

the insider

Spring 2025

Some research projects funded over the years

FIRST PAEDIATRIC GASTROENTEROLOGY LABORATORY IN UK

T CELLS IN PAEDIATRIC CROHN'S?

PINPOINTING KEY GENETIC TRAITS

BENEFITS OF ENTERAL NUTRITION

NOVEL THERAPEUTIC APPROACHES

QUALITY OF LIFE STUDY

MAKE SURE YOUR CHILD SEES THE RIGHT SPECIALIST

GENE DISCOVERY POINTS TO INCREASED RISK

REPORTS ON GROWTH STUDIES

CD8+ T CELL STUDY

FIRST PIBD BIORESOURCE SET UP

EPIGENETICS IN PIBD

PROFILING INFLAMMATORY MEDIATORS

GUT MICROBIAL TAXONOMY FUNCTIONALITY

OVER £10M SPENT ON RESEARCH

3 YEAR TRAINING FOR 27 PAEDIATRIC GASTROENTEROLOGY SPECIALISTS

FUNDING 61 RESEARCH PROJECTS

cicra 
better lives for children with crohns and colitis



CONTENTS

Message from the Chair	2
What's new at CICRA	3
PIBD Bioresource update: Spotlight on Southampton	4
My Crohn's Journey	6
Ask the Doctor	7
Spotlight on Southampton's IBD Research	8
Update from North of the Border	10
Our amazing supporters!	12
A Fond Farewell	19
Draw winners	20

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Chairman's Message

Dear Friends and Supporters,

Welcome to the Spring 2025 edition of the Insider Newsletter. In this edition, we have included as many examples of the local fundraising that our members have been carrying out as possible – as you will see everyone has done a fantastic job, however large or small, and it shows how much people are generously giving their time to provide support for the people affected by this condition.

Following our research grant callout during 2024, our three main research initiatives are all under way in Southampton, Dundee and Edinburgh. You can find updates on research funded by CICRA on several pages throughout the Insider, including an update on the 3-year Fellowship in Southampton which is funded by CICRA.

We are very lucky to have regular access to the IBD medical community, so turn to page 7 for answers to some of the questions the office staff regularly get asked by our members.

We have another wonderful story as part of our popular series on Crohn's journeys from Amber on page 6, who talks about her experience from a young person's experience.

Sadly, since our last Insider, Rod Mitchell, who has been a long standing supporter of CICRA, passed away after a brief illness. Rod was a Trustee of CICRA for many years and continued to be a volunteer for the charity up until last year. To read more about his contribution to IBD research please refer to page 19.

As ever, we are always keen to hear from people who wish to volunteer or become a Trustee of CICRA. In particular we would be delighted to hear from anyone who has a medical background or is interested in helping manage our research-grants.

Best Wishes
Graham Lee,
Chair of Trustees





What's new at CICRA?

Research

All three grants started in the last quarter of 2024 are now well underway in Southampton, Dundee and Edinburgh. You will also see from the update from Professor Holm Uhlig, the ongoing Paediatric BioResource project is going really well and much is happening North of the Border.

Support

School attendance reward schemes – we need your help!

We are pleased to announce our collaboration with The Children's Liver Disease Foundation to explore the effects of school attendance policies and reward schemes on children with medical conditions. Our goal is to understand the impact these policies have and to identify if changes are necessary to better support children.

We are inviting young people, parents, and carers to share their thoughts and experiences - Your input will help us gain insight into the challenges faced by children with medical conditions in educational settings. Please email support@cicra.org if you would be happy to share your experiences.

By participating, you will contribute to a better understanding of how current policies affect children with medical conditions and help us advocate for necessary changes. We appreciate your willingness to share and look forward to hearing from you.

Fundraising

Three very dedicated doctors, who have all been supported by CICRA took on the challenge of walking the equivalent of three marathons in three consecutive days to raise a better awareness of children with IBD and raise funds for CICRA. We thank Dr Marco Gasparetto, Dr James Ashton and Dr Zachary Green for coming up with the idea and carrying through this tough challenge. Their justgiving page will be open for a while yet if you wish to add a little thank you for thinking of the children they care for and treat on a daily basis.

We were recently contacted by Intrum - a financial services firm based in Reigate to say that their employees had voted for CICRA as their local charity partner for 2025 thanks to one of CICRA's members whose daughter has Crohn's disease. If you or someone you know has links to a company who would consider supporting CICRA, please contact fundraising@cicra.org

Another CICRA supporter, who has first hand knowledge of what we do from a family member who has been supported by CICRA, nominated us for her Captaincy year at Kingsdown Golf Club, Wiltshire. We look forward to hearing about the events they have planned.

