

DATE FOR YOUR DIARY

VIRTUAL EDUCATION EVENT

Date: THURSDAY 17th NOVEMBER 2022

Venue: Zoom

Time: 7.00 - 8.30pm

Speaker: Dr Caroline Adgey

Topic: Modern Treatment of IBD, plus a short Q&A.

Register:

<https://ni-online-education.eventbrite.co.uk>

Northern Ireland Network

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FAREWELL—VALERIE BOYD

Our founding member, Ms Valerie Boyd, has stepped down from the Organising Team after a whopping 35 years of service here in NI.

Valerie has been instrumental in supporting our members and particularly passionate advocate for mental health and lobbying our ministers for recognition of IBD.

We will miss Valerie's contribution greatly and wish her all the very best.

WARMEST WELCOME WISHES TO ALL! IT'S BEEN QUITE A WHILE SINCE OUR LAST NEWSLETTER!

Since our last update, Lead Volunteer Kim, has stepped away from the Organising Team and Ruth has stepped into the role. Ruth has been with our local network for over 15 years and spent over 10 of those volunteering for us, many will know her as our Facebook Admin. Ruth is keen to keep our charity as the trail-blazing network set in place by predecessors Peri and Audrey, and has high hopes that we maintain and achieve this aim! Ruth is very keen on working together for the good of our network and those of us living with IBD, here in NI especially.

We have been listening to your feedback and we plan to arrange many more social and All-age events open for all to attend! Please keep an eye on your emails and our social media for updates.

We thank each of you for your continued support and look forward to seeing you at our events this year.



CARNFUNNOCK GET-TOGETHER - JULY

We had our first in-person event since the pandemic began at Carnfunnock Country Park, Larne on Saturday 2nd July!

This all-age event was well attended and we met many new members as well as those newly diagnosed during the past year.

The day started off sunny and warm, but rain quickly followed with an epic downpour! It didn't dampen spirits though, as everyone gathered together under the cover of the picnic area to continue to chat, share stories and get to know each other.

A great day was had by all and many have already been asking when the next one is! Keep an eye on your email and social media for updates!!



We take photos at all of our events to share with members in our newsletter and across our social media. We understand that you may wish to attend an event but do not want your photograph taken and/or shared for whatever reason, therefore, please contact us prior to the event, or on arrival to inform us of your wishes.

We've listened to your feedback and hope to host more social get-togethers across Northern Ireland in the next year. These will be all-age, family friendly events where possible, we will endeavour to cater to everyone and host across NI where possible.

FUNDRAISING & DONATIONS 2020 - 2022



Customer Direct Team at Danske raised £230 wearing Christmas jumpers! Looking good everyone!!



Enya Lawlor raised £207 selling her lovely eyelash kits!



In both 2020 and 2021, Sarah who has Crohn's, her Dad Paul, and friends, completed in 48 hours 5k runs every 4 hours, 12 runs in total, and through the night! A fantastic £4500 was raised for our Network! Thank you so much!!



Claire Hammond held a tea party at Ulster Hospital raising a fantastic £125!

OTHER DONATIONS 2020-2021

- £80 in memory of Jennifer Ruth Duffy
- £50 Joanne & Mark Goodfellow and Gwen McKee
- £50 Heather, Colin & Ross Nelson
- £1300 in memory of Deirdre Mills
- £100 Ulster Transport Bowling Club, Veterans Section
- £150 Hutchinson Family
- £88.70 Hunt's Traditional Fish & Chips, Lambeg
- £2000 legacy donation Mary Nevin
- £31.36 Hughes Eurospar, Carrickmore
- £475.97 Margaret and Eurospar Crumlin

FUNDRAISING & DONATIONS 2020 - 2022

The McCann family took on a massive 6 MILLION step challenge, over a month, smashing their goal early and raising a fantastic £2413.47!!

What an achievement!



Thanks to Justyn for hosting his Annual Golf Day in July 2021, raising £2000 for our network!

So glad the sun shone for you all!

Tyla donated £30 in lieu of teacher gifts.

Very kind of you Tyla!

