

FIGHTING INFLAMMATORY BOWEL DISEASE **TOGETHER**

Local Network Webinar

04/06/2019

Newsletters Jenny Cooper (South Manchester, Lead Volunteer)



Be Prepared

Keep a calendar

Make notes

Take lots of photos!



Be Prepared

Get personal

CROHN'S AND COLITIS AWARENESS WEEK DECEMBER 2018

Then the finale MACCLESFIELD!!! CAKE CAKE CAKE!!! MACCLESFIELD KNOWS HOW TO BAKE AND CHAT!! Amazing team! They ran the cake sales of all cake sales and sold out! Our awareness stand was well fueled by a sugar high. We even did a radio interview for a local student radio station while we were there!

While we were there the team handed over a cheque for an amazing £1,640 - the result of two bake sales, and a sponsored sky dive by IBD nurse Sammy!!



The Macclesfield IBD team at their cake sale, and handing over the cheque for £1,640!!

Thank you so much to all the hospitals for their hardwork, time, enthusiasm and friendliness during awareness week. Some of the staff were so dedicated they had even taken annual leave to run their awareness cake sales, which is amazing support. We raised hundreds of pounds by working together across the Manchester area hospitals, and raised a priceless amount of awareness.

A massive THANK YOU to everyone that helped me with the awareness stands, in particular Dave who has helped lug all the leaflets, tables and stands to all the events, his niece Sarah who crocheted some beautiful Christmas decorations for us to sell, and Andrea who sourced us the Christmas cards to sell.

New Recruits

In recent months we have welcomed new volunteers to the group, and would like to introduce Emma Greenwood.

"I'm a mother of three young boys, and I have worked as a nurse for the last 18 years. I have had severe indeterminate IBD for 4 years. I never have had the joy of experiencing remission but one day it is a goal! I've been on many treatments including steroids, mercaptopurine, infliximab, vedolizumab and golimumab. I've had several hospital admissions and collected post op complications! Last year I had potentially curative surgery. I had a total colectomy, got my life back with an ileostomy and then had a formation of a J pouch and reversal in May.



"I started volunteering for the South Manchester Network in 2017. I decided to join the CCUK group to help raise awareness and funds for people with IBD. I am the volunteer that works with local hospitals to improve services - of which I have had plenty of experience now from both sides! The hardest part of living with IBD for me has been the effect it has on family and those close to you. I think it's important we all work together to raise awareness, and support each other in any way we can. We can work with hospitals to improve care, and raise awareness of the needs of people living with IBD. Our fundraising efforts also contribute towards researching for a cure and better treatment options, so ultimately there could be a future where people, families and friends no longer experience life with IBD!"

FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

Creating The Newsletter

Audience

Order

SOCIAL MEET UP

Our social meet ups at Cafelito in Stockport have gone from strength to strength, with around 20 people attending the sessions in January, March and April.

We have had really positive feedback from these events, where people living with Crohn's or Colitis have had the chance to speak to others in the same position.

We will be back at Cafelito on Saturday 8th June, 10am-1pm.



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Creating The Newsletter

Headlines

Be Clear

Inspiration

CROHN'S AND COLITIS AWARENESS WEEK

1-7 December is Crohn's and Colitis Awareness Week.

Last year we held various activities to raise awareness and funds, and with the support of Stockport Town Council, the town hall was lit up purple for three days!

This year, why not get your school or work place to have a bake sale, or get everyone to dress in purple!

There will be more information about Crohn's and Colitis Awareness Week on charity's website in the next couple of months: <u>https://www.crohnsandcolitis.org.uk/</u>

Volunteer With Us

We are looking for more volunteers to help us to organise and attend awareness and fundraising events.

It is a great opportunity to make a significant difference to the lives of people living with Crohn's and Colitis.

It is simple and rewarding to get involved. Whatever interests, experience or skills you have, there are many ways to volunteer your time!

