



the insider

Autumn 2023

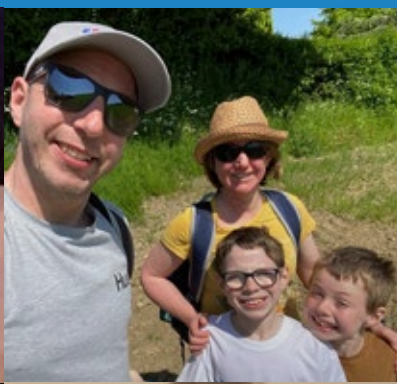
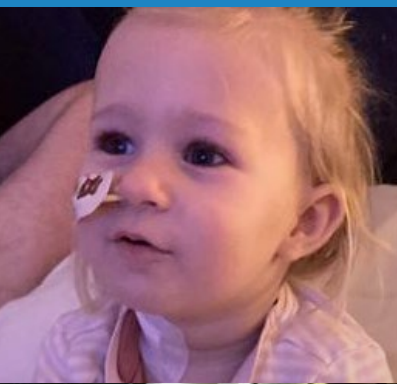


1978 **45** 2023
years
research & support



Make a difference to 1,000's of children with IBD

If everyone reading this donated, or raised just £4.50 we'd have £22,500 extra to spend on research to end IBD.



cicra 
better lives for children with crohns and colitis



Chairman's Message

Dear Friends and Supporters,

Welcome again from the Trustees and Staff to the Autumn 2023 edition of the Insider Newsletter. During this very special anniversary year for the Charity, it is very exciting to be able to report on the return of our Family Days. We held our first Family Day for 3 years in June at Nottingham racecourse, and as you would expect it was an extremely popular event. We have various articles relating to presentations from the day on pages 8, 10 and 11 of the Insider. I am delighted to also announce that we will be holding our 45th Anniversary Family Day in Bristol on 21st October. More details will follow soon, but see page 9 for some initial information on the plans for this event. Note that this event will be very popular and early booking of places will be essential.

This year we have had an excellent response to our 45th anniversary fundraising appeal, and the Trustees would like to thank all of those people who have raised funds for CICRA this year – as you look through the Insider you will see the amazing ways that our supporters have contributed. Congratulations to everyone involved!

At this time of year, the team in the office are already very busy preparing for the Christmas Cards and Christmas Draw. Do look out for the Christmas Cards which will be available on our website soon – as ever these are very popular and sell out very quickly so grab them while you can.

Finally, a quick reminder for our 45th Anniversary appeal (<https://www.cicra.org/news/cicras-45th-anniversary>), as the more we raise through our appeal the more we can continue to fund the research and support that are so desperately needed.

Best Wishes

Graham Lee
Chair

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CICRA's 45 years

Our 45th Anniversary Year will finish on 31st March 2024. 45 years after CICRA was founded and what better way to celebrate than to try and raise funds to increase the £10,000 million already spent on improving the lives of children with IBD. As a medic said to his students when he was about to retire some years ago 'Thirty years ago we didn't have a service that we could offer families of children affected by IBD but thanks to CICRA we now have support, research and hope for the future' We couldn't have done this without the help of the CICRA members over the years, many still contributing to the cause in gratitude of the help and hope given. Those who have been around long enough to see the changes agree that they are amazing but we are not there yet and still need to continue in our aims of a healthier future for children with any form of IBD.

We have always planned to commission new research this year and have had had a great research response to a recent grant application process. We have a large number of projects, PhD Studentships and Fellowships submitted relating to childhood IBD that will be forwarded to the Medical Advisory Panel for assessment.

Depending on the recommendations of the Advisors, following the rigorous Peer Review that all research funded by CICRA has to go through, in all probability we will receive back a list of far more approved applications than we can currently afford.

We are therefore looking to maximise what we can commission this year with our 45th Anniversary appeal.

<https://justgiving.com/campaign/cicra-45th>

Every penny donated will be used wisely to fund research so anything you can add to our appeal will be greatly appreciated.

Over the remaining 7 months of our appeal we challenge you to support our 45th Anniversary appeal by partaking in or arranging an activity or event to support us, making a donation or even buying a few more raffle tickets than normal.

With our 45 theme could you undertake a 4.5 or 45 mile challenge, could children undertake a 45 star jump/hop/skip/press up challenge?

With our Research Programmes we are making a wise investment for the future of all children affected by IBD and every little bit of help will enable us to accelerate this programme during this special year.

Invaluable help from the experts

On behalf of all CICRA Trustees, staff and members we would like to say a special thank you to our Medical Advisors and external referees for reading through each and every application in detail and scoring them under 6 different categories. This is all done in an honorary capacity by busy doctors and scientists who give up some of their family time to ensure that CICRA only funds good quality research. One way or another this will benefit children already affected by any form of IBD and those who will be diagnosed in the coming days, weeks, months.



Ask the doctor

At the Nottingham meeting we run out of time for the panel to answer all the questions so put them to our medics since. We thank them for their answers.

Q Is there a link between IBD and ADHD or autism? I have read about possible inflammatory causes of ADHD and know IBD can have systemic inflammation effects.

A This is a very delicate question requiring particular attention to the difference between an association and a cause-effect relationship. There is increasing awareness of associations between somatic and mental symptoms in developmental disorders. Children with autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and learning difficulties appear to develop other medical conditions more often, including problems in their immune system and gastro-intestinal symptoms. Previous studies have shown a potential association between ASD and inflammatory bowel disease (IBD)¹. While the mechanisms causing both conditions remain partly unknown, it is very hard for researchers to address and demonstrate the existence of an actual link or a shared mechanism between the two.

There are studies showing that any state of chronic inflammation during pregnancy, such as poorly controlled IBD, may affect fetal brain development².

Earlier this year, Zhu J et al.³ identified a panel of genes that are similarly active ("gene expression") in ASD and in IBD. While this might suggest the existence of a shared mechanism between the two conditions, further research will be necessary to confirm these findings. In parallel, environmental factors (particularly related to pregnancy and birth) are also being looked into.

Hopefully, the bioinformatics tools increasingly available for scientific research will provide further insight into the fascinating area of gut-brain axis as well as the role possibly played by inflammation to brain development disorders.

References:

- 1: Lee M, et al. Association of autism spectrum disorders and inflammatory bowel disease. *J Autism Dev Disord.* 2018; 48(5): 1523-9.
- 2: Shero N, et al. Impact of Crohn's disease during pregnancy on children with attention deficit hyperactivity disorder: A review. *Annals of Medicine and Surgery* 2022; 75: 103369.
- 3: Zhu J et al. *Journal of Translational Medicine* 2023; 21: 372.

Do you have questions you'd like featured on this page? Email support@cicra.org



Q Is there any evidence that taking Turmeric tablets is beneficial?

