

# the insider

Autumn 2024



## Back to school

Tips from a mum, who is also a teacher

**inside** >

- PIBD BioResource | 3
- Website help needed | 7
- School support | 8
- London meeting details | 9
- Christmas Cards changes | 20

**cicra**   
better lives for children with crohns and colitis



## CONTENTS

Message from the Chair	2
BioResource update	3
Cicra Bursary Grant	6
Trustee news	7
Support for students with IBD	8
Manchester Family Day	9
Simeon's diving success	10
London Landmarks	11
The Patel Family Story	12
Kiss the Sky Festival Fundraising	14
All the Amazing Fundraisers	15
Draw winners	19
Christmas Card update	20

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## Chairman's Message

Dear Friends and Supporters,

Welcome to the Autumn 2024 edition of the Insider Newsletter. We have had some great fundraising from our members, including the children, and we thank you all. The stories of why they take on these challenges are an inspiration.

As children return to school, Sarah Brown – a CICRA Trustee, shares her personal experiences on supporting students with IBD, which we know can be a real challenge for parents.

The update on the Paediatric IBD Bioresource project, led by Professor Holm Uhlig at Oxford, shows how important it is for CICRA to fund the setting up of national projects. With the support of the paediatric gastroenterologists nationally and 350 families signed up so far, this will really benefit future research.

The Family Day held in Manchester went very well and on page 9 you will be reminded to contact the office for details of how to register for the special half day meeting in London on 5th October.

What an inspirational story we have from Simeon on page 10 explaining how, despite Crohn's, he managed to continue with his dream of competing in the National Diving competitions, and bringing home the medals.

With Winter approaching, we are gearing up for the Christmas draw and Christmas Cards. Do look out for more information on the last page.

Finally, a request. We are looking for a person with practical experience of website and social media management to help either as a Trustee or a volunteer. Please contact me at [grahamlee@cicra.org](mailto:grahamlee@cicra.org) for details.

Best Wishes

Graham Lee  
Chair



# Paediatric IBD BioResource project supported by CICRA



Since the last report of the UK Paediatric IBD BioResource in the Spring 2023 edition of this newsletter, the study has grown from 3 UK hospital sites to 9 hospital sites. The study sites include Oxford Children's Hospital, Royal London Hospital, Barts; Cambridge Children's Hospital; Jenny Lind Children's Hospital, Norwich; Bristol Royal Hospital for Children; Great Ormond Street Hospital, London; Sheffield Children's Hospital; Southampton Children's Hospital; and Birmingham Children's Hospital.

Around 350 participants with Crohn's disease, ulcerative colitis (UC), IBDU or monogenic IBD have been recruited. There are plans to open more hospitals in England before the end of the year, including Alder Hey, Liverpool; Evelina Hospital London, and the Royal Free in London, as well as hospital sites in Scotland.

This is a large national collaborative project. One of the PIBD Bioresource's top recruiting sites is the Jenny Lind Children's hospital in Norwich which opened to this study in March 2023, and have since recruited nearly 50 participants. The local PIBD BioResource team is led by consultant Dr Marco Gasparetto, supported by Emily Tropman, the Research Nurse. The team clinical nurse specialists Sue Underhill-Smith and Eleanor Goodale also play key roles in identifying and consenting a large proportion of the patients recruited.

**Dr Gasparetto is a research-active paediatric gastroenterology consultant who supports several UK research activities including the PIBD BioResource. Dr Gasparetto knows how much CICRA has to offer since he was a CICRA Fellow himself in Cambridge from 2015 to 2018. We approached the team at the Jenny Lind Children's hospital to ask them what it was like working on the PIBD BioResource study.**

## Why did you get involved in the PIBD BioResource?

**Dr Gasparetto:** It was really important for the Norfolk and Norwich Trust to be involved in this project, as IBD is a chronic condition and the symptoms and side effects that children and young people experience on treatment can always be improved. With the advancement of scientific techniques, such as a multi-omics approach looking into genetics, epi-genetics, microbiota and other data layers, there could soon be a chance to diagnose IBD earlier and more accurately, to prevent its disease course and to find better treatments for our patients. This can only be possible if people continue to contribute samples and data to facilities like the BioResource to enable researchers to study the disease fully.

### What work is involved in recruiting patients to the PIBD BioResource?

**Dr Gasparetto:** First of all, we go through the upcoming clinic appointments and paediatric endoscopy lists to identify those patients who will be eligible for the study and invite them to take part by sending out letters or emails in advance of their appointment. When they come into the clinic the team will explain the study to patients and parents and answer any questions they may have. We provide participants with the study paperwork and if they consent, they go on to give blood or saliva samples, stool samples and sometimes some biopsy samples. It is completely voluntary so they can always change their mind later on and withdraw. Almost all of the patients that we have asked have agreed to take part as they know how valuable it would be if they could receive better care to treat their IBD.

### What is the best part about being involved in the PIBD BioResource?

**Dr Gasparetto:** It's really interesting talking to the patients about the study as they come up with all sorts of questions and really make you think. They are also generally really keen to get involved when they know they could be helping similar people in the future with IBD. We are extremely grateful to all the families, the children and the young people involved, for their

enthusiasm and collaboration. We are all making a difference, altogether!

Without research, healthcare would not move forward. So it is an honour to be part of this. We meet so many fantastic young people and it's a pleasure to get to know them and their families. The best part of being involved in the study is knowing that the work we are doing will help contribute to a better future for patients diagnosed with IBD and being able to give our patients hope that we are working towards a greater understanding of the condition which will hopefully lead to more effective treatments for these life changing conditions. It has become very apparent to us whilst recruiting to the study that the patients and their families are just as enthusiastic. Patients know that IBD is a life-long condition and are very keen to participate to hopefully make a difference for their child's future treatment and management.