If you belong to a club, or know someone who does, and who would like to nominate CICRA, please let us know at fundraising@cicra.org





Prof Holm Uhlig CI



Hazel Johnson

PIBD Bioresource update: Spotlight on Southampton

Six months on since the last CICRA update, the PIBD BioResource continues to grow with 12 hospital centres now recruiting children and young people with IBD to the BioResource. The latest centres to open are the Royal Free and Evelina Children's Hospital in London and Alder Hey Children's Hospital in Liverpool. Overall, these specialist centres have recruited over 500 participants across the country, providing valuable samples and data to help advance research in IBD.

One of the highest recruiters over the last 6 months is the team at Southampton Children's hospital, recruiting an average 5 patients a month. The team have been using their experience from the Southampton genetics of inflammatory bowel disease study to accelerate recruitment. The work, supported by the clinical and wider research teams, has provided Southampton with ability to offer multiple research studies to patients, something patients and families really value.

Jenny Pond, senior research nurse coordinating the team in Southampton, is optimistic that this recruitment can continue: 'Patients are generally very happy to be recruited, and the process is

straight-forward for the family.' Jenny says a common theme amongst those approached is that 'families really want to help families in the future.'

Dr James Ashton, Paediatric Gastroenterologist and Associate Professor at Southampton, is very pleased with the recruitment: 'All credit to our outstanding research nurses on driving this forward, contributing to a multicentre study like this is very important and we are looking forward to using the data generated to advance understanding and treatment of children and young people with IBD'.

The study represents a real opportunity for collaboration, and as the number of participants increases the data generated from PIBD Bioresource can be a real opportunity for researchers across the UK to make differences for those with IBD. The team at Southampton are working on additional tools, including artificial intelligence methods, that will improve data usage in a responsible way.

If you would like to get in touch with the PIBD BioResource please contact Professor Holm Uhlig or Hazel Johnson at paediatricibd@ndm.ox.ac.uk





What's new in inflammatory bowel disease? **PUBLIC INFORMATION EVENT**

22 May 2025 5.30pm – 7.30pm

Lecture Theatre 2, Academic Centre, John Radcliffe Hospital, Oxford
Patients, the public and healthcare professionals WELCOME

What's on...

We are very pleased to invite you to attend our third educational evening focussing on progress in Crohn's disease and ulcerative colitis. Presentations from Oxford consultants and specialists will cover latest progress in the medical and surgical management of these diseases, current research studies.

A special session focussing on young people growing up with inflammatory bowel disease.

In addition, we are delighted that Professor Kevin Whelan, from King's College London is coming to give a state of the art talk on diet and inflammatory bowel disease. He is a well-recognised expert in this area.

All of the speakers will take part in a Q&A session.

The Oxford IBD Team contributors include:

Dr O. Brain | S. Cripps | Dr H. Gordon | Prof P. Klenerman
Prof H. Uhlig | Prof J. Satsangi | Dr A. Walsh | L. White

**CROHN'S
AND
COLITIS**
#crohnsandcolitis

Registration required: Book your free place to attend in person
Send any questions about the event to: verity.davies@ndm.ox.ac.uk

www.eventbrite.co.uk/e/crohns-disease-and-ulcerative-colitis-public-information-event-tickets-1235853102899



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My Crohn's journey

Amber, age 12, tells us about her Crohn's journey



“ I was diagnosed with Crohn's disease in October 2021. Before my diagnosis, I had been going to the toilet much more frequently than normal, which led to many doctors' appointments and then my first endoscopy. At the age of ten, you would expect me to be nervous and, as suspected, I certainly was. I was overwhelmed at the prospect of an unpleasant experience, however with support from family and friends, I felt able to go through with it. After countless observations and never-ending blood tests, the doctors found inflammation on my right side from the endoscopy procedure, which was found to be Crohn's.

After the diagnosis, my consultant decided my first line of treatment was the Modulife plan. I remember it vaguely, having to take the skins off apples and eating only eggs, chicken, potatoes and bananas - the allowed food for phase 1. The taste of the Modulen and the bland food, however, I can still recall, along with watching my friends feasting on delights they brought to school every day, whilst I tucked into the limited food I could eat. I found it quite overwhelming, from time to time, with constant questions from classmates, eager to know why I was frequently gulping down an unfamiliar liquid. Challenging as it was to share this personal obstacle, I knew that it was helping me.

Since then, I have taken medication daily which has helped me to remain well even though the taste is revolting as it dissolves in my mouth. This has now become a daily pattern of mine. Although I have got used to the persistent routine, it has been challenging, but I do believe that Crohn's, and the journey I have been on to get to where I am now, has made me into the person I have become today. I also would never have become who I am without the influence of my

Mum and Dad. They have been so supportive these past few years, participating in one of the 10K vitality runs, raising funds for CICRA, as well as bringing me to the countless appointments I attend, which I will be eternally grateful for.

