

# CROHN'S & COLITIS UK

FIGHTING  
INFLAMMATORY  
BOWEL DISEASE  
TOGETHER

## OXFORDSHIRE Newsletter

Issue 65

February 2023

### Were Still Here - Just!

**J**ust in case you thought we'd disappeared, no - we're still here working on your behalf.

How long are we going to be here? Well that's a different matter, we'll come to that later.

The last Newsletter we issued was unbelievably in March 2021, two years ago. I find that amazing and apologise for not being able to keep in touch with you more.

Back in March 2021, we were still right in the middle of covid. Now whilst the pandemic is not over - and probably never will be - it's not affecting us in the way it was two years ago.

Back then, Head Office was essentially in lockdown so we were unable to get the usual sticky label address label list printed.

That meant we were only able to send out our Newsletter electronically via email as data protection prevents us from holding contact details locally.

Now we know there are a number of you that have not registered an email address with us. In fact there are 52 members in Oxfordshire who fall into that category.

Fortunately, we are now able to post a hard copy of the Newsletter to this group. The rest of you, nearly 500, will be receiving it via email.

I know that not everyone reads Newsletters that come through electronically. I'm guilty of sometimes ignoring such communications myself.

However, there is the issue of cost. Email costs us nothing. Hard copies need to be printed, put in an envelope and then posted, all of which incurs a cost, not least the postage which even using second class costs 68p each.

So anyway, here we are with a new Newsletter. However it has come to you, we hope you are able to read it.

Two years is a long time. We normally try and send out at least one, hopefully two, Newsletters every year. The reason this one has been so long is partly due to ill health. Most of your organising Network are sufferers like many of you and our health can stop us doing things like many of you will no doubt experience.

The other reason is that there aren't so many of us and those that remain are all getting older!

Some of us have been doing this for nearly 40 years and, as much as we'd like to, we can't go on forever.

"Succession Planning" is a bit of a buzzword, but it's one that increasingly has quite a high profile for us.

What it means is that we need fresh blood to carry on the work we have been doing. We particularly need some young blood.

So many charities and organisations are in a similar position and we realise modern life leaves little time for many to

get involved.

The fact of the matter is that if we don't get new people involved, CCUK Oxfordshire will eventually disappear and that's a fact.

On a positive note, we are involved with the Gastro team at the JR in organising another Open Meeting which will take place on 21 March.

Full details are enclosed and it promises to be just as successful as previous ones with a lot of interesting content. The event will be open to people visiting the JR (numbers are limited though) as well as online.

Please try and read through the information inside and think about getting involved. We are lovely people!!

Dave

---

**If We Don't Get New  
People Involved, CCUK in  
Oxfordshire May Well  
Disappear - and That's a  
Fact!**

---

# Will You Join Us?!

**A**s mentioned on the front page, the Oxfordshire Network representing CCUK is struggling to continue in the way we have since the Charity was formed nearly 40 years ago. Some of us have been involved since the start so you can imagine how old we are now!

We continue to do the best we can. Crohn's Disease and Colitis can be particularly difficult diseases to cope with. Newly diagnosed patients often struggle to understand what they are faced with and need support and reassurance that they will be able to continue and carry on with the life they want to after the initial diagnosis.

The charity started in 1985 as the National Association for Colitis and Crohn's Disease (NACC), literally out of someone's front room.

It's been called Crohn's and Colitis UK (CCUK) since 2016 and has now grown to be a well respected and award winning national charity recognised as being excellent at supporting sufferers, funding valuable research and campaigning to raise awareness and achieve positive change that benefits members in many different ways.

The Oxfordshire Network works closely with the Oxford University Hospitals, particularly the Gastroenterology Departments at the John Radcliffe and Horton hospitals. In fact Jack Satsangi, one of the Gastro Consultants is our medical advisor.

What are you in for if you decide you wanted to get involved? Well nothing too onerous. The level of activity is very much down to the individual.

We try and have two or three meetings a year although, again mainly due to covid, we haven't achieved that for some time.

We get involved with fundraising, mainly helping and supporting others rather than doing it ourselves these days.

However, if you are in a social circle where you would be able to get involved in fundraising events, that would be brilliant, but it would be a bonus, not an expectation.

We are helping to organise the meeting advertised on page 3 and this is typical of the things we get involved in.

Prior to covid we were present at Friday Outpatient Clinics helping patients with any practical issues they were unsure about. Unfortunately that activity has been another victim of covid and today, many such appointments are undertaken via the telephone or a video link so face to face clinics are much less populated.

Any money we do raise or receive from donations goes, in the main, to Head Office but we are allowed to help fund certain things at the local hospitals if asked.

We produce the Newsletter you are reading now and we are available via the telephone, video link, email or even a get together over a cup of tea to help any patient, existing or newly diagnosed. This is mainly in the area of general support, we are not qualified - or able to - give any medical recommendations or advice.

So if you want to get involved, maybe give something back, be amongst like minded people, many who will have gone through similar experience as yourself with regard to health, then get in touch. We like to think we are sociable and welcoming and although it can be daunting to get involved in an environment you are not used to, we're sure you won't regret it.

