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## EDINBURGH Network



### *WELCOME TO THE 2018 NEWSLETTER FOR EDINBURGH NETWORK OF CROHN'S & COLITIS UK*

2018 has been an exciting year for the Edinburgh network of Crohn's & Colitis UK. We hope you enjoy this newsletter and thank you for your continued support.

If you have any feedback on this issue, please email us at [edinburgh@networks.crohnsandcolitis.org.uk](mailto:edinburgh@networks.crohnsandcolitis.org.uk)

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*As the Edinburgh Network we want to raise the profile of Crohn's & Colitis UK, our network and the underlying conditions in our local community. We will fundraise for Crohn's & Colitis UK and support those fundraising on our behalf.*

#### **Key events - 2018**

- **Edinburgh marathon**
- **WALK IT**

#### **Looking ahead to 2019**

- **Park Run**
- **Marathon**
- **WALK IT**



## **Edinburgh Marathon – May 2018**

by Bonnie Macmillan

Although it started out as a dreich day, the sun made its appearance just in time for the first runners at this year's Edinburgh Marathon Festival on Sunday 27th May. Volunteers from the Edinburgh Network were there to support the runners in the full and half marathon events. Thank you to all of the amazing runners who took part in the various events during Edinburgh Marathon festival weekend. We had participants in all events ranging from the 5K to the full marathon.

It was great to see so many visiting our tent after their race and sharing their reasons for running - many to support friends and family with IBD. Our volunteers worked hard and made sure there were plenty of post-run treats on offer. There were homemade cupcakes, empire biscuits and tablet, as well as a mountain of Mars Bars. We also had Crohn's & Colitis UK goody bags and the return of students from Edinburgh College giving ever popular sports massages. Our mascot Roary was also in attendance and was out meeting the runners and supporters, shaking hands and posing for photos. It was a fantastic day and we can't wait to cheer on more runners at the Edinburgh Marathon Festival 2019.

## **Future event – 2019!**

We are planning to brave the Scottish weather to help raise awareness at the Cramond Park Run. Date to be confirmed – so keep an eye on social media for more information.

Please say hello if you see us there – and even better if you have a branded t-shirt to help us create an impact on the day.

## WALK IT – June 2018

by Laura Martin

The sun was shining at the Edinburgh WALK IT fundraiser in June 2018. Over 500 IBD warriors took to the beautiful streets of our capital city to raise funds and awareness for Crohn's & Colitis UK. It was a great atmosphere with over £55,000 raised for the charity.

We couldn't have done it without our trusted volunteers with over 30 giving up their morning to ensure we had a really successful event.

The date for 2019 will be released soon – so keep an eye on [www.crohnsandcolitis.org.uk/walkit](http://www.crohnsandcolitis.org.uk/walkit) for more information.



## Support in our local community – Lothian Buses

by Bonnie Macmillan



Lothian Buses Employees Charity Fund committee chose the Edinburgh Network to receive funds raised by Lothian Bus employees. Crohn's and Colitis UK Edinburgh Network was put forward by one of the bus drivers who has family members that are affected by IBD. After he spoke to the Charity Fund committee giving them anecdotal information on how IBD affects the lives of his family members the committee unanimously agreed to support the Edinburgh Network. We are forever grateful for the generous donation we received.

One of our volunteers, Bonnie, meeting Mark and Jim from Lothian Buses.

## Crohn's and Colitis Awareness week

by Sarah Harris

The annual Crohn's and Colitis Awareness Week took place from the 1st to 7th December and aimed to increase public understanding of IBD. Throughout the week the network shared information on social media about the illnesses, as well as ways people could get involved such as wearing purple for Purple Friday or donating to the charity to receive a Star of Hope. Over 300,000 people are affected by Crohn's and Colitis in the UK, with half facing discrimination due to the illnesses and 47% experiencing mental health issues as a consequence of the disease. Awareness week is important in bringing the disease into public view and raising awareness and funds. During this week Jeremy Corbyn and other members of the Labour party were spotted wearing Crohn's and Colitis UK badges in parliament. This was a huge step for raising publicity and a sign that we are being noticed by politicians. Crohn's and Colitis was also making headlines in the news, with people such as vlogger Hannah Witton, explaining what it is like to live with these illnesses and stomas.

