EDITOR’S NOTES
We have continued to take our awareness stand to various events, including, most recently, the South Eastern GP Inflammatory Bowel Disease Education Meeting and the Causeway Hospital Patient Panel meeting.

Volunteer Hazel at one of our stands

See page 4 for upcoming venues for our awareness stands.

I was invited to present the patient perspective at a significant meeting in the Northern Trust at which the Lead Health Commissioner was present. While he said that he couldn’t promise anything with regard to psychological services, he would make a bid for more IBD nurses and talk to mental health colleagues.

Included with this newsletter is an information card about our local network which we would hope you will ask to be placed in your local GP practice. If more are required, please get in touch with us.

See page 4 for details of the next get-together in the South Down area.

On behalf of the NI Network I wish you good health and look forward to seeing you at some of our events. Audrey (Chair)

DATES FOR YOUR DIARY

EDUCATION MEETING
Date: Wednesday, 23rd October
Venue: Dunsilly Hotel, Antrim
Time: 8:00, with refreshments from 7:30
Speaker: Martin Larkham from Achieve Wellbeing

Martin’s talk will address emotional support; improving living with an invisible condition

EDUCATION MEETING
Date: Tuesday, 19th November
Venue: Wellington Park Hotel, Belfast
Time: 8:00, with refreshments from 7:30
Speaker: Dr Ali Gordon, MB FRCG, Consultant Gynaecologist

Topic: Pregnancy and Fertility with Crohn’s or Colitis

Whilst this subject is about women’s health, the meeting is not exclusively for women. It is open to all.

Both these meetings are open to anyone who wishes to attend. We look forward to seeing you at either or both.

IN THIS ISSUE
2 & 3 Donations in words and pictures
4 Coffee morning in memory of IBD Nurse Evelyn Warwick
4 Awareness stands
4 Get-together in Ballinahinch
5 Report on IA Wellbeing event
6 RADAR key; Accessible Toilets
6 Network Volunteer Training Day
7 Award winner
7 Stress Management
7 IBD Patient Survey
8 Contact Details

Congratulations to our Organising Team member, Kim, on graduating from Queen’s University with a First Class Honours degree in English.
FUNDRAISING & DONATIONS

Our treasurer, Patricia, collected £710 from Philip Mitchell. Philip’s workplace, Ristretto Ltd, donated this money to the NI Network because Philip lives with Crohn’s.

Mrs Margaret McKee nominated us to be one of Progressive’s charities of the year, which made us the recipients of a magnificent £2,500. Margaret’s daughter, Angela, has Crohn’s. What a fantastic donation!

Cappagh Young Farmers Club from Omagh raised a fantastic £656.75 from their WET KNOCKOUT event and proceeds from their tuck shop and a stock sale. What an evening of fun that must have been! Crohn’s & Colitis UK/NI member, Jill Wilson, collected the cheque on our behalf.

Ruth Stewart, whom we featured in our last newsletter for raising a significant sum of money with the Wallace High School, Lisburn, is proud of her aunt, Shirley Bustard, who raised a superb £500 by running the Hillsborough Castle Half Marathon.

£20 + £50 for research In memory of the late Mrs Sheila McAllister
£70 Hunt’s Traditional Fish & Chips from collecting box
£30 Additional donation in memory of the late Mr Peter Ming
£351 Ms K Clifford, from Hard as Oak Obstacle Course
£800 First Ballymena Presbyterian Church, nominated by member Mrs Harriet Hanna
£20 Donation from Mrs Katherine Huggins
£70 Isobel Lennon, in lieu of flowers
£130 (150 Euro) Donation from Mr Wilf Chambers, Australia
DONATIONS

Cloughfern Rainbows, the Rainbow Guide Company where our late co-chair, Peri, was a leader, gave us a donation of £152.

CHARITY GOLF DAY

Justyn Galloway’s charity golf day was initially cancelled because of heavy rain, but he chose the perfect day for it later in September, as the blue sky indicates. With perfect golfing conditions, he raised a magnificent £850.

We are grateful that Justyn has made this an annual event.

FUNDRAISING

Anne Girvan and her daughter Kathleen ran the VHI Women’s Mini Marathon in Dublin, raising £200. Well done to both of you.

Have you any plans to do some fundraising?

