk factors, every year, 3 years or 5 years to minimise the risk." "And who will organise that?" he was asked. "When you come to our clinic appointment we should be advising that. If not, tell us."

Next up was Susan, an IBD nurse. She told us not to call – once the team had 80 messages to listen to. Now they had an email address with rapid response thanks to Chloe, "She's amazing!" someone shouted out followed by a round of applause. In the email, they need to know your full name, hospital number and/or date of birth, diagnosis, symptoms (usually the last 24 hours), pain, medications you're currently taking, allergies and questions. "If it's an emergency go to A&E," Susan insisted.

"In future, we will have a new nurse starting, better communication and the phone apps, Care4Today and MyIBDCARE."

Then it was the Consultant Colorectal Surgeon, Michael

Dworkin. Surgery could be either urgent, within days or planned and only happens when medical drugs aren't working. With a more complex disease like Crohn's, 3/4 of patients need a form of operation, from a stricture (a part of the narrowed bowel is widened to cure ulcers - avoiding removing the bowel) to treating an abscess.

"That was my surgeon," a man sitting next to me had said. He had Colitis and an ileostomy fitted a year before the talk. He explained it gave him a better quality of life.

"The bags are very secure, and you can drain them without taking them off. They're not as bad as people fear. It's just a different way of evacuation and when it's associated with good wellbeing it's a much better option than being tied to the toilet and going 20 times a day in pain."

Afterwards, we all made our way back to the refreshments and each discussed how we felt about what we'd heard. The Crohn's and Colitis UK Mid Essex Network raised £252 altogether and every single person left feeling more educated and hopeful about their disease.

>TO FIND OUT ABOUT OUR NEXT MEDICAL MEETINGS PLEASE SEE OUR UPCOMING DATES ON THE LAST PAGE.

GENEROUS DONATION

Mid-Essex Volunteer team member Kirsty's employer, Thomas Miller, recently donated an amazing £1000 to the group. We are so grateful and thrilled. This will go towards funds for more accu-vein machines for more local hospitals.

DATES FOR YOUR DIARY

MEDICAL MEETING

Date: 2nd November 2019
Time: 2pm
Venue: Medical Academic Unit, Broomfield Hospital. CM1 7ET
Speakers: Patient advocate and medical professional with pediatric view point.
Also: tea and cake and general chitchat!

UPCOMING MEDICAL MEETINGS

Please keep an eye out for 2020 dates, which hope to include medical meetings at Broomfield Hospital, Southend Hospital and also brand new for 2020, Harlow Hospital.

Please check our social media, website and newsletters for the latest dates and information.

FAMILY QUIZ NIGHT

Date: Sat 25th April 2020
Time: TBC
Venue: Beaulieu Park Community Centre

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 ~~groups@crohnsandcolitis.org.uk~~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.

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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*
Mon, Tue, Wed and Fri - 9 am to 5 pm
Thu - 9 am to 1 pm

Email: 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*

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