If you do get involved, there is no obligation to continue if you subsequently feel it's something that doesn't meet your expectations.

Our contact details are at the bottom of the back page so go on, give it a go. We look forward to meeting you.

**NIHR** | National Institute for  
Health and Care Research



**NHS**  
Oxford University Hospitals  
NHS Foundation Trust



# CROHN'S AND COLITIS

#crohnsandcolitis

## OPEN EVENING

21 March 2023 5.30pm - 7.30pm

Patients, the public and healthcare  
professionals **WELCOME**

Lecture Theatre 1, Academic Centre,  
John Radcliffe Hospital

**The Changing Face of Inflammatory Bowel Disease -  
Progress in research and clinical care**

### What's on...

- **Updates on new therapies:** State of the art lecture (Dr Oliver Brain)
- **Diet and IBD:** Progress at last (Dr Miranda Lomer, London)
- Presentations on the latest research into the causes, treatment & monitoring of Crohn's and Colitis
- Panel Question & Answer Session
- Presentations from charities CCUK and CICRA

### The Oxford IBD Team contributors include:

S. Cripps | Dr O. Brain | Prof P. Klenerman | Sr P. Love  
Dr A. Walsh | Prof H. Uhlig | Prof J. Satsangi | RN H. Woodley

Registration required: book your free place to attend in  
person or online at <https://tinyurl.com/Infoeve2023>

Places to attend in person are limited. Please send any  
questions about the event to:

[alison.monk@ndm.ox.ac.uk](mailto:alison.monk@ndm.ox.ac.uk) or [verity.davies@ndm.ox.ac.uk](mailto:verity.davies@ndm.ox.ac.uk)



In association with:

**CROHN'S &  
COLITIS UK**  
OXFORDSHIRE

FIGHTING  
INFLAMMATORY  
BOWEL DISEASE  
TOGETHER

**cicra**   
better lives for children with crohns and colitis

With kind support from:

**nākd.**

**TREK**

# The Open Evening

**O**n page 3 you will see full details of an Open Evening due to take place at the John Radcliffe Hospital on Tuesday, 21 March. The session will consist of a number of presentations followed by a Question and Answer session.

This will be the fourth such event in recent years and promises to be even better than the previous three. It will take place live in the hospital but will also be available online via the appropriate link. Whichever medium appeals to you, it is essential that you register if you want to attend - in person or online - again using the appropriate link.

The event will take place in Lecture Hall 1 in the Academic Centre as detailed on page 3. **However, be aware that places are limited so it's best to register as soon as you can.**

We will be available, along with a number of other organisations, in the foyer of the venue prior to the start of the presentations. So come along and meet us, have a cup of tea, coffee or a glass of water. There may even be some biscuits (don't get your hopes up!).

It would be great to meet you. A few years ago we counted many of our members as friends as we often met them at different events. These days there are a lot more of you but so many that we haven't had the pleasure of meeting.

At the time of writing, we are hoping that if the lecture hall is full, the presentations may be available on a monitor in other areas within the venue. However, this has not yet been confirmed so keep an eye on our Facebook page for the latest updates.

Hopefully you will agree that the evening looks very interesting and we look forward to welcoming as many people as possible to join in. It will start at 5.30 pm and will run until 7.30 pm. If you can't make it in person or online, the whole event is being recorded and will subsequently be available to view on YouTube and a link on the CCUK Facebook page.

If you're worried about parking, a permit will be available to everyone who registers so we hope you will be able to make it, in one form or another.

## Facebook

**F**acebook has been an ideal forum to post the latest news we have about our activities and it existed quite happily for a number of years. Unfortunately, for some unknown reason, a couple of years ago, Facebook took our site down and we were never able to recover it.

It always amazes me that for a \$multibillion organisation that exists to help people and organisations communicate with each other, trying to contact anyone at Facebook to get help and support is virtually impossible!

So, the only option was to create a new site and this can be found at

***<https://www.facebook.com/crohnsandcolitisoxfordshire>***

For some reason, we have never reached the number of followers as we had on the "old" page. It would be great to know that we are reaching lots of our members and anyone else that has an interest in what we are trying to do.

So, please look at the page detailed above and "follow" us so that we can build up the audience again and make sure that we can continue to communicate with as many people as possible.

### Contacts

Telephone No; 0300 222 5700 - Email; [oxfordshire@networks.crohnsandcolitis.org.uk](mailto:oxfordshire@networks.crohnsandcolitis.org.uk)

Facebook page; <https://www.facebook.com/crohnsandcolitisoxfordshire>

Website; <https://www.crohnsandcolitis.org.uk/get-involved/volunteering/local-network/south-east/oxfordshire>

The Oxfordshire 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

Crohn's and Colitis UK

Charity registered in England Number 1117148 - Charity registered in Scotland Number SC038632

A company limited by guarantee in England: company number 5973370

**CROHN'S &  
COLITIS UK**