

## Northern Ireland Network



The ORGANISING TEAM wishes all our members and readers a healthy and happy New Year.  
Top row: Valerie, Kim and Patricia  
Bottom row: Una, Ruth and John

### EDITOR'S NOTES

The year 2020 will certainly not be forgotten. The coronavirus pandemic has made life incredibly difficult for us all, and our sincerest thoughts are with you all at the moment. Charities have been impacted greatly by this pandemic, and on page 3 you will read a message from Crohn's and Colitis UK explaining the difficult decisions they have had to make in the past few months. In April, a significant contribution from the Northern Ireland Network was made to national funds to assist in these trying times. But, we have been adapting to the circumstances.

The NI Network, along with several other networks across the UK, have been taking part in a pilot project of 'Virtual Social Events.' As we can't meet for coffee at our get-togethers, this alternative on the Zoom platform has been a great way for members to connect with each other and share their Crohn's and Colitis stories. But we know that some members are not online,

and we want to acknowledge that we are thinking about you and we are looking forward to a time when we can meet face to face once more. You will see to the right that we are holding our first ever Virtual Education Event on Zoom in November, which we hope to see many of you at. With Audrey stepping down in February, after 32 years of service to the network, I'd like to introduce myself and John Collins MD FRCP as your new Co-Lead Volunteers. We want to thank you for your continued kindness and support.

On behalf of the NI Network I wish you all good health and please know that we are here for you during these strange times.

Kim, Lead Volunteer.

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### DATE FOR YOUR DIARY

#### VIRTUAL EDUCATION EVENT

Date: Monday, 23rd November

Venue: Online on Zoom

Time: 7.00-8.30pm

Speaker: Dr Graham Turner

The speaker will focus on the latest treatments for Crohn's and Colitis, and will take your questions.

Register for this free event via Eventbrite at the following address: <https://ni-virtual-education.eventbrite.co.uk>

### Patient Panel 2021

The Belfast Trust are aiming to set up a Patient Panel. If you are interested in being a part of this please email [IBD-Nurse@belfasttrust.hscni.net](mailto:IBD-Nurse@belfasttrust.hscni.net) with your interest. The aim is to commence in January 2021 with a virtual Q&A session.

## FUNDRAISING & DONATIONS

It has been an exceptionally difficult year for many. Social distancing restrictions has made it more difficult to fundraise. Yet the people of Northern Ireland have still shown their support and enthusiasm, with incredibly kind donations. Your support is appreciated now more than ever, and we thank you for every donation. Every bit helps the charity's goal of finding a cure for Crohn's and Colitis.



## JUSTYN'S DAY OF GOLF

In August, Justyn Galloway hosted his annual Golf tournament at Clandeboyne Golf Course. The sun came out and a great day was had by all. Congratulations to the winner Harry O'Hara. An incredible £1,200 was raised. Well done to everyone involved, and thank you!



## NI HEALTHCARE AWARDS



In February, at her last official engagement with the Network, Audrey attended the Northern Ireland Healthcare Awards with IBD Nurse Jacqueline Kearns and Dr Joanne Brown. The trio, along with two other OT members, took part in an IBD workshop for Pharmacy students at Queen's University Belfast in Nov 2019, and was submitted for consideration at the awards. Audrey made a speech appealing for donations, and an exceptional £1,936.70 was raised.



Left to Right: Jacqueline, Joanne and Audrey

## OTHER DONATIONS gratefully received

- £140.50 H Doyle
- £60 Lorraine Gillan
- £60 Emma Lewis. Despite a flare up, Emma completed the 2.6 challenge and ran 2.6 miles. Her parents also completed a long walk!
- £60 Barclay Kennedy
- £124 Margaret McGrandles. Collection box at Eurospar, Crumlin.
- £500 Harriet Hanna and all those at First Ballymena Presbyterian Church.
- £60 Gail McAleenon. Gail sold homemade Halloween sweet cones



Thank you to all continuing to raise money during these difficult times

## IMPACT OF CORONAVIRUS PANDEMIC

A message from Sarah Sleet, CEO at Crohn's and Colitis UK:

“Here at Crohn's & Colitis UK we are facing unprecedented challenges as a result of the coronavirus pandemic. Our community need us more than ever to help them navigate their way through the maze of information about what coronavirus might mean for them, especially if they are taking immunosuppressant drugs.

Our website has received over 2 million visitors looking for information and Helpline enquiries have quadrupled since the crisis began. Helping people with the right information and supporting them through a very scary time is our focus over the next few months. We know our information and support helps individuals and we know this takes some of the pressure off hard-pressed NHS staff.