*Thank you to our colleagues at the Jenny Lind Children's hospital, and all the other sites that are actively recruiting to the PIBD BioResource for all the work that goes into recruiting participants. If you are interested in being involved and can be seen at one of the research active hospitals please reach out to your consultant for further information or refer to the following website: [www.ibdbioresource.nihr.ac.uk/index.php/the-paediatric-ibd-bioresource-pibd/](http://www.ibdbioresource.nihr.ac.uk/index.php/the-paediatric-ibd-bioresource-pibd/)*

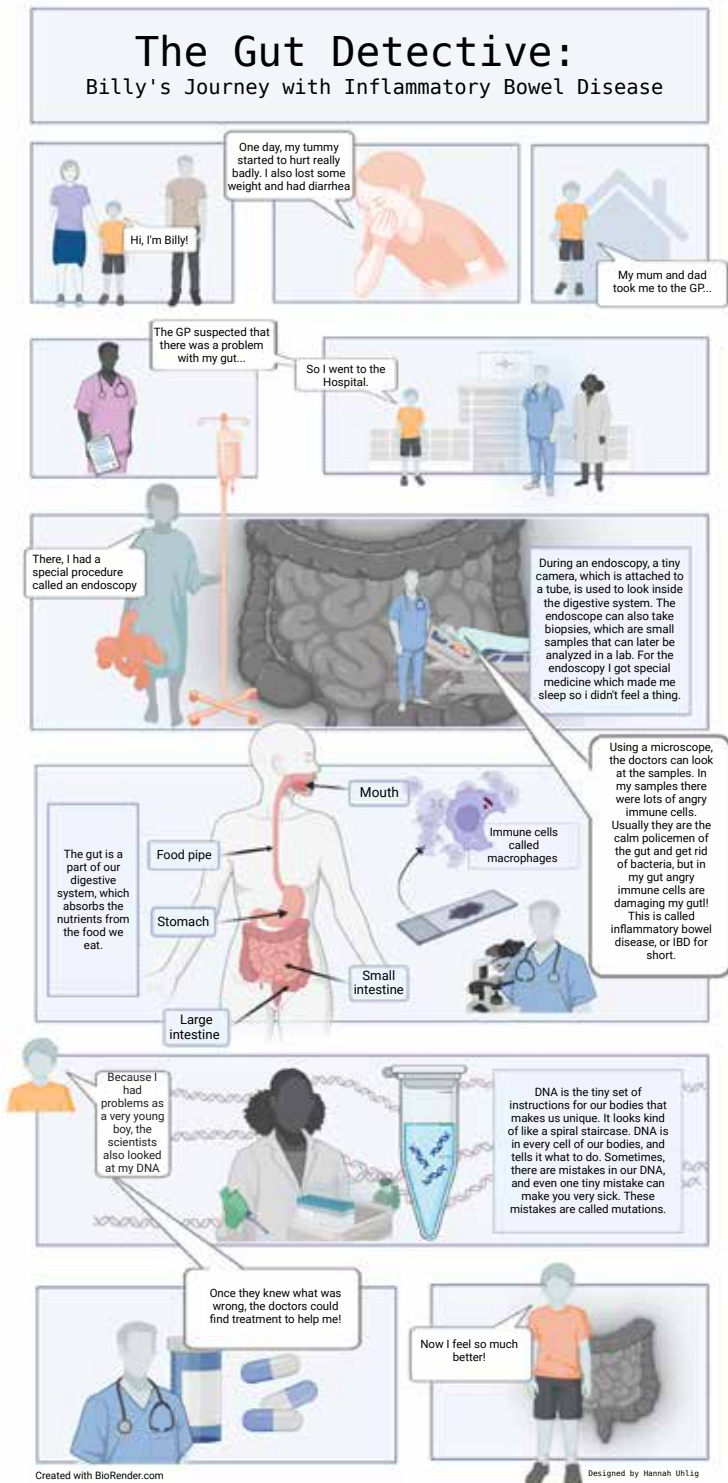
To get further insight into what it's like to be involved in the PIBD BioResource, a short film has been produced at the Oxford Children's Hospital where the first participant who signed up to the BioResource was recruited and talks about his experiences being involved with the study. To view the film please visit [www.youtube.com/watch?v=bjqe9LjSNS8](https://www.youtube.com/watch?v=bjqe9LjSNS8)

Lastly, a very big **thank you** to everyone who is involved in the PIBD BioResource – the research staff who set up the study and support the patients through the study pathway, and to the guardians and patients themselves who agree, on behalf of their child, to give samples and information to the BioResource. All your efforts will go towards improving the clinical benefits that can derive from research advances in paediatric IBD, so that current and future children with the condition can benefit earlier.





For young participants who have recently been diagnosed with IBD we have explained some aspects what research is about using a short comic strip: 'The Gut Detective'. The 'The Gut Detective' has been created by a summer intern student Hannah Uhlig who joined the lab in Oxford to learn about research and help the team communicating with young patients.



## COVID impact

In early 2020 with CICRA halfway through the assessment process for future funding, COVID arrived and changed everything. Knowing that fundraising had stopped overnight, and not sure how much would be needed to keep CICRA going without dipping into research reserves, the Trustees had to make a swift decision to cut back as much as possible and not offer any new funding until the future became clearer. After contacting all applicants it was decided that, although funding couldn't be offered at that time, if they wished we would go ahead with assessments and hopefully fund any projects recommended by our Medical Advisory Panel when COVID was over. What a good decision that was because amongst the submissions was an application for funding to set up a Paediatric IBD BioResource.

We are proud to have been able to fund the setting up of this truly special project, once again adding another long term benefit to Paediatric Gastroenterology, a sub speciality of paediatrics which wasn't in existence when CICRA was formed

Our thanks go to Professor Holm Uhlig, his team and the paediatric gastroenterology teams around the country, and their patients.

**The CICRA Trustees**

## Questions?

If you have any questions about the PIBD BioResource, please email the team

[paediatricibd@ndm.ox.ac.uk](mailto:paediatricibd@ndm.ox.ac.uk)

Professor Holm Uhlig  
Sarah Hearn  
Hazel Johnson





Dr Gkika explaining his research at the ESPGHAN European meeting which demonstrates how important attendance at these meetings are for researchers to be able to discuss their findings and to learn about other researchers work.

