CROHN'S & COLITIS UK
DURHAM & WEARSIDE

NEWSLETTER

February 2020
Issue 97

Happy New Year to all our members! Here is your latest update and news from your local network ...

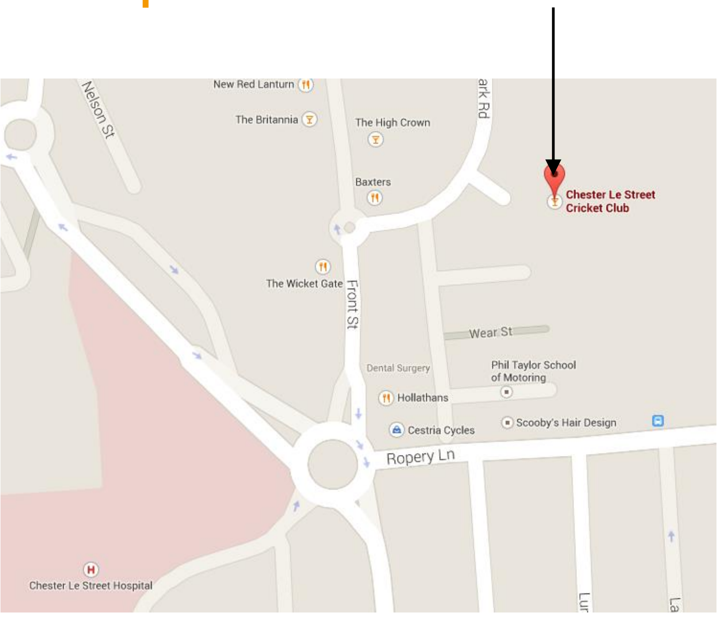
In this issue

Next Meeting - *Durham and Wearside*

Saturday 29th February 2020

At Chester le Street Cricket Club, Ropery Lane, DH3 3PF

2pm till 4pm



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@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

Our Guest Speaker will be Dr John Painter, Consultant Gastroenterologist, from Sunderland Royal

Dates for your diary

2020 Network Meetings

Saturday 16th May, 2-4pm

Saturday 26th September, 2-4pm

Saturday 5th December, 2-4pm

KEEP AN EYE ON OUR FACEBOOK PAGE FOR DETAILS OF SPEAKERS AND VENUES

Walkit

Join with other local members to Walk or Volunteer at this fabulous annual event at Leazes Park in Newcastle. Full details,including how to sign up, at https://www.crohnsandcolitis.org.uk/get-involved/walk-it

NEWS

To mark **Crohn's & Colitis UK Awareness Week** in early December we were asked to help our local IBD nurses with a stand at University Hospital of North Durham. Emma on our organising team rose to the challenge, and here she is (centre) with her **tombola** which was located in the Outpatients Reception area. The stand was visited by many staff and visitors and raised significant funds for Crohn's & Colitis UK. We hope this will become an annual event and if you'd like to get involved next year just let a member of the organising team know.

Mug Shots

Every now and then the Network likes to provide direct support to our local hospitals to help with supporting patients and raising awareness of our network. After asking what they would like, the hospitals in Durham and Sunderland asked for mugs, which we donated in December. As luck would have it (!), two of the first users of the new mugs were members of our own organising team. John, who chairs the group is pictured here in the Sunderland Royal, and Emma (see next page) is pictured at Durham Hosptial. We've been told that the mugs are being really well received. We're hoping to make some more donations in the year ahead.

SPOTLIGHT ON THE ORGANISING TEAM

In each newsletter we throw the spotlight on a member of our Organising Team. This time it's Emma's turn. We asked her some questions about how she manages with Crohn's Disease ...

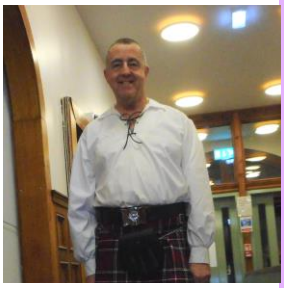
When and how were you first diagnosed?
I was diagnosed in May 2016 (the date never leaves you!) aged 23 years old and after symptoms for the previous 2 years. My partner and I were buying our first home and my symptoms became worse. I went to the doctors who said it was IBS due to my age and stress. Six weeks after moving my health deteriorated quickly, I lost 2.5 stone in weight, and when I ate anything I would be soon running to the toilet. My family urged me to go back to the doctors which lead to being admitted to hospital where there were various tests and scans and a colonoscopy until it was confirmed as Crohns.