Remember, if you want the donations to come to the Northern Ireland Network, then it is important that you notify the Fundraising Team at Crohn’s & Colitis UK if you are setting up a JustGiving page.

Thank you for every donation, however large or small. Every pound counts and ultimately helps the charity reach the goal of finding a cure for inflammatory bowel diseases.

Contact: fundraising@crohnsandcolitis.org.uk

By adding Gift Aid, this means that Crohn’s & Colitis UK can claim back from the government 25p for every £1 donated, boosting the value of the donation by a quarter.

You can request t-shirts, vests and some merchandise.

DONATION: £2,090

Greenans of The Square, Kilcoo, Co Down, was the venue for a fundraiser which generated a huge amount of money for the Northern Ireland Network and Mandeville & Glenanne Unit, Craigavon Area Hospital. Our share was a magnificent £2,090.

We are grateful to Kate Bloomfield who told us that Crohn’s & Colitis UK/NI is special to her family, as her son attends the clinic of Dr Seamus Murphy, Consultant Gastroenterologist in the Southern Trust.

Local businesses donated prizes for raffles and an auction which formed part of the fun-filled evening, with Michael Greenan winking lots of money from those present. Music was provided by Raglan to make the evening a great success.
COFFEE MORNING in memory of IBD Nurse, EVELYN WARWICK

Sister Betty Boyd, Lead Nurse, Ambulatory Care Service in the Royal Victoria Hospital, sent us this report on a coffee morning organised by Evelyn’s colleagues.

We held a coffee morning for Macmillan, in memory of our dear friend and colleague Evelyn Warwick on Saturday the 14th September 2019 in the Ambulatory Care Centre RVH. Evelyn had worked with us for years and all the staff and patients were devastated and in shock to hear of her passing. On the memorial day we had a book to allow colleagues and patients to write a memory of Evelyn. We felt this would allow people to say good bye and also be a comfort to Evelyn’s husband Ivan, as the book will be presented to him when it is completed. The coffee morning was a success and was filled with so many people all wanting to show their respect and love.

They were all so generous and we were able to raise over £3000 for MacMillan, a wonderful service which looked after Evelyn in her final days.

There were speeches from her colleagues who all had only good words for Evelyn, and finally a plaque was revealed that will be displayed in the Ambulatory Care Centre and the words are so fitting.

In Loving memory of
Sr Evelyn Warwick IBD
14/01/1967-13/04/2019
Founded the IBD Service in the BHSCT
“Always smiling and dedicated to her work”
Sadly missed by Colleagues and Patients
“An Inspiration to all who knew her”

Get-together

When? Saturday, 16th November

Where? Café Rossi, 1 Main Street, Ballynahinch

Time: 11:00—12:30

Come along for a coffee/tea and a chat and meet others with Crohn’s or Colitis. Bring along a family member or friend. All are welcome; you don’t have to be a member of Crohn’s & Colitis UK to attend.

CROHN’S and COLITIS WEEK

1st—7th December is Crohn’s and Colitis Awareness Week, so let’s go all out to raise as much awareness as possible in these shopping centres.

If you can help for a couple of hours, please get in touch by social media or e-mail. All help will be gratefully received.

Request a Crohn’s & Colitis UK t-shirt in advance from fund-raising@crohnsandcolitis.org.uk

AWARENESS STANDS

Saturday, 26th October

Moneymore Presbyterian Church Hall, Circular Road: 10:00—13:00

This is a community wellbeing event organised by Moneymore Girlguiding Company.

Friday, 29th November

Bloomfield Shopping Centre, Bangor 09:00—20:00

1st—7th December inclusive
All day, every day!
Stand and bucket collection

Abbey Centre, Newtownabbey

Saturday, 7th December

Ards Shopping Centre, Newtownards 09:00—18:00
Account of Ileostomy & Internal Pouch Association event as told by our Organising Team member and Facebook administrator, Ruth

On Saturday, 21st September, I attended the Ileostomy & Internal Pouch Association event at Dunsilly Hotel, Antrim. This was the first stoma-related event I have attended, having had my ileostomy formed in early February due to active Crohn’s and multiple fistulas. I am fortunate to have a temporary stoma and as I am due a reversal soon, I was slightly apprehensive about attending this event. However, the information proved very relevant and I was made to feel very welcome.