My routine tests were recently repeated and, due to inflammation still being present, it was decided I would start Infliximab biologic infusions. At the time of writing this, I am about to have my third one. At first, I was nervous as the infusions meant I had to miss school, and I felt anxious that I would miss important lessons. However, when I arrived, I was greeted by the nurses on the Assessment Unit, who were really welcoming and they soon put me at ease. Now, my teachers understand every now and again I have to miss a day of school, and they kindly send me the work I miss, so that I do not fall behind. I

am grateful that I can do the things I love, such as dancing, swimming, and running, even if sometimes I get quite tired doing it. Despite the journey I have been on, and the ups and downs along the way, I have accepted that Crohn's is a part of me, and I choose to see it as something that truly makes me unique. ”

What Amber didn't say was that she was awarded the 'Junior Department Musical Theatre Cup' at the prestigious Laine Theatre Arts in Epsom. Well done Amber



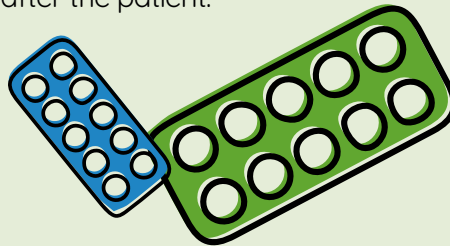
Ask the Doctor

Q My child is autistic and is struggling with having to take any medication, blood tests and treatment. What options do we have if they just can't tolerate it?

This can be very difficult and can also be true of patients without autism. All children's services should have access to support for such issues with professionals such as play therapists and psychologists in addition to the nurse specialists, dieticians and medics. Making progress can take time but it is usually eventually possible to find a treatment and monitoring regimen which is feasible and pragmatic.

Q Do probiotics help IBD and if so, which ones should I give them?

Pro-biotics have not been shown to work in IBD anywhere near as well as drugs available and there are many different pro-biotics out there which may not have been tested at all. They probably do not cause harm and many patients take them (and no doubt some believe they benefit from them) but we cannot recommend any single one. This is best discussed with the team looking after the patient.



Q Do siblings of children with IBD also have to avoid certain vaccines?

In general the answer is no, siblings can have their usual vaccinations. But if this is raised by the vaccine team discuss with the team looking after the sibling with IBD who know the treatment he/she is on.

Billie Nuth



New 3 year CICRA PhD Studentship

A three year PhD Studentship at Dundee University under the direction of Dr Mairi Mclean:

// I'm delighted to be awarded a PhD studentship for my lab.

We are using cutting edge experimental models of the cells lining the gut called organoids, created from human IBD tissue samples. In health, these cells lining the gut create a barrier between the gut contents and the underlying tissues. This barrier changes in active IBD and becomes 'leaky', and allows gut contents such as bacteria to interact with underlying immune cells.

This project will define ways in which gut barrier cells are injured and the cell mechanisms they use to repair. This will create new knowledge on the underlying cell biology in IBD with the aim of identifying new treatment targets for future development.

Billie Nuth, the appointed PhD student, is enthusiastic and dynamic and is making great progress. It's great to be given the opportunity to supervise and mentor the next generation of scientists within the IBD field. Thank you once again to CICRA for this funding award. **//**



Spotlight on Southampton's IBD Research



Dr James Ashton

We were pleased to receive this report from Dr James Ashton keeping us up to date with all the good work being carried out by the team at Southampton Children's Hospital including the three year CICRA funded Fellowship.

The paediatric gastroenterology team in Southampton continue to work closely with CICRA on inflammatory bowel disease research for children and young people. With a focus on genomics, 'big data' and personalised medicine, the team are making strides to put their research into practice.

Dr Zach Green has settled in well to the CICRA research training fellowship. He is working with the group using large-language models to structure medical reports, aiming to utilise these clinical data in a variety of research projects. He is currently working with these data to explore how blood tests taken at IBD diagnosis might predict disease outcomes. He aims to use the "big clinical datasets" he is generating to help predict risk of key, patient-relevant issues such as surgery or poor medication response.

Several recent publications and submission are highlighting this ground-breaking work, including original research 'Application of Generative Artificial Intelligence to Utilise Unstructured Clinical Data for Acceleration of Inflammatory Bowel Disease Research', led by one of the talented post-doctoral researchers Dr Alex Kadhim, and an editorial piece titled "Prediction in Inflammatory Bowel Disease—Do the Answers Lie in Big Clinical Data?". Dr Zach Green, alongside Professor Mark Beattie, Professor Sarah Ennis and Dr James Ashton, his PhD supervisors, have attracted international attention and collaboration with sites in the USA. Excitingly, results from our genetic cohort study are translating into the clinic. Working with our scientific and clinical teams, we have identified single-gene causes

of disease in roughly 1/400 of our patients. For some of these individuals we will be able to modify treatments and provide additional prognostic certainty.

One of the most exciting avenues of research is focused on a specific gene known to be very important in Crohn's disease. NOD2, shown to increase the risk of surgery and bowel narrowing (strictures), is increasingly thought of as a single-gene cause of IBD. Working across centres, and with international partners, we are looking to establish novel treatments for patients with this type of disease. We hope these options will be effective and available to patients in the future.

Closer to the clinic, Mick Cullen, a paediatric gastroenterology clinical nurse specialist in Southampton, has been





conducting service evaluation work on the use of pre-medication in IV infliximab infusions, aiming to improve children and family experience of the medications. Mick has been selected to present this at this year's BSPGHAN annual meeting in Newcastle. Keeping things clinically relevant, Zach has also completed the closure of the ultrasound NIMBUS study, which he was involved in during his time in Cardiff. He is now in the process of writing up the study's findings for publication. He is also actively working on

several other research papers related to his fellowship.

The team are actively recruiting to our local genetics of IBD study, and currently we have over 3000 participants across patients and family members. Our research nurses are fantastic advocates, offering research opportunities for all patients with IBD and keeping our recruitment levels at brilliantly high levels. We are also recruiting to the national PIBD Bioresource study and are looking forward to working with other centres to generate

patient-relevant results.

The Southampton IBD team continue to keenly engage with patients, families and the public on our research strategy. Through close ties with CICRA, alongside patient groups, allows us to better explain and explore research priorities. Our newly revamped website contains a number of patient stories and lay explanations of our recent publications - **southampton.ac.uk/ibdresearch.**



Alongside their research they are also raising money for CICRA

Looking ahead, Zach, alongside Dr James Ashton and Dr Marco Gasparetto (previous CICRA research fellow, now consultant paediatric gastroenterologist in Norwich), are planning to raise money for CICRA by taking on a three-marathon-length walk of the South Downs Way in March 2025. Their JustGiving page can be found at: justgiving.com/page/marco-james-zach1736287327552 or scan the QR code



PIBD in a devolved nation Update from North of the Border



Prof David Wilson

CICRA last visited Scotland when supporting the 6th paediatric IBD global symposium (PIBD 2022) in Edinburgh. For our associated patient and family education day, we invited UK and Irish families affected by PIBD to attend with multiple speakers including PIBD luminaries as Professor Anne Griffiths (Toronto) and Professor Marla Dubinsky (New York). In this article I wish to update on Scottish PIBD activity since then.

We advocate for PIBD patients and families. Professor Richard Russell (Edinburgh) is highly influential as chair of the ESPGHAN PIBD Porto group. We are both authors on an ESPGHAN-NASPGHAN position statement arguing for modification of pharmaceutical industry PIBD clinical trial design to expedite the disgraceful 6-10 year delay between PIBD and adult IBD drug approval; currently 14 biologics/oral small molecules are approved for adult IBD but two for PIBD! We are both authors on the latest ESPGHAN-ECCO international guidelines on management of UC (being published in 2025 in JPGN) and Crohn's

Mikkel is currently validating PIBD algorithms in Scotland which can then be used for adult and PIBD through the UK.

disease (to be published in 2026 in Journal of Crohn's and Colitis).

Our nationwide PIBD research is mainly in epidemiology/clinical outcomes. With 8% of the UK population in 32% of its landmass, our Scottish regions combine for nationwide research. Dr Mikkel Malham (Copenhagen) is in Edinburgh for a year (part-funded by a CICRA project grant) working on classical and advanced PIBD epidemiology. Our paper on nationwide PIBD incidence/prevalence 2015-2018 manuscript is submitted for publication; once accepted our Scottish durable PIBD incidence rise 1969-2018 (620% increase in 50 years!) paper will be submitted. Mikkel is performing a Scottish COVID-era PIBD incidence 2019 to 2024 study but it is very difficult to enumerate UK-wide PIBD patients. Dr Paul Henderson (Edinburgh) did so via the PINPOINT study on UK-wide PIBD incidence 2021-2022; the first paper has been submitted for publication. The problems in collecting nationwide individual patient data means that advanced epidemiology (use of administrative health data registries plus data-





linkage between these) is vital. Mikkel is currently validating PIBD algorithms in Scotland which can then be used for adult and PIBD through the UK.

We continue to publish on therapies through our Scottish PIBD advanced therapy registry – Dr Gregor Scott's (Glasgow) publication compared real world anti-TNF in CD experience to guidelines, recently published in IBD journal. Our nationwide EEN experience in CD showing use beyond the mild CD to combination with anti-TNF was also recently published in IBD journal by Dr David Wands (Glasgow).

Professor Kostas Gerasimidis (Glasgow) continues to lead on nutritional therapies. Having completed the BIOPIC study in adult CD, he obtained funding for BIOPIC-kids. I lead a Scotland-wide translation PIBD project (Mini-MUSIC) funded by Edinburgh Children's Hospital Charity and with CCUK funding are extending to English centres also; this similarly will be all-ages with the adult IBD MUSIC study. Lastly, we have explored non-immunosuppressing therapies in the SE Scotland region, publishing on underused therapies (azithromycin/metronidazole in CD, published in JPGN and repurposed therapies (oral vancomycin for non-PSC UC, an oral presentation at ESPGHAN 2025).

