

# Under the Microscope

**Bumper issue!**

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Chambers, age 9

Paediatric Gastroenterology Research Team newsletter  
Addenbrooke's Hospital, Cambridge University Hospitals NHS Trust

Issue 8

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## HELLO!

Welcome to issue 8! After a few rainy weeks, we're looking forward to a sporty summer ahead, with the final stages of EURO 2024, Wimbledon and the Paris Olympics on the horizon.

We held our 2024 EEPGN study day in June, working together with hospitals across our region to share information and make sure everyone gets the best care possible.



We had fun at the Cambridge Stem Cell Institute annual retreat 2024 - this is a bit like a school trip where everyone who works in the lab goes to a special place to learn new things, share ideas and work together on cool projects!

The lab team has said goodbye to Francesca and Ranney recently, and we wish them both well in their new adventures. We have included Ranney's story in this issue, as she has been such a valued member of our team. We are looking forward to welcoming Dr Rebecca Poole as a new consultant to the medical team from July.



Congratulations to Dr Gasparetto from NNUH on running the London marathon in a speedy 4 hours and 2 minutes, raising money for Crohn's and Colitis UK. Well done Marco!

We are excited to be working with Dr Paul Henderson from Edinburgh in this issue. He is sharing his research from the PINPOINT study on page 3!



We had such fun meeting so many of you at our first family day in April. Well done again to the winners of the drawing competition. Find out all about the day later in this issue, and see the winning pictures from our drawing competition!

A big thank you to Bea, our guest editor for her hard work on our newsletter.



**Cheesy science joke!**

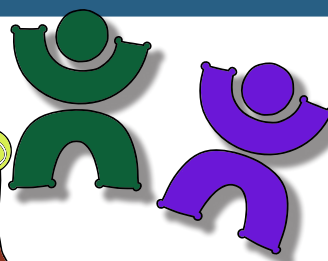
Why did the physicist  
break up with the biologist?

Because there was no  
chemistry!

**An interesting (and gross!) science fact!**

The biggest piece of fossilised dinosaur poo ever found is over 30 centimetres long. Scientists think it came from a Tyrannosaurus rex. This big old dino poop, called a 'coprolite', helps scientists learn what dinosaurs used to eat.

# Meet our team...



Scan here to see all our newsletters!

## EMMA

'I own a stand-up paddle board and often float along the river in St Ives during the summer evenings!'

'My 3 favourite cuddly toys, Teddy and Biscuit (both bears) and Pablo (a penguin) often sneak into my suitcase and come travelling with me!'



'I have been playing the piano since I was 5 but I was always terrible at sight-reading so I play by listening instead!'

Hi, my name is Emma. I have been the pharmacist for the paediatric gastroenterology team for just over 5 years. As a pharmacist, my role is to be the "medication expert" for the team, making sure that medicines are prescribed correctly for patients and providing advice when the doctors, nurses or dieticians want to do something a little bit complicated! I also work behind the scenes to make sure that children with inflammatory bowel disease, intestinal failure or other gastroenterology conditions can have access to the specialist medicines that they need. This involves doing a lot of research - looking at clinical trials and papers that other experts have written and deciding if their research was good or not! I love working with everyone in the team and I also enjoy spending time with them outside of work - we often go for very tasty dinners out together!

At home, I used to have a campervan called Monty, but we have recently sold him and bought a new caravan called Clyde. I have lots of adventures already planned in Clyde - travelling across Europe next year whilst I am on maternity leave to try and find some nice warm weather and sunshine for camping!

## RANNEY

Hi, my name is Ranney. Until recently I worked as a research assistant with a bunch of awesome scientists in the lab. They are trying to learn more about inflammatory bowel disease (IBD) and hopefully figure out ways of solving the disease! One of the cool things I did was creating mini-intestines in dishes from biopsies, which we call "organoids." It's like growing tiny versions of intestines in the lab. I took care of them by feeding them the right nutrients and making sure they were happy and growing strong. Sometimes, I even sang to them so they grew better (or the opposite sometimes!). I also kept track of all the data from the organoids. It was a bit like being a teacher, making sure all my little students (the organoids) were growing well and keeping records of their progress.

In my free time, I enjoy playing badminton with friends and going out for walks in the garden when it's nice and warm. These activities help me relax and recharge, so I'm ready for more exciting discoveries in the work I do!

'I love watching movies, I can watch five movies in one day!'

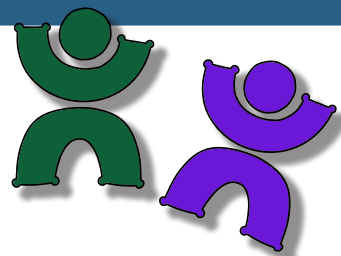


'I can't live without spicy food!'

'I'm always hungry in the middle of the night!'



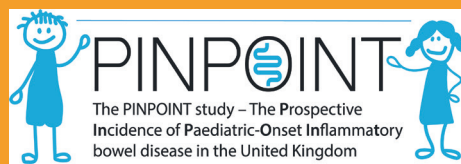
# Our research...



