EDITOR’S NOTES
As we pass the halfway mark of 2019 and review the first six months, our main success is the amount of awareness of Crohn’s and Colitis that was raised. On page 4 you can read about our radio and television adventures.

We manned awareness stands at Health Fairs in Omagh, Belfast and Magherafelt, and we will be attending another one in September. (See page 6.)

We were saddened to learn that IBD nurse, Evelyn Warwick, had passed away, following illness. Evelyn had been co-opted onto our Organising Team. You can read a lovely tribute to Evelyn on page 3.

Despite a wet start to the day, our All-Age Picnic at the Ulster Folk and Transport Museum brought together families from all over the country.

The new IBD Standards 2019 were launched at this year’s British Society of Gastroenterology Conference. ‘People with Crohn’s and Colitis should receive safe, consistent, high-quality, personalised care whatever their age and wherever they live in the UK’.

For more information on the Standards, log onto https://ibduk.org or the Crohn’s & Colitis UK website.

Thanks to the generosity of our amazing fundraisers, we have been able to make a further donation to some of our IBD Nurse Specialists to purchase Microsoft Surface Pro laptops, such as we see Jolene Milligan (Clinical Research Nurse) and Caroline Collins (IBD Nurse Specialist) displaying here.

Do please get in touch to let us know what you want to see in these newsletters or what talks you would be interested in at our medical/education meetings.

Let’s hope that decent summer weather is on its way. Whether you have planned a staycation or a holiday outside Northern Ireland, on behalf of our Organising Team I wish you a safe, pleasant and healthy summer, and we look forward to seeing you at some of our events over the next couple of months.

Audrey (Chair)
FUNDRAISING & DONATIONS

Ruth and Audrey accepting a cheque for £1,500 from the president of the Northern Ireland Land Rover Club, Gordon McIlwaine. Gordon’s grandson, Steven, has Inflammatory Bowel Disease.

Audrey was invited to The Wallace High School, Lisburn, to receive cheques to the value of £1,575. Year 12 pupil and NI Network member, Ruth Stewart, raised awareness of Crohn’s and Colitis throughout the school, and with an enrolment of over 1100 pupils, Ruth did a magnificent job in spreading the word. Ruth undertook significant personal fundraising, despite often being unwell.

CONNECT is a cross-community group of seniors who meet in Comber, and one of their members is a member of the Northern Ireland Network. We are grateful to Mrs Myrtle Brown for nominating us to receive a cheque for £1,000, the proceeds of various fundraising activities.

Audrey was treated to a delicious choice of desserts when she went along to accept the cheque from Myrtle.

Belfast Marathon

Martin Avins (Avo to his friends) was inspired to run the Belfast Marathon on behalf of a 7-year boy, ‘Harry’. The children in Martin’s street showed him their support, and Martin was keen that this photo should be included. This is done so with the permission of the parents. ‘Harry’ is in the photo.

Belfast Marathon

This was Martin’s first marathon, and he vowed that he would never run a marathon again, but with the fantastic donation of £1,652, which will amount to over £2,000 when Gift Aid is added, he might change his mind! Well done, Martin.

Colin McClinton of Hunt’s Traditional Fish & Chips, Lambeg, continues to make regular donations through a collecting box on the counter. Since February, three donations have totalled £169.57. Thank you, Colin.

Enjoying the run and sharing her joy with her husband.

Martin with his wife and daughter
Mrs Evelyn Warwick, IBD Nurse Specialist

Tribute by Dr John Collins

It is with deep regret that the local network has learnt of Evelyn’s recent death. I had the privilege to work with her for 15 years and know her as a friend for 20 years.

She completed her nurse training in the Royal Victoria Hospital and worked for several years as a Staff Nurse in one of the busy surgical wards. In 1998, she started working as an endoscopy nurse in the Royal where I was a Consultant Gastroenterologist at the time. It was clear immediately to all of the medical staff that she was an excellent nurse and colleague, eventually rising to the post of Sister in Charge of the unit.