Prof David Wilson, University of Edinburgh

Professors David Wilson and Richard Russell join Europe & North American Societies in an effort to speed up drug approval for paediatrics

Scottish regions combine for nationwide research

Dr Mikell Malham (Copenhagen) is in Edinburgh, part funded by CICRA, working on PIBD epidemiology

1969-2018 research shows 620% increase in PIBD

Professor Kostas Gerasimidis (Glasgow) continues to lead on nutritional therapies.



Our amazing supporters!

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

John Walker RAF WOSM Cheltenham Inflatable Event



Raised
£267

// Our inspiration for this was my son who was diagnosed with ulcerative colitis 2 years ago after suddenly becoming very ill over the summer holidays of 2022.

Alex was a healthy 11-year-old boy at the start of the summer holidays and by the end of the 6 weeks he was in a lot of pain, experiencing bleeding and lost a huge amount of weight, all within a few weeks

He had many trips to the doctors and was referred to hospital where in the October he was diagnosed with having quite severe ulcerative colitis, with his consultant finding the disease throughout most of his intestines

Alex has since been under the care of the hospital and his IBD is under control at the moment, it's not been without its ups and downs

He's a real inspiration to us all and we are all so proud of how he has dealt with this and tries to just be normal.

and when Alex gets poorly it sets him back. It's not been easy to see your child suffer and be helpless along the way.

He's a real inspiration to us all and we are all so proud of how he has dealt with this and tries to just be normal.

We took part in this event on Saturday the 19th of October and all completed 15k of inflatable obstacles and my son went there to complete 5k and manage to do 7.5k in the end

We hope that one day there will be more to help Alex and others in the same situation and hope that our donation goes somewhat towards that. //

We thank John and his RAF team for their very welcome support and especially Alex, for going further than he had signed up for – a real fundraising inspiration!



Mark Euesden Tough Mudder

Mark's son was diagnosed with Crohn's disease in 2018 at the age of 10. He said CICRA has held a special place in their hearts ever since, so he decided to fundraise for CICRA.

Taking on the Tough Mudder Mark said: -

'It was the most mud I've ever seen but what a great event!

My highlight of the day was on one of the final obstacles, Everest, (image above) where you rely on people at the top to drag you over.

By chance the group who pulled me up were fund raising for Crohn's & Colitis UK - IBD fund raisers unite!

We thank Mark and all his supporters; those in the mud and those who were not!

Raised
£1,075



Jagdeep Sehmbi Summer 6 Challenge

We would like to thank Jagdeep and 4 year old Arjun for raising an amazing amount over the summer. Sadly, at the start of August they had to put the challenge on hold but still managed to raise an incredible amount.

Raised
£1,294



Navneet Jammu Half Marathon

Our family was faced with the challenge of our daughter's diagnosis with Crohn's disease. To show my gratitude and help others experiencing the same situation, I decided to run a half marathon for CICRA. Not only did I get to challenge myself physically and mentally, but I also had the opportunity to raise awareness and support for a cause close to my heart. CICRA has played a crucial role, providing us with valuable resources, information, and support during her battle with Crohn's disease. I am thankful for organisations like CICRA that provide support and resources for families like mine, and I am honoured to have been able to contribute to their important work.

Thank you, Navneet -
very much appreciated.

Raised
£350



Mark Farren Cardiff Half Marathon

Mark has been a member of CICRA since 2018 when his son was diagnosed with Crohn's.

He ran the Cardiff Half Marathon after signing up through Run for Charity, pledging to raise £350.

We are very happy to say Mark exceeded this target by an incredible amount!

After the run Mark said 'I'm really pleased with my fundraising efforts'.

We are too Mark, thank you for your amazing support.



Peter Horsting Climbing that mountain!

On 5th June 24 our 14-year-old daughter Ella was admitted to the Chelsea & Westminster hospital (amazing team) and by the 14th June we were given the news all parents dread that Ella had an incurable disease that would affect her life.

She would need to have a liquid diet for 6-8 weeks fed via a tube up her nose into her stomach, and an immune suppressant drug to reduce the inflammation. Ella has been amazing throughout and is determined to get better and get back to life as before, with school, friends & family, ice skating and swimming.

In August, Peter and 5 friends decided to climb Scafell Pike, the highest mountain in England, with 4 others, including Ella and best friend Ava doing part. Following this tremendous effort there was a big pub celebration and then home.

Peter posted: 'So proud of us all for conquering Scafell Pike yesterday! It was an epic adventure in brutal weather conditions. What a fantastic group of adventurers raising money for Ella and a great cause'

Thank you goes to Peter, his family and friends for committing to an incredible challenge, we hope you all have some great memories.