But, in common with many other charities, our income has dropped very significantly, and we expect that trend to continue for the rest of the year as many of our fundraising activities will not be able to take place. And while we urgently look for other sources of funding such as the government fund for charities, for many different reasons we appear unlikely to access much money through these routes. As a result of the sudden and dramatic drop in income we have had to take action to protect the financial security of the charity including cutting many of our costs. Even with these actions, we reluctantly had to ask our Local Networks to release their locally raised funds to support our vital services, such as our Helplines and trustworthy information on our website, providing information and support for everyone in the UK.

We are very grateful to our supporters in Northern Ireland, and the Northern Ireland Local Network, who have made a significant contribution to charity funds. We know how hard you have all worked to raise this money and we will use these funds to ensure the charity can continue to operate. We have received an increased demand in enquiries from people affected by Crohn's and Colitis living in Northern Ireland, and across the rest of the UK, and we know that you need our services more than ever at this difficult time.” - April 2020.

### Farewell to Rosemary and Zoe

It is with sadness that we say goodbye to two of our Organising Team members. Rosemary Patterson is stepping down after over 20 years of service to the NI Network. Rosemary has always been a kind presence at countless get-togethers and educational meetings over the years. Zoe McAteer is stepping down from the Organising Team after over 8 years of dedication. Zoe has been a friendly face at countless events and kept all our members and the public up-to-date on Twitter. Both ladies have volunteered their time and efforts for us and all those with Crohn's and Colitis in NI for many years. We at the OT will miss them both greatly, but we wish them the very best in their future endeavours. Above all else we wish them good health, and you'll be sure to see them at future events.



Concerned about Coronavirus? The Crohn's & Colitis UK website is an excellent resource during this time. It is updated regularly with relevant information regarding shielding and your level of risk. Find at: <https://crohnsandcolitis.org.uk/>

### IBD Clinical Psychological Support Meeting

In September, on behalf of the NI Network, John attended a virtual meeting regarding the discussion of clinical psychological support offered to IBD patients in Northern Ireland. Cases were made for more support in this area for patients, and the need for funding and service development was identified.

## YOUR LOCKDOWN STORIES SHARED

For many months this year it seemed as though the world had pressed the pause button. Here we document stories by members about their experiences of 'Lockdown.'

### CHARLENE MCKINNON

I believe my lockdown happened long before Covid-19 had hit. I took ill last year calling it the '1000-day cough.' They couldn't figure out what was wrong - X rays were clear. I worked through so many antibiotics and steroids till my body couldn't take anymore. Being signed off by the doctor was the worse feeling in the world. Not knowing what was wrong, my mental health took a serious dip - I felt so exhausted, irritated, taking it out on those close to me. I was able to go back to work only to be taken off again after developing an infection and signs of Covid-19. I then worked up until I got the letter of shielding. I couldn't believe it! There I was off again but this time for 12 weeks with no face-to-face contact. I wasn't allowed to go to college, work or even visit family. This was the soul destroyer for me. My routine was completely lost. The first couple of days I had plenty to keep me busy: finishing college work and sorting out my UCAS forms. But when this was finished, I had to come up with strategies in which I knew would keep me busy. I started upcycling old furniture that I had in the house, completed little home-made craft projects for Christmas. I started to redecorate and deep clean the house, moving rooms around to be able to get a study area for when I started University. My mum was cracking up as I had

the house upside down! I was now running out of rooms, so I needed something else. I was allowed to start a bubble with another family member who also had been shielding. I started to go out cycling as I



couldn't cope any longer in isolation, which my professionals agreed to. I was able to keep myself safe and healthy, in both my physical and mental health. I truly believe it's not the illness itself that brings us down, but all the secondaries: fatigue, loss of sleep, anxiety, self-criticising and other symptoms, My family were amazing, having FaceTimes with my loved ones that I couldn't see helped. I also had my lovely mother to look after only being through heart surgery before lockdown. My hands were truly full when she also decided to break her ankle!  
*Charlene*

### PIARÁS TOOLAN

Hi, I'm Piarás Toolan, I am 22 years old, exactly one year ago I was diagnosed with Crohn's disease. At the start I was confused and scared, but after lots of research I came to terms and understood what Crohn's disease involves. Little did we all know what the world was about to go up against, a vicious virus and put lots of people at risk.

At the start of the lockdown in March I was told to shield by public health authorities but I was also in the middle of finishing a 4 year sports degree at Ulster University. At this point of the course I had many assignments and presentations to submit, but the work really helped me keep my head sane being locked up. Lockdown also gave me the time needed to finish my degree, which I recently graduated with.

I feel that keeping my mind active during these crazy times really helped me stay positive, be it by learning, being active or just having fun, it all contributed to me having a good mind set.

If I could offer any advice it would be to surround yourself with people that make you happy and keep your mind active as it will create a positive environment for you to be in during these mentally challenging times.

Stay safe! *Piarás*

# YOUR LOCKDOWN STORIES SHARED

## LEONIE GRACEY

Back at the beginning of 2020 if you'd told me everything we'd go through, I would never have believed you!

For me, lockdown life coincided with post-op recovery— a prospect that filled me with dread, but it turned out to be a blessing in disguise. I was able to rest fully and indulge in many, many Netflix series and get lost in the pages of countless books. My top tip to anyone enduring shielding, lockdown measures or isolation for whatever reason, is to *be kind to yourself!* Do what keeps you safe and happy.

*Leonie*



A member who wishes to remain anonymous underwent a successful surgery in May during Lockdown. He details his journey and what he's learned:

"Panproctocolectomy and ileostomy recommended", were the words I jotted down when phoned by a gentleman from the City Hospital's Consultant's team. I was told I had a 40% risk of Bowel Cancer within 5 years if we do nothing (I am 69 years old). I was told the operation would involve losing the large intestine, rectum and anal passage and being sown back up again. They could operate within 4/6 weeks, Covid permitting. It was a lot for my wife and I to take in but like my quadruple by-pass 6 years previously, the nettle had to be grasped and lots of major decisions had to be made in a short space of time. My advice at this stage is to research and seek advice from GP, CCUKNI, and talk to close friends. Be positive and think about the future post-op. I also found prayer hugely comforting. Ask your Consultant's permission to tape your discussions.

A week later we were 55/45 in favour of the op, and a wonderful straight-talking Consultant laid out the pro's and con's. We felt if he was to be my Surgeon I would be in very good hands. 10 days later he operated. My tips on recovery would be:

- A. Whilst I did not feel pain higher than 4/10, nurses will stress they have painkillers and there's no need to suffer unreasonable pain.
- B. Bring your phone, charger & earphones with you to contact relatives, as Covid restrictions will likely mean no visitors.
- C. Bag emptying becomes a frequent chore, but do not worry. Very caring staff will help you get into the way of it quite quickly. When you get home more help is at hand RE stoma carer.
- D. Set an alarm at intervals throughout the night to empty your bag. Always attach a TRE Seal at bag change.
- E. Men – try braces instead of belts, much more freedom.
- F. Once home set targets for extended daily short walks. Within 10/12 weeks gentle sports like golf or longer walks should be getting within reach. // I am so grateful for the wonderful care I received

from the NHS, thank you sounds inadequate but heartfelt gratitude is hard to express. *Anon*

## OT MEMBER RUTH'S LOCKDOWN SURVIVAL TIPS

Here are some things that helped me during Lockdown:

- ⇒ Set your alarm! I made sure to get up at the same time every morning.
- ⇒ Use your usual commute time to do things around the house.
- ⇒ Take breaks during the work day! Move around the house, check in with colleagues, phone a friend or family member.
- ⇒ Stick to your finish time! I made sure to log off at the proper time as I would in the office, switch off and enjoy the evening.
- ⇒ Exercise! I used what would be the commute time home to get in daily exercise. Do online classes, or a simple walk outside.
- ⇒ Eat dinner at a set time.
- ⇒ Wind down! Use the evenings to catch up with friends/family via social media or calls. Zoom quiz nights, Netflix binges or catch up on your hobbies!

**ORGANISING TEAM MEMBERS**

Lead Volunteers:  
John Collins MD FRCP & Kim Montgomery

Finance Volunteer: Patricia Henderson  
Facebook: Ruth Kyle  
Twitter & Instagram: Kim Montgomery

Valerie Boyd Una Smart

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)

**ILEOSTOMY & INTERNAL POUCH SUPPORT GROUP**  
e-mail: [info@iasupport.org](mailto:info@iasupport.org) [www.iasupport.org](http://www.iasupport.org)

Newsletter printed by



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**



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Website: [www.crohnsandcolitis.org.uk/ni](http://www.crohnsandcolitis.org.uk/ni)



Crohn's & Colitis Northern Ireland Network



CrohnsColitisNI



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**GENERAL ENQUIRIES**

Crohn's & Colitis UK  
1 Bishops Square, Hatfield Business Park, AL10 9NE  
[www.crohnsandcolitis.org.uk/contact](http://www.crohnsandcolitis.org.uk/contact)

Volunteer Enquires: 01727 734 475

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 for anyone affected by Crohn's or Colitis.

Our team can:

- help you understand more about Crohn's or Colitis, 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 Crohn's or Colitis and understands what you are going through

**CONTACT US BY:**

Telephone: 0300 222 5700\*  
Monday to Friday - 9am to 5pm  
Email: [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)  
Live Chat: [www.crohnsandcolitis.org.uk/livechat](http://www.crohnsandcolitis.org.uk/livechat)

*\*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.*