This week-long event saw increased public exposure and awareness, and hopefully demonstrated that *#ittakesguts* to live with Crohn's or Colitis.

## Fundraising spotlight – Amanda Rarity

by Sarah Harris

As a charity we rely on donations to allow us to continue fighting inflammatory bowel disease. This year Amanda Rarity hosted a Race Night in aid of Crohn's & Colitis UK and we chatted to her about her event.

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### Q: Why did you choose to fundraise for Crohn's & Colitis UK?

I wanted to fundraise for Crohn's & Colitis UK as my daughter Ruby, age 9, was diagnosed with Crohn's Disease in August 2017. Before Ruby was diagnosed I had never heard of Crohn's or Ulcerative Colitis.

Ruby has been brave and experienced so much. She has undergone an endoscopy, colonoscopy, 6 weeks of Exclusive Modulen (EEN), various forms of medication, regular blood tests and now she is also getting regular injections.

I wanted to raise money for and awareness of IBD. Throughout my fundraising I came into contact with quite a few people that were affected either directly or indirectly with Crohn's or Colitis.

### Q: What did you do and how much did you raise?

I held a Race Night and raised £2,944



### Q: What was your favourite and most rewarding part?

Hosting the evening and seeing all the months of planning beforehand coming together. Everyone who came had a fantastic night and I raised a great amount for the charity.

### Q: What advice would you give to others wanting to fundraise?

Make it something fun where all of your friends and family can get involved. They also help to spread the word and get other people to attend. I even had one of our local councillors come along.

I also got Crohn's & Colitis UK merchandise from Head Office for my evening. My husband and I wore the t-shirts. We had banners, balloons and collection tins as well. It was extremely eye catching.

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Thank you to all of our fundraisers for your hard work!

We would love to hear from you and we are happy to share your stories on our social media networks.

## Fundraising spotlight – Spring Ball

by Laura Martin

As a charity we rely on donations to allow us to continue fighting inflammatory bowel disease. Angus Mclean, a Crohn's & Colitis UK volunteer, has been involved in organising an Edinburgh based fundraising event for the last seven years. We chatted to him about this annual event.

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### Q: What is the Spring Ball and how did this event get created?

It is an annual black tie fundraising extravaganza. Alan McGuiggan, manager of the Prestonfield Hotel, kindly donated a prize to a ceilidh I was organising in 2011 and expressed an interest in organising a bigger event at the Prestonfield. A close family member of Alan's, like me, has ulcerative colitis. Another thing we have in common is our love of a great party. We knew that friend of the Prestonfield, Boogie from Forth One, has Crohn's disease so he was the obvious choice to host the event. All the key ingredients for a great night were now in place – supporting a great cause, the best venue in Edinburgh for a party (Prestonfield's Georgian Stables) and a first class host. "If we build it, they will come!" The Spring Ball was born and we hosted the first event in 2012.

### Q: How much has been raised in total over the last seven years?

Thanks to our fantastic guests, prize donors and the support of Prestonfield owner, James Thomson OBE, the Spring Ball has raised £400,000 in seven years. Our aim is to smash through the £0.5 million mark in 2019.

### Q: What is the connection with the Edinburgh Children's Hospital Charity?

The money raised is split 50/50 between Crohn's & Colitis UK and the Edinburgh Children's Hospital Charity Crohn's Research Fund. Professor David Wilson, a member of the Spring Ball Committee, puts these funds to excellent use to fund research into childhood onset IBD.



### Q: What is your favourite and most rewarding part of being involved?

Alan and I have been very clear from day 1 regarding the three key objectives of the Spring Ball – raising money, raising awareness and having fun. I'm pleased to say that we have delivered on these in each of the 7 years. We have had a diverse range of entertainment including Altered Images, Hardeep Singh Kohli, Hue and Cry, Fred MacAulay and Dirty Harry (Blondie tribute). £400,000 is an incredible amount to raise and more and more people are now talking about IBD as a result of attending the Ball. We have a sell-out crowd of 350 each year so we must be doing something right!