# Sharing information

## A CICRA Bursary Grant awarded to Dr Konstantinos Gkikas to attend the 56th Annual ESPGHAN meeting.

Dr. Konstantinos Gkikas is an early career researcher at the University of Glasgow, working in Prof. Kostas Gerasimidis's lab. Dr. Gkikas is particularly interested in the role of diet in managing inflammatory bowel disease. He holds a BSc in Nutrition and Dietetics from Harokopio University in Greece and a PhD in Clinical Nutrition from the University of Glasgow. In his current role, Dr. Gkikas leads the intensive post-enteral nutrition study (IPENS), a multicentre, prospective study conducted across 11 paediatric hospitals in the UK. He recruited 116 children with Crohn's disease immediately after they completed treatment with exclusive enteral nutrition (EEN) and monitored them for one-month post-EEN to explore dietary and microbial triggers of Crohn's disease.

Dr Gkikas extends his gratitude to CICRA for supporting his attendance at the 56th Annual ESPGHAN meeting, held earlier this year in Milan. This conference is the largest annual European event on paediatric gastroenterology and nutrition. At the meeting, Dr Gkikas had the opportunity to present new and exciting findings from two different projects and network with world-leading experts on the field of paediatric gastroenterology.

The aim of the first presentation was to explore various parameters that might explain why exclusive enteral nutrition works better in some patients than

others. Dr Gkikas used data collected from a subset of patients recruited in the IPENS study. He included clinical data and data related to the gut microbiome. He found that specific microbial parameters like the PH and the total number of bacteria in the stool are the most important in predicting which patients will have lower levels of gut inflammation at the end of a course of exclusive enteral nutrition. These pilot data further highlight the role of the microbiome in Crohn's disease and could provide important insights on the mechanism of action of exclusive enteral nutrition and similar dietary therapies in Crohn's disease.

In his second presentation, Dr Gkikas examined methods for assessing compliance to a gluten-free diet. Recently, the detection of gluten immunogenic peptides in stool and urine have been proposed as objective biomarkers for gluten-free diet adherence. As exclusive enteral nutrition is a gluten-free formula, using a laboratory objective biomarker of gluten intake could be useful in establishing compliance to the treatment and assessing its true effectiveness. Using samples collected from the IPENS study, he found that there was moderate agreement between the two methods, with the method in stool being more accurate to capture small deviations from a gluten-free diet.



# Trustee news

## We welcome Professor Nick Croft to the Board of Trustees



At a meeting held on the 16th July the CICRA Trustees were delighted to co-opt Professor Nick Croft to the CICRA Board of Trustees. Confirmation of this appointment will be made at the AGM on 14 September 2024. Many will know Prof Croft from his time as our Medical Director when he attended almost all CICRA meetings no matter where they were held. We have been extremely grateful for all the help and advice that he has given over the years and look forward to continuing to have his help as a Trustee.

### Do you have the experience and a few hours a month to help us?

In accordance with the recommendation of the Charity Commission we seek to maintain a good mix of skills and experience amongst our Board of Trustees and currently we are looking for somebody with practical experience of website management and social media to either join as a Trustee or as a volunteer.

Our main office is based in Surrey, but since most of the work involved can be done remotely, we would be happy to consider people from across the UK. If you have the skills, please email [grahamlee@cicra.org](mailto:grahamlee@cicra.org) for more information.

## Research Highlights

As we move through 2024, we are putting the financial help we have received from your fundraising efforts into further scientific research, and support for families of children affected by any form of Inflammatory Bowel Disease - the two reasons for CICRA's existence since its formation in 1978. Over £10 million has got us to where we are today with huge improvements in the understanding, treatment and management of children with IBD. Here are a few highlights from previously CICRA funded research.

- Confirming the involvement of T cells in paediatric Crohn's disease
- Identifying the benefits of enteral nutrition as a component of paediatric Crohn's treatment strategies
- Profiling the inflammatory mediators responsible for chronic bowel damage in paediatric IBD
- Broadening our knowledge of the commensal bacteria associated with paediatric IBD
- Understanding links between body composition, nutritional status & likely disease outcomes
- Pinpointing key genetic traits associated with paediatric IBD

Research is expensive, and slow, but without it we won't find the answers we all want, to give children with IBD a better quality of life and hope of a healthy future

### And for the future...

With your help we will continue to raise the profile of childhood IBD and put the proceeds from your hard-earned fundraising into supporting only top-quality research.

We are grateful to all the wonderful fundraisers and really appreciate your support.

For fundraising ideas please contact [fundraising@cicra.org](mailto:fundraising@cicra.org)





# Support for students with IBD

Here are some tips from our Trustee Sarah Brown who is a mum of a child with IBD and also a teacher, so understands the difficulties faced by students with IBD, from both sides.

// My son started primary school a year after he was diagnosed with VEOIBD. At that age, he had several medicines throughout the day and the teaching assistant would give him his Sulfasalazine at breaktimes from a fridge in the staffroom. Although I was glad that this medication stopped in Key Stage 2, I think it maybe meant staff overlooked his illness a bit as it became 'invisible' (adalimumab injections and other oral medicines all taken at home). Every September I have asked to meet with his new teacher and go through his condition and agree a Health Care Plan; this document lists needs such as access to a private toilet, dietary information, letting us know of serious infections in school, importance of sun cream etc. CICRA leaflets are very helpful and I always direct teachers to the website [www.cicra.org](http://www.cicra.org) too.

