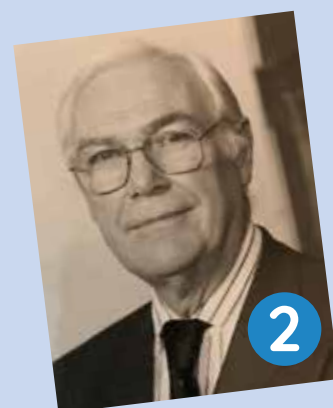


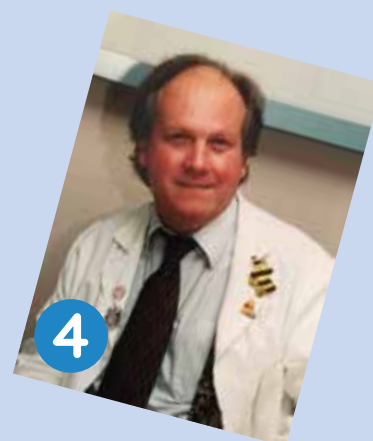
the insider

Spring 2023

Looking back
over CICRA's firsts



1978 **45** 2023
years
research & support



1. **1979** Professor John Walker-Smith set up the **first** Research Fellowships.
2. **1980** Sir Anthony Dawson set up and chaired the **first** Medical Advisory Panel
3. **1982** The opening of the **first** Paediatric Gastroenterology Laboratory in the UK
4. **1983** Professor Ian Sanderson, was the **first** to research enteral feeding.
5. **1985** Professor Thomas MacDonal set up the **first** CICRA PhD studentship scheme.
6. **2001** Professor Walker-Smith with some of his **first** patients diagnosed Crohn's disease as children.

Chairman's Message



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Dear Friends and Supporters,

A very special welcome to the Spring 2023 edition of the Insider newsletter. This year, as you will see from the front cover, we are celebrating our 45th Anniversary and it is always interesting to look back at the work that CICRA has funded. On page 12 we have highlighted how many medical fellowships CICRA have funded over the years. Many of these medical professionals have gone on to advance the knowledge of Crohn's and colitis and you may recognise some of these people who have treated you or your family in years gone by!

We are also able to announce two pieces of very exciting news. Firstly, to celebrate our anniversary year we have been able to commit more funds to research. This is of critical importance to us as CICRA as seen in the medical world as being a key funder of this training and research and it is great that we are able to devote funds to this. Secondly, in March we have been able to have our first in-person CICRA Family Day for over 3 years. This is a huge step for the post-COVID recovery and it was fantastic to see so many families attending. Look out for further family days as we start to schedule them.

There are a number of exciting articles in this edition of the Insider, and I hope you enjoy reading these. As you will see, CICRA continues to be involved in many areas and can only continue to do this with your support. Please do not forget our 45th Anniversary appeal (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





CICRA commits more funds to research

The Trustees have just put a call out for research applications in three funding streams and a lot of interest has been shown already. The process of Peer Review does take months but ensures that hard earned funds are used wisely on only the highest quality research. Obviously, the Trustees may have to restrict the amount of grants they are able to award if there are many more really worthwhile applications than normal. However, it is hoped that with additional funds raised during this Anniversary year the Trustees will be able to fund all that are recommended by our Medical Advisory Panel. After three very difficult fundraising years we will be doing all we can, with the help of the membership, and outside of the membership, to maintain and increase our research and support programmes.

Research is sometimes frustratingly slow, and expensive, **but we couldn't have made the progress we have without it.** The £10million raised since CICRA's formation has:

- Supported thousands of children through a sometimes traumatic childhood
- Set up the first Paediatric Gastro Laboratory in the UK
- Enabled earlier diagnosis through the funding of 3 year specialists training for 25 doctors who now care for children with this complex condition

- Developed a liquid diet as a first line treatment for children
- Identified a factor causing gut damage, which led to new therapies, now used world wide in treating children and adults with severe IBD
- Funded 24 young scientists to research IBD through a 3 year PhD studentship scheme
- Provided a wealth of knowledge on the management of this condition in children through the funding of 62 research projects
- Funded the setting up of the Paediatric IBD Bio Resource, leading to researching key genetic traits associated with paediatric IBD

Nobody in 1978 could have envisaged the numbers of children who would be diagnosed during the 45 years and especially that IBD would affect the very young, some just a few months old. Fortunately, we now have specialists to treat these children, but we can't relax, there is still a lot of research, and more specialists needed, to cope with the relentless increase in numbers.

The Trustees welcome any help from outside of the membership so if you know of a trust, company or club who may be sympathetic to our cause please let the office know and we will do the rest.



Our beautiful daughter Shylo

Shylo was a bright, buzzing and confident little girl at pre-school, unfortunately Covid happened and lockdown began, this is when we started seeing changes in Shylo's health.