### Q: What would be the best advice you would give someone organising an event?

Start planning early. There is a lot of admin involved in putting on an event on this scale. Assembling a committee with a range of skills and connections is vital for a number of reasons – sharing the workload, selling tables, sourcing prizes and securing top class entertainment.

### Q: What changes are planned for 2019?

We have a formula that works so no major changes planned. The entertainment is always a closely guarded secret but rest assured, you will not be disappointed.

### Q: How can people get tickets for 2019?

Tickets for the 2019 Spring Ball are on sale now at £85 per person and include a welcome drink, three course meal, half bottle of wine and exceptional entertainment. For more information or to reserve your place, call 0131 662 2323. The Ball will be held on Saturday 30 March 2019.

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**WE ARE  
COMPASSIONATE**

*As the Edinburgh Network we want to support those affected by Crohn's or Colitis in our local network.*

**Key events - 2018**

- **Social nights**
- **Medical event**

**Looking ahead to 2019**

- **Family day – late 2019**
- **Social events**



**WE ARE  
COMPASSIONATE**



## Social Night – September 2018

by Sarah Harris

Friday 21st September saw a gathering of our volunteers and local members at All Bar One on Lothian Road. It was a chance to meet new people and also an opportunity to share both IBD related and unrelated experiences. We had a great turn out with 15 people coming along, both old faces and new.



Everyone is welcome at our social events so keep an eye on our website ([www.crohnsandcolitis.org.uk/edinburgh](http://www.crohnsandcolitis.org.uk/edinburgh)), Facebook (@[Edinburgh.crohnsandcolitis.uk](https://www.facebook.com/Edinburgh.crohnsandcolitis.uk)) and Twitter (@[CrohnsColitisED](https://twitter.com/CrohnsColitisED)) for our next event. We look forward to seeing you next time.

If you have any ideas for future events, please let us know!

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## Coming soon...Family day – late 2019

by Laura Martin

We are excited to announce that, in collaboration with our head office team, we are planning a family day for late 2019. This will be a free event designed for families impacted by this condition – with a mixture of education, networking and fun for all involved. Spaces will be limited so keep an eye on our social media for more information.

If you would like to be involved in shaping the event, please get in touch with [volunteering@crohnsandcolitis.org.uk](mailto:volunteering@crohnsandcolitis.org.uk)

## Medical evening – October 2018

By Laura Martin

Consultant gastroenterologist Charlie Lees from the Western General Hospital hosted a medical evening and we were lucky enough to be invited along to a really interesting and engaging presentation on IBD. It was really surprising to learn there are 10,000 people with IBD living in Edinburgh which shows the importance of our local network presence.

The medical event was webcast and the feedback was really positive. Keep an eye on his twitter feed for details of future events @charlie\_lees

Our volunteers: Colin, Nancy, Elisa and Laura at the event.



## Network supporter – Alexandra Clarke

You can follow Alex journey on facebook @AlexandIBD



So here's a little about me. I was diagnosed at 17 and for a while truly believed I was the only young person in my community that had this diagnosis so young.

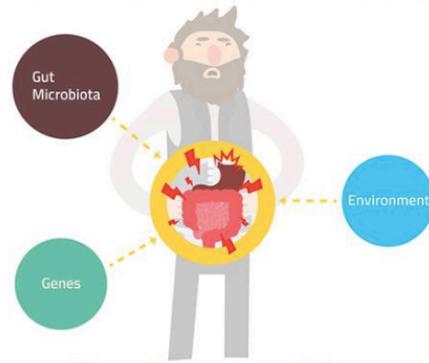
I had so many pills to take, so much overwhelming information to take in within weeks of being diagnosed which took over a month during March 2015. 9 months later on 12th December 2015 I had my ileum removed as a result of a blockage caused by inflammation and a resection in the same surgery. This changed my pain suffering levels once removed and made the best difference to my life before I had to start Humera in November 2016.

