

Summer 2018

# York IBD Matters

## IBD Patient Education Evening & Patient Forum

Our next patient education evening will be in October and will be held the Friargate Quaker Meeting House in York. Check our Facebook page for more information nearer the time. At the last meeting Dr Simon Smale gave an excellent and informative talk about Functional Gut disorders and how they overlap with IBD.



The nearest car park to the meeting house is Clifford's Tower. Parking cost is £2.00 after 6pm or free to city of York discount badge holders

## Don't let Crohn's stop you doing things.



That's the message from 76 year old Sheila who was diagnosed with Crohn's Disease in 2010

Sheila explains "This picture shows me eight years after being diagnosed with Crohn's Disease. At first, I couldn't

believe it was with me for life. Toilets, pain and tiredness seemed to be the order of the day; it was easy to stay home and say no to going out. With the patience and help of all the clinicians I realised I could take part in life. I have had many different medications and a resection. I bought a Radar key, joined Crohn's UK, who gave me a 'Can't wait' card, and lost the embarrassment of asking people where the toilet is".

"I now say YES to any outing to which I am invited, if there is space in between to rest. As the clinicians say, "Be kind to yourself". Now when I have the chance to go gliding or any other activity I am always willing. Next time it's sailing. There are always clubhouses nearby and people are very understanding".

If you have a story of achievement that you would like to share then please email :- [maxine.rawle@york,nhs.uk](mailto:maxine.rawle@york,nhs.uk)

# Travel and IBD

*Don't avoid a dream holiday or business trip because you suffer from Crohn's disease or ulcerative colitis. That's the advice from Kay Greveson IBD Nurse Specialist from the Royal Free Hospital London.*

Kay explains that during her work as an IBD nurse, she found that patients were often not aware of where to obtain accurate advice to help them travel with IBD and they often received conflicting advice from their family doctor and IBD team. She decided to research this further and conducted research to explore the experience and preparation for travel with IBD. A total of 62% of patients in her research said that IBD limited travelling. Only 23% of patients sought pre-travel advice and only 40% obtained travel insurance to cover their IBD. The main reasons for this did not know where to obtain insurance or the excessive cost of premiums to cover IBD. She also found that 52% of patients taking immunosuppressant medication were not aware that they should not have 'live' vaccinations. This told her that there was a need for further education and information for people planning to travel and because of this she developed the IBD Passport website.



Kay Greveson Royal Free Hospital

Some of Kay's top travel tips taken from her website are as follows: -



Evidence-based travel advice for individuals with Crohn's disease or ulcerative colitis.

IBD Passport is an award winning website that aims to provide comprehensive, practical and reliable information on all aspects of travelling with Crohn's Disease or Ulcerative Colitis (Inflammatory Bowel Disease). IBD Passport is the first website to combine this information into one resource to make planning your trip easy. IBD Passport is a UK registered non-profit charity (Registered number: 1171268) with a global reach aimed to support IBD travellers of all nations and regions in the world.

## Vaccinations

If you are receiving immunosuppressive medication (such as corticosteroids, azathioprine or biologics), you may have an increased risk of catching some vaccine-preventable infections, but your immune system may also have a lesser response to some vaccinations. If you are taking any of the medications previously mentioned, it is important to be aware that you should not have 'live' vaccinations as your immune system may be a little weaker than normal. You should plan at least 12 weeks ahead of your trip to ensure you have enough time to obtain travel advice from your IBD clinic and local travel clinic so that you are armed with the appropriate education and resources to stay healthy during your journey.

## Travel Insurance

Travel insurance is extremely important but something that many people may overlook or perhaps obtain with inadequate cover for their IBD. It is a good idea to 'shop-around' and get a good deal as some insurers will have lower premiums than others. As a general rule, insurance premiums will be higher when you have recently had surgery or have been hospitalised for a flare of your symptoms. Your age, travel destination and other medical conditions will also influence premiums.

## Additional Travel Tips

1. It is better to travel when your IBD is stable. This will prevent the risk of a flare-up and help reduce your insurance premiums.
2. Obtain a letter from your specialist outlining your medical history and medication to take on your trip and ensure you take an adequate supply of medication with you.
3. Consider your travel destination. Take into consideration your current health and the facilities available in the country you are visiting.
4. Choose accommodation to suit you. Does it have a private or shared bathroom? If shared, is the bathroom on the same floor?
5. Visit your local Crohn's and colitis patient charity website and IBD Passport websites for details of travel insurance.
6. Tips on travelling with IBD and a multi-language 'can't wait card' to take with you in case of toilet emergencies.
7. Pack your medication and any medical supplies in an
8. Emergency travel kit - Pack this in your hand luggage and check with the airline for any product restrictions.

*For more information register for free at: -*

[www.ibdpassport.com](http://www.ibdpassport.com)



# THE GREAT BRITISH COVER UP



Juliet Chambers  
Communications Manager CCUK

**New research from Crohn's Colitis UK has revealed that 34% of Brits have lied over the true reason they are taking time off work when unwell, for fear of stigma in the workplace.**

Their new survey of 1,000 UK adults found that employees frequently pick a 'one-off' or short-term health complaint when calling in sick, instead of telling the truth about reoccurring problems. It also showed that long-term health conditions are deemed the 'least valid' reasons for not attending work, despite their often devastating symptoms. Only 15% of people said that Crohn's Disease and Ulcerative Colitis were acceptable reasons to call in sick. Other often invisible long-term conditions, such as depression, anxiety, and fatigue scored even lower.

