

# CROHN'S & COLITIS UK

FIGHTING  
INFLAMMATORY  
BOWEL DISEASE  
TOGETHER

## OXFORDSHIRE Newsletter

Issue 63

March 2021

### A Year to Forget!

Well, that was a heck of a 12 months wasn't it? This time last year I was one of the people playing down the flu like problems being experienced by a relatively small number of people over in China!

What did I know? Just a few days later we went into the first lockdown and - apart from a few weeks in the summer - we've been more or less in that state since.

If, like me, you're classed as being in the vulnerable group, it's just been worse.

Fortunately with the vaccination programme being one of the few things that has gone really well during the pandemic, things seem to be a little more optimistic at the time of writing!

The last twelve months have been difficult for the Charity nationally and locally.

The building at Head Office was not suitable to be used with all the restrictions imposed by the virus so all staff are working at home and, due to the financial implications, the number of staff employed had to be reorganised.

Locally, it was a challenging year healthwise for your writer which meant I was out of action for long periods.

Another problem was that Facebook decided to block our local page which meant that, although it is still visible, we can't gain access to post anything new. For a multibillion dollar

organisation that exists to help people communicate, it is virtually impossible to have a dialogue with them when you need help. So despite hours of trying, the only option has been to create a new page.

Thus part of the reason for this Newsletter is to tell all those people who follow the original page that they now need to look elsewhere.

Another reason for communicating is that after

the success of

our Open

Evening at the

John Radcliffe

Hospital in

February last

year, we are

helping to

organise a

similar - but

virtual - event in

April.

We realise that

not everyone has

access to digital

events but,

unfortunately,

this is the only option available to us at the moment.

There is a limit to the number of people who will be able to view the live event on Zoom but it will also be available on YouTube live and after the event. Read inside to view how to register for the event.

Despite the constraints imposed by the pandemic, we were very grateful to everyone who was able to fundraise or donate to us. Full details are included.

We hope that in the near future we can get back to some sort of normality. In the meantime, make sure you get your jabs when offered!!

David Lee



The Chilton Stall held in September, one of the very few fundraising events that were able to be held last year.

## Facebook

Facebook has been an ideal forum to post the latest news we have about our activities and our address has always been

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

It has been in existence for a number of years now and has 390 followers.

Unfortunately, as mentioned on the front page, for some unknown reason, in July last year Facebook decided to bar us from our own site. Now, although the page is still visible at the above address, we can no longer gain access to post anything new.

As mentioned, after many weeks and months of trying to rectify the situation, the only option available to us was to create a new page which can be found at

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

So, if you were following us on the original page, you won't see any new posts. Please look at the new page 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.

If there's anyone out there who knows the innermost workings of Facebook and thinks they may be able to help resolve our situation with the original page, please get in touch.

## Who Are You?

For many years the membership in Oxfordshire was fairly constant at around 300. In the last couple of years, that number has increased considerably. The last update we had from Head Office was that we have a total of 493 members of which 427 have submitted an email address. What's behind this increase, we're not sure, but hope that we can help all our members.

It struck us that with this increased number of members, there are many people who don't know us and we don't know them. So we thought it might be useful to clarify what we are about, what we try to do and what is the meaning of life!

Crohn's and Colitis UK was originally called the National Association for Colitis and Crohn's Disease (NACC) and started in a front room in St Albans in 1985. The Oxfordshire Group, as it was called then, started soon after.

Some of the team have been involved since the beginning and most of the others have been involved for many years. In the early days our focus was very much on fundraising and we got involved in just about every activity you can imagine. Grand balls, clay pigeon shooting, discos, dinner dances, concerts, horse racing nights - you name it, we've had a go! Of course we are talking pre internet and social media days. The only way of communicating was by word of mouth or the written word via the post.

There was also the support function, which still exists of course. Helping newly diagnosed patients or sufferers with specific problems to come to terms with their situation. Whilst we are unable to get involved with medical or surgical issues, we can provide lots of experience of about just every emotion and difficulty you are likely to go through.

The Charity has obviously grown over the years and is now a large organisation. The national website is a valuable source of information with booklets and fact

sheets available to download or request on many health related issues. We are still here to offer local support of course and are always happy to help in any way that we can. As far as fundraising is concerned, we have taken a bit of a step back in recent years finding it more productive to encourage members to do the heavy lifting so to speak although, again, we are always happy to help.

Finally we try and help the Oxford Trust as much as we can, the John Radcliffe and Horton Hospitals. Over the years we have donated many items that help with the comfort of patients as opposed to equipment that the NHS should be expected to provide.

A couple of years ago, at the request of the gastro consultants, we started having a presence at the Friday outpatient clinics at the John Radcliffe. Again, the objective was to help patients answer questions they may have forgotten, or were uncomfortable to ask, during their appointment.

Of course the world changed in March last year and many of our usual activities have had to be curtailed due to the pandemic. Unfortunately, Head Office is unable to provide us with address details for the 66 members in Oxfordshire who either don't have an email address or haven't submitted it to Head Office.

This means that we have no way of communicating with those members which is a shame. You will therefore be receiving this Newsletter via your email address. If by any chance, you know anyone who is a member but not on email, it would be great if you could pass it on to them. In the meantime, we hope that the recent encouraging signs of progress with regard to the battle against the pandemic will enable us to get back to some sort of normality. Having said that, we are always available via our email address at the end of this publication if you want to discuss anything with us (except, as stated, any comments about your medical or surgical treatment).