Now I am on Mercaptopurine 50mg as well as weekly injections of Humera and I live a relatively normal life at 21, managing to go climbing on my best days and working towards getting my Climbing Wall Instructor Award and an SVQ in leisure management. I feel my journey with IBD has been dark, difficult but has shown that there will be very good and bad days and with this I intend to save up for a video camera for blogging purposes along with my Facebook page about how I live with this chronic disease from day to day.

The Edinburgh Network has given me the chance to meet people suffering with Inflammatory Bowel Disease and show me that I'm not alone - I'm not a failure because I have this disease - and just because you look ok to everyone else there are people who understand that everything is achievable and you just need extra time and support to get where you want to be.

I hope to raise awareness of young people suffering with this disease in my local area Perth and create a network as powerful as the Edinburgh one.

## JOIN THE BIGGEST STUDY ON PREDICTING IBD DISEASE FLARE



Please sign up on our website  
[www.predicct.co.uk](http://www.predicct.co.uk)

### Spotlight – PREDiCCT STUDY

As a network, we like to promote local research initiatives and PREDiCCT is one of these. The following information is provided by them.

This research study is not funded or organised by Crohn's and Colitis UK, and therefore we cannot take responsibility for your involvement in the research.

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This is the first study of its kind and is specifically directed toward understanding how environmental factors and the gut microorganisms influence IBD flare and recovery. For the PREDiCCT study we hope to recruit 3100 people in remission from Crohn's disease or ulcerative colitis (illness under control) from approximately 30 inflammatory bowel disease clinics across the UK.

We hope to conduct the study in the following stages:

- People with IBD in clinical remission (under control) will be approached in gastroenterology clinics across the country and invited to take part in the PREDiCCT study.
- Participants will attend a clinic visit for routine tests and also to complete several questionnaires with a research nurse. This takes no more than approximately 20 minutes.
- At home over the next week participants will complete detailed questionnaires assessing their environment and diet. Participants will also collect a stool and saliva sample and send this to our laboratories (we've developed easy ways of doing this reliably by post). The stool sample is to analyse both the microorganisms in the participant's gut and the level of gut inflammation (faecal calprotectin), and the saliva is used to analyse their DNA.
- We will then follow participants' progress over 24 months. They will be asked to complete a short online questionnaire every month with a longer questionnaire at 12 months and 24 months after their initial clinic visit.
- If a participant experiences a flare, we will collect an additional stool sample; but most importantly we'll look to see how the environmental and microorganism factors recorded at the beginning differ for those that flare up versus those that don't.

What we hope to achieve:

- Finding out the environmental and dietary factors for patients to avoid because they trigger flare.
- Finding out behaviours for patients to adopt because they bring about remission.
- Finding out what the microorganisms that predict flare look like.
- Gaining information which helps future studies aimed at finding better diets for IBD sufferers.
- Developing ways of gathering information online from IBD patients about their well-being that doctors can routinely use.

We have assembled expert doctors, epidemiologists, microbiologists, nutrition scientists, and bioinformaticians. These experts will use the systems we've put in place to make sure PREDiCCT succeeds. It will yield a lot of new information to help sufferers right away; but the information will also help to kick start many important future studies that will bring us ever closer to a cure for Crohn's disease and ulcerative colitis.

We reached 1000 recruited participants on 6 September this year. As at September 2018, we have recruited 1076 participants with 554 of them being recruited from NHS Lothian.

We are currently opening up sites and the plan is to have 30 recruiting centres across Scotland, England, Wales and Northern Ireland by end of 2018.