When asked for the most 'legitimate' reason for taking a sick day, the British public's top three answers were short-term illnesses: vomiting (43%), flu (36%) and food poisoning (33%).

The survey revealed that 57% of people with a long-term health condition felt that they had to down play their condition at work. One lady explains that before she

phones in sick, she gets extremely anxious that her colleagues will judge her for taking more time off and often down plays her colitis as a stomach bug as she doesn't want others to think her condition will have an impact on how well she can do her job.

Another person explained that they would often asked their GP to put something other than Crohn's Disease on their sick note for fear of judgement that they were unable to do their job. The findings are supported by CCUK's 2018 Quality of Life survey, which shows that 44% of people living with Crohn's or Colitis in the UK today agree that their long-term health condition has affected their careers. It is also easy to understand why. Their study also found that just under one in five workers feel 'frustrated' towards colleagues who are frequently off sick, and 6% feel 'angry' towards these colleagues.

Juliet Chambers from CCUK explains that living with any long-term condition is hard. Crohn's and Colitis are a growing but hidden health crisis in UK workplaces – and people need better support and understanding to manage these conditions. Right now, too many people feel forced to downplay the severity of their illness at work because of stigma.

What's worse, the stress and Anxiety experienced by employees calling in sick will only increase the already devastating symptoms of their disease. We need to break down this taboo in the work place and help employers and colleagues understand the true impact of these hidden diseases



The Crohn's and Colitis weekly lottery gives you the chance of winning £25,000 jackpot, and at the same time helps to improve lives today and build a world free from Crohn's and Colitis tomorrow.

Each entry costs just £1 and the draw takes place every Saturday.

When you join the lottery, you're allocated your own 6-digit lottery number. A random winning number is drawn – the aim is to match the winning number.

**Six** digits in the correct place wins **£25,000**

**Five** digits in the correct place wins **£1,000**

**Four** digits in the correct place wins **£25**

**Three** digits in the correct place wins **five prize entries into the next draw**

All winners are notified, and cash prizes are posted by cheque automatically if you win and prize entries are automatically entered into the next draw - so you can't miss out!

For every £1 entry at least 50p goes directly to improving the lives of people with Crohn's and Colitis. The rest goes towards running the lottery and the amazing prize



For more information see the CCUK website

# Great North Run Fundraiser



John has worked alongside the IBD specialist nurses at York Hospital along with a small group of patients helping to organise the Patient Education Evenings for several years. He explains that as he is running the Great North Run (9<sup>th</sup> September 2018) it seemed a good opportunity to help secure the future of these important meetings for IBD patient and carer support

[www.justgiving.com/crowdfunding/yorkibdpatientinformationsessions](http://www.justgiving.com/crowdfunding/yorkibdpatientinformationsessions)

With hospital budgets cut to the bone, there is no additional money to cover these meetings. The costs are not high - a room in a community venue for the evening, plus tea and biscuits, but it's a burden to ask those who come for anything more than a token donation. Each meeting includes new faces, people who may be meeting fellow-IBD patients for the first time, so the less infrastructure to do with money the better.

There are usually two of these sessions each year. They take place away from the hospital, as we've found this makes them more informal, more sociable, and less intimidating for first-timers to come along.

The meetings help patients and their families understand a range of issues relating to Crohn's and Colitis; medication, new research, diet, lifestyle, psychological support, employment and other legal rights, procedures such as endoscopies or surgery. All the bits and pieces that go with a long-term incurable but non-fatal medical condition.

To offer your support to John, sponsor him at: -



Global's Make some NOISE is the official charity of Global, the media and entertainment group. This year they have chosen to support CICRA (Crohn's in Childhood Research Association), a national charity set up to help children living with Crohn's Disease and Colitis.

The charity offers support to over 600 children and young people a year and conducts research into better treatments with the help from health professionals. CICRA also campaigns to give children living with Crohn's and Colitis a voice and to increase public understanding of both

conditions.

Global explain that they want to make lots of noise about CICRA because of the support it provides to children like Mansi, who is affected by Crohn's Disease.

She said: "I was put on steroids, they gave me severe puffiness from the neck up. I was in primary school at the time and because I have always been quite skinny people asked me why I had gained so much weight in such little time. I got bullied, because of this I suffered with anxiety and felt sad all the time. When I first came to CICRA I felt that there

were other people in the same boat as me which helped me open up a bit more. Last year I was in Year 7 and I struggled to talk about Crohn's, this year I've been able to open up more about it with my friends at school."

Global's Make Some Noise is supporting CICRA to deliver a new project that will provide support to children with Inflammatory Bowel Disease and their families, to help them deal with the impact of Crohn's and Colitis. This project aims to help even more children have the best chance of enjoying childhood, despite their condition.

**Visit our website:** - [www.yorkhospitals.nhs.uk/our-services/a-z-of-services/inflammatory-bowel-disease/](http://www.yorkhospitals.nhs.uk/our-services/a-z-of-services/inflammatory-bowel-disease/)

**Find us on Facebook:** - York IBD Services

**Email us:** - [yorkibdurses@york.nhs.uk](mailto:yorkibdurses@york.nhs.uk)