A There is no hard evidence for IBD but few studies (in Adults) have shown the anti-inflammatory properties of Curcuminoids (turmeric). I don't think turmeric alone no matter how high the dose will cure things, but as combination therapy with a good 'anti-inflammatory' diet (healthy eating), medications may help dampen down the inflammatory response on long term.



Q Mental health seem to be at the forefront so much in IBD, why is a psychologist not automatically assigned to a child with IBD?

A Ideally every child diagnosed with IBD would have access to psychological support if they want it, however we are also mindful that not every child will want it or experience psychological struggles with IBD. Young people with IBD are supported by a medical multi-disciplinary team due to the young people being really physically unwell at the start of their journey. Often several hospital admissions or appointments are required in order to find a diagnosis. Going through all of these tests and appointments can already be a large burden with children missing out on school or aspects of their lives that are important to them in addition to the potential difficulties of living with IBD. We would love every child to have access to psychological support as they need it to better support them, however, this is not always possible with resources needing to be maximised to meet the needs of as many as possible.

Q Are there any long-term effects of taking Mesalazine?

A Mesalazine is a medicine called a 5-amino-salicylate and it can be used to treat flare ups as well as to maintain remission where there is mild to moderate inflammatory bowel disease in the large bowel or colon. There is good evidence that mesalazine is an effective treatment for ulcerative colitis, but it tends to be less effective for Crohn's disease. Mesalazine is in a group of medicines that have been used since the 1940s for the treatment of inflammatory bowel disease, so we are able to confidently say there are rarely long term side effects from taking mesalazine.

The vast majority of patients tolerate mesalazine very well. It can sometimes worsen diarrhoea. Rarely it can trigger a condition called pancreatitis which causes severe abdominal pain. Very rarely patients can experience low blood counts or have reduced kidney function. These conditions tend to be short term and can all be picked up on routine blood tests, which your doctor will request as part of monitoring IBD and/or its treatments. The good news is that even young people who are unlucky enough to have side effects from mesalazine are almost certain for these to resolve completely if the medication is stopped.

There are no long term complications associated with taking mesalazine, in fact on the contrary, taking mesalazine in the long term has actually been shown to reduce the risk of colorectal cancer, and this is a reason some consultants advise taking the medication, even when additional medications are required to gain better control of a young person's IBD.



Worried about the future?

This inspiring story from Muzher Sharif may help ease your concerns

I was diagnosed with Crohn's at age seven. I don't remember things being too bad back then, but I do recall needing to take a course of steroids to get me through my final year of primary school. My classmates didn't recognise me when I turned up after the summer with swollen cheeks!

My teenage years were by far the most difficult. Every other year I experienced a major flare-up. I had two operations in my first two years to deal with a nasty fistula. Moreover, the constant stomach cramps, running to the toilet, low appetite and extreme fatigue made getting through even a good week tough. Needless to say, my studies took a considerable hit. I lost count of how many missed attendance slips I had to fill out, deadlines that I missed and catch-up work I had to complete. I was lucky though, that as well as a supportive family and physician, I had one stand-out teacher who got me through my GCSE year. She convinced me to lighten my load and focus on my core subjects, given my significant health troubles. It's a lesson I strive to remind myself of even now.

At fifteen things came to a head as it was decided that medication had done as much as it realistically could, and I needed my large bowel removed. The two weeks in hospital felt like an eternity, but once I was back home, I recovered much quicker than I expected – and also got used to the ileostomy gradually over the following months. Whilst the

stomach pain and urgency were largely gone, the fatigue was still a heavy burden, and I had some skin problems to contend with too. It was around then that I began to regularly take biologics to keep things under control, and by and large they did a good job.

I was able to move on to university, and whilst the tough times of school were behind me, I still had to deal with the odd flare-up over the next decade. And although I had to undergo a minor procedure or two, switching to an injectable treatment instead of the infusions meant fewer days in hospital.

My last major Crohn's related event was in my mid-twenties when it was agreed that the remaining "stump" of bowel needed to go. It involved another two-week stint in hospital and period of recovery, but since then I feel I haven't looked back. I was able to land a great job less than two years after the surgery, and where possible I've been working on improving my general health. Eating, exercising, and sleeping right are top priorities for me now to keep the lingering fatigue at bay.



Inspired by

the
insider



A bouncy 5K

I'm Jessica, I'm 10 years old and I love school, reading, playing tennis and netball, I have pet Guinea Pigs who are called Teddy and Nelly. I was diagnosed with Crohn's disease in June 2022, when I was nine, after being ill for nine months. It took a long time for doctors to diagnose what was wrong and I was in and out of hospital a lot, the eventual diagnosis came following a colonoscopy.

I have a Humira injection every two weeks and the district nurse comes to my school to administer the injection, I also take azathioprine tablets every evening. I am now putting on weight and only go to the hospital for regular check-ups and blood tests.

I really enjoy sport and play tennis and netball for my local teams as well as many school sports and I have represented my school at athletics, netball, football and cross country running.

I have been reading The Insider magazine and it inspired me to raise some money for CICRA myself. After searching on the internet, I entered the 5k Inflatable Obstacle Course, this was a 5km run with inflatable obstacles along the way to make it harder, my big sister ran with me and my Mum did it too as we needed an adult to supervise.

We really enjoyed the run and raised over **£650** for CICRA through a Just Giving page which I made myself. *Well done Jessica, big sister and Mum. We are very proud of you and thank you for raising such an incredible amount.*

Starbaker!

9-year-old Beulah Grant wanted to help her older brother Louis, who suffers from Crohn's so she taught herself to bake by watching YouTube videos. She made delicious cakes and cookies; all wheat and gluten-free. It was her own decision to sell them to their neighbours, and did so with great success as she raised **£280.75** which at her request, was donated to CICRA.

How amazing that Beulah taught herself to bake and then used her newfound skill to fundraise - a truly inspiring young lady and could be a future star of 'Bake Off'!



Full House Gathers At Nottingham Family Day

It is a sad fact, that as a part of our everyday conversations, we find ourselves constantly using the phrase 'Pre-Covid', and indeed it is equally sad that our last CICRA Family Day event was November 2019.

Little did we realise then, that with a record number of over 300 CICRA Members, Medical professionals & supporters together at the Oval Cricket Ground that this would be our last Family Day for over 3 years!

At various points during 2022, the Trustees looked at the possibility of putting a Family Day on, but as Covid kept rearing its ugly head we decided it was pragmatic to wait.

..... and so, at last, on the 18th March 2023 the gates opened at Nottingham Racecourse, heralding the resumption of these very important events in the CICRA Calendar.

It really was a packed house as some 200 people took their seats in the Centenary Suite and were welcomed by Chairman Graham Lee and Hon. CICRA Medical Director Dr Kate Blakeley.