Raised
£5,314



Rebekah Hand painted cards

// My name is Rebekah and I was diagnosed with Ulcerative Colitis at the age of 8. I have raised money in the past for CICRA, selling handmade cards and holding a coffee morning with my Mum and Dad. I am now studying for my A-Levels and wanted to raise awareness and money again in aid of CICRA and my Dad and I decided to hand paint Christmas cards to sell. We painted about 200 cards and raised £250, selling them to friends, family and neighbours. //

Well done Rebekah and Dad – they are beautiful.

Raised
£250



Tom Cooke Berlin Marathon

// Let me tell you about my sister Louise. She lives with Crohn's disease, and calls it a "wild ride," and let me tell you, it's one hell of a journey. CICRA supported our family when she was a kid, and continue to support families in the same situation

Fast forward to today, and Louise? She's badass. Travelling the globe, inspiring young minds as a teacher, and being the best mum to Felix, whilst still living with Crohn's disease every day of her life.

As for me, I've been hitting the pavement to raise funds for CICRA. I've not done an event for them since 2016. Sooooo, It was time to get back to it and I set my eyes on the 50th Berlin marathon.

Super proud to raise money for CICRA on my 5th Berlin – a great day and race. I wanted to enjoy it and managed a 3:16, 2mins off my personal best, so the good vibes were there! //

Many thanks Tom.
Louise has always been an inspiration to others.



Raised
£1,792

Interclub Taekwondo Competition

Thanks to James Welsh and his Scunthorpe based Taekwondo club for entering a recent interclub competition.

Posting on Facebook James said: -
Interclub Competition Success!

Our Interclub Competition wasn't just a day of hard-earned victories and friendly matches — it was a testament to our students' courage, morale, and teamwork!

Every single participant showed amazing spirit and determination, making us so proud of their growth in confidence and skill.

A huge thank you to our supportive Taekwondo family!

Not only did we have an amazing day, but together, we raised an incredible £508.75.

Raised
£508

FUNDRAISING

Raised
£1,216

Nik McKean Ultra Spartan

// In May this year, my youngest daughter was diagnosed with IBDU, a form of Inflammatory Bowel Disease. CICRA has been a great resource for our daughter and ourselves to answer questions and understand more about the condition, in a manner that is easily received by kids. It has a brilliant facility too, that allows kids of similar ages to connect with each other, re-assuring them that they are not alone.

So, in October this year, I participated in a Spartan Ultra in aid of raising funds for CICRA. It was brutal!!!!

11 hours and 15 minutes (ish) and about 37 miles. All through bog, woodland, hills, lake swims and trails, with about 60 obstacles chucked in for good measure. I loved it!!!

I felt remarkably mobile the following day too and slept well. I made a point of wearing the CICRA t shirt in the second lap, although it didn't stay white for long!

Fundraising has gone above expectations, I'm really pleased with the amount I managed to raise, and hope that this will help in whatever way for the charity. //

Thank you Nik – yes brilliant and will be spent wisely



Robin Hood Half Marathon

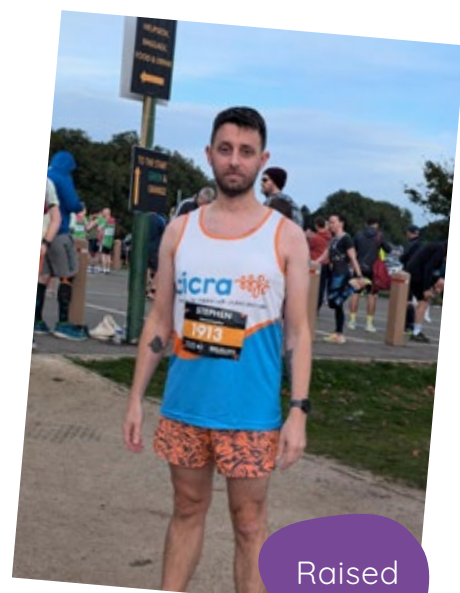
This year was the first year we offered The Robin Hood Half through Run for Charity and were thrilled when we had two people sign up to run in this event.

Laura Wilkinson

// My little Boy, Charlie, was diagnosed with IBD (inflammatory bowel disease) at the end of June 2024 after just turning 1 year old. Charlie had suffered with an unknown condition since the age of 4 months old and after taking him back and forth to the GP and endless hospital trips and admissions, we finally got the diagnosis that is IBD 9 months later. Charlie is the most smiley, happiest and laid-back little boy with a heart of absolute gold and his diagnosis of IBD came after the simplest test, a stool sample which could have been diagnosed all those months ago. We are still attending and waiting for appointments on how Charlie's diagnosis can be managed but, in the meantime, I want to raise awareness for this condition as I hadn't even heard of it prior to researching and pushing the doctors to perform tests to get Charlie's diagnosis which is extremely rare in children.