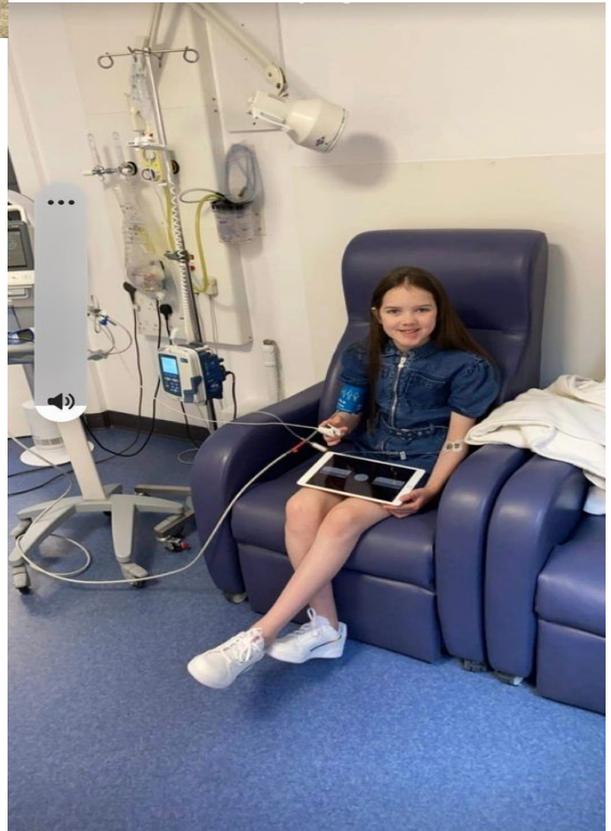
Have you any plans to do some fundraising?

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 *Just-Giving* page.

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 also request t-shirts, vests and some merchandise.



FUNDRAISING & DONATIONS 2020 - 2022

ATHLETIC BREWING CO
ALCOHOL-FREE BEERS
IRONMAN
BARCELONA

OCTOBER 3RD 2021

Catherine Butcher

SWIM	00:12:45	FINISH	
BIKE	06:48:47		11:50:49
RUN	04:23:47		

OTHER DONATIONS 2022
 £20 Angeline Adams
 £142.13 Hunt's Traditional Fish & Chips
 £580 Antrim Area Hospital, Radiology Dept.
 With thanks to Amanda Getty and Suzy Larkham
 £400 in memory of Mrs Shirley Ina Elliot
 £390 in memory of Mr Cedric Stewart
 £80 Kevin Healey
 £30 Pauline McClure
 £110 in memory of Mr William McDowell
 £1000 Capper Trading
 £100 Dan McQuillan
 £450 Bank of Ireland
 £2500 P&S Beagan

Catherine Butcher completed IronMan Barcelona! Raising a fantastic £2051 for our Network!



Dallas Houston and family held a socially distanced BBQ in their cul-de-sac raising a fantastic £350!



Martin Alves took part in the Great North Run in September 2021, raising a fantastic £1000 for our network!

LEONIE GRACEY: PORTADOWN CARES DOES STRICTLY, MARCH 2022



In March 2022 our Organising Team member and Instagram admin, Leonie, put on her dancing shoes and took on the challenge of learning six exceptional routines! Performing over two consecutive nights, to a sold-out audience at the Seagoe Hotel, Portadown, it was quite an achievement and baptism of fire! Leonie even had some family rivalry going, as her brother was also a competitor!

This was quite the challenge for Leonie as a non-dancer, but she smashed it, showing hidden dance talent and natural flair; she was 'practically perfect in every way' and was awarded the prestigious honour of 'Spirit of Strictly' for her determination, comradery, positivity and all-round approach. This comes as no surprise to those who know Leonie personally, and we are so proud of all she has accomplished.

Leonie's efforts and continued fundraising have raised a fantastic £750 for our network so far!



JUST GIVING

INFORMATION FOR PAGE SET UP AND DONATIONS TO NI NETWORK

We are so appreciative that many of you fundraise for us here in NI via *JustGiving*.

Due to policy changes within the national office, you **MUST** specify on **set-up of your page** that the money raised will be donated to us here in NI, and inform the fundraising team of this on set-up of your page, otherwise all money raised will be allocated to the national office. No exceptions.

We would also ask that you let us here in NI know about your fundraising, to give us the opportunity to promote your event and thank you for your hard work.

Contact us for more information, or use the link on the Crohn's & Colitis UK website:
<https://www.crohnsandcolitis.org.uk/get-involved/fundraising/organise-your-own-event>

To ensure that the NI Network receives donations made through the page, the following steps must be followed:

- To inform donors where their money is going, the following text must be included on the page, specifying which Network is being supported by the funds.
"This page is raising money in aid of the Crohn's & Colitis UK - Northern Ireland Local Network. All money received by Crohn's & Colitis UK through this page will be passed onto the team and used by them locally to continue their work."
- You must give your page an appropriate close date, as money will only be transferred to the NI Network when the page closes.
- You must notify the Fundraising Team at fundraising@crohnsandcolitis.org.uk with the link to your page as soon as it goes live and specify the close date which has been entered and that the money raised should be allocated to the NI Local Network.

****Please note that if the purpose of the page is not made clear as in the above steps, the money will be transferred to national funds as per the default process.**

**CROHN'S &
COLITIS UK**
NORTHERN IRELAND

—
FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER



WORLD IBD DAY 2021



Huge thanks to Cllr Ross McMullan, Alliance, for organising City Hall, Belfast to be illuminated for World IBD Day 2021 and 2022.

2021 City Hall, Belfast. Photo credit Kim Montgomery

2021 Lagan Valley Island, Lisburn. Photo credit Brian Higginson



WORLD IBD DAY 2022



2022—Organising Team members Leonie, Ruth and Valerie at City Hall, Belfast. Photo credit Leonie Gracey



Inspirational stories

You can achieve anything when living with IBD!



Our previous Lead Volunteer Kim was awarded the ANJOO MALDÉ JOURNALISM AWARD (co-hosts Queen's University Belfast) in 2021.

Well done Kim! Showing that dreams and goals are still achievable when living with IBD.



“Yes, it took Jenna 9 years to get her degree due to her health, but now she has finally achieved her goal. If there was ever a definition of determination, it is Jenna!

Jenna suffers from Crohn's disease and has been unwell her whole life. She started her Midwifery degree in London in 2012, but in her second year took very ill and lost a lot of weight due to the condition. She was forced to return home to Coleraine and needed emergency surgery to remove some of her bowel.

Jenna had to abandon the career she loved, but I knew she wasn't going to give up, no matter how ill she was. She applied for Midwifery at Queen's but due to bad health didn't take up a place. She applied again the next year and was successful but was also working and struggled with the long, early train journeys. Jenna was always worried about needing the bathroom at short notice and hid her constant pain and fatigue to push through, but ended up having to take a year out.

During this time, she volunteered for Tiny Life and worked part-time as a community carer. Eventually she got back to her studies and was acing it! Then Covid-19 happened. Jenna was in the shielding category due to the biological immunosuppressant drugs she gets intravenously every 8 weeks for her Crohn's and was forced to stay at home. When she was able to return she had missed out on many opportunities to gain the competencies needed to qualify, due to the pandemic. This meant she went on call 24/7 for seven weeks to ensure she gained them.

Jenna delivered her 40th baby on 28th January 2021 and is finally a registered Midwife, despite everything that life has thrown at her.”

What amazing determination, Jenna Doherty. Anyone would be lucky to have you by their side during delivery.

Shared via Queens University Belfast on Social Media on 31st March 2021

TRIBUTE WILLIAM MCDOWELL



Crohn's & Colitis UK—Northern Ireland Network wish to pay tribute to one of our long-standing members and supporters, William McDowell, who passed away in May 2022.

William lived with Crohn's for many years and rarely missed a meeting or event. He was a familiar face to many of you and an incredible support to our Network, a regular at meetings, always welcoming new faces and chatting with members.

William also made time to check in with our Organising Team to see how we were doing and offer words of encouragement and advice.

Our Organising Team members, past and present, will miss him greatly, and we offer our sincere condolences to William's family and friends.

Before his passing, William made arrangements for donations in lieu of flowers to be sent to our network.

We would like to thank William's wife, Irene, and his family and friends for supporting his wishes and for their very kind donation of £110 in his memory.

VIRTUAL SOCIAL - OCTOBER

WEDNESDAY 26TH OCTOBER 2022

6.30–8.00pm

Register:

<https://ccukni-social.eventbrite.co.uk>

Join Organising Team members, Leonie and Una virtually to chat with others from across Northern Ireland who live with IBD.