There is more information on volunteering here: https://www.crohnsandcolitis.org.uk/get-involved



Creating the Newsletter

Email vs Post

Frequency

Covering Letter

WELL DONE EMMA!

Emma Raynes joined the Network in 2018.

She is passionate about several charities, but has taken part in many Network events, including the Sainsbury's bag pack and Family Day at Chill Factore.

Ahead of undergoing stoma surgery, Emma set herself several physical challenges and targets to achieve - with the mindset that having Crohn's Disease was not going to hold her back.

She has already achieved two half marathons and a 10k, and is signed up to complete two marathons and two ultras!

To raise awareness of the disease, and her plans, she was interviewed for an article that was both printed in her local newspaper, and published online.

Read the article here.



'I want to show this disease who's boss'

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CROHN'S≗ COLITISUK

Creating The Newsletter

Thank You

THANK YOU AVA

During the Family Day at Chill Factore we were delighted to receive a cheque on behalf of Crohn's & Colitis UK from a local family.

Ava presented the £500 cheque to the South Manchester, and Family Networks - after raising lots of money by having her long hair cut to donate to the Princess Trust.



MOTOWN

A Macclesfield Hospital patient, and Congleton resident, James Williams has organised two Motown and Northern Soul nights in Congleton this year, raising a fantastic £470 for the South Manchester Network!

People have travelled from as far as Blackburn to attend these events!

We would like to give a massive thank you to James, DJ Melvin Lloyd and his wife Margaret, as well as Alan and Linda for all their help.

We would also like to thank the Cygnet Club for allowing the use of their room for free.





Sending The Newsletter

Check It

Share It

Crohn's and Colitis UK South Manchester Network Published by Jenny Cooper [?] - 1 May - 6

Our latest newsletter is out now!

Have a look at what we've been up to, and a few of the things we have planned: http://s3-eu-west-1.amazonaws.com/ .../South_Manchester_SPRING...

CROHN'S & FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

NEWSLETTER

Spring 2019

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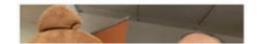
South Manchester Network

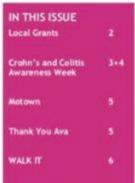
WELCOME TO OUR SPRING 2019 NEWSLETTER

Thank you for taking time to read our latest newsletter.

You will find more information here on what we have been up to for the last six months.

2018 was a fantastic year for the Network, which saw us raise funds and awareness across the area, hold more social meet ups, and help improve services for patients with Crohn's and Colitis through local grants to hospitals. We have already had a great start to 2019, with new faces joining us, and more plans in place for the months ahead.





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Thank you.

Follow us

f /crohnsandcolitisuk
@CrohnsColitisUK
@crohnsandcolitisuk

FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

LINCOLNSHIRE NETWORK'S SOCIAL



SOCIAL MEDIA TIPS!



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SHARON TOOK OVER FACEBOOK & TWITTER IN NOV 2015 & CREATED AN INSTAGRAM ACCOUNT

MELLISSA BECAME ADMIN IN NOV 2018 TO HELP WITH THE WORKLOAD & INCREASE NUMBER OF POSTS

FOLLOWERS/PAGE LIKES

DATE	FACEBOOK	TWITTER	INSTAGRAM
NOV 2015	140	100	0
MAY 2019	622	273	387

WE'RE ON A MISSION TO RAISE THESE FIGURES TO RAISE AWARENESS



SOCIAL MEDIA CHANNELS

INTERACT WITH ALL OUR OTHER NETWORKS!

We are AMBITIOUS, we are COMPASSIONATE, we are STRONGER TOGETHER



@crohnsandcolitisuklincolnshire



@crohnsandcolitis_lincs







KEY TO SUCCESS? ENGAGEMENT

Increase engagement = growth = raised awareness! BUT HOW?