How did you find out about CCUK and how are you involved?
It was when I was in hospital, the IBD nurses gave me a 'newly diagnosed with IBD pack' and the leaflets from CCUK were the most helpful. We started to read up on diet to various medication options on their website. I stumbled onto the events page and found the Durham and Wearside group was meeting that coming Saturday. I attended my first meeting on my own, then with my family. I remember noticing that there were a variety of ages of people with IBD, I wasn't the only 'young person', there were children younger than me who were attending with their families. It wasn't long before John (Lead Volunteer) asked me if I wanted to become involved in the charity. I noticed that there were not many young people in my age group, so I thought I could encourage people to come along and put them at ease as walking through the door for the first time was one of the hardest things I did but I needed to do it that first time on my own. I also decided that I would do a craft table to attract families with young children to help entertain them while we had speakers or presentations. IBD effects everyone regardless of age, I didn't want any age group to feel as though they couldn't attend meetings.

What treatments and surgeries have you received?
When I was diagnosed I found out that because I had been misdiagnosed for 2 years my Crohn's was all the way through my digestive system. The consultant said that if I was 20 years older he would have removed a large amount of my bowel as that was the worst area, however at this stage he wanted to try and manage the flare with medication first. I was put on Humira injections which is Adalimumab. Although it controlled my Crohn's the side effects were at times unbearable. My partner and I wanting to start a family and since the side effects of the injections were so bad my consultant agreed to change my medication to Mercaptopurine (Azathioprine). After the birth of my little boy my IBD nurse realised that those tablets weren't having the effect they should and that I needed stronger medication, so I went back onto the Humira injections. In Sept 2019 I noticed I was losing weight and wasn't eating much - my body was in a flare. In Dec 2019 I became seriously ill with a stomach bug and was admitted to hospital, and ended up having emergency surgery of a right hemicolectomy. I am now in the recovery process and my ongoing medication will be reviewed shortly.

How do you feel about it all now?
Having IBD does not stop me from doing anything with my life, the year I was diagnosed I achieved a promotion at work. The year I was pregnant I was told my body might not be able to carry my baby, however my baby was born healthy and only 4 weeks early rather than 16 weeks early.
When I was first diagnosed I hated Crohn's and I hated IBD. Some days I still do, the days when I'm suffering from exhaustion and I can't lift my son or walk up the stairs. However I have grown to accept that I will always have Crohn's and that's okay. I can't change it and I can't remove it out of my body, therefore I have to grow with it. I have the strongest family/friends around me who keep me physically and mentally strong, they're my biggest supporters. I decided to become a volunteer as I go through life everyday with Crohn's, and I wouldn't want anyone to go through what I do without having the opportunity of having more support. At the Crohn's & Colitis Durham & Wearside network all the members that attend support each other as we listen and share advice on living with IBD. We all take each day as it comes and understand the ups and downs of this horrible disease but we have a willingness to share our experiences, the good and the bad with each other.

Tim and Meg Walk the Wall



Fundraising couple plan to walk the length of Hadrian's Wall in 10 days for Crohn's & Colitis UK

A couple from County Durham will be walking the 84 miles of Hadrian's Wall over ten days in June for Crohn's & Colitis UK. They say they're doing it "because currently there is no known cause and no cure" for IBD.

Tim (pictured above), a former referee for Sussex Football League, was first diagnosed with Ulcerative Colitis in 2010, and the following year he was told he also has Primary Sclerosing Cholangitis. Their youngest granddaughter has since also been diagnosed with UC.

They have held a number of fundraising activities but this will be their first sponsored walk.
They tell us "this will be quite a challenge, although we have kept ourselves fit over the years, we have not undertaken a walk like this before.

You can support them, donate and follow their progress
at https://www.justgiving.com/fundraising/MegAndTimGilks

Future Meetings and Speakers

We are always open to suggestions to how we can reach out to all our members across the Network, whether this be arranging social gatherings or providing information to new members.
Also, if there is a specific topic that you would like to see addressed in our Educational Meetings, please let us know and we will do our best to arrange a specialist in that area to come along and chat to us.
Any suggestions, or if you would like to be more involved, please drop us an email at
dw@networks.crohnsandcolitis.org.uk

Crohns and Colitis UK Durham and Wearside

CrohnsColitisDW

CONTACT US

Durham and Wearside Network
Lead Volunteer: John Rodgerson
Helpline: 0300 222 5700*
Website: www.crohnsandcolitis.org.uk/dw
Email: dw@networks.crohnsandcolitis.org.uk

Crohn's and Colitis UK
1 Bishops Square, Hatfield Business Park, AL10 9NE
enquiries@crohnsandcolitis.org.uk
www.crohnsandcolitis.org.uk

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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 purposes.