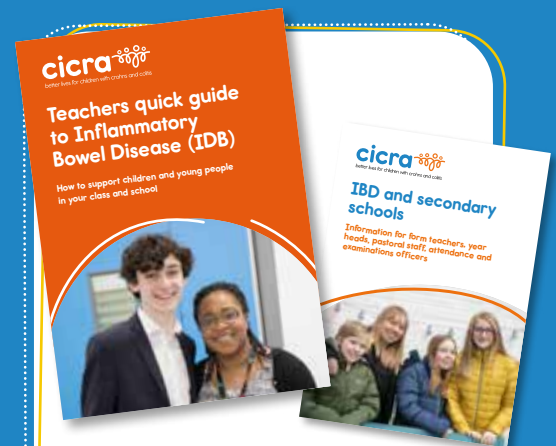
**I am a Primary teacher myself and know how busy classrooms are. I have no qualms about reminding or letting the school know if there is an issue.**

smaller things!) I always say to my son's teachers – if you are not sure about anything at all, please ask me. Teachers may well not have come across IBD before; however, a good teacher will listen to parents' concerns and should show empathy and kindness.

Health conditions must be taken into consideration by teachers and provision must be made.

**Teachers may well not have come across IBD before; however, a good teacher will listen to parents' concerns**

I am now in the throes of secondary school transition – wish me luck! I will make sure there is a named point of contact at school and keep them informed and up-to-date. As we all know, our child's health is a constantly changing picture. It takes strength, and buckets of it, to keep on top of our children's health and wellbeing. Take care of yourself too and all the best to all the children and young people for the new academic year. //



CICRA understand that there can be challenges that come with attending school while living with IBD. We have a number of resources that you can view and download from our website and that you can take in to schools to help teachers understand the condition, and to become more aware of what kind of reasonable adjustments can be made to make things a little easier. These include leaflets for primary schools, secondary schools and guidance around exams. We can send paper copies of these if you prefer.

If you would like further advice or guidance around school support, please contact Carly at the CICRA office on **0208 949 6209** or [support@cicra.org](mailto:support@cicra.org). We are always happy to talk things through and offer advice and guidance.





# Manchester Family Day

In July this year CICRA headed to Manchester for one of our information packed Family Days.

After a warm welcome from our Chair Graham Lee, the first speaker on stage was Dr Kwang Yang Lee (Paediatric Gastroenterology Consultant – Bristol C H) who gave an overview of Paediatric IBD, especially interesting to those who had little knowledge of the condition. Dr Lee spoke briefly about current treatments and procedures and then answered questions from the audience.

Professor Tom McDonald gave a most enlightening talk about the latest research looking into the causes of Paediatric IBD, and also the research studies into new treatments, Research can be very hard to understand, but Tom, as always, made the latest steps much easier to understand.

Always a popular part of our Family Days, are talks from young sufferers. Having been featured in the Spring 24 newsletter we were very pleased to welcome George and his Mum, Lisa, onto the stage to tell us how George has dealt with IBD, followed by Chris Guy from the New Brighton Victoria FC, Liverpool who took George under his wing and has helped enormously in George's battle with IBD.

Professor Tom McDonald returned, to talk about 'CICRA – Past, Present & Future', and picked out some of the highlights from the early days of the Charity, through to the present day, highlighting just how much had been achieved in 46 years.

Following a coffee break Dr Fiona Cameron, Consultant Paediatric Gastroenterologist at Alder Hey Children's Hospital in Liverpool took to the stage, seeking the audience's views on what aspects of IBD they would like to see being investigated as part of future research projects, creating welcome and interesting comments from the audience.

The final session of the morning gave an opportunity, to ask questions of the assembled panel of medical experts comprising of Prof. Tom McDonald (London), Dr. Fiona Cameron (Liverpool), Dr Kwang Yang Lee

(Bristol) and dietician Helen Garrett (Liverpool). The session was chaired by Dr. Anna Pigott (Cons. Paediatric Gastro – Stoke on Trent)

Following a welcome lunch, time to visit the various stands including Dr Falk – one of our much appreciated sponsors, and a stand hosted by Dr Cassie Screti from Aston University.

Younger children were very happy to stay with professional entertainer Stevie Mandini who taught them balloon modelling, magic tricks and other skills while the parents and older children returned to the main lecture theatre and heard from CICRA Chair, Graham Lee, how CICRA's work benefitted so much thanks to the efforts of our amazing fundraisers, supporters and from Trusts.

The rotating group sessions were then introduced, where members had the option to partake in a number of different groups of their choosing, the teenagers and young adults having their own group, although some of them just choosing to sit and chat with new friends made during the day.

On behalf of the Trustees our Chair Graham closed the meeting by thanking sincerely all the health professionals for giving so generously of their time – it is truly appreciated.

## Join us at the next one!

Our next Family Information Day will be held in London on the afternoon of 5th October

Please contact the office for further details.

MEETINGS





# Simeon's diving success

**My name is Simeon, I am 14 years old and this is my whirlwind of a story.**

I was diagnosed with Crohn's disease after a painfully ill winter of 2017 that consisted of numerous doctor appointments that weren't getting me anywhere. They eventually referred me to the Sheffield Children's Hospital in March 2018 where I was immediately checked out in a colonoscopy - leading to the diagnosis of Crohn's. This was the start of a rollercoaster of a journey that has been my life.

I was admitted to hospital for 4 days and upon release was put on a gruelling 6 weeks of drinks only diet along with weekly blood tests. It was as early as this, at the age of 7, that the drive diving gives me came into action. I had my very first diving competition out of Sheffield and was barely back into training with just a drinks diet. The nurses allowed an increase in my daily intake to compensate for the preparation for my competition leading to the start of a still developing career in diving.

However, just as I thought things were getting better I was forced back into a drinks only diet in August of 2018 which was made even worse by the fact I had to miss out on the phenomenal food served before my eyes at our family holiday to Greece that year. Throughout this period the weekly blood tests continued along with an introduction of an iron infusion until eventually, we found what really worked: infliximab. In 2019, infliximab changed my life.