She became more and more tired and just started losing motivation, we put it down to lockdown and the fact that maybe she wasn't getting out as much. September 2021 came and she was ready to start reception class at Primary School, she absolutely loved school and got on really well with her peers and teachers, but we noticed there was something just not right. As time went on that year we noticed her bowels becoming frequently looser so we thought she may have a food intolerance, the doctor said it was probably toddler diarrhoea. Then we noticed sore rashes on her legs which was put down to eczema, then came mouth ulcers that her dentist said was quite common in her age. Coming to the end of her first year at Primary her loose stools were frequent, and tummy pains started.

Before making another doctor's appointment I decided to go on good ole Google, I typed in everything that Shylo was experiencing....loose bowels, rashes on legs, mouth ulcers, tiredness, tummy pain, achy limbs....and that's when I first saw the words Crohn's Disease! I clicked on this page and started reading and that's when it clicked, all these symptoms she was suffering from and being treated for individually were

connected, I just instantly knew this is what my baby girl had. At first I just sat and cried, then I rang my husband and cried some more, then I rang the doctor.

We were lucky enough to get a GP appointment quickly and explained that I thought Shylo had Crohn's, she seemed a little hesitant at first but then agreed to do some stool samples. We had results within a week and they wanted to follow these up with a blood test, as they were a little concerned.

That's when things changed, she had her blood test done at our local hospital in the morning, by the afternoon we had a call with the results....they wanted to see her the next day as they were concerning. After a good check

over and asked about her symptoms, a member of the paediatric gastro team came and I said I was adamant she had Crohn's....she looked at me and said "I think you're right" and made a call to a Specialist at another hospital. The Specialist wanted to see her within 3 weeks to perform a Colonoscopy and Endoscopy, putting Shylo to the front of his waiting list as they knew she needed to be seen.

Skip forward 3 weeks and she was in for the scopes, my husband took her as only one parent

I decided to go on good ole Google, I typed in everything that Shylo was experiencing.... loose bowels, rashes on legs, mouth ulcers, tiredness, tummy pain, achy limbs....and that's when I first saw the words Crohn's Disease!





was allowed and I needed to be home for our other child.

It was confirmed Crohn's....she had ulcers and sores from her mouth all the way down into her bowels. She was instantly put on steroids intravenously (IV) and stayed in for 5 days. My husband was absolutely amazing and stayed with Shylo so that I was able to support our other child who was just starting Secondary School.

Shylo was incredible, not a single moan with the IV and all the prodding and poking, she even told the Specialist that he was her hero!

She picked up within days and was able to come home and continue her steroids orally. She put on a stone in weight in 3 weeks, she was buzzing again and smiling constantly.... we had our happy child back. We had a lot of hospital checks and they decided to put Shylo on Mercaptopurine with weekly blood checks. Unfortunately within a few weeks they saw changes in her liver function so lowered her dose and things looked OK again. Before we knew it her steroids were coming to a end but we started to see little symptoms creeping back, within a few days of stopping the steroids she had pretty much relapsed so it was back to the Specialist.

**Shylo was incredible,
not a single
moan with the IV
and all the prodding
and poking, she
even told the
Specialist that he
was her hero!**

She then started on Adalimumab injections as well as the Mercaptopurine and gradually things picked up, which brings us to now. We saw her specialist last week and he was really happy with everything, bloods look good and she is finally in remission.

This week was her first week back at school after 4 months of being too unwell. We finally have our baby back, more energy, happier and generally healthier. I know with this disease things can change quickly but for the moment we are enjoying everyday.

Shylo has been a star throughout, not once did she moan, not once has she cried through weekly blood tests, iron infusions, injections...she has just been incredible and has certainly kept me and my husband going.

We also received so much support from her school which has certainly made life easier, and the amazing support from groups like CICRA and Crohns and Colitis UK, we realize we are not alone and there are so many families going through the same with their incredible Warrior's.

If there is one bit of advice I can give to any parents....it's to always go with your gut instinct! It is never wrong.



The John Earnshaw award

This annual award is taken from a legacy left by the late John Earnshaw whose grandson, Simon, has Crohn's. Simon, despite his Crohn's, followed his dream and qualified in medicine so is now caring for others.

This grant was originally towards travel and registration fees for young healthcare professionals studying IBD to present their work at seminars both here and abroad. Since COVID and lockdown, things have changed, and many meetings are now virtual. With the agreement of John's family we have added a 'start-up' award for young scientists with an innovative idea to do a short pilot study. The first of these grants was awarded to Zachary Green from the Noah's Ark Children's Hospital in Wales. The full title of this pilot study is "To examine the feasibility

of Non-Invasive Monitoring with Bowel Ultrasound in Paediatric Inflammatory Bowel Disease and correlation with inflammatory markers, disease activity scores and as a predictor of changes in treatment (NIMBUS Study.)