Friends and family are welcome to attend



We are currently planning our meetings, and social events for the year!

Keep an eye on our social media pages for arrangements.

These events are open to all, and we welcome you to join us informally to get to know each other and make new friends and connections with others living with IBD.

FESTIVE SOCIAL - Clifton House, Belfast

SATURDAY 3RD DECEMBER

2.30-4.30PM

Clifton House Heritage Centre
2, North Queen Street, Belfast, BT15 1ES

This Crohn's & Colitis Awareness week, we welcome you to join us for our festive social at Clifton House.

This is an All-Age event and we encourage you to come in festive attire! A light sandwich buffet will be provided.

This will be a FREE event but places will be limited, with registration required. Details to follow on social media pages and website as we confirm final arrangements.

We are currently planning to host both virtual and in-person events as far as we possibly can.

Our virtual meetings have been really popular during the pandemic, and many of you have communicated that you would like for these to continue as it allows you to connect with others, even if you don't feel well enough to travel to an in-person event.

We are keen to get back to our regular events too, so we are picking up where we left off, and organising our informal social get-togethers for all to attend. We are trialling different ideas for these to suit the needs of members, for example, short meet ups for walks, to appeal to as many of you as we can.

If you have a suggestion for an informal get-together you would like to see take place, or a location, please get in touch with our team and we'll see what we can do!

In the meantime, keep an eye on our social media pages to see what is coming up!!

ORGANISING TEAM MEMBERS

Lead Volunteer: Ruth Kyle

Finance Volunteer: Patricia Henderson

Facebook: Ruth Kyle

Instagram: Leonie Gracey

Una Smart, John Collins, Charlene McKinnon

Medical Advisor: Dr G Turner MD FRCP

IBD NURSE SPECIALISTS**Northern Trust:**

Jacqueline Kearns, Antrim, 07881654799

Rebekah McFarland, Antrim, 07881654799

Louise Scullion, Antrim, 07881654799

Catherine Butcher, Causeway, 02870346290

Stevie Ann Martin, Causeway, 02870346290

Belfast Trust:

Noreen Kennedy, RVH, City

Caroline Collins, RVH, City

Caroline Masterson, RVH, City

Susan Doherty, RVH, City

Karen White, Nurse Admin Support Worker

Tracy Close, Paediatric Nurse Specialist, RVH for Sick Children, VM:02896156489 Secretary: 02890633728, Tracy.Close@belfasttrust.hscni.net

Stacey Watson, Stacey.Watson@belfasttrust.hscni.net

Southern Trust:

Ruth Hall, 07788726875, ibdadvice-line@southerntrust.hscni.net

Niamh McCabrey

South Eastern Trust: IBDINFO@setrust.hscni.net

Gayle Martin, Belfast, Ards & North Down, 07843345386

Claire Flynn, Belfast, Ards & North Down, 07779960123

Dawn Kilpatrick, Lisburn & Downe Areas, 07971322937

Western Trust:

Stephanie Dunn, Altnagelvin

Tracy Hill, South West Acute Hospital,

Tracyhill@westerntrust.hscni.net

ILEOSTOMY & INTERNAL POUCH SUPPORT GROUP

e-mail: info@iasupport.org www.iasupport.org

Welcome to all new members. We look forward to seeing you at some of our events. Please introduce yourself to us, and remember, family members or friends will be equally welcome.

CONTACT US

Northern Ireland Network

Lead Volunteer: Ruth Kyle

Website: www.crohnsandcolitis.org.uk/niEmail: ni@networks.crohnsandcolitis.org.uk**CROHN'S & COLITIS UK**

Crohn's & Colitis UK



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GENERAL ENQUIRIES

Crohn's & Colitis UK 1 Bishops Square, Hatfield

Business Park, AL10 9NE

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 Team can provide information on a range of subjects including:

Managing symptoms

- Medication
- Diet
- Test and diagnosis
- Wellbeing
- Employment
- Disability benefits
- Help to find support from others living with the condition.

We also signpost people to sources of expert advice on disability benefits and options for specialist emotional support. If you need specific medical advice about your condition, your GP or IBD team will be best placed to help.

CONTACT US BY:

Telephone: 0300 222 5700*

Monday to Friday - 9am to 5pm

Email: helpline@crohnsandcolitis.org.ukLive Chat: 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