

# **NEWS**LETTER

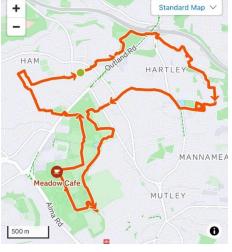
**SUMMER 2025** 

#### **East Cornwall & West Devon Network**

# LINDSAY & DIZZY RAISE £700!

Local volunteer Lindsay Lane-Lobb and her 4-legged companion, Dizzy, completed over 10km for My WALK IT this June. They followed their own route around the streets of Plymouth and Central Park, stopping for a well-deserved "cheeky ice cream break" on a pretty hot day. Not only did they raise plenty of awareness on their walk, but they also raised a fantastic £700!







Lindsay has lived with Crohn's Disease for over 10 years and it has been an uphill battle. None of the medications have worked and she has had over 30 operations in the last 9 years, including major surgery this year. Despite all this, she's a committed volunteer who cares deeply about helping

others who are struggling with Crohn's or Colitis.



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#### **JOIN US FOR A SUMMER BEACH CLEAN**



The Marine Conservation Society (MCS) are organising a Beach Clean on Saturday 9<sup>th</sup> August, with the aim of improving the local environment whilst also supporting Crohn's & Colitis UK via an optional donation.

We hope this event will also provide an informal setting for people to meet and chat with others living with Crohn's Disease or Ulcerative Colitis, a bit like one of our coffee mornings, but outside!

Family, friends and the general public are very welcome to attend and we'd love for you to be part of it. Please spread the word so we get a great turn-out on the day!

We will be gathering at Wembury Beach for a Beach Clean and Litter Survey in partnership with Beachwatch - a national beach cleaning and litter recording programme run by the Marine Conservation Society (MCS). This programme aims to tackle beach litter and help stop polluting our ocean by gathering data which is used for international scientific research and to drive campaigns for environmental change. Volunteers from the East Cornwall & West Devon (ECWD) network of Crohn's & Colitis UK will be attending to raise awareness of the charity and to share their experiences of living with Crohn's or Colitis.

The beach clean will involve cleaning up litter and recording what we find along a 100m stretch of the beach. There will be a selection of equipment to borrow (litter pickers, bags, clipboards, gloves), but feel free to bring your own if you prefer!

- Meeting Point: Wembury Beach, Wembury, Devon, PL9 0HP
- Date: Saturday 9<sup>th</sup> August 2025
- Start Time: 9:00 am (please arrive 15 mins early)
- Estimated Duration: 1-2hrs no pressure to stay the whole time
- Facilities: Car park (JustPark app), Toilets, Café
- What to Bring: Weather-appropriate clothing, suncream, suitable footwear
- Note: Dogs are NOT allowed on the beach between 1st May 30th September

When you arrive, look out for the people in high-vis vests! They will welcome you upon arrival, explain how to complete the litter survey and hand out any equipment. Once the clean is complete, the litter will be weighed and we'll give ourselves a well-deserved pat on the back for our efforts!

In the event of bad weather, updates will be posted on our social media pages and on the MCS event listing (<a href="https://www.mcsuk.org/beach-cleans/crohns-colitis-uk-beach-clean-09-08-2025/">https://www.mcsuk.org/beach-cleans/crohns-colitis-uk-beach-clean-09-08-2025/</a>) where you can also access full event details and registration information.

We hope you can join us for a beautiful morning by the sea, sharing memories with like-minded people and supporting a cause close to our hearts!

This event is hosted by Marine Conservation Society. Please contact them at <a href="https://www.mcsuk.org/beach-cleans/crohns-colitis-uk-beach-clean-09-08-2025/">https://www.mcsuk.org/beach-cleans/crohns-colitis-uk-beach-clean-09-08-2025/</a> if you would like any further information.

#### **CHANGE TO IBD NURSE CONTACT DETAILS**

We always get a hugely positive response to anything we publish about our local specialist IBD nurses at Derriford and you all know how hard they work. Well it turns out they have been too nice to everyone and are struggling to cope with their ever-increasing workload! This is mainly because people are emailing the IBD nurses with numerous requests for things like routine medication, medical letters, help with PIP, etc - all things that should really be dealt with by their GP.

Because of this, they have decided to run a trial for 3 months or so, starting on Monday 14<sup>th</sup> July 2025, which involves having two IBD email addresses, one purely for flare-ups and the other for everything else. The email for flare-ups will be <u>plh-tr.ibd-acuteflare@nhs.net</u> and the IBD nurses will continue to respond the same day, as they do now. The existing email address (<u>plh-tr.ibd-advice@nhs.net</u>) will be looked at once a day as it will be classed as non-urgent.

I'm sure you can all understand why this email separation has become necessary and will do your best to comply. *Please also pass this message on to anyone you know who uses the IBD nurse service at Derriford*.



#### **MEMORABLE MAY FAIR**



We had a lovely time at the May Fair in Plympton and we were very pleased to have raised £150. As usual, our Shoot the Poop game drew in plenty of people, including the newly-elected Plympton Stannator, Cathy Loft and Youth Ambassador, Grace Nicholls.

But our favourite part of the day was chatting with people like us, who are living with IBD, advising them of the benefits of the Crohn's & Colitis UK website, and offering support based on our own experiences.