**When I wasn't in such a good place with Crohn's, my coach told me that she wanted me to qualify for Junior Europeans in 2024; I couldn't believe her.**

By 2022, I was a Junior British medallist and qualified to be on multiple England squads and earned myself a chance to represent England at an international competition in Canada. I had worked so hard to be where I was then and claimed a gold and a bronze medal. The year later, I became a

triple Junior National Champion and travelled to places like Holland and Croatia with my club. Yet 2024 has still been my biggest and best so far. When I wasn't in such a good place with Crohn's, my coach told me that she wanted me to qualify for Junior Europeans in 2024; I couldn't believe her. However, in an older, more difficult category, I proved myself again and came home from British Nationals with two gold medals and a silver. This

led to my trip to Junior Europeans cementing myself as one of the best divers in Europe in my age category.

Diving has allowed me to travel the world and meet some incredible people but I am lucky as there was a point I thought it was never going to happen.





# London in the Spring

We had 4 fabulous participants in this year's London Landmarks Half Marathon, each giving time and effort to achieve impressive fundraising totals.

## Sarah

6 months ago, I was struggling through 5k runs and never thought in a million years I'd be able to run a half marathon! The training in the wind and the rain through the winter months paid off and I was more than happy with my time!

I genuinely did not know how I was going to make it to the finish line, my legs were in pieces! But the amount of support and donations kept me going, I couldn't let anyone down! I was lucky enough to have a number of friends and family there on the day who somehow managed to get to several points throughout the day to cheer my name and give me a high five!

The real hero of the day and my number one supporter though was ultimately Josh - he is what kept my aching feet, legs & hips moving! If he can go through what he did with such strength and maturity, I can run a "few" miles right! //

Sarah  
£1,890

## Michael

In 2023 my wife got a place through the ballot, but I didn't. Our son, Alfie, had been diagnosed with ulcerative colitis, so my wife decided to run for CICRA.

From the start, we received unparalleled support from CICRA, especially from Sharon, the fundraising officer. CICRA only required us to raise £250, which we found reasonable compared to other charities. We were impressed by the check-ins from the charity, making us feel special. Just before the event, I got a vest from them, and at the start line, I was proud to represent CICRA among the other charities.

During the race, I got overwhelmed and missed most of the landmarks, but with determination, I finished the race. After the race, I met Sharon's daughter and another charity runner. I was filled with overwhelming pride and gratitude for CICRA.

In the end, I raised £859.85 and I look forward to doing more events to support this wonderful charity in the future. //

Michael  
£859

A massive  
**thank you**  
to Michael, Dani  
and Sarah all their  
supporters.

Also big  
**thank you**  
to Danny who  
raised £707 taking  
on this event

Dani  
£481



Dani and Michael



Sarah and Josh





# The Patel Family's Inflatable Fun

Mum, Natasha, tells her son, Logan's, IBD story and how they decided to raise money for CICRA to help other children going through similar situations.



I have always been a big kid - the ultimate female Peter Pan. It's partly what bonds me to my children. They, being children, have an enormous capacity for joy, and positivity in the face of adversity that mainly comes to the fore when their passions and determination to live in the moment take over. They seem to almost effortlessly achieve what most adults nowadays, have to read books on or listen to podcasts to relearn: that mindfulness and ability to seize each moment.

Logan has always been a character and a half, described as being a force of nature, one that doesn't do things by halves, and who commits 110% when invested in an endeavour. It made it more difficult for people to fully understand that in the 9 months leading from his first symptoms to his long awaited and dreaded diagnoses: he was indeed a poorly boy. He seemed to get more and more pain, more diarrhoea with fresh blood, more fatigue, and was increasingly irritable and frustrated because he couldn't fully engage with his meals, snacks, playdates, school, and his favourite activities. Yet he tried so hard. His enthusiasm would have him working through his abdominal cramps, despite us asking him to please just rest. Increasingly he looked paler, and it was harder for him to gain weight. I am a specialist dietitian and was able to understand he needed food fortification plus over

**Logan couldn't fully engage with his meals, snacks, playdates, school, and his favourite activities.**

the counter iron supplements. His dad, a medic, and I pressed forward with emails fortified with pictures to illustrate and describe our fears and request that his reviews were expedited. Logan was not referred to a specialist children's centre for almost 7 months following his first presentation in Hospital. He had been referred from the GP after I explained that I feared IBD was possibly the cause, and that this was not constipation etc. I have a mother and an aunt who both have IBD, and they have had incredibly different journeys with this disease. I recognised that Logan had symptoms consistent with IBD. Logan was very quickly assessed at a children's hospital, and as his liver enzymes had elevated to extremely high levels, he received an endoscopy, colonoscopy and a liver biopsy. They all confirmed sadly, what we had feared. Logan was just 6 years of age and had Crohn's

disease with an associated condition called Primary Sclerosing Cholangitis (PSC). This is a long term and often progressive disease, characterised by inflammation and scarring of the bile ducts.

He was indeed very poorly, but he was very lucky in that his treatments using high levels of steroids plus Mesalazine, worked well to abate the symptoms, and within a week he reported to be 'feeling normal again, just his old self' His regained energy levels suddenly matched his appetite for



life again! We were told that we wouldn't be able to keep up with his appetite for foods once he was feeling better combined with the side effects of the high steroid doses: this advice was on point.

**He regained weight and he has luckily only had a few minor flares.**

A week after diagnoses, and we were on holiday. We kept running out of food to give him and had to keep going to shops and cafés for more. He regained weight and he has luckily only had a few minor flares. Due to the possibility that his PSC may not progress as much if his IBD is controlled, Logan was started on Azathioprine (an immunosuppressive drug). He has coped well with this, though it does make him more vulnerable to infections and has had pneumonia twice whereas the rest of the family simply got colds. He has autism and has been assessed for ADHD as he has many of these traits also. Logan has not only experienced the mental, emotional and physical strains related to having lifelong conditions, but these difficulties are augmented in an individual who struggles when he feels he is not 'perfect'. He becomes sad and frustrated at having to go for regular reviews and feels he is 'faulty'. He is brave in reviews and having blood tests, but most of all he has had to learn to be brave discussing his fears and admitting when he is feeling poorly as he knows he will have to rest. He doesn't tend to even sit for a meal, he is so hyper. As a family we have come to terms with his conditions, but we still worry.