When the post of IBD Specialist Nurse was advertised in 2011, Evelyn was appointed as the first specialist nurse in this area in the Belfast Trust. It was her dream job and I had the pleasure of seeing her develop into an outstanding nurse specialist.

Evelyn treated everyone with kindness and great expertise and she was loved and respected by all.

Outside her work, she and her husband Ivan were involved in car rallying, with Ivan driving and Evelyn navigating. Just before she became ill, Evelyn and Ivan built an Audi Sport Quattro which they had hoped to rally.

Evelyn’s illness quashed this dream. The car was rallied at Goodwood Festival of Speed in 2017 and 2018 on their behalf. Evelyn Warwick dedicated her entire professional life to patient care in the NHS and created a legacy of nursing excellence as her lasting memorial. Our deepest sympathy goes out to Ivan and her family circle at this sad time.

Photo by permission

ADVICE NI

When CAB (Citizens Advice) ceased to operate in Northern Ireland last year, the offices have continued to provide the same functions under the banner of Advice NI.

If you need help in negotiating the intricacies of PIP, (Personal Independence Payment), ESA (Employment and Support Allowance) or any other forms for claiming support, ADVICE NI is there to help you.

Crohn’s & Colitis UK also run a Disability Benefits Service Helpline; a 30 minute appointment where volunteers can discuss your eligibility and help with completing the DLA or PIP form. If turned down, they can also help with the mandatory reconsideration. Telephone appointments with DBS volunteers can be made by calling the Helpline on 0300 222 5700.

DONATIONS

Fourteen-year-old Megan underwent surgery recently, and her father wanted to express thanks for her care and raise awareness of Crohn’s and Colitis. He opened his new business premises with a Pool Competition, with the proceeds coming to our NI Network. This came to £483.84. Many thanks to the Davis Family of Rustic Decor, Rathfriland.

OTHER DONATIONS

gratefully received

£100: Lakeside Bowling Club
£1,480: In memory of Mr Peter Ming
£45: Ballot at Killyhevlin meeting:
£70: All-Age Picnic
£129: Bowes Brothers, Omagh

FUNDRAISING

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.
Ten months after we applied for a slot on the monthly BBC Radio Appeal slot, we were allocated the last Sunday in April.

Audrey wrote the script and had it approved by our Medical Advisor, Dr Graham Turner, who made a few tweaks to it.

The recording of the voice-over took place in the Nolan Show studio, with Audrey sitting in Stephen’s chair, but the stars of the programme were our three members who shared their story.

Eight-year-old Alex’s mum, Valerice, explained how he had been diagnosed with Crohn’s and oral Crohn’s at the age of 6, and talked about how it affected him.

David then talked about his symptoms, reminding us how important it is to get help and not be afraid to go to the doctor, despite the embarrassing symptoms.

Laura McCart wanted to share her story to raise awareness of Crohn’s and to show that not everyone’s symptoms are the same. Paul Clarke on UTV Live cautioned listeners that they might find some of the details of Laura’s story upsetting. Laura, now 23, didn’t know that she was four weeks pregnant when she underwent bowel surgery.

Ruth explained how she was recovering from major surgery, having been diagnosed with Crohn’s Disease 16 years ago, and promoted the support of the local network, because many people find it difficult to talk about their Crohn’s or Colitis.

A separate BBC Newsline report, featuring two young people talking about how they are living positively with Inflammatory Bowel Disease, was featured shortly after our radio broadcast.

You can read Erin’s story on page 5.

Photos of Alex, Valerie and Ruth courtesy of the BBC

Audrey was called into the UTV Live studio at short notice to talk about the prevalence of Crohn’s and Colitis, being interviewed by Paul Clarke.
Erin’s stomaversary

Way back in 2012, our newsletter carried the story of a young gymnast living with Colitis, having been diagnosed at the age of 11. She had just won the title of ‘Young Gymnast of the Year’. Now looking forward to her third year as a student at Queen’s University, Erin puts her talents to good use as a gymnastics coach. However, the following article doesn’t address any of those things, but describes a very positive young woman living life to the full. She featured on BBC Newsline recently, and her positivity came across for all to see and hear.

My Stomaversary

Hiya! My name is Erin O’Hara. I was diagnosed with Colitis at age 11 and within a matter of weeks I had an emergency surgery to remove my large bowel, so I have been living with a stoma bag ever since. I am now nearly 21 and living my life to the full! I had a severe case of colitis and didn’t respond to any treatment - because of how sick I was I had many complications but really my stoma bag saved my life.

I have always had a positive outlook on living life with a stoma and it has never stopped me. I have celebrated my stoma every year since and it has quickly become one of the biggest events of the year! My ‘stomaversary’, as I call it, falls on the 22nd January every year. Every year since 2010, I have marked the date and had a party. They started as very small family affairs - with cakes and treats - just like a birthday! But as I got older, I have become more open about my stoma and my friends have joined in the celebrations. I can confidently say it is now officially a bigger event than my birthday! As soon as New Year is over I have all my friends asking me when the festivities will begin and what will they involve! This year was definitely my biggest stomaversary - my house was packed with all my friends! I had stoma bags stuck on the wall and the door (so people knew the house of course) - and my friends even came out with a stoma bag on my cake! After the party, we headed out to see where the night took us and everyone had a great night.

My next stomaversary will be number 10. The past ones have been such a hit that I am excited to see how I can outdo them for the big one!

Do you have a story you would like to share with our readers? If so, please get in touch via e-mail or Facebook. We would love to hear from you.

Killyhevlin medical meeting

We were delighted to welcome Dr Eugene Campbell from the South West Acute Hospital, Enniskillen, to speak at our meeting in May. Dr Campbell gave a comprehensive power point presentation and answered questions afterwards.

IBD Nurse Specialist, Tracy Hill, was also present, and we are grateful to them both for their time on a Saturday afternoon.

This was the first time we had hosted an afternoon meeting on a Saturday, and we were delighted with the number of people who attended.

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.
ALL-AGE PICNIC

After so much rain and cold weather, we had hoped that the day of our All-Age Picnic at the Ulster Folk and Transport Museum would be bright and sunny. Alas, that was not the case, and no doubt contributed to a number of families who had registered deciding to stay at home. The 50+ adults and children who braved the elements were rewarded when the rain ceased and they were able to enjoy exploring the Folk Museum.

The Museum’s basket-weavers have been known to make brilliant crafts for Game of Thrones.

Freshly-baked soda farls hot off the griddle were eagerly awaited.

The boys (above and top right) enjoyed visiting the farmyard.

Erin (right) brought her brother and grandmother (also a member) along for the day.

Who didn’t visit the sweetie shop before heading home?

This is just a brief snapshot of the day. For more photos, check them out on our Facebook page and Instagram.

We were especially pleased to meet some families who hadn’t been to any of our events previously, and some of them who have children with Crohn’s or Colitis had the opportunity to chat to the team and to other parents.

We hope to have another event before the end of the year, so keep an eye out for notices on our social media pages or on our webpage.
EVENTS

CHARITY GOLF DAY
Claneeboy Golf Club, Bangor
Friday, 9th August

Justyn is hosting this annual event, with the proceeds coming to our network.

For further details, contact Justyn on 07795 607346.

Prize donations welcome.

AWARENESS STANDS

Wednesday, 18th September
Health Fest
City Hotel, Derry-Londonderry
16:00–20:00
Organised by Drink Wise Age Well

Friday, 29th November
Bloomfield Shopping Centre, Bangor
08:30–20:00

Come along to this Vintage Fun Day in beautiful Cushendall. We will have an awareness stand manned by Kim, Margaret and IBD Nurse, Mary Kane, who was instrumental in nominating our local network to be one of the recipients of the proceeds of the event.

(Left) Rosemary and Charlene at our stand in Sainsbury’s, Ballymena, to raise awareness of World IBD Day.

(Right) Patricia in JAMM, in the Richmond Centre, Derry-Londonderry, when we hosted two get-togethers that day.
ORGANISING TEAM MEMBERS

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)

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

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.

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