CICRA has helped me feel heard and helped me understand the symptoms Charlie is experiencing since he doesn't have a voice. They have even provided ways to help explain Charlie's condition to my older boy who is only 3 years old himself. We yet don't know how/why Charlie has got this condition but with the focus of the charity being research in IBD specifically in children, it really does help myself and our little family come to terms with this'. //

Raised
£388



Raised
£768

Stephen Garton

// I started running 2 years ago, as I was about to turn 40 and nowhere near as fit as I wanted to be. I started with a target of being able to run 5k to do a fun run with our dog for Battersea. Once I'd completed couch to 5k and was comfortable, I signed up for my first 10k run in September for Crohn's & Colitis UK - my wife has had microscopic colitis for nearly 15 years, and we now have a family membership with it. I like to sign up for things to commit myself, so I don't lose interest, which is what happened last year.

Late last year my daughter (14) was diagnosed with Crohn's. She's had 3 infliximab infusions so far to start her treatment off, and a couple more scheduled. She is having a really tough time of it, the most noticeable of which is problems with anxiety, which have led to a lot more absence from school than any of us would like. She's going to be getting some counselling through school, and the hospital have said that the psychologist would speak to her at her next infusion to try and put some plans together.

It only seems fair that if I wanted to challenge myself to be able to do a half marathon, committing to raise money for a charity means I will stick to the training!

We thank both runners for their dedication to the training and for getting out there and promoting CICRA. We are sure their families are very proud of them. //



Tom Rumsby 12 challenges in 12 months

Tom and his friends took on the challenge to raise funds for CICRA, CALM and Pancreatic Cancer UK and what a challenge it was.

Every month, something different – 24 swimming marathon, Brighton half marathon, Walk up Snowden, Scuba diving with sharks, 100k steps in 24 hrs., Cycle London – Brighton, Pretty Muddy 5k, Ice Bath each day of a month, Triathlon, Self-love month, Movember and unfortunately not being able to compete in December due to illness, Tom took part in a forfeit – a body wax – ouch!

“As someone who grew up with Crohn’s, officially being diagnosed at 14, I have personally witnessed the impact of this disease, I am passionate about supporting CICRA’s efforts to find a cure. Over the last 15 years I have had my fair share of ups and downs. I have many friends who have been so willing to support me, from scoping out the nearest loo, to finding loo roll when I was caught short!”

With supporters like Tom, who give up time and show dedication to fundraising and raising awareness too, we are very grateful - thank you.

Raised
£561

Thank you so much to these awesome people!

Tyrell de Oliveira

Raised £228.75

Ultra Mixed Martial Arts Charity event

David Johnston

Raised £260

David’s talks including The Shackleton Trans-Atlantic Expedition, Life in the 1950’s and Japanese Culture has raised another £415 bringing his total to date to £1,436 since 2023.

The Youth Section of the West Hampshire Caravan and Motorhome Club

Raised £528.89

We thank Bethany, 2024 Youth Chairperson who kindly chose CICRA to support.

Sarah Burns

Raised £2,632.20

Sarah did a sponsored walk - walking 5 miles a day every day, throughout June and July 2024. Sarah said ‘the challenge went great, I did the whole 61 days and never missed one!’

Alison Johnston

Raised £266

Alison Johnston and her line dancing Ladies and Gentlemen donated £32 in August and £234 in January 2025 from class raffles and donations. This takes their fundraising to over £7,500 since 2014 – amazing!



Kelly Martin The Big Half



Raised
£1,342

Kelly Martin's friend Nicola ran the London marathon in October 2022 and signed up to the Big Half marathon in February 2024 as she hadn't run since the marathon and was keen to get back into it. Kelly did a few short runs with Nicola but normally only 3 mile. She then decided to challenge herself and sign up to the Big Half Marathon with her son Jay and his girlfriend Isabelle. Their training began and all agreed that they would "run to raise money for CICRA as it's a charity close to our hearts"

Kelly wrote "My son was diagnosed with Crohn's disease 3 years ago when he was only 9 years old and I've been wanting to give something back to this charity as a thank you for all the help and support they give to families like ours. The day of the run was hard as it was 27 degrees, but we all completed it and got our medals and managed to enjoy the day."

Thank you for the financial support and kind words.

It's a family effort



Raised
£291

Patrina and son Torin decided to take on the Virtual Run to fundraise yet again for CICRA. They ran 25 runs of over a mile during January.

We thank them for this commitment, in what is a difficult month, with dark, wet and cold days, what exceptional fundraisers!

The Law family have been fundraising for CICRA for the last 5 years. Each year they hold a Plant Sale from their garden, scheduled this year for May 10th-11th. Patrina told us that 'If the plant sale goes well, we should well exceed our £1000 target again this year.'

We can't thank the Law family enough for their fantastic fundraising efforts and wish them well with the Plant sale in May.

Ingrid Clemo's School Support

I was diagnosed at 13 with Crohn's Disease and had a very long and painful battle, spending many weeks in hospital, having multiple surgeries & missing a lot of school. I am now in remission and have been an ambassador for this charity, speaking at a 2023 research event.