This project will be supervised by Dr Amar Wahid, a paediatric gastroenterologist, and Dr Martin Edwards a general paediatrician with a background in research. The work is also in collaboration with Dr James Ashton and Professor Mark Beattie at the University Hospital Southampton

Previously Zachary has been involved with research during a clinical fellowship at Southampton where he helped plan a research project evaluating the nutritional status of children with inflammatory bowel disease using MRI imaging, which led to publication.

Zachary also audited and created a guideline for the use of parenteral iron infusions which was accepted as a poster presentation at a World Congress of Paediatric Gastroenterology. Unfortunately, due to COVID, the meeting was cancelled but Zachary was awarded the "Young investigator of the year" prize for this work.

If ultrasound is demonstrated to be a useful tool for monitoring inflammation, in time, this would decrease the number of invasive investigations utilised in this group. This would reduce hospital appointments and overnight stays for children and their families, as well as the potential for distress involved with sedation or anaesthetic and associated procedures.

We look forward to hearing the results and will report this in a later issue of the CICRA newsletter.



Zachary Green
Noah's Ark Children's Hospital



The Paediatric IBD BioResource project

Once again CICRA has been instrumental in getting a very important study started. When this application was received from Professor Holm Uhlig there was no hesitation from our Medical Advisory Panel in recommending this for funding. The Trustees took their advice and as the report from Professor Uhlig and Sarah Hearn shows this project, supported so well by multiple centres around the UK, will now be taken forward by funding from the National Institute of Health Research

The Paediatric IBD BioResource project aims to translate today's science into tomorrow's treatments by supporting research into the causes of paediatric inflammatory bowel disease (IBD). By forming a research network across multiple centres of paediatric gastroenterology in the UK this project will allow us to study a wide range of mechanisms that make young people more susceptible to develop IBD or drive the progression of their disease.

Following on from the report in last Autumn's CICRA newsletter of the opening of the Paediatric Inflammatory Bowel Disease (PIBD) NIHR BioResource, several hospital sites across the country have progressed to recruit participants into the PIBD BioResource or are in the process to open as study sites.

After starting the project at Oxford Children's Hospital in April 2022, two other study sites have started to recruit patients; The Royal London lead by Professor Nick Croft and Addenbrookes Hospital in Cambridge lead by Professor Matthias

Zilbauer. These 3 hospital sites have already recruited over 65 paediatric IBD patients. About a third of these participants are newly diagnosed with IBD (within the last year). Of the total participants approximately 35% have Crohn's disease, 50% ulcerative colitis and 15% with IBD unclassified.

The Jenny Lind Hospital in Norwich, GOSH London and Birmingham Women's and Children's Hospital plan to recruit participants in due course. A further 8 key centres of paediatric gastroenterology aim to be set up across the UK to recruit paediatric patients including the paediatric gastroenterology units in Alder Hey, Bristol, Sheffield, Southampton, Evelina, Glasgow and Edinburgh.

Research projects into the genetics of childhood onset inflammatory bowel disease are ongoing in collaboration with the adult IBD BioResource led by Professor Miles Parkes and Dr Carl Anderson from the Sanger Centre in Cambridge.

News when hospital sites open to patients and key recruitment milestones are met are being announced on social media platforms and there is also further information on the PIBD BioResource webpage ibdbioresource.nihr.ac.uk/index.php/the-paediatric-ibd-bioresource-pibd/

The setup of the Paediatric IBD BioResource was supported by CICRA, while additional funding has been secured since, to allow the expansion of the project and patient recruitment at the study sites, supported by the National Institute for Health and Care Research (NIHR).

Professor Holm Uhlig and Sarah Hearn

My Top Tips for hospital visits

Isabel Rose, 15, a young person living with Crohn's, shares her ideas for making those long hospital stays slightly less boring



We all know there is nothing worse than sitting in noisy hospital waiting rooms for hours on end with only Cbeebies as a distraction, being bored to the point where a maths worksheet looks interesting! So, these are my top tips for staying entertained in hospitals, I have to warn you they are all tried and tested:

- Books are the perfect form of travel and the good news is you don't need a passport! I know sometimes you would rather be anywhere other than in a waiting room, a hospital bed or lying on your sofa at home, but books can transport you wherever you want to go. Enchanted forests, 1920s murder mysteries, beaches at sunset, you name it, there's a book for every occasion and everyone. If you're in pain or struggling with symptoms then focusing on a book can be difficult but audiobooks are a great way to still enjoy a good story and unwind at the same time. If you're in hospital, you might be lucky enough to receive a visit from 'Read for Good'- a charity that bring books to children in hospital and there is always something for everyone. Whatever works best for you, just remember 'Don't let the Muggles get you down!'





2. Want to dance the night away? Music is a great distraction and an excellent way to boost your mood. From soothing mellow playlists, to head-banging rock everyone has their own

favourite tracks, so why not put on some headphones and get lost in the music. How about deