

# West Yorkshire Ileostomy and Internal Pouch Association

Web address: <a href="https://westyorkshire.iasupport.org">https://westyorkshire.iasupport.org</a> Telephone: 07931 881204 (Due to Nicky working full-time, calls may not be answered or responded to immediately) Email: <a href="https://westyorkshire@iasupport.org">westyorkshire@iasupport.org</a> Post: Contact Nicky for address

### Welcome to the August 2020 West Yorkshire IA newsletter

Hi everyone, I hope this newsletter finds you and your families well. I am sure for many of you these last few months will have been very difficult, however we hope you are ok and fingers crossed things will continue to get better every day. You may remember from the last newsletter that Dylan, my 4-year-old and I had moved in with my parents given my husband's (David) job as a Police Officer and my more vulnerable circumstances. After 14 weeks living away from home, we moved back just in time for Dylan's 4<sup>th</sup> birthday and to coincide with David taking a longer period of annual leave. We have loved being back at home and like many will be adjusting to a 'new normal'.

We were lucky that we had booked some time away at a lodge in the Lake District many months ago for July, so we had a lovely family holiday and we tried eating out. Although I was initially a little apprehensive, I have personally found any cafes or restaurants that we have visited very well set up and taking lots of precautions, so we felt comfortable. July also saw me turning the grand age of 40 – although my party was cancelled, we celebrated the day with some family and had a wonderful time.

If you have any trips booked or are apprehensive at all about going out, trying shopping or eating out, I would be happy to speak with you and share my experiences. Please either email me on sarah.minto@iasupport.org or call Nicky (07931 881204) and she will pass me your number. Take care everyone and stay safe, your newsletter editor, Sarah Minto

## We are here if you want to talk

We know that these last few months will have been extremely lonely for some of you, or you may be having some issues with your new or long-standing ileostomy or ileo-anal pouch and struggled to speak to anyone about it. If you would like to talk to anyone, please do contact one of us. Emma can chat to you or can co-ordinate who would be best for you to be in contact with based on experiences, or Lindsey is a member of our organising group but also a stoma nurse so would also be happy to speak with you. You can contact Emma on 07815 579205 or email emma.pryde@iasupport.org or Lindsey on lindsey.walker@iasupport.org.

## **Meet-up and Walk in Roundhay Park**

Although we cannot hold our members meeting this year, we would like to hold an event to allow people the chance to get out, get some exercise and have a chat to others. This will however depend on government guidelines at the time and how settled things are. Assuming it is possible, we will be going for a (socially distanced) get together and walk at Roundhay Park on Saturday 26th September. You can bring with you a chair/picnic blanket and a drink, or there are take-away options nearby, plus ice cream! We will require you to book onto this event so we know numbers and can ensure we split into the correct number of groups to meet the latest guidelines. If you would like to register your interest to attend, please contact Sarah via email at sarah.minto@iasupport.org or call Nicky on 07931 881204. We can tailor where we meet based on peoples travel arrangements and where those who also want to walk to suit any mobility issues, please let us know these on the email or call. Given how quickly things can change, we would confirm if it is still going ahead and if you still want to attend 24 hours before the event.

### Zooming to the future....

Although many things stopped at the start of COVID-19 it did force companies and groups to consider how they could continue without face to face contact. Nicky is a member of the Leeds Hospital IBD Patient Panel who have successfully moved their meetings to Google meet. If there is anything you would like raised at the IBD Patient Panel or would like to know more about it then please contact Nicky. The research work that Maureen is involved with has also restarted and she has some Zoom meetings soon. It is good to know things are re-starting and finding new ways of operating.

### **Members meeting – Postponed to 2021**

We were very sorry we had to postpone the planned members meeting scheduled for the 21<sup>st</sup> March. We had hoped to be able to run the event in September however, given latest advice and circumstances we have decided to now move the booking into 2021. We will hopefully provide further details with a date, venue etc in our November newsletter and will also include this on our website and Facebook page.

### Open Days & Support Groups – postponed until further notice

Due to COVID-19 all open days and support groups are still postponed until further notice. Government advice is changing frequently, therefore, I would suggest that if you had any dates in your diaries for future events, that you make contact with the organiser before setting off on your journey to ensure it is still going ahead. For now, events remain cancelled. We will hopefully advertise new dates for events in our November newsletter.

#### **Data Collection Exercise**

You should have received since the last newsletter some forms to check your personal details, gift aid forms for if you are eligible and possibly standing order forms for your annual renewal. Hopefully you had no issues completing these, but any problems please contact National Office on 0800 018 4724. This one-off data collection exercise will help National Office ensure they have the correct information for you and allow the group to be run as efficiently as possible.

## **IBD Appointments (reminder)**

One of the West Yorkshire IA committee attend the monthly IBD patient panel at Leeds hospital to feed in any views, understand their priorities and provide an ostomist/internal pouch perspective. Following a recent meeting, the panel asked that we remind any of our members who are also IBD patients to please ensure that if you change your address and /or GP, then the Hospital Trusts will not necessarily be informed (by NHS) and you should make sure that your new details are listed with any clinics you attend. Leeds Hospitals have advised that each missed IBD appointment costs the Trust £115 and it means that patients with a flare up cannot always be seen promptly. If you cannot attend your appointment, please do cancel or amend it. Leeds Trust does send out text reminders to patients who have an appointment, but this is not always resulting in full attendance at clinic. Please ensure therefore that you also keep your mobile number updated with the hospital and ideally, allow them to contact you by letter, text and email.

Your West Yorkshire IA volunteers are made up of the following people: Nicky Lyall, Emma Pryde, Maureen Naylor, Lindsey Walker and Sarah Minto. We would love some more volunteers to help us if you could spare any time. Please inform IA National Office if you change address and if you are moving out of the area please ask if you are interested in finding out if there is a group closer to you. Depending on your preferences, occasionally, we may send you information on behalf of stoma related companies which we think may be of interest to you. At no stage will we ever divulge your details directly to the companies.

For easy fundraising on our behalf please see: www.easyfundraising.org.uk/westyorkshireia. Using this as your