We are blessed that the treatments and support is available, as these were not available to my mum, who was diagnosed with Crohn's over 50 years ago. I wonder if her journey with IBD would have been an easier one, had she had access to Logan's line of treatment.

We decided to do the 5 km inflatable course as a family as we are well, able and want to make

people aware that IBD symptoms are not to be taken lightly: they need investigating quickly for quicker remission with treatments. We know that it is very rare to develop IBD at 6 years of age and even rarer for these individuals to develop PSC, but it happens and there is support and hope.

We had enormous support from friends, family, and acquaintances. It was a powerful experience, as he understands that while he was running the course, others with his condition were poorly and trying to regain some sort of normality. He was especially proud that we had raised so much (£940.91) to help CICRA, which would in turn help other sufferers and families. He was also incredibly proud of his younger brother completing this distance at only 6 years of age: as were we as parents. It was an incredible experience, and all the more because Logan was fit enough to complete this. Thinking back to how poorly he was at diagnosis, I got emotional as he could barely walk without pain at times and was so afraid of what might be causing the problem. On the day though, the weather was fantastic, the atmosphere was electric, and many people were completing the event, including other children, to raise money for their chosen charities. We all felt like Peter Pan, happy, motivated, and proud. Logan declared he wanted to attempt the 10 km inflatable run next year!

**We all felt like Peter Pan, happy, motivated, and proud. Logan declared he wanted to attempt the 10 km inflatable run next year!**

We encourage anyone who is able to try out events for charity: there is no better motivation. We thank CICRA for everything they provide. And wish everyone with IBD the very best of health.



# Weekend festival raises £11,800



A massive thank you to Dave and all his amazing friends, family and contacts from all of us at CICRA. You have made a difference!

**Dave Gurney talks to us about the Kiss the Sky festival he puts on in memory of his brother Nipper.**

“ Kiss the Sky 2024 was another really inspiring weekend. Bringing family and friends together to celebrate through means of a music festival inspired in the memory of my brother Nipper who passed away having suffered Crohn's for many years before being taken by Cancer in September 2020.

This year's festival was always going to be a tougher challenge to bring together after so much generosity to stage the first one the previous year. Knowing this and intent on not letting cost of putting on the event deter us, the KTS team took on the 3 peaks challenge in early May to raise set up costs so not to impact on our donations to CICRA & TCT. What an amazing experience it was over the weekend and enjoyed in the company of some fantastic people. Our aim was to try and get £10k from the 3 peaks and we exceeded by just over £1k. This proved invaluable as it helped towards about 80% of set up costs.

The festival itself was a huge success, with a full weekend of bands, DJs, acoustic sets, amazing food and the debut of our new "Sky bar" run solely by volunteers over the weekend and supplied by our great friend, Dale from The White Dog. With also a incredible supply of kegs, bottles and cans from my cousins husband Kieran via work contacts. The bar was a winner especially in a fundraising way as not only by attending and enjoying the festival as a way to raise funds every

time you purchased a drink every penny of profit went to our charities. A huge thank you to all our volunteers over the weekend and especially to James Hook & Mike Penfold who turned into landlords for the weekend! The music was nonstop from Friday afternoon until Sunday afternoon, and we are so appreciative to all artists for playing for a pass and a few drinks. All adds to the intimacy of the festival. Saturday night saw the return of our themed evening, this year's being celebrity past or present and what a turnout there was. I bumped into myself (another Kurt Cobain!) which was amusing. Another incredible raffle organised by the Riggs families and Leanne Standen which raised in excess of £3k!

We did have challenges over the weekend with high winds, a wet Saturday morning making the entrance for some a fun challenge. Also, various technical issues all thrown in to challenge the team. But all issues were solved, and the fun continued, just like Nipper would have wanted it too.

We are all so proud to have been able to exceed our total from last year and without all the community coming together again the total raised of just over £11.8k for CICRA wouldn't have been possible.

So, here's to next year's KTS and watch this space to see what the team get up to for next time.

We love and miss you dearly Nips ❤️ //





# More of our amazing supporters!

Thank you to all our amazing fundraisers - YOU make the difference

## 5k Inflatable Obstacle event Liverpool

Raised  
£576



'Having been unwell for a number of years our 11-year-old Daughter Maisie was diagnosed with Crohn's disease. The support we received from CICRA has been invaluable - especially the information with helping to go back to school with a feeding tube.

The family days have been a brilliant way for Maisie to speak to others her age who can understand what she is going through, as well as enabling us to meet other parents. Not to mention the lifesaving can't wait card and radar key!

When I received an email earlier this year with ways to fundraise and support CICRA, me and my friends, Clare, Aaran and Imogen, decided doing the Liverpool Inflatable 5K seemed like good idea... although a bit tougher than we thought, we managed to complete it in 66 minutes.' **Rachel Kay**

Raised  
£1,600

## Just keep running!

'Running a half marathon for CIRCA was something I had thought about doing for a while and when the Edinburgh half was advertised, I decided to give it a go!

My daughter, Willow, was diagnosed with Crohn's at age 12. I have always been into running although I have never run to raise money for a charity before. People were incredibly generous, and I easily reached my target, I managed to raise an amazing £1600 .

The run itself went well although it was a bit wet and windy, but it was an incredible atmosphere, and crowds lined the streets giving lots of encouragement and sweets. I was incredibly proud of what I had achieved and would encourage anyone thinking about it to give it a go!' **Marianne Jamieson**



Raised  
£1,131

## Is it a bird? Is it a plane? No, it's Tracey!

'Our son, Iwan was diagnosed with IBD at age 7, we have watched him as he has taken the challenges of this condition in his stride, it's a daily rollercoaster.