After arriving to a warm welcome and linking up with one of our members, the busy day commenced and lasted from 10am-4pm, consisting of several speakers sharing valuable information. I was very surprised on entering the room to find stalls with ostomy suppliers and their range of products for us to browse.

The first presentation was by Liz Simpson from University of Ulster, who spoke on the psychological aspects of dealing with a stoma/ internal pouch and discussed coping strategies. This was of particular interest as the psychological aspect of dealing with IBD in general is lacking somewhat within the care of IBDers and Ostomates alike, and it felt like we are finally being listened to and our concerns in this area are now known and considered by Medical Practitioners.

This was followed by a ‘Mindfulness’ session led by Person-Centred Counsellor, Julie Demick. I usually don’t find Mindfulness helpful; however Julie’s approach was very different to what I had experienced before, and I found the relaxation techniques and breathing exercises beneficial and helpful. Her relatable approach to the session made it easier to imagine practising these tools in daily life.

After a delicious hot buffet lunch we then had a Pilates session led by Gillian Clarke. This was one of the best Pilates sessions I have attended! Gillian takes a physio-led approach and her emphasis is on rehabilitation after operation or injury - this being the key to such a great session. Previous classes I have attended haven’t been understanding of health needs or different body issues and led me to feel cautious that I would harm myself; as Gillian looks at the physio side, I found this to be so helpful and not in any way harmful. Her approach was very therapeutic yet made me feel that I was achieving something without having to break a sweat!

The final presentation was led by Kirsty Pourshahidi on Nutrition, Exercise and Wellbeing. This was a very informative talk on the do’s and don’ts of ostomy life and IBD in general, as well as other conditions and it provided some thought into good nutrition for life with a stoma and how it can be achieved.

It was then time to gather our goodie bags and say goodbye to those we had met that day! I was so surprised by the event and the benefits I experienced that I would have no hesitation in attending another. It really is a great experience with positive focus and outcomes.

It is also worth noting that there is a Young IA group led by committee member, David. This is such a valuable group for young adult ostomates, allowing them to meet others in the same circumstance, and I would highly recommend that you check them out for yourself or those you care for.

Events like these are great to meet others in a similar circumstance, to make contact and have a link to someone.

Photo:
Young IA committee member, David; Chair of IA Northern Ireland, Anne; Chair of NI Network, Audrey; Ruth (author of this article); IA secretary, Jenny; and NI Network member, Leonie

Hearing Impairment
If you are reluctant to attend a meeting because of hearing loss, please get in touch with us and we’ll endeavour to provide a sign language interpreter.
If you are looking for a flexible volunteering role and you are interested in helping to run awareness stands in local hospitals or shopping centres, please get in touch with the Volunteering Team at volunteering@crohnsandcolitis.org.uk or visit www.crohnsandcolitis.org.uk/volunteering to find out more.

It has come to our attention that not everyone knows what a RADAR key is or what it is for.

A RADAR key is a key which opens public accessible (disabled) toilet doors and is particularly useful when public toilets are locked in the evening.

Our travel hubs, airports, many of the large supermarkets and some towns have fitted ‘NOT EVERY DISABILITY IS VISIBLE’ signage on their accessible toilet doors. Many members have found this reassuring, as there is often criticism in the form of angry looks or verbal abuse because they don’t LOOK disabled. Some local Councils provide a free key, or they can be bought online, although you are cautioned to ensure that you purchase a genuine RADAR key. However, if any of our readers haven’t joined Crohn’s & Colitis UK, please note that you will receive one free (subject to availability) when you join. The other benefits of taking out membership are that you will receive a CAN’T WAIT card, (which is available in 30 languages), a quarterly CONNECT magazine, and you will be linked to the Northern Ireland Network.

Contact: membership@crohnsandcolitis.org.uk

Have you seen any of these signs on the public toilets in your local hospital?

If there is a Patient Panel in your hospital, this is something you could encourage them to take on.

If that is not possible, try contacting the Service Manager and let us know the outcome.

NOT ALL COUNCIL AREAS have adopted the signage. What can you do to ensure that YOUR town will do so? Try writing to the Chief Executive of your local Council or contact your MLA or the Councillor of your District Ward.