The morning session featured Professor Tom McDonald updating us on the latest from the world of Research, Dr Kirsteen Meheran (Sheffield Children's Hosp.) talking about the Psychological impact of IBD, and Dr Jeng Cheng (Alder Hey) reporting on a 'First milk' study with the audience invited to the taste testing session. Two awesome young members completed the first session, very movingly telling their own personal stories of living with IBD.

Following a break for refreshments the programme resumed with Dr Kelsey Jones (GOSH) giving a very interesting talk about very early onset IBD (VEOIBD), sadly affecting an ever increasing number of children. Professor Chris

Probert (University of Liverpool) then gave some facts about Faecal Calprotectin, followed by Dr. Marco Gasparetto (Norwich & Norfolk) outlining the uses of digital technology.

After a 'racecard' packed solid with interesting speakers, time was unfortunately a little limited as the panel session took place, with audience questions being answered by Dr Anna Pigott (Royal Stoke), Dr Suchandra Pande (Leicester), Dr David Devadason (Nottingham) and Dr Rafeeq Muhammad (Birmingham).

Following lunch the afternoon's events kicked off with a most interesting talk from Dr Sumit Jagani, a Radiologist from QMC Nottingham explaining various test & procedures in the diagnosis and monitoring of IBD, followed by the ever popular rotating discussion groups plus two groups for teenagers giving them the opportunity to ask questions of medical professionals and share experiences with others.

The younger children were most certainly not forgotten, as throughout the day they were kept well occupied and entertained by our ever popular professional entertainer Ian Shaw, ably assisted by Paige Lee. Going by the noise and mess the youngsters clearly had a great time.

It was a hectic, but, hopefully beneficial day for those attending. We apologise the venue was tight for space, and for the long lunch queue, but we were keen to give as many people as possible the opportunity to attend.

Our thanks go to everyone who helped to make the event such a success. Most importantly, our thanks and gratitude go to the large number of Medical Professionals who gave up their valuable time to once again come along and support CICRA, we simply could not do these days without you. Thank You!

'Game On' at Bristol for 45th Anniversary Family Day

We are delighted to announce the date and venue for our special Family Day to celebrate 45 years since CICRA's inception back in 1978.

This event will take place on Saturday 21st October 2023 at the 'Seat Unique Stadium', home of the Gloucestershire County Cricket Club in Bristol.

The format of the day will be similar to previous Family Days, but we also hope to be welcoming along, and hearing from, just a few of the many amazing Paediatric specialists who have been the most important part of our growth and our journey over the past 45 years.

This is bound to be a very popular event, and places will be allocated on a strictly 'First come - first served basis' so please do contact the office promptly to secure your place. The venue is located in Central Bristol but just outside of the recently introduced 'low emissions' zone, and there is free car parking available on site adjacent to the venue. It is also a bus or taxi ride away from Bristol Temple Meads Station. The majority of the venue has full disabled access.

There will be a variety of talks from medical specialists in the field of IBD, along with some of our young members telling their own personal stories of living and coping with IBD. There will also of course be plenty of time for you to meet and chat with other Families going through similar experiences of having a child with IBD.

Lunch and refreshments will be provided and entertainment will also be available for the younger children.

This special meeting is being kindly sponsored by the Harold Berman Trust

All places must be booked in advance and we regret that you cannot just turn up on the day. To register your interest please call or email the CICRA office team at the earliest opportunity.

We look forward to see you for this 'Match Winning' opportunity to learn more about living with Paediatric IBD.

Paul Cooper - Trustee



Good news for IBD Research

CICRA Friend and former Honorary Medical Director, Dr Richard Hansen recently moved from a full-time clinical consultant post at NHS Greater Glasgow and Clyde to a new research position at the University of Dundee. Dr Hansen is working to set up a new research laboratory dedicated to studying paediatric gastroenterology, particularly the gut microbiome and especially IBD. He is still a clinical consultant for half of his time, working across the North of Scotland network in Dundee, Aberdeen and Inverness.

We wish Dr Hansen well in his new research endeavours and are sure there will be more opportunities for partnership between CICRA and him in the future. We will give updates in the newsletter from time to time and hope that once the hard work of setting up a new lab, recruiting staff etc are complete he will perhaps have time to come along again to one of our meetings. We look forward to this, and to hearing how well the research is going.



Faecal Calprotectin

A word that we have heard more and more over the last few years and something that we get questions about frequently. At the Nottingham Meeting Professor Chris Probert, Professor of Paediatric Gastroenterology at the University of Liverpool, gave a very interesting presentation explaining what Calprotectin. With his permission we print some of his presentation.

What is Calprotectin?

A. Calprotectin is a protein found in white cells and is quite stable

Why is Calprotectin found in stool?

A. If there are white cells in the stool, they will release calprotectin into the stool. White cells are released into the bowel when the bowel is inflamed for ANY reason

What kinds of inflammation cause calprotectin to rise?

A. IBD is top of our list, but infection can do it. So can piles, ulcers, anti-inflammatory drugs (aspirin etc). Untreated coeliac disease and surgical joins (anastomoses) – there is often an ulcer at a join, it is not due to Crohn's disease

Can calprotectin be raised without inflammation?

A. White cells are present in blood. Any time there is blood in the stool, there will be white cells and thus calprotectin.

How is calprotectin measured?

A. Using a stool sample. Calprotectin is stable at home for a day or two.

How quickly do we get results?

A. 2 days – 2 weeks

How are results interpreted, what's normal?

A. The numbers around Calprotectin vary very widely so if your child does have a test, ask either your GP, paediatrician or IBD nurse to explain exactly what the numbers mean.

How should we use calprotectin?

A. Strictly – to support the diagnosis of IBD. Less strictly – to monitor response to treatment.

Take home messages

- FC can be used to aid diagnosis – cut off is not entirely clear
- Higher levels (pre-diagnosis / pre-treatment) = support diagnosis
- Low levels may occur in ileal CD
- False positive from other disorders
- Change (reduction) = good news
- But if not close to normal, risk of later flare increases even without symptoms

Take home messages for established CD

- Low levels may occur in ileal CD
- False positive from other disorders and after surgical joins
- FC improves with treatment – but may not become 'normal'
- Look for a "step in the right direction"
- No test is perfect, and FC does not replace clinical skills

Freya's Story

Freya, a young person with Crohn's, came to our Nottingham meeting and gave a really interesting talk about her journey and her younger brother Rob who also has Crohn's.

After years of appointments, medications and food diaries, my little brother Rob was finally diagnosed with Crohn's. He went through various methods of treatment before something worked. Fortunately for me, we knew what signs to look out for and it was caught quickly compared to him. I was diagnosed 2 years after him and in February 2020 we both had colonoscopies on the same day and in the same ward. It was a great family day out!