Attending the family days we gained a wealth of knowledge to help support our son. We met many professionals who were happy to answer our questions and concerns, also parents of other children with IBD, best of all Iwan loved making friends with children who understood how he felt.

Iwan is 10 now and currently in a flare, and getting to understand his condition. He talks frequently about his fears for the future. Not being able to take this fear away is heartbreaking.

My eldest son, Kian and I decided to self-fund a 15,000ft skydive to raise money for this amazing charity. It means so much, knowing that we can always get support when we need it.' **Tracey Jones**





## Ella runs up mountains for her brother

Raised  
£735

'On June 29, 2024, I successfully completed the Trail Pursuits Half Marathon in Snowdonia, and it was an incredible experience. This journey was deeply personal for me, as it was inspired by my 9-year-old brother, Jensen, who was diagnosed with Crohn's disease last year. While it's certainly not been an easy journey, Jensen has and continues to take every obstacle in his stride through the help and support of CICRA.

With minimal training and no prior experience as a runner, I embarked on this challenge with determination and hope. The stunning yet demanding trails of Snowdonia made it a tough but memorable experience. I am proud to report that I finished the half marathon in 4 hours and 5 minutes.

Adding to the joy of the day, my 9-year-old brother also completed a 1-mile run, despite his Crohn's diagnosis. His determination and spirit were truly inspiring and served as a powerful reminder of why this cause is so important.

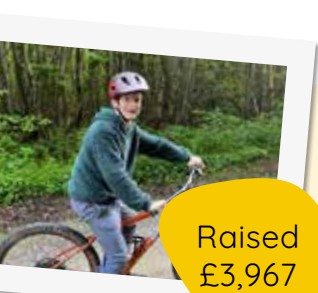
This achievement would not have been possible without the immense support and encouragement from all of my friends and family. Every step I took was motivated by the desire to raise awareness and funds for children like my brother, who are living with Crohn's disease.'



Raised  
£562

## 'Team Cox' running the London 10K

Ellie Cox ran the race with her dad Anthony, telling us after the event, 'I am pleased to say all went really well yesterday with my dad and both of us got times we wanted. We all really enjoyed the day, it was nice weather, slightly too warm but made seeing all the London sights more exciting! I can confirm that my dad won the title of Team Cox champion by 8 minutes'.



Raised  
£3,967

## Henry didn't give up!

Update from Henry Milne who we featured in the Spring newsletter.

**"Hi everyone, sorry it's taken so long but I've finally done my sponsored bike ride. I did 10km in Kent over the May half term. Thank you so much."**

## Snip snip!

'My name is Pippa Mason, and I am 8 years old. I wanted to raise money for this charity because my brother has bowel disease and I wanted to help him and other children who are sick. I raised money by having my hair cut and I gave 12 inches of my hair to The Little Princess Trust. I only wanted to raise £100, but I raised double the amount, so I was very happy.'

Raised  
£226



## David Johnston raises over £1,000 in less than a year

David has been giving talks to various groups. His first talk was 'The Shackleton Trans-Atlantic Expedition - 'A unique Story of Survival' came about after taking an inspirational trip to Antarctica. He now has added two new talks to his repertoire - 'Life in the 1950's' and 'Japanese Culture'.

If you or anyone you know would like David give a talk to a group i.e. Rotary club, WI or Tangent organisations in exchange for a donation to CICRA, David who is based in Sheffield would be willing to travel up to 30 miles.

Contact David: [dcjohnston@outlook.com](mailto:dcjohnston@outlook.com) or call **07800818516**

## Dancing the night away

Raised  
£477

Barbara Ellard organised a great evening in the Upton Noble Village Hall.

The Hammervilles (a local function rock band) played to 90 people.

The profits from the event were split between CICRA, Leukaemia Research and for the upkeep of the village hall.

We thank Barbara (one of CICRA's long time supporters) for the donation of £477.



## Awesome people!

Heather Reid and her daughters who completed the Aberdeen Kiltwalk on 2nd June 2024 raising - £500.

### 80th Birthday

Alison Veitch who donated £352.50 collected from her mother's 80th Birthday lunch.

Friends of Lydgate School donated £260 after member **Simeon Greig** nominated CICRA as a beneficiary of the 'The Crosspool Crawl Run'.

### Line Dancing Classes

Alison Johnston and the Ladies and Gentlemen from her line dancing class donated another £138 in May and £241 in August from their class raffles and donations.

**Steph Ward** for asking for donation's instead of gifts at her 40th Birthday in June raising £275.00

### Two tunnels 5k

April Kelly for running in the Two Tunnels 5K in Bath, on the 2nd June raising £343.75 as part of her Silver Duke of Edinburgh Award.

**Jaz Martin-Betts** whose Annual Tennis Tournament raised £1,350. Jaz you are a brilliant CICRA supporter!

### Inflatable 5k

Sian and Naomi signed up for the 5k inflatable walk but unfortunately Naomi was having tests at that time. However, she was determined to try and as Sian said - 'even if we crawl over the finish line' and finish they did.

Sian said 'We managed to raise appropriately £230. This was beyond our expectations as we only have a small family and circle of friends, but at least we can make a little difference.'





## Eva Brown runs half marathon

Raised  
£1,530

After months of training, it was great to finally complete the half marathon which I ran to raise money for CICRA, a cause close to my heart. My brother was diagnosed with UC at the age of 11 and my dad also has the condition. Now a few years on they are both doing well but we know that as a lifelong condition it will continue to impact our family.

As well as raising money I wanted to raise awareness of UC and the work that CICRA do leading research to find better treatments.

The run was tough, but it was a bright sunny day and the mainly flat course and beautiful surroundings at Dorney Lake took the edge off. Plus being spurred on by fellow runners and the 'fan club' of family and friends who cheered me on complete with banners also helped. The last four miles were super tough but before I knew it, I was crossing the finishing line. I felt incredibly proud, not just of the accomplishment of running a half marathon but also knowing that money I raised, albeit a drop in the ocean, might go some way to make a small difference. Thank you to CICRA for sending me the T-shirt which I wore with pride!