Three JAKs are currently approved in the UK; tofacitinib (brand name Xeljanz) and filgotinib (brand name Jyseleca) are licensed for ulcerative colitis (UC), while upadacitinib (brand name Rinvoq) is licensed for both UC and Crohn's disease.

JAKs can do amazing things — but sometimes they come with unexpected side effects like acne. Acne may affect more than 1 in every 10 people taking upadacitinib, so it's common, manageable, and nothing to be ashamed of.

If you're struggling, chat to your GP or your IBD care team and don't suffer in silence.



#### **JAK inhibitors & Acne**

Taking a JAK inhibitor like Upadacitinib for IBD and noticing breakouts?

You're not alone - acne is a known side effect.

#### What are JAK inhibitors?

Janus Kinase (JAK) inhibitor - JAKs are proteins that play a part in activating the body's immune response. This can cause gut inflammation in Crohn's and Colitis. JAK inhibitors block the effects of JAKs, easing inflammation in the gut.

# Why does it happen and what can you do?

For an excellent description of the causes of acne and the best treatments, go to the NHS website at <a href="https://www.nhs.uk/conditions/acne/">https://www.nhs.uk/conditions/acne/</a>

You may also find it helpful to consult your GP or your IBD nurse.

If you're raising money locally for Crohn's & Colitis UK please get in touch with us so we can promote and support your event by emailing

ecwd@networks.crohnsandcolitis.org.uk

or message us on our **Facebook page** 

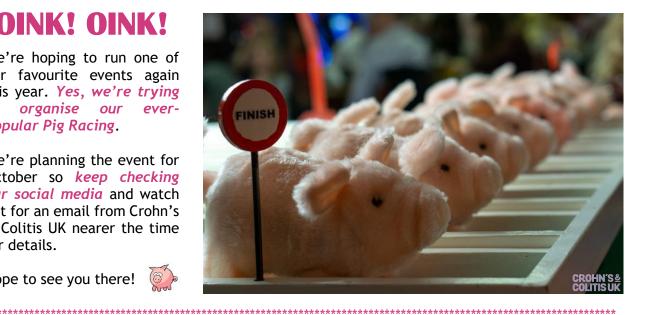
#### **OINK! OINK!**

We're hoping to run one of our favourite events again this year. Yes, we're trying to organise our everpopular Pig Racing.

We're planning the event for October so keep checking our social media and watch out for an email from Crohn's & Colitis UK nearer the time for details.

Hope to see you there!





# Licensed Restaurant & Takeaway

#### MULLED WINE ANYONE?

DEC

As many of our long-standing members will know, Karen Kestell, owner of Karen's restaurant in Tavistock, has hosted us for Dickensian Evening for many years. Every year, this wonderfully generous lady and fabulous cook has provided us with her famous (or should that be infamous!) mulled wine and mince pies to sell in aid of the charity.

Last year was supposed to be the final time as Karen was planning to sell up but sadly, the event was cancelled due to the weather. However, Karen hasn't managed to sell yet so has kindly invited us back again this year!

Keep checking our social media for more details!



## FOLLOW US ON SOCIAL MEDIA



**f** crohnscolitisuk.ecwd crohnsandcolitis ecwd

#### **CONTACT US**

#### EAST CORNWALL & WEST DEVON NETWORK

Leads: Shas Chilcott and Dani Brown

**2** 0300 222 5700 (via Helpline Service)



ecwd@networks.crohnsandcolitis.org.uk



www.crohnsandcolitis.org.uk/ecwd



crohnscolitisuk.ecwd



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#### **CONTACT FOR LOCAL IBD NURSES**

Derriford Hospital, Plymouth

2 01752 439224 ⊠ plh-tr.ibd-advice@nhs.net

#### **HEAD OFFICE CONTACTS**

1 Bishop Square, Hatfield, AL10 9NE

<u>helpline@crohnsandcolitis.org.uk</u>

Website: www.crohnsandcolitis.org.uk

HELPLINES 2 0300 222 5700

Mon-Fri & 9am-5pm (except English bank holidays). Answer phone service outside these hours.

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If you have received this newsletter by post and would be happy to receive future editions by email please send your name, membership number and email address to

#### networks@crohnsandcolitis.org.uk

This will save the Network valuable funds which can be used to benefit all those affected by Crohn's or Colitis.

### BIG SUMMER SKIP

Did you miss My WALK IT this year? Are you up for a challenge? How about joining the Big Summer Skip!



Take on a fun, feel-good challenge: 123 skips a day for 31 days - one for each of the 1 in 123 people in the UK living with Crohn's or Colitis.

- Sign up for free
- Receive your FREE skipping rope and challenge tracker
- Do 123 skips a day throughout August
- Access to the exclusive Facebook group for encouragement, community, and a few laughs
- Raise awareness and funds to support vital research and lifechanging support services

Get skipping — anywhere, anytime, solo or with friends. Every skip counts. <a href="https://crohnsandcolitis.org.uk/challenges/big-summer-skip">https://crohnsandcolitis.org.uk/challenges/big-summer-skip</a>

The East Cornwall & West Devon Network has made every reasonable effort to ensure the content of this newsletter is accurate but accepts no responsibility for any errors or omission.

The views of the contributors do not necessarily reflect the views or policies of Crohn's & Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.