- follow topical accounts, influencers, forums
- eye catching/easy to read posts
- personable, empowering and positive
- respond to every comment be social!
- be helpful post links, give contact details
- invite 'lurkers'
- boost posts





WHY FOLLOW OTHER ACCOUNTS?

INVOLVING YOURSELF WITH OTHER ACCOUNTS RELEVANT TO THOSE AFFECTED BY CROHN'S AND COLITIS IMMERSES YOU IN YOUR TARGET AUDIENCE. YOU WILL LEARN WHAT MATTERS TO THE PEOPLE AT ANY GIVEN TIME AND CAN TAILOR YOUR POSTS ACCORDINGLY.

BEGIN WITH FOLLOWING ALL OUR OTHER NETWORKS. LOOK AT WHAT WORKS AND WHAT DOESN'T. ENGAGE IN OTHER NETWORK'S POSTS. A QUICK LIKE OR A COMMENT RAISES ENGAGEMENT, SHOWS WE'RE A TEAM AND TOGETHER, WE CAN GET A STRONGER PRESENCE ONLINE.

MAKE YOUR POST ATTRACTIVE. HOW MANY TIMES DO YOU START READING A POST AND JUST SCROLL ON BECAUSE IT'S WAY TOO LONG? IT'S A SCIENTIFIC FACT THAT DIGITAL TEXT IS HARDER TO READ THAN PRINTED PAGES. MAKE IT EASY ON THE EYE...

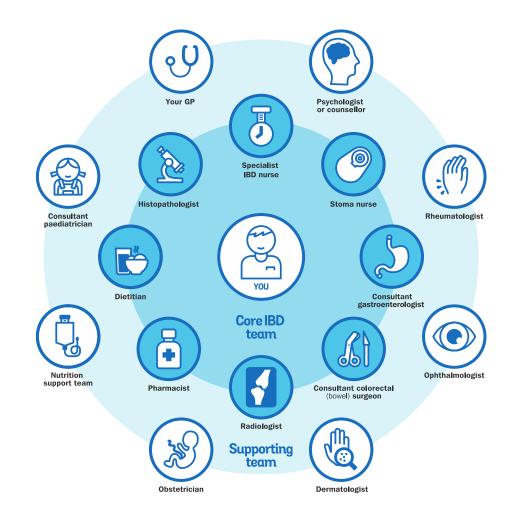
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FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

EASY ON THE EYE

Core IBD Team and supporting team. Your GP, Psychologist, Consultant Pediatrician, Histopathologist, Specialist IBD Nurse, Stomas Nurse, Rheumatologist, Dietitian, YOU, Consultant Gastroenterologist, Nutrition support team, pharmacist, radiologist, Consultant Colorectal surgeon, Ophthalmologist, Obstetrician, Dermatologist.

WHICH ONE WERE YOU DRAWN TO?



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- ✓ Line Spacing
- ✓ Brand language
- ✓ Personable
- ✓ Empowering
- ✓ Positive
- ✓ Emojis
- ✓ Relevant
- ✓ Interactive

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FIGHTING INFLAMMATORY **BOWEL DISEASE** TOGETHER

Which one is more appealing?

Formatting is make or break with lots of text.

Edit the post to correct the formatting.

Use the Notes app to draft post and paste already formatted.

> Don't forget the hashtags!

Post current links in bio.