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**How to get involved**

Visit: [www.predicct.co.uk](http://www.predicct.co.uk)

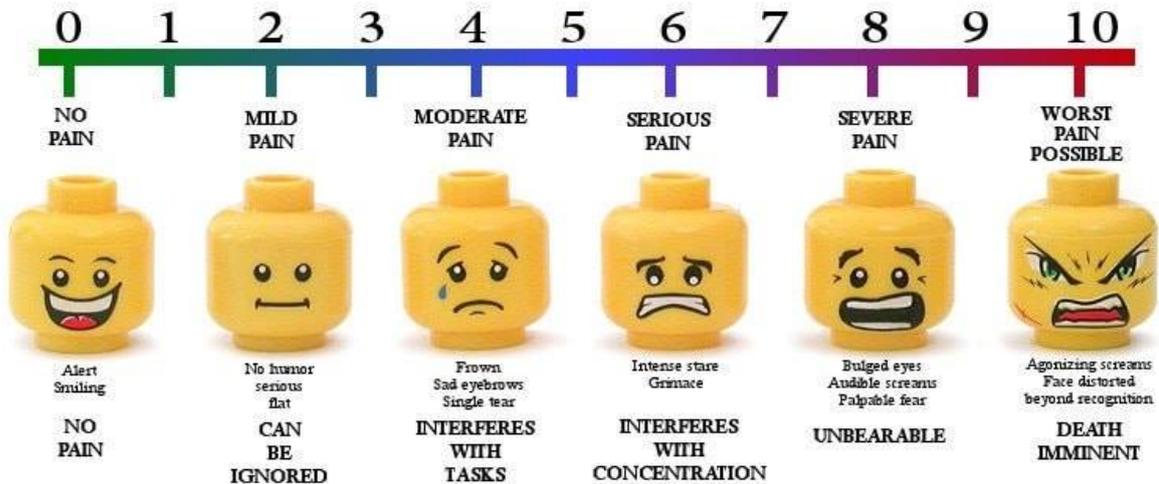
Facebook and twitter: @PREDiCCT

E: [predicct@ed.ac.uk](mailto:predicct@ed.ac.uk)

Or ask next time you visit your IBD clinic!

## Spotlight – Pain management

By Jennifer Arthur



Unfortunately, many of us with IBD are affected by pain, both acute and chronic. Chronic pain can cause a great deal of distress and is difficult to control. I recently attended a five week intensive pain management course run by Pain Association Scotland. This was held for three hours each week, for five weeks.

Over the course of the five weeks, topics covered included: Setting and achieving goals, staying positive, benefits of being active, complementary therapies, understanding the mechanism of chronic pain, dealing with other people and managing flare ups.

On completion of the course, Pain Association Scotland run monthly support/refresher groups that give the opportunity to continue the support.

As always, we are all different and this type of approach will not be for everyone and conventional medication is clearly very important many of us. However, it could be helpful for some to explore, especially as it can feel positive to be self helping.

## Stoma Open Day in Falkirk

By Jennifer Arthur

I had the opportunity to attend an open day for ostomates in October. This event is held bi – annually in Falkirk and is organised by the stoma nurse team in Forth Valley Royal Hospital. I was only too happy to go along, as I'm still learning and think that many will relate to that feeling! The day was held in a local hotel and hosted by one of the stoma nurses. The great thing about this, was the informal opportunity to chat and discuss any concerns without a formal appointment.

Many of the large medical companies were there and the idea was that all attending were freely able to chat to the reps, discuss any needs of problems and request samples of pouches and other stoma accessories. Information was also available to take away on various topics such as skincare, leaks, odour control and so on. Information was also available on suitable exercise and rehabilitation guidelines, to help those best recover from surgery and regain core strength etc. All could be discussed with the stoma nurse too. The afternoon was concluded by a guest speaker invited by the stoma team. This was a holistic therapist explaining relaxation techniques such as mindfulness etc.

Plenty of tea, coffee and tables were available to chat to others, share experiences and just generally enjoy the day. I came away, armed with information, samples & more to follow by post. All in all, a productive day and I found it to be very useful.

## Spotlight – Cross party group on IBD

By Nancy Greig (Crohn's & Colitis UK)



The Cross Party Group on IBD was launched in the Scottish Parliament nearly two years ago, in February 2017.

The group includes Members of the Scottish Parliament (MSPs) from all the major parties, Health Care Professionals, policy makers and patients. The Cross Party Group provides a focus and drive for service improvement with the support of the Scottish Government and key members of the IBD community. Crohn's and Colitis UK provides secretarial support for the group.