The first treatment we followed was the 8 week liquid diet and that is one of the hardest things I've ever had to do. The nutrition drinks tasted like a load of vitamins put together, it felt like it was never going to end.

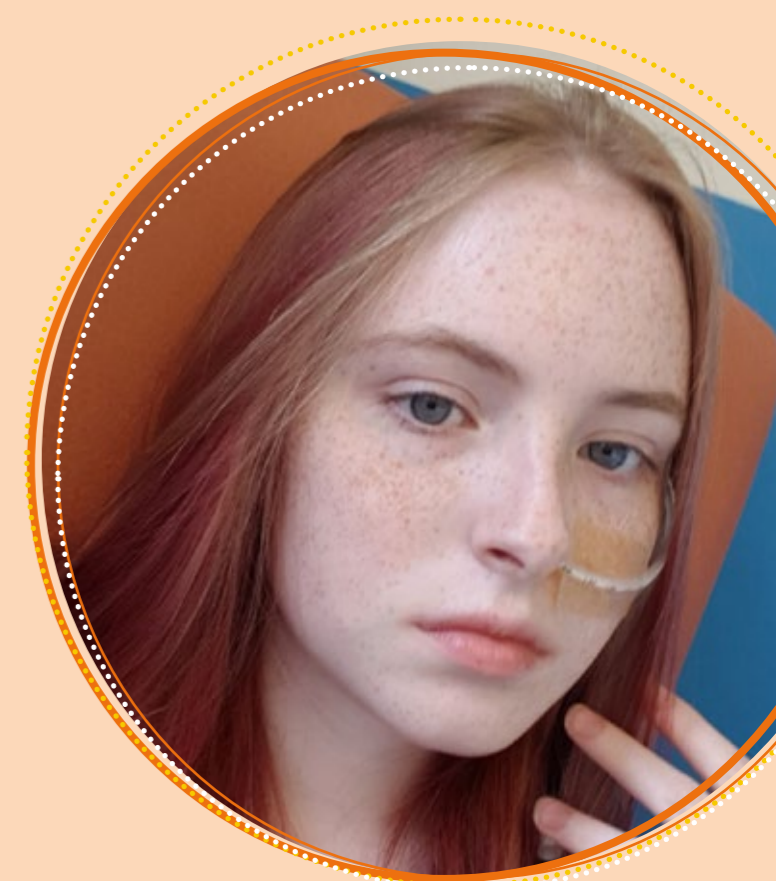
After the liquid diet, we went to Azathioprine, which didn't work for me but Rob was on it for quite a while and had it alongside infliximab, he had to stop due to his white blood cell count dropping. Sometimes it feels like you are fixing one problem but creating more.

Rob has stuck to infliximab but after azathioprine I went back to steroids for a bit and then tried mercaptopurine and it works very well for me. I have regular blood tests as anti-inflammatory drugs make you immuno-suppressed, meaning you may get colds more often and are at risk of catching other infections. I don't let this stop me going places and having a good time, I take extra precautions like wearing a mask and carrying hand sanitiser.

When you are first diagnosed it is a big deal and it's your choice who you tell including family and friends. Living with IBD might mean you need a little bit more rest and to take it easy some days, but it does not mean you can't live life to the full.

We both had colonoscopies on the same day – It was a great family day out!

Something that really helped me and Rob was Cicra's e-pal. It is where you can be added to a list of other people, you mention a little about yourself and choose and request to chat to someone. It is a nice way to make new friends too.





Transforming Patient Care

Workshop on Clinical Genomics for Monogenic Inflammatory Bowel Disease Held in Oxford

St. Catherine's College, Oxford, known for its mid-century modernism and timeless design, provided an ideal setting to host a workshop that brought together clinicians and scientists from various disciplines to explore the use of clinical genomics in the context of monogenic forms of inflammatory bowel disease. This workshop aimed to summarize recent developments in the field of genetics and immunology to improve patient care for individuals with gastrointestinal immune system problems.

“Monogenic forms of IBD, although rare, profoundly impact patients' quality of life”

Inflammatory bowel disease, which includes conditions such as Crohn's disease and ulcerative colitis, affects millions of people worldwide. While significant progress has been made in understanding the causes of those major forms of IBD, a small percentage of patients may have different genetic and immune causes underlying their condition, as inborn errors of the immune system can present with symptoms similar to IBD. Monogenic forms of IBD, although rare, profoundly impact patients' quality of life and pose significant challenges due to the limited effectiveness of conventional treatment options. With over 100 known genetic causes that can disrupt the immune barrier and lead to intestinal inflammation, diagnosing these conditions accurately is often a complex and protracted process, with patients and their families encountering multiple doctors and enduring long diagnostic journeys.

Road map to improve patient care

During the workshop, Professor Holm Uhlig from Oxford University discussed the roadmap to improve patient care, emphasizing the need to understand how genetic variants affect barrier function and immune cell dysfunction in the gut, how to and how to identify the most suitable medications for different patients. He highlighted that the workshop provided an amazing opportunity to explore strategies for implementing genomic medicine care pathways in routine National Health Service (NHS) care, ultimately introducing the concept of precision medicine.

Resistant to conventional therapy

The workshop provided ample opportunities for those attending to contribute. One of the participants, Professor Ian Sanderson, shared his experiences from 30 years ago when he encountered children with likely genetic causes of intestinal inflammation. He recalled patients, including two pairs of siblings, with severe symptoms, resistant to conventional therapy but with no ability to make a specific diagnosis. The advancement of genomics in IBD, to NHS implementation for these children, has occurred over his career in paediatric gastroenterology and has accelerated hugely in the last five years.

The central goal of a transformative project supported by the NHS is to establish a network of multidisciplinary teams that enable medical professionals to discuss patients for whom a genetic cause of the disease could inform precision medicine interventions. By setting up these networks, specialist advice and support will become more accessible to trust t Central and South region, encompassing Southampton, Oxford,

Birmingham, ultimately informing the best possible treatments and care for patients.

Dr. James Ashton, from Southampton Children's Hospital and Dr. Wolfram Haller from Birmingham Children's hospital discussed the different populations served by hospitals throughout the UK and explained the concept of purpose-built local settings that integrate within a network of specialists. James Ashton explained that 'designing the infrastructure and expertise to implement genomic medicine for monogenic IBD must be focused on the specific needs of the population, which will vary from region to region'. The importance of links of regional services to national networks were also highlighted by the team across the Central and South region.

Dr. Jochen Kammermeier from the Evelina London Children's Hospital illustrated the National monogenic IBD diagnostic guidelines, which have facilitated standardized and evidence-based approaches to diagnosis and are supported by the British Society of Paediatric Gastroenterology Hepatology and Nutrition and the British Society of Gastroenterology.