## Andy runs Brighton Marathon

Raised  
£437

'My wife and my eldest son both have ulcerative colitis. My son Billy is 14 and got diagnosed when he was about 10. We have had a couple of information packs from CICRA, they were full of really good stuff so when I entered the Brighton Marathon I wanted to raise some money for the charity.

Billy has had a couple of flare ups but mostly manages it with medication and he leads a very active life, playing football, doing Tae-Kwondo and going to the gym.'

### After the run Andy said

'Recovery is going ok - basically been eating a lot which I'm pretty sure is what all top athletes do?!

## Manchester Marathon

Following on from Ben Gibson's article in the Spring newsletter we are pleased to say Ben completed the Manchester Marathon. Updating us after the event Ben said: -

'I'm feeling elated that I got round in one piece first and foremost and incredibly happy that I managed to achieve a sub 4 time! The old legs are still suffering a little which is as to be expected, but absolutely all worth it!

I'm really pleased and proud to do such a fantastic thing for my son and CICRA, such a wonderful charity that will remain close to our hearts forever!

As far as the event is concerned it went really, really well! Inevitably there were some difficult moments, especially in the latter parts of the race but I kept reminding myself why I was taking part and who I was doing it for which gave me an extra energy boost and kick up the a\*\*e to keep going! :-)

Sunday was most certainly a massive milestone in my family's lives that I'm sure they'll remember forever, and I hope I have inspired them greatly.'



Raised  
£4,588



Thank you  
to our other runners  
who were unable  
to take part,  
Chelsea and Niamh,  
for the support.

Raised  
£495

## Leeds Running Festival 2024

Hayley and Gemma ran in the Leeds Running Festival for CICRA and raised £380 and £112 respectively, a big thank you.

Hayley told us about the race the day after, 'The race was amazing, but tough in parts there were lots of hills. I did 10km, so glad we didn't do the half marathon! I'm glad to help towards the difference your charity makes.'

## Esme climbed Yr Wyddfa (Snowdon)

Esme is a brave and determined 9-year-old who lives with Ulcerative Colitis (UC). She's a fighter and wanted to raise £5,000 help fund research that will help find better treatments and hopefully, a cure.

Esme decided she was going to climb Yr Wyddfa (Snowdon), a tough climb for anyone. Esme trained hard and with her friends and family climbing with her, she wanted to make it to the top.

Esme's said "Apparently, it's quite a long way and I may need to stop for a sandwich or two."

Team Esme reached the summit in 2hrs 55m. Her mum, Erika said: - 'It was much harder than expected but was worth every minute, the views were stunning.

Esme was a little mountain goat she flew up and didn't moan once, she pretty much led everyone up and didn't struggle with any of it. We're so very proud of her and what she has achieved!

Coming down took 2hrs 30m. My body hurts in places I didn't know I had. People were also so kind on the mountain and handed over money for the charity."

*Thank you Esme - an incredible girl, taking on such a big challenge and raising an amazing amount!*

Raised  
£7,382



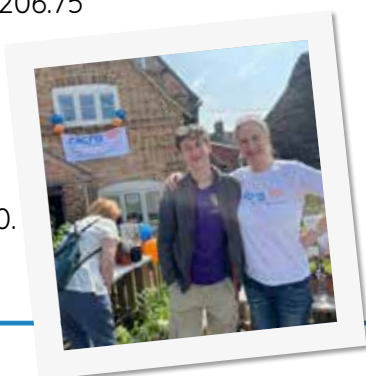
## Growing money!

Patrina Law and her family held their annual plant sale on 11-12 May.

The weather that weekend looked to be amazing and they had around 400 plants to sell! They raised around £800 and told us they 'were flat out'!

They continued to put plants on their front wall over the summer and by the beginning of July had raised a total of £1206.75

We thank Patrina and all her family for their ongoing support over the last 4 years they have raised over £5,000.



Raised  
£1,207

## Summer Draw Results

The Summer Draw took place on Tuesday 30th July 2024 at the CICRA office, Pat Shaw House, Sutton. Thank you to Tracey Currie from Sutton Housing Society who drew the winning tickets.

Prize	Ticket No.	Name
1st prize	33142	J King
2nd prize	43650	B Waring
3rd prize	22737	D Whitlock

### Thank you

We are so grateful for your support and are delighted that the proceeds can go towards funding vital new research as well as helping us provide support to children and families affected by IBD.



# Got to be in it to win it!

Please continue to support our Summer and Christmas Draws

We need you!

Due to rising costs we need to change the way we sell tickets for our draws – but we still need you!

For many years our two annual draws have been **essential fundraising sources** for us. However, with increased postage and an increased move to online, we are looking to change how we do this but it is essential we do so without losing our supporters who may not wish or be able to support us online. For the Christmas 2024 Draw we are in transition and will be sending paper tickets out to known supporters and those who have requested tickets.

If you haven't had any tickets and would like to support this Draw please contact [admin@cicra.org](mailto:admin@cicra.org) or call the Office 0208 949 6209

Your support is hugely appreciated and all proceeds go directly towards new research, giving hope of a healthier future to everybody with IBD and particularly our children and young people.

## Spread festive joy and support CICRA

As with the Christmas Draw and newsletters we are trying to reduce our costs, and waste, whilst continuing to ensure that our loyal supporters and families can respond in the way that suits them best. We will be asking if you prefer paper or digital – it is entirely up to you but as most cards are now sold through the website shop [www.cicra.org](http://www.cicra.org) we are not enclosing a Christmas card order form. However, if you would prefer the usual brochure please contact the office on 020 8949 6209 and we will send one to you. There is the usual range of good quality, reasonably priced cards, wrapping paper, money wallets, children's classmate packs. 50% of the cost of the cards will go towards maintaining and expanding our research and support programmes. Thank you for your support.



Order direct from us: [www.cicra.org](http://www.cicra.org)