(...and interesting research other teams are doing!)

This is Dr Paul Henderson. He's a paediatric Gastroenterologist at the Edinburgh Sick Children's Hospital. A few months ago he asked us to take part in his study. Here he explains what it's all about...

## The PINPOINT study... don't worry, you're not alone!



How many children and young people have inflammatory bowel disease (IBD) in the UK?

**Great question!** The last time anyone looked at this was probably before you were born, back in 1999 (25 years ago, the year Sponge Bob Square pants was invented!). So we thought it was time to take another look - lots of other countries have done similar research and found that more and more children and young people are being diagnosed with IBD.

So, with the help of all the hospitals in the UK who look after children and young people with IBD we set out to count all the people diagnosed with IBD from June 2021 to December 2022. We also attempted to count how many children and young people were living with IBD in February 2023.

Although it was a tricky task to get everyone on-board, the team did a great job and we were able to count over 2400 people with IBD. This showed us that **around 130 young people are diagnosed with IBD every month in the UK.**

We also found that there are **just over 6000 children and young people living with IBD in the UK right now** - so if you are someone who is living with IBD then you're not alone!

Our next plan is to contact all the patients that were keen to stay involved and to get them involved in some new and exciting studies looking at fatigue and other difficult aspects of living with IBD.



If you want to get in touch with PINPOINT (even if you didn't sign up first time round)

just email [pinpoint@ed.ac.uk](mailto:pinpoint@ed.ac.uk) and we'll be happy to have you in the PINPOINT team!

# Family day!

Scan here to see a short Family day film



...or go to  
<https://tinyurl.com/5x7a28cw>

In April, we held our first PIBD Family day, and what a day it was! Lots of you brought your families to join us for a day full of fun and learning...



crafts and activities!



fun with friends!



games!



discussions groups and research!



drawing competition!



Our 'Draw the Team' competition was a highlight of the day, and it was hard to choose our three talented winners. Here are their winning entries (and we've included more of our favourites on the opposite page too!)



Winner!  
Under 10's

'Dr Franco'  
By Jan, age 8



Winner!  
10 - 16's

'Mary'  
By Lara, age 12



Winner!  
Grown ups

'Marco'  
By Kezi, a grown up  
(and Hugo's mum!)





# Holly's story

Holly is 12, and she took part in our research discussion group at the family day, sharing her experience of taking part in a clinical trial. Here's her story...



(Find out what else Holly has been up to over the page...)

1

"Hi, my name is Holly. I was actually really nervous to take part in a study."

2

"The idea of a research study really scared me, particularly the thought of leaving everyone from clinic 6. But when I was offered the option of doing the study, it was either that or surgery so it very much felt like a last resort"

3

"When we joined, we were given lots of leaflets and forms which told us about the study, such as side effects, how to take the drug and other information. It helped me to know more about what was happening."

4

"I don't particularly like injections, I mean, who does?! But the staff and medical team really helped lighten the mood by singing funny songs and even reenacting scenes from movies!!"

5

"It became easy to have blood tests in the research centre and go there for my hospital appointments, instead of clinic 6. Everybody there is really nice and welcoming."

6

"Even though I'm not on the research study any more, I'm glad that it kept me well until there were more drugs available to my age group."

7

"I would love to do a research study again. I wish I was still on it now - it was brilliant!"

Nurse Mary, by Bea age 8



Anna, by Krystyna a grown up!



Kim, by Lydia age 7



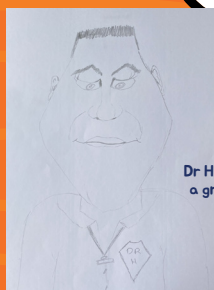
Dr H, by Sebastian age 9



Doctor Matt Z, by Angelina, age 7



Dr H, by Kelly a grown up!



Anna, by Sophie age 10



Mary, by Myra age 5



Claire, by Ayla age 9



Nurse Mary, by Connie, age 10



Jen, by Hugo age 7



Dr H, by Thomas age 10



Mary and Dr Torrente, by Holly, age 12



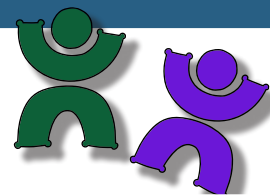
By Daisy, age 12



Rob and Franco, Anon

Our PIBD Family day 2024 was a great success, and we are excited that family days will now be part of what we do every year! We hope you can join us at the next one!

# Over to you...



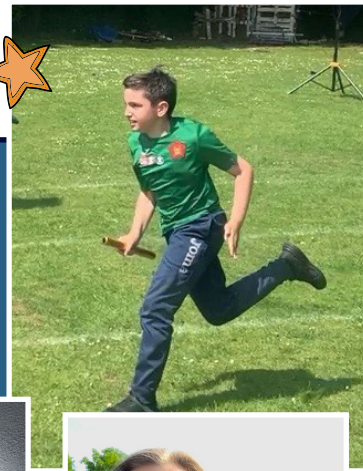
A space to share your news, talents and things to celebrate!