On the 14th September several members of the Organising Team travelled to Edinburgh for a training day, led by the Volunteer Development team from Crohn’s & Colitis UK. We met with volunteers from the Clyde, Edinburgh and Durham & Wearside networks. We gained valuable insight into the best ways to support our members, including looking at the benefits holding medical/educational events has. We also learned new ways to spread awareness, and we are hoping to put these skills to good use throughout Crohn’s and Colitis Awareness Week 2019 on the 1st-7th December.

Northern Ireland Network members Patricia, Rosemary, Kim and Audrey with Mark Thistlewood, Volunteer Development Officer and April Trawicki (third from right), Volunteer Development Manager at Crohn’s & Colitis UK
CONGRATULATIONS!

Northern Ireland has its own share of sportsmen and women with a disability, and we share with you now the success of Portstewart man, Michael McMil- lan, who won the award for Sports Person with a Disability at the recent Coleraine Sports Awards night. Michael is a black belt in Judo and lives with a stoma as a result of Crohn’s.

Michael is on the right.

Below: Michael’s award

Above is a sample of the type of free courses that are offered by our Health Trusts.

Each of the five Trusts provides a programme of stress management.

Check out mindingyourhead.info/stress-control-classes, and the list for all Trusts will be on your screen, detailing the autumn and winter schedule.

Stress Control is a class—not group therapy. You do not have to talk about personal difficulties in front of others. Come along by yourself, or bring a friend or family member.

Have you completed the IBD Patient Survey yet? It is of huge importance that you have your say about what healthcare is like for you. The closing date has been extended to 22nd November, so please take 20 minutes now and go to ibduk.org/survey
ORGANISING TEAM MEMBERS

Chair: Audrey Derby
Treasurer: Patricia Henderson
Facebook: Ruth Kyle
Twitter: Zoe McAteer
Instagram: Kim Montgomery, Erin Scott
Valerie Boyd: John Collins MD FRCP
Rosemary Patterson: Linda Scott
Una Smart: Michael Williams
Medical Advisor: Dr G Turner MD FRCP

IBD NURSE SPECIALISTS

The following are the Lead IBD nurses in the main hospitals.

Mary Kane, Northern Trust (Causeway)
Jacqueline Kearns, Northern Trust (Antrim)
Noreen Kennedy, Belfast Trust
Ruth Hall, Southern Trust (Craigavon)
Stephanie Dunn, Western Trust (Altnagelvin)
Gayle Martin, South Eastern Trust (Dundonald)
Tracy Close, paediatric nurse specialist, Belfast Trust (Royal Belfast Hospital for Sick Children)
Tracy Hill, South West Acute Hospital (Enniskillen)
Dawn Kilpatrick, South Eastern Trust (Lagan Valley & Downe)

>Welcome to all new members. We do not receive membership updates, so we are unable to send new members a ‘welcome’ e-mail.

CONTACT US
Northern Ireland Network
Chairperson: Audrey Derby
Website: www.crohnsandcolitis.org.uk/ni
Email: ni@networks.crohnsandcolitis.org.uk

Crohn’s and Colitis UK
Facebook: @CrohnsColitisNI
Twitter: @CrohnsColitisNI

Crohn’s & Colitis UK, First Floor, Helios Court, 1 Bishop Square, Hatfield Business Park, Hatfield, Herts, AL10 9NE
enquiries@crohnsandcolitis.org.uk
www.crohnsandcolitis.org.uk
Charity registered in England Number 1117148
Charity registered in Scotland Number SC038632
A company limited by guarantee in England: company number 5973370

HELPLINE
Our helpline is a confidential service providing information and support to anyone affected by Crohn’s and Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:
• help you understand more about IBD, diagnosis and treatment options
• provide information to help you to live well with your condition
• help you understand and access disability benefits
• be there to listen if you need someone to talk to
• put you in touch with a trained support volunteer who has a personal experience of IBD

Contact us by:
Telephone: 0300 222 5700*
Monday, Tuesday, Wednesday and Friday - 9 am to 5 pm
Thursday - 9 am to 1 pm

Email: info@crohnsandcolitis.org.uk

Web Chat (Live Online): see the Crohn’s & Colitis UK website for details

* Calls to this number are charged at a standard landline rate or may be free if you have an inclusive minutes’ package. Calls may be recorded for monitoring and evaluation purposes.

The Northern Ireland Network has made every reasonable effort to ensure the content of this newsletter is accurate, but accepts no responsibility for any errors or omissions. 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.