## 2020 and to Date

**B**elow is a brief summary of what we've been involved in during the year. We sincerely thank everyone involved in raising money for our charity. If you want any more details about our finances, please contact us and we would be happy to answer any questions you may have.

Date	Activity
January 2020	Benson carol singers sent us £200. They have supported us for many years in memory of Jean Harcourt, a member who sadly passed away some years ago.
February 2020	We held a very successful Open Evening at the John Radcliffe Hospital and received £12.50 from a collecting tin. We were very grateful to receive £28.00 from a collecting tin in the Outpatient's Clinic where we helped on Friday afternoons. Santander in Abingdon nominated us as their local charity and a couple of us went to the branch to receive a cheque for £400.00.
March 2020	We received £16.02 from EasyFundraising which is a painless way of raising money for us if you shop online. Look at <a href="https://www.easyfundraising.org.uk/">https://www.easyfundraising.org.uk/</a> for more details. Gloria Rawlinson sent us £140.00. Gloria is the mother of Julie Andrews, a long time supporter who sadly passed away some years ago. John Paine sent us £195. For those of you who don't know, John gives regular talks on many subjects to many different organisations. He has sent us his fees for years now and has raised £1000's for us. Obviously John's booked talks were all unfortunately cancelled for the rest of the year. David and Yvonne Wright have been great supporters over the last few years and have staged many events for our benefit. Just before lockdown they were able to put on a 60's night which raised £280.00 for us.
April 2020	We were able to send £2800.00 to Head Office.
September 2020	In normal times The Chilton Stall takes place on a monthly basis and donates money to a different charity every month. We have been so grateful that they have chosen us in as one of the charities to benefit in recent years. So we were amazed to receive £1034.00 raised in September in the brief period of reduced constraints last year. Sincere thanks to Judy Goodall, the organiser, her sister, Pam Roberts, who is one of our Organising Team and Karen Einig, another OT member. We decided to send all the proceeds from the Chilton Stall, £1034.00, to Head Office.
November 2020	Another £19.14 from Easyfundraising.
December 2021	A donation from a supporter in lieu of sending Christmas cards. John Paine sent us £50.00 Gloria Rawlinson sent us another £130.00.
January 2021	£250.00 from Benson carol singers. £60.00 donated by Yvonne and David Wright.
February 2021	In February 2020, we were very pleased to find out that Oxford Immunotec, who are based on the Milton Trading Estate, had chosen us to be their nominated charity for the year. Despite the pandemic they raised £1094.13 via a mixture of means including an online bicycle event, an online prize draw and a Christmas jumper day. Many thanks to everyone at Immunotec who contributed to the event

# Virtual Open Meeting

Last year in February 2020 we were able to help staff at the John Radcliffe Hospital stage a very successful open evening which consisted of a number of presentations followed by a Question and Answer session.

Even though we are all hopeful that the worst that the pandemic can throw at us is over, it is still too early to consider repeating the exercise. However, because it is felt that there is a lot of interest in the subjects covered, it has been decided to hold a virtual meeting on Thursday, 29 April.

This time last year, my only knowledge of the meaning of the word Zoom was to describe rapid movement. Now there can't be many who haven't been involved in a Zoom meeting or something similar! To be involved you need to register at

**<https://ccinfoapril2021.eventbrite.co.uk>**

When you do, you will find links to the agenda for the evening and details of how to participate in the Zoom webinar. There is also a link to the YouTube address if you prefer to use that medium. You will have the opportunity to submit written questions. There will also be the opportunity to post "live" questions during the event although this will not be possible via YouTube. Feedback from last years event indicated people would have liked a longer Q&A session so having questions prior to the event means that we will be able to answer as many as possible.

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.

There is a registration limit of 500 which we hope will be more than adequate. If we do reach that limit, or for people who can't join us live, the whole event will subsequently be available to view on YouTube.

If you don't have internet access, you can always give us a ring on

**0300 222 5700** or drop us a line at;

**31 Brinkinfield Road, Chalgrove, Oxon. OX44 7QX**

We have been asked by the Gastroenterology Department at the John Radcliffe Hospital to help make our members aware of an exciting national project called OCTAVE (Observational Cohort Trial-T-cells Antibodies and Vaccine Efficacy in SARS-CoV-2).

This multicentre study aims to assess COVID-19 vaccine responses in patients with chronic disease with Oxford leading on Liver Disease and IBD. The study has been granted NIHR high priority status and includes being able to deliver 150 Oxford/AZ vaccines to liver/IBD cohorts with bloods taken for immunophenotyping before and after each dose. This study is currently being undertaken at only two sites nationally who are actively vaccinating.

If you suffer from any of the diseases detailed below and have not yet received your Covid vaccination and would be willing to be contacted by the OCTAVE research team, email your details (name/MRN) to;

**[ouh-tr.octave@nhs.net](mailto:ouh-tr.octave@nhs.net)**

You will then be approached with the aim to deliver the vaccine as soon as possible as part of the study. This will be both clinically beneficial and of huge research interest.

Groups of interest:

- Cirrhosis (compensated and decompensated)
- Liver transplant recipients
- Autoimmune liver disease on immunosuppression
- Patients with IBD of any type taking immunosuppressive medications (including infliximab, adalimumab, vedolizumab, ustekinumab, and tofacitinib)

In summary, eligible participants must be an unvaccinated adult patient either on biologics or tofacitinib, able to travel to either the John Radcliffe or Churchill Hospitals, and willing to give blood samples to assess vaccine response. Travel expenses/parking may be able to be covered. Both doses will be given, of course.

#### 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

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Crohn's and Colitis UK

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