Some adult patients also affected by monogenic conditions

Indeed, while the historical focus has been primarily on paediatric gastroenterology and immunology, there is increasing recognition that some adult patients are also affected by monogenic conditions. Professor Simon Travis, a gastroenterologist from Oxford, commented: 'Age matters most: onset of IBD under the age of 6 year should raise the possibility of mIBD. Adult IBD specialists are increasingly aware that mIBD can very occasionally present in adulthood and the regional genomic multidisciplinary team structure provides a mechanism for precise diagnosis and guidance on management.'

Dr. Kimberly Gilmour and Dr Kelsey Jones from Great Ormond Street Hospital as well as Professor Sophie Hambleton from Newcastle University, showcased several patients who have benefited from modern genetic and immunological technologies. Revolutionary technological advancements, such as genome sequencing where all 3 billion letters of the genome are analysed at high precision also offer exciting research opportunities. At the

workshop several significant advances such as the identification of novel genes associated with colitis susceptibility were presented, further expanding our understanding of the underlying genetic mechanisms involved in monogenic IBD. Dr Rofaida Desoki reported on an ongoing research project aiming to investigate rare monogenic IBD variants in thousands of patients of the UK adult and paediatric IBD Bioresource, a collaborative project with recruitment at over 100 hospital sites across Great Britain.



Along with the use of novel technologies comes the need for continuous education in genomics to harness these technologies effectively. One important aim of the workshop was therefore to train paediatric and adult gastroenterologists with many registrars and consultants throughout the country attending.

Notably, patient stakeholders, including individuals receiving care from the Genomic Medicine Service and four patient charities, actively contributed to shaping the project and participated at the workshop, ensuring that the voices and perspectives of those affected by the condition are at the forefront of decision-making.

Sarah Brown who represented the CICRA, a charity to support children with Crohn's and colitis discussed: 'It is hugely reassuring to know there are established clinical genomics guidelines in the UK for children and adults and that patients meeting specified criteria can undergo genomic analysis to diagnose or exclude rare forms of inflammatory bowel disease.'

The ongoing efforts of the project team throughout the UK hold tremendous promise for the future of patient care in relation to monogenic IBD. By harnessing the power of clinical genomics and establishing robust care pathways, clinicians and researchers are working to improve the lives of those affected by these challenging conditions.



Kiss the Sky Festival

Dave and Samantha set up a festival in the wake of their brother's death to raise money for charities which meant a lot to him.



On the weekend of 16th-18th June we put on an intimate music festival for family & Friends inspired by our brother Matt "Nipper" Gurney, who sadly passed away in September 2020.

Nipper was a talented musician playing in many bands throughout his life as well as being a husband to Becky and a loving Dad to their boys Jack & Freddie. He was also very creative in his work as a landscaper in finer weather and an arborist through the cooler months. A very well-loved man you'd find in the core of his community in and around Bodiam, East Sussex, a great uncle, brother, son and friend to all who knew him.

13 years ago, he was diagnosed with Crohn's disease and unfortunately this hit him hard. When he went through flare ups of the Crohn's it would go on for months and leave him unable to work and at times in hospital which put his family life on hold. But once he got over the bouts, he was straight back into doing everything, work, family, and community life. It would take a lot to keep him away from those important to him. But it

"It wasn't the Crohn's that took Nipper from us so early at 43 years of age, it was Cancer."

wasn't the Crohn's that took Nipper from us so early at 43 years of age, it was Cancer, which appeared 4 years ago and a very rare aggressive Leiomyosarcoma in his bowel. All this happening during the peak of the pandemic, which made things even harder for all wanting to support, love and help but couldn't. Nipper passed away in September 2020 and being so popular it was impossible for all to pay respects in those times, although we did our best to do what we could.

This has led us to the event we put on "Kiss the Sky" festival. A festival of music inspired by Matt "Nipper" Gurney. What better way to get all family and friends of Nipper to come together in an amazing setting for a weekend. Plus, we wanted to support relevant charities and chose CICRA & Teenage Cancer Trust, both great charities helping the younger ones and their families whilst they navigate their journey. The amazing community all pulled together and gave equipment and their time for love and without that this may not have happened. A weekend of great music, stories,



Raised
£5,868

Dave Gurney and Becky Gurney (Nippers wife)

laughs, tears, food & drink enjoyed by all. This was such a special event and the atmosphere and love felt over the site was spoken about by all. We had bands, DJ's, silent disco, kids feeling freedom and parents being able to relax as they were all amongst friends, well it truly felt more like a huge family. Our wonderful hosts, Lucinda & Tom from Park Farm whose field they gave for the event, we thank for the space to do this, and it was great they joined us to party over the weekend too. We were also lucky to have Abbey & Michelle Rigg onboard too who organised our incredible raffle over the weekend and what a selection of fabulous prizes donated.

It really was such an incredible weekend and I'm going to quote a message received from one of Nippers friends after the event which I think reflects the sentiments felt, and gained by all who attended and we're so glad you did!

"Loss is a unique experience but helping all to celebrate Matts/Matthews/Nipper's life through this unique and valid event enabled family and friends to address the source of that pain in a

"Kiss the Sky will be back next year and continue to support our charities."

positive way; maintaining emotionally supportive relationships. He would LOVE this as it aligns with his positive inspirational character. Like he said... "sometimes it's neat to just kick the door in and plough straight ahead. We only get one life so live it unashamedly".

This tribute to Nipper was exceptional. Be proud. It elicited positive emotions such as hope and gratitude and I love the idea of a 'crossroads theme' for the next one. Kiss the Sky will be back next year and continue to support our charities, as well as each other.

We would like to thank everyone involved in raising such a huge amount for CICRA, especially Samantha who set up a JustGiving page in the hope of raising £200 so she could sing with her brother Nipper's band. Samantha smashed her target raising an incredible £1,548.75 which we have included in the event total. Those singing lessons certainly paid off Samantha, we hope you enjoyed singing and your supporters will back you again next time!



Amelia's Story

I'm Amelia, I'm 17 and have Crohn's disease. Not the typical introduction I use when meeting new people, there's more to me than that. I'm an artist, a musician, a reader, a sister and a full-time cheesecake enthusiast! I'm also currently halfway through completing my A Levels in Art, English Language and Psychology. There's lots of things to talk about besides my IBD, and all link to how I live with my condition. I'm going to talk a bit about these as well, so I don't completely bore you with medical jargon.

My symptoms first arose in January 2016. I experienced severe tummy pain, dizziness, constant exhaustion and loss of weight. Multiple blood tests and appointments later, I was diagnosed with Crohn's and instantly felt relieved. I had an answer to what had been making me feel so awful for the last 9 months. Then I realised I didn't really know what it was, why I had it, and that there was no cure.