crohnsandcolitisuk I was diagnosed with Ulcerative Colitis when I was 13 years old. When I was this age I didn't understand what this illness was or what was wrong with me as it took over a year to be diagnosed. I always pushed the thought away thinking that something like this wouldn't happen to me but the pain became unbearable. I started taking a range off different medications and treatments, such as infliximab, steroids, Azathioprine etc (I can't remember them all) I have had a number off different Xrays, countless blood tests every week, MRIs, and five colonoscopies. From taking these medications I dealt with a number of side effects such as my hair falling out, fainting, vomiting, losing weight, mouth ulcers and so on. As I was only young I begab to feel depressed and felt down all the time, I couldn't leave my house/ socialise as I was afraid I wouldn't be near a toilet. I was starting GCSEs which brought on a lot more stress as I hated going to school because I was always weak and running to the bathroom over 20 times a day. I felt like a zombie walking to different classes, but school was understandable and very helpful. I finished my GCSEs I stayed to do my Alevels. When I was 16 all medications stopped working for me, I was losing so much blood every time I needed the toilet and due to the pain I always threw up. In that year doctors kept giving more treatments and medications to try, none off them worked. At 17 years old in 2017, I had been told that my only hope would be surgery, having my colon removed and resulting in a colostomy bag on my stomach. Before my operation a lump had developed on my neck and they may off had to put back the surgery, they told me it was my lymph nodes and I would have to attend the cancer centre for a few months. But they went on with the surgery and I was in hospital for exactly a week and stayed off school for two months. Now I'm a fit and healthy, I'm taking this year to get my life back on track and begin a new chapter!

#ItTakesGuts to talk about Colitis. This is Naomi's story View all 68 comments

any dowden Inspiration! Go girl!!!! Enjoy this next year F

C

metr

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— Liked by crohnsandcolitisukeastlondon and 1,900 others

crohnsandcolitisuk Hello, my name is Charlie, I am 25 years old and I have been battling with Crohn's for the past six years.

Over the last 6 years I have tried many ways too ease the pain from steroids and tablets to injections and drips ! Last May, I was at work when I collapsed with the worst pain in my stomach!

After driving myself to hospital and undergoing some more tests and scans they found that half of my stomach had collapsed and I had to undergo a operation removing half of my small and large intestine.

After the operation I felt like people would judge/stare at me for having such a large scar over my stomach but after time reading some other people's stories (from you guys) I just wanted to thank everyone for spreading such a positive vibe through Instagram it makes peoples lives like myself a little easier!

I'm now fully comfortable with myself and have even started my own little family!

5

#ItTakesGuts to talk about Crohn's and Colitis... this is Charlie's story. @c.k.pullum

View all 70 comments

0

thegrumblinggut Stay strong. It looks like you have a good support system which makes things easier 😂

F

C

FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

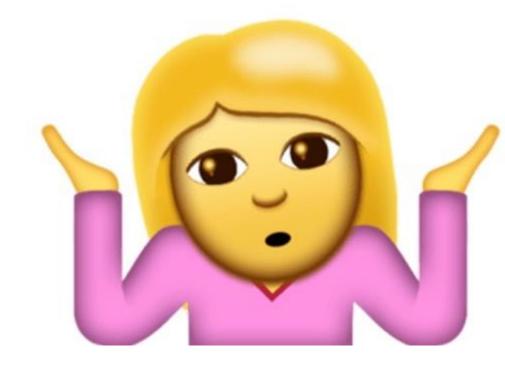
SHARE & INTERACT TO INCREASE REACH

- React to every single comment
- Engage where possible
- Advertise your next event
- Share to local events pages, selling/wanted pages, town/city pages
- Create excitement
- Review the reach results
- Learn and use what works well



FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

BE SOCIABLE! OTHERWISE, WHAT'S THE POINT?



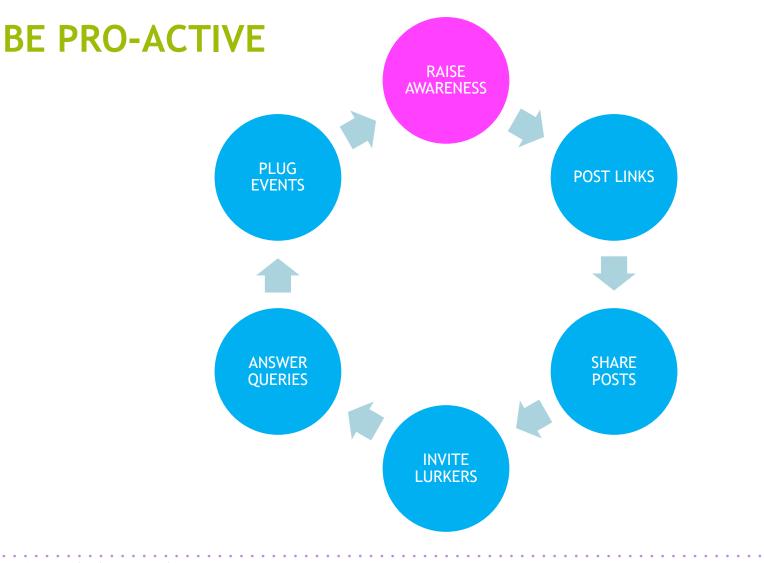
RESPOND TO COMMENTS

People love to feel valued. Replying to them with an individual comment or reaction helps with this. Steer them to your events or membership.

RESPOND TO MESSAGES

Pro-actively take every opportunity to invite people getting in touch, to the SMUs. Offer to arrange to meet them or look out for them so they don't feel alone. Sign message off with your name.





FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

Comment

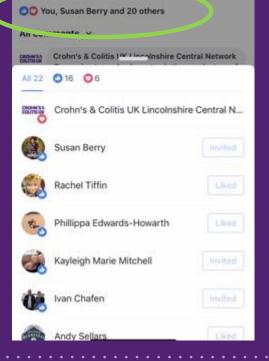
A Share

INVITE 'LURKERS'

O Love



TO SHOW THE LIST OF LURKERS



Page

Comments

...

CROHNSE Crohn's & Colitis UK Lincolnshire Central Network 5 May at 19:46 · ©

Our Lincolnshire Central Network volunteers travelled to Rutland Water this morning to help run the annual Bluebell Walk & Cycle Ride alongside the Leicestershire & Rutland, Northamptonshire and Nottinghamshire Networks!

We all had a great day and saw hundreds of you raising awareness of Crohn's & Colitis either on foot or two wheels $k \ll k$

Thank you to everyone who attended to take part, to all the volunteers and the event organising team - we can't hold events like this without you 👍

(if you're interested in volunteering we would love to hear from you! Any time at all is helpful at our numerous events throughout the year)

We would love to see your pictures from today! Post them in the comments below and you may even feature in our next newsletter! Get posting



FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

BOOST & SCHEDULE POSTS



BOOSTED

Targeted promotion

- Small cost
- Big return
- Increased reach
- Runs on Instagram
- Time your posts
- Schedule posts
- Review results



NOT BOOSTED

crohnsandcolitis.org.uk



FINAL TIPS

- DON'T CREATE AN EVENT NEGATIVE IMPACT (requires early commitment)
- USE FUN APPS SUCH AS 'BOOMERANG'
- SPICE UP YOUR PHOTOS TRY TYPORAMA, FONT CANDY, PIC STITCH
- USE THE NEW BRANDED GIFS COMING SOON
- BEWARE OF FILTERS CAN CHANGE THE BRANDED SHADE OF PURPLE.
- BLOCK ANY USERS WHO POST ABUSE OR MIRACLE CURES

FINAL TIPS

- PIN IMPORTANT POSTS TO THE TOP ON FACEBOOK
- DON'T JUST SHARE EVERTHING POSTED BY HEAD OFFICE BE CREATIVE!
- TAG @crohnscolitisuk, @crohnscolitisFR and @crohnscolitisV ON TWITTER
- RUN A POLL! GREAT FOR MARKET RESEARCH
- MAKE YOUR POSTS RELATABLE WE'RE ALL HUMAN
- SMILE AND LOOK LIKE YOURE HAVING FUN!





THANK YOU

GIVE US A LIKE/FOLLOW - LET'S SUPPORT OUR NETWORKS

RAISE THE REACH - RAISE AWARENESS

PLEASE ASK QUESTIONS!