At each meeting, members identify one or more key 'asks' or parliamentary activities – such as writing letters to decision makers or seeking meetings with Ministers. Pushing to implement the recommendations of the 'Scotland Leading the Way' Blueprint is one of the main aims of the Cross Party Group. These recommendations include improving patients' access to advice and information as well as continuing to develop responsive specialist IBD services.

The meetings have covered:

- Service redesign, opening dialogue with Health Board Chief Executives, the use of data and e-health technologies
- Children and young people, high incidence of IBD in Scotland and the need for age appropriate services
- Self-management and psychological support
- Specialist IBD nursing

In an opinion piece for the Health and Social Care Alliance Scotland, the group's Convener, Pauline McNeill MSP reflected on the profound impact that hearing directly from people living with the conditions has had on her.

Any members of the public can attend meetings of the Cross Party Group on IBD and contribute to its work. If you would like more information, please contact Nancy Greig at: [nancy.greig@crohnsandcolitis.org.uk](mailto:nancy.greig@crohnsandcolitis.org.uk).



**WE ARE  
STRONGER  
TOGETHER**

*As the Edinburgh Network we want to be collaborative and encouraging to attract and retain volunteers and supporters*

## Meet the Edinburgh Network...!

Here are the volunteers who contributed to the success of the Edinburgh network during 2018.

<b>Chair / Lead</b>	<b>Laura Martin *</b>
<b>Finance</b>	<b>Bonnie Macmillan</b>
<b>Social media</b>	<b>Sarah Harris</b>
<b>Activities and Awareness</b>	<b>Tracy Cameron Susan Groat Phillip Jones Nancy Creaney Christine Harrison Alex Johnston Elisa Montesinos Lennie Fawcett Jennifer Arthur Dan Barr</b>
<b>Regular event volunteers</b>	<b>Colin McLuckie Simon Fawcett Fiona Wightman</b>

\* From 2019, Annie Scott will re-join the network and will share the lead volunteer role with Laura Martin.



## Building our network during 2018

by Laura Martin

We started 2018 a little light on the ground after a number of departures from our organising team. With only four registered volunteers covering Edinburgh and Lothians we decided rebuilding our team was a key goal for us this year and we have made good progress on this.

Through a volunteering information day in March, several facebook campaigns and targeted emails we have recruited a number of new volunteers who have supported us with social media and at events.

We are still looking for volunteers to help us create our newsletter and to plan and organise events. If you are interested in this, please contact [volunteering@crohnsandcolitis.org.uk](mailto:volunteering@crohnsandcolitis.org.uk) to find out more.

## Volunteer information event - 2019

**JOIN OUR TEAM**



We are holding a volunteer information event during March 2019 which is a great way to find out more about volunteering with our network. Date and location to be confirmed.

Follow us on social media for more information.

## A couple of thank yous...

### Donations

We would like to say a big thank you to each and every person who donated to our network during 2018. We really appreciate it!

### Previous volunteers

At the end of 2017, three volunteers stepped down from the organising team. We would like to thank them for their hard work and commitment in supporting the Edinburgh network and Crohn's & Colitis UK. Thank you to Angus Mclean, Marie King and Annie Scott.



## CONTACT US

### EDINBURGH NETWORK

Lead Volunteer: Laura Martin

Helpline: 0300 222 5700\*

Website: [www.crohnsandcolitis.org.uk/edinburgh](http://www.crohnsandcolitis.org.uk/edinburgh)

Email: [edinburgh@networks.crohnsandcolitis.org.uk](mailto:edinburgh@networks.crohnsandcolitis.org.uk)

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[enquiries@crohnsandcolitis.org.uk](mailto:enquiries@crohnsandcolitis.org.uk)

[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

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registered in Scotland Number SC038632

A company limited by guarantee in England: company number 5973370

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](mailto:networks@crohnsandcolitis.org.uk). This will save the network valuable funds which can be used to benefit all those affected by Inflammatory Bowel Disease.

*The Edinburgh 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 and Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.*

### 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](mailto:info@crohnsandcolitis.org.uk)

*\*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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