I have had to come to terms with this, and my family has helped me by finding new recipes and giving me lots of hugs. It was hard joining my first year in secondary school a term late, with an NG tube. I felt like I stuck out like a sore thumb and just wanted to be normal

like everyone else. It felt like I would never be able to do what all my friends were doing because I would never not have Crohn's. And yeah, at times I've had to miss out on things but I now have a better understanding of my limits. I know that it's more important

to listen to my body rather than completely exhaust myself, something my friends have always supported me with, which I'm really grateful for.

Since I was diagnosed, I've tried multiple different medications, starting with a liquid diet, steroids and now infusions. Dealing with my symptoms and side effects of medication has been a challenge but I've always had my school on my side. It can be daunting talking to teachers about your IBD but having a level of understanding can be really helpful when you just need to rest. Always put your health over your education; learning can wait! Despite your condition and with the right support, you can go on to achieve great things, academic or not.

Although it has caused some negative changes, having Crohn's has also changed me in a positive way. IBD can be stressful, and it's super important to have an 'escape' to help you relax. Over the last few years, I've discovered my love of painting and playing the piano. Art and music just help me to zone out for a bit and, I've improved my skills so it's a win-win situation! By managing my condition and interacting with doctors, my independence and confidence has improved massively, and I think I'm more empathetic towards people. I've also been provided with unique opportunities that have helped me deal with my condition and help others. I completed an EPQ on how IBD is represented on social media, am currently part of an IBD research group and have been able to write articles as well as making online friends with other young people with IBD.

Looking back at 11-year-old Amelia, I wish I could have told her that it would all be alright. That I'm doing ok, and that there is so much more going on in my life. I'm starting to look at universities and I also have a really cute puppy to cuddle on days that I don't feel as good. Sometimes I still get frustrated and upset when I'm feeling unwell but that's ok. IBD has changed me, and it will change you too. My main piece of advice is to focus on how you can take control and make some of those changes positive.



Raised
£9,006

Our Marathon Marvel Man

We would like to give a 'Big Thank you' to George Taylor who was selected for the one charity place we had in the 2023 London Marathon.

George had a very personal reason for wanting to run, having just lost his partner Nancy's Mum in November 2022. Amanda had been diagnosed at the age of 34 years old with Crohn's Disease, shortly after giving birth to Nancy. Knowing how important the need for research is, George wanted to support CICRA.

This was the first Marathon George had taken part in, he had run half marathon distances every few months and ran 10k twice a week. He said he was 'extremely confident be able to run a marathon' and he didn't disappoint!

George ran in a very respectable **4 hours 05mins 38 seconds**.

Contacting George, a couple days after he said: -

'I was flying on target for a 3:45 until I got to about mile 22 and really hit a wall but just battled through to complete it in 4:05:38. I'm in absolute bits still today, my hamstrings are in pieces; definitely a learning curve for my first marathon!

Thank you picking me, I know you only had one space and I'm glad we raised a decent amount of money for the charity, in memory of Nancys late mum. I had an excellent crowd out supporting me, a lot of Nancys mums' friends were on the course cheering me on, alongside our families.'

George is a selfless, humble young man who wanted to make a difference to the lives of others; he has certainly done that raising a fantastic £9,006.92 - Thank you George.

Our amazing supporters!

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

The Law Family

Raised £1,343

Once again we thank the wonderful Law family for raising an incredible £1,243.50 from the sale of plants over the weekend 6-8th May and then selling more from their garden wall for a further 6 weeks!

This year Yvonne, grandmother of Torin added to this amount by holding a Bring & Buy Sale in her local church. We thank Yvonne and all who helped her on the day - we really appreciate the hard work involved in setting up an event and we are sure the people who attended enjoyed looking for a bargain!

Along with collecting for Recycle4Charity, sales of clothes/toys, a collection box in the local shop and with donations directly to their Just Giving page, the Law family have gone above and beyond yet again for CICRA, raising well over £1,000 a year for the last 4 years. Thank you so much.

Ollies Family Walk

Raised £866

9-year-old Oliver walked (with his family) 10 miles of the Cotswold Way, Pennsylvania to Bath.



Ollie was diagnosed in January 2022 and was fortunate to get a diagnosis in just over a year. His symptoms first presented with a persistent swollen upper lip. He was immediately put on a 6-week liquid only diet and this early diagnosis of Crohn's disease gave him the best chance of managing the condition. He has since suffered mild to moderate flare ups.

Chris, Ollies' Dad reported after the event: 'it was a glorious sunny day and despite an already tiring week Ollie made it all the way (and a bonus extra mile) without complaining once. Also, a great effort from his younger brother too, for getting all the way without being carried. Both kids up and bouncing around the next day... parents rather less so!'

The family achieved an impressive time of 3 hours 57 mins - amazing guys, what a great team effort!

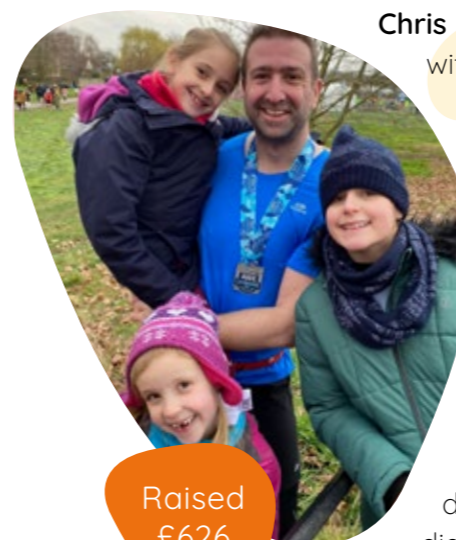
Golfers raise over £30,000

After a tremendous year of fundraising, we thank **Mike Breton and Sally Ferrers** for nominating CICRA as their Charity of the Year during their Captaincy. Mike, Sally and all the members of the **Rochester & Cobham Golf Club** showed their generosity by raising an incredible **£13,997**. We know members enjoyed many charity events whilst raising funds including a Golf Day with raffle, auction and lunch which CICRA Trustee Chloe Malloy attended. We thank the Golf Club for inviting Chloe to tell members about our support programmes and how any funds raised will be used to help children with IBD.

We were extremely fortunate to also have been nominated by **Martin Sluckis** and **Linda Banard** during their year of Captaincy at the **Whitefield Golf Club** and thank Martin, Linda and all members of the Club for raising a fantastic **£7,093**

We are so grateful to these Golf Clubs for their support. If you know of any other clubs, not only golf, who would also like to nominate CICRA, please let us know at fundraising@cicra.org

Cambridge Half Marathon



Raised £626

Chris Breavington - My wife came across a Facebook post asking for people to run the Cambridge half marathon for CICRA and knowing I like a challenge; she messaged me to see if I was interested. Our middle daughter was recently diagnosed with Crohn's during lockdown and as a sufferer of UC myself, we know first-hand how debilitating this disease can be, so it just seemed right to find out a bit more about it.

I did have some reservations, however. I had never run that distance before; I wasn't sure I would be able to raise enough for the charity place. After speaking to the CICRA organisers, the fundraising side did appear to be a lot more achievable than I had first thought and it turned out that my amazing friends and family more than stepped up to the challenge of helping me raise money.

Then, the hard work began. I only had 5 weeks from signing up to train! I started going to the gym 2-3 times a week and to be honest, this was the motivation I needed. A few weeks in however I started to suffer with shin splints and as much as I needed to train, I needed to rest it also, so a combination of lighter training and lots of ice packs, tiger balm etc managed to calm things enough.

On the day of the run, I was nervous about the distance to cover and the injury getting worse forcing me to stop, but I had a plan. If need be, just jog and walk.

The atmosphere at the start was amazing. It was a cold morning but everyone there was in good spirits, we were soon on our way. Starting

the run in the centre of Cambridge was great, so much to take in and lots of supporters on the side-lines. Before I knew it I was 4 miles in and managed to see my family stood on the side in the winding lanes of the centre of Cambridge and them cheering me on was a welcome pick me up. The run continued through the stunning grounds of colleges and then out in the countryside of Cambridge. Support was brilliant all along the route as well as the much-needed drink stops.

Coming back into the city centre, the supporters increased and seeing my family again around mile 12 added a little spring into some tired and aching legs. So far, I had managed to keep running the entire way and hadn't needed to revert to my plan of jog/walk. The end was soon in sight and even managed a slight sprint at the end.

I really enjoyed the entire run, so much so I would be happy to do it again next year.

We are so grateful to Chris and his supporters for raising a fabulous £626.25 it just goes to show how determination can get you through, even when the odds seem against you!

Thank you Chris, a true inspiration to others.

Dr Priya Sukhtankar - Another fantastic supporter of CICRA, Priya also replied to our urgent appeal for runners. With only a few weeks before the event Priya posted on her JustGiving: 'Didn't really have a training plan but am getting some miles in despite poorly little one at home and too much going on in general'.



Raised £386

We can not thank Priya enough, combining a busy job, home life, poorly little one and training is not easy and raising £386.55 is a superhuman effort - thank you so much.



Raised
£800

'Pimms & Puds'

We have featured Toby Shephard and his Mum Jan, in the newsletter during the ups and downs of Toby's battle with IBD, his fundraising and his skills with the camera. Recently Jan decided to host a 'Pimms & Puds' Fundraiser in lieu of her birthday and as a great excuse to meet up with friends after having spent the last few months in hospital with Toby.

Prizes for the raffle and the scrumptious puddings were all donated by friends; the first prize being a canvas print, of a photo of the moon over St Albans Cathedral, taken by Toby himself – we all agree a fabulous photo.

A great night was had by all, everyone left with something, and CICRA received a whopping £800

We are pleased to say that Toby is well now and heading towards a healthier future and possibly a career in photography. Well done Jan and Toby.

Jan said: "We started our CICRA journey back in year 3 of school; 10 years ago, so it feels fitting to fundraise for CICRA and to mark the end of such an era!"

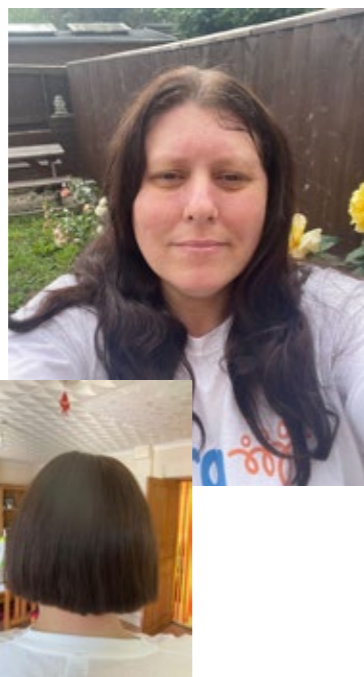
Loch Ness Challenge

Raised
£3,783

Having received support and materials from CICRA to educate himself and family around the challenges they were encountering when his daughter (now 21) was diagnosed with Crohn's, Ian Penman wanted others to be able to receive the same, so decided to set himself a challenge. Ian cycled the Etape Loch Ness, a 66 miles (106 km) cycle on traffic free roads around the breathtaking, Loch Ness in Scotland.

Ian kept us informed about the training saying 'the training is going well and surprisingly I'm quite enjoying it. I recently visited a section of the circuit, the hill claims section, approximately 500mtrs above sea level, to the summit over 5 miles. It was a very long drag but my daughter (who has Crohn's) and I both completed it, we were both very chuffed'.

We are so grateful to Ian and all his supporters for raising £3,783.50, a fantastic amount and as an added bonus Ian's employer has promised 'matched funding' so hopefully we will receive that amount again and all will be put to very good use supporting many families as they get that overwhelming diagnosis.



Haircut fundraiser

In January Karen's son Freddie was diagnosed with Crohn's disease. Karen wanted to do something to raise money to help with research, which could help Freddie and other children.

Karen settled on a haircut, not just a trim but had 15 inches (38.1cm) cut off! A very big decision but made to support Freddie and others like him – we thank Karen so much; the new haircut looks fab!

Karen raised £216 – a fantastic amount.

Raised
£216

Golden Wedding Anniversary

Raised
£5,719

Recently Prue and David Ruback celebrated their 50th Wedding Anniversary. Sadly they have three generations of family with IBD, including their Grandson Max, so rather than having presents they asked for donations to CICRA.

Max was diagnosed 5 years ago and is still fighting the challenges that Crohn's brings to young people, he faces them with bravery and stoicism but as grandparents Prue and David want him to experience a better life in the future and to help bring about the day when children can be free from IBD £5019 was donated to CICRA. We thank Prue, David, their family and friends for their generous support.

"Variations on a Theme" by Prue Ruback

We are always looking for new opportunities to raise funds for CICRA, and having just donated all our golden wedding gifts, in the form of money rather than actual presents, we thought we needed a different approach!

David is a very keen and long-standing amateur photographer who has mounted several successful exhibitions over the years. So, he put together some of his most interesting and creative shots, which believe me took ages to select, and whittled them down to 60 really unusual photos.

Lo and behold an exhibition called "Variations on a Theme" - Where Photography becomes Art was assembled. David uses Photoshop to manipulate his images and he exhibited both original photographs and then those images developed into something significantly different.

Luckily our synagogue had just moved into a new building with completely blank walls and they were

keen to introduce the surrounding neighbourhood to the premises and delighted to host an exhibition.