Meet Zachary, he's 9 years old and here his mum tells us about his great week!

'Zachary had a superb sports day and came 1st in two of his races. We are so proud of him, proving to everyone that having IBD does not stop you from achieving great things.

Zachary also got awarded 'Star of the Week' for kindness at school.'

Well done Zachary!



Meet Emily, who tells us about her exciting trip!

'Hi! I am Emily and I am 10 years old. I have Crohns and have infusions every 8 weeks.

On Friday 7th May I went to a camp with my brownies for two nights. Me and my little sister Lydia, who is 7, went together.

We did lots of activities and our theme was wizards, so we got to bring cloaks as well!! We did lots of potion lessons and got to invent our own magical creatures.

On Saturday, we did rock climbing and I was very proud of myself as I got to the top. We got to help out by setting the tables before meals and cleaning up afterwards. We also got to help cook the meals (with help of course!!). We made witch hats and painted cauldrons. We also had a campfire which we sang songs around and when we got back we had hot chocolate and marshmallows.

I also managed all of my medication during the camp.

Just remember, if things get tough, don't let Crohn's and colitis stop you, you can do whatever you put your mind to.'



Meet Arthur, who tells us about sharing his story with the media and his school!

'My name is Arthur, I am 11 and I have Crohn's Disease. I was interviewed about taking part in the Tripp Study by someone from Cambridge University, who wrote an article about the study and asked me questions about Crohn's and my life.

It was quite cool to see the article published about me and about Crohn's Disease. We sent the article to my school, and to friends and family. My teacher asked if I would do a talk to my class about the interview and about having Crohn's. My classmates asked me questions afterwards, like how long have I had Crohn's Disease and what are the burdens of having it. It feels quite nice to have everyone be aware.'







**Meet Daisy. She's 13 years old and here she tells us about her big surprise!**

'Last week I had the best surprise EVER. I was feeling really tired after a long day at school when mum gave me a silver envelope to open in front of my brother and sister. I was really confused. When I opened the envelope, the first words I saw were 'You're invited' and then I read that I was going to Florida for the holiday of a lifetime with a charity called Dreamflight! I will be going with a lot of other children with chronic illnesses and conditions as well as doctors and nurses. Normally I dread going away, but knowing I will be going with other children who will understand how hard it can be makes it easier. I am so excited to go and so thankful to have been nominated. I am jumping for joy!'



**Sienna is 8, and here her mum tells us about her good news!**

'Sienna has ulcerative colitis and has been struggling with a massive flare up recently. She was given a double infliximab infusion earlier in June and had a couple of days of feeling really rough and tired. But the following Monday Sienna was feeling less pain so she was able to focus on school work and have more energy. Her teachers have said they have seen a vast improvement and gave her the 'star of the week' award for her year group for her perseverance and good work. We are very proud of her, she's finally able to show her true self.'

**Well done Sienna!**



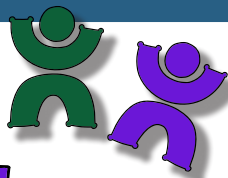
**Meet Romilly!**

She's 10 years old, and a talented artist! Here she shares a picture she drew of her furry friend!



Holly (the same Holly who shared her research story on the previous page!) had an exciting time filming with Katherine Nash from Channel 5 News. She talked all about taking part in the Tripp study, and research in general, and was a complete natural in front of the camera! Her interview was shown on the news on the 11th June.

# Time to play!



## calling all young journalists!

Would you like to write, or draw, or share something for our newsletter? Or do you have ideas about what we could add? We'd love to hear from you.

We'd also love to know what you enjoy about our newsletter, and what could be better (You can ask us to stop sending you our newsletters here too).

To get in touch, scan this QR code or email: [claire.glemas@nhs.net](mailto:claire.glemas@nhs.net)

Can you complete this research dot to dot and missing vowel game, both designed by our guest editor!



## DOT TO DOT

challenge!



Find the missing vowels for each of these words (they're all related to the dot to dot!)

1. T \_ st t \_ be
2. S \_ mpl \_
3. M \_ cr \_ sc \_ p \_
4. Sl \_ d \_
5. L \_ b \_ r \_ t \_ ry
6. \_ nl \_ rg \_



Have you spotted the extra bit - join the letters!

## Meet our guest editor...

Hi my name is Bea (short for Beatrice). I'm 9 years old and I live with my family and two cats in Hertfordshire. My favourite colour is orange, I love all sports, especially playing football with my friends, and my favourite animals are red pandas.

I was diagnosed with Ulcerative Colitis aged 6. At first I was quite poorly and scared but my medical team were really kind and helped find the right medications for me. I take part in research because it feels good knowing I'll be helping other children in the future. Ulcerative Colitis can be hard at times but it makes you unique and special and I don't let it stop me from having fun.



Would you like to be our guest editor and help create a future newsletter? Let us know - [claire.glemas@nhs.net](mailto:claire.glemas@nhs.net)