This is why I feel so passionate about helping to raise money for such an important cause.

As Head of Bloomsbury House, I wanted to raise as much money as possible, so more research can be conducted into Crohn's and Colitis, and children with these diseases will have better futures, and not suffer like I did in my early teens.

For the charity week, we had many ideas including - a group triathlon (totalling up and logging distances on Strava). This didn't work out as well as hoped ("surprisingly" not many teenage girls wanted to run!) but we did a charity netball match with tuck shop & clothes sale, as well as a bake sale in February and were pleased with the results.

We thank Ingrid and all her fellow students at Bloomsbury House for this splendid amount. Ingrid has now left school and has started the next chapter of her life at university, we think this determined young lady will do very well.

Raised
£903



A Fond Farewell

We were saddened to hear that Rod Mitchell, a long standing supporter of CICRA, as a Trustee and a volunteer, had passed away following a short illness. This is not only a huge loss to CICRA but to IBD in general. Rod dedicated so much of his time to helping in so many ways, from giving talks, sitting on various committees, writing letters for funds, stuffing envelopes, attending meetings, selling merchandise and chatting to, and reassuring patients, parents and children.



Rod was born to a farming family on the Isle of Wight and used to recall helping out on the farm when he wasn't at school. When it came to a career Rod chose banking and this is where he met his wife Myra. When offered a Manager's job on the mainland they moved to Hampshire and lived there for the rest of their lives. Unfortunately, Myra had Crohn's disease so Rod decided that he would devote any spare time to this cause.

When CCUK was formed in 1979, Rod and Myra joined their local group and eventually Rod joined the Executive Committee (Trustee) becoming Chair for a spell. The American and Canadian Foundations were in existence and with groups being formed in Europe the European Federation of Crohn's & Colitis Association was formed (EFCCA). Rod chaired EFCCA for ten years and when he stood down he rang to ask if we needed any help! He became a very special knowledgeable volunteer and in 2008 became a CICRA Trustee representing CICRA on various committees. Myra sadly passed away just a few years ago.

Rod will be sorely missed especially at our Family Day meetings where he was such a popular member of the CICRA team.

If you remember Rod and would like to give something in his memory please via our justgiving site or with a cheque to the office.

Margaret Lee

IN MEMORY

We are sad to report that two CICRA members, Amy Grime and Charles Wintour, passed away recently and we send our sincere condolences to family and friends.

In Memory

We are very grateful to have received over £8,000 from family and friends in memory of their loved ones.

Eileen Wake

Roger Webb

Katy Jade Sutton

Margaret Bates

Heather Reid's Dad

Rosemary Hynes

Anne Cartledge

Amy Grime

Margaret Elizabeth McGowan

200+ club results

The CICRA 200+ club offers you a thrilling opportunity to win cash prizes each month while supporting a great cause. By joining the club for just £26.00 per year, you stand a chance of winning a cash prize of up to £250.00. Thank you to all our members who took part in 2024, and congratulations to all our winners. If you would like to join, please email admin@cicra.org

January	V Batchelor	21	£50
	J Parker	129	£50
February	L Billett	99	£50
	S Neary	235	£50
March	J Haslam	1	£250
	S Jefferson	190	£75
	J Caine Goldsmith	32	£75
April	R Eames	241	£50
	C Ram	72	£50
May	P Miller	242	£50
	S Lazenby	5	£50
June	B Warne	262	£250
	H Brady	18	£75
	B Plumb	61	£75
July	C Hougham	92	£50
	J Speed	12	£50
August	K Piatt	136	£50
	A Feakin	14	£50
September	H Brims	159	£250
	M Coupe	83	£75
	M Lee	46	£75
October	L Pegg	248	£50
	R Hostler	257	£50
November	S Bramble	209	£50
	L Outterson	135	£50
December	J Gibson-Wyer	201	£250
	M Harvey	19	£75
	M Miller	227	£75

Christmas Draw Results

The 2024 Christmas draw took place on Thursday, 12th December at the CICRA office, located in Pat Shaw House, Sutton. We are grateful to Penny Hughes from Xeinadin accountants for kindly drawing the winning tickets.

Prize	Ticket No.	Name
1st Prize	£500	G Bone
2nd Prize	£250	S Mohammed
3rd Prize	£100	C Ram

Thank you

Your support is invaluable, and all proceeds from the draw will go towards funding vital new research and support for families affected by Inflammatory Bowel Disease (IBD). Thank you for your generosity and commitment to making a difference!

Summer Draw

**WIN
£500**

**You can now take part
in our Summer Draw online!**

All proceeds from the draw go towards funding our research programme.

Take part in the CICRA Summer Draw to be in with the opportunity to win exciting cash prizes while supporting us.

Each ticket costs just £1

Be in with a chance to win one of the following prizes:

1st Prize £500

2nd Prize £250

3rd Prize £100



To play visit:

raffleplayer.com/cicra

or scan the QR code above on your phone