It took David and a band of helpers some time to mount 60 pictures on the blank walls but the results were very striking. Flyers were distributed to local libraries and shops, the synagogue community and beyond. We decided to hold two private viewings, in addition to the month-long public views and provided wine, soft drinks and nibbles to any of our friends who turned up to view the exhibition.

David sold 12 pictures in total, including a commission to develop and enlarge one picture which a buyer wanted to be 4 foot across, to cover an entire wall in his lounge! At the time of writing £700 has been donated to CICRA by David, which is the total profit, after materials and expenses such as hall charges and photo frames etc.

One very "arty" friend thought David should submit some of his works to the Royal Academy Summer Exhibition next year! One never knows how one thing might lead to another... Watch this space!

All in all, hard work but plenty of fun and a goodly sum of money raised for such a worthwhile cause.

If anyone would like David to exhibit his photos at a location near them, or would like to buy an interesting photograph for themselves or as a gift for someone else, please get in touch with him via email david@ruback.co.uk or look at his website www.davidrubackphotography.biz

Anyone for tennis?

Once again, we thank **Jax Martin-Betts** for generously donating monies raised from organising an annual Tennis Tournament.

This year CICRA received **£1,200** taking donations from Jax to over £100,000 since 2009.

We cannot thank Jax enough for her continued support over an amazing number of years - the true definition of a fundraiser!

Raised
£1,200

Non-Uniform day

Sandra Saganowska is 9 years old and attends Westlea Primary School.

Sandra was diagnosed with Crohn's Disease in 2022 and one day stood up in class and approached her teacher, saying she would very much like children suffering from Crohn's Disease and Colitis to be 'more seen'. The teacher told Sandra to write a letter to the headteacher, Not hesitating, the next day she handed over the letter. The school management agreed with Sandra and organized a day - March 31st to publicise CICRA and for everyone to wear purple. Families were asked to donate directly to CICRA.

We thank Sandra for all she has done to raise funds, and the profile of CICRA not only in her school but also the local community.. Sandra said that she really would love for children not to be ashamed of having Crohn's disease. Because each one is unique!! We agree.



Raised
£801

25th Wedding Anniversary Party

As their 8-year-old daughter Gabriella has IBDU Clare and Kevin Banyard decided that instead of presents to celebrate their 25th Wedding Anniversary they would ask their guests to donate to CICRA. We are extremely grateful for this support and thank Clare, Kevin, their family and friends for raising a fantastic £ 801.25



Raised
£160

One lump or two?

A big thank goes out Marie Baker's cousin - Lin Seeley, who organised an Afternoon Tea at the Yelverton Bowls Club in April - a lovely way to spend an afternoon.

Thank you to all the Bowls club members who raised £160 for CICRA.

Raised
£1,098



Yorkshire 3 Peak Challenge

We would like to thank Chris and his 7 friends, John, Leon, Darrell, Dave, Dave, Andy and Dan for taking on the Yorkshire 3 Peak Challenge.

Chris is Uncle to Teddie, one of our members. Teddie was diagnosed with inflammatory bowel disease 2 years ago when he was just 5 years old.

Chris stated, 'We aren't the fittest or fastest, but we are doing this for a wonderful cause and a wonderful little boy.'

We thank them all for taking part in such a challenging event and raising **£1,098.75**.

We are sure Teddie feels very proud of his uncle and his friends.

Amazing recovery

Raised
£250

After suffering a hip injury Helen Ellis was unsure if she was going to be able to compete in the Great Birmingham Half Marathon but decided to give it a go - raising £250.

Helen raises funds for CICRA as her daughter Beatrice was diagnosed with Crohn's at the very early age of one year. We thank Helen for this fundraiser and take the opportunity to publicly thank Helen and family for their very generous financial support over the last few years which has been a wonderful contribution to the research and support programmes.

In loving memory

We are very grateful to the family of the late Mrs Marlene Hattersley for a generous bequest left to CICRA in her will. We learned from Mrs Hattersley's nieces, who were executors of the will, that Mrs Hattersley's husband had suffered from Ulcerative Colitis, so knowing what it was like to live with this she wanted, when making out her will, to try and help children with Inflammatory Bowel Disease. We are very grateful for this gift which will go straight towards the new research grants we will be awarding later this year. We are pleased that we are able to fulfil Mrs Hattersley's wish and to give hope of a healthier future to our young people with this complex condition.



200+ Club winners Autumn 2023

Our sincere thanks to those of you who are supporting our research and support programmes by subscribing to the 200+ Club. For those still thinking about joining; for 50p a week, which can be paid either quarterly, half yearly or annually by standing order, you will be in with a chance of winning either a monthly or quarterly cash prize. If preferred the £26 can be paid annually by cheque or credit card. If you are interested in joining, please email admin@cicra.org or ring the office on 020 8949 6209.

January

131 Andrea Ramsden £50
155 Pauline Carver £50

February

13 Mrs G O'Neill £50
167 Monica Khurajiam £50

March

122 Andrew Govey £250
146 Linda Hall £75
37 Beth Goose £75

April

182 Helen Wilson £50
169 Tim Lack £50

May

66 Clare Shipp £50
19 Judith Taylor £50

June

198 Tony Wagstaff £250
11 Doreen Fullbrook £75
265 Eleanor Seymour £75

Summer Draw

On Tuesday 12th July the 45th Anniversary Draw Summer Draw took place in the CICRA office.

Michael Kilkelly, from the Sutton Housing Society, came to the CICRA office and drew the three winners listed below.

Prize Ticket No. Name

£500 39182 Caroline Prosser, Cardiff
£250 20841 Ian Grimley, Wolverhampton
£100 26515 Clare Shipp, West Sussex

Thank you

Sincere thanks to members who bought or sold tickets for the Draw during another difficult year. We are so grateful for your support.

Admin and savings

If you would like to have a list of winners before they are published in *The Insider* could you please indicate this when returning stubs, giving an email or enclosing a stamped addressed envelope.

If do not wish to have draw tickets please let us know on **020 8949 6209** or email

support@cicra.org.

Thank you.



Collection Boxes

To our members who have CICRA collection boxes in their home or have arranged for a local shop, pub, leisure centre etc. to have a box, we are delighted to say that from Mar 2023-Aug 2023 a further **£622.70** has been raised. Our grateful thanks go to:

- Karen Tree
- Mrs Q. Chen
- Patrina Law (Village Shop)
- Marie Baker (Honicknowle News)
- Brian McKinney (The Tower Bar)
- Gavin McDonagh
- Gail Crampton

If you hold collection boxes and your circumstances have changed and you no longer wish to have them, we would like the red plastic type (not the cardboard one) returned for re-use. Please let us know and we will send out a prepaid postage bag for you to send them back to us.

If you would be interested in having a collection box, or have any queries or questions please contact the office on **0208 949 6209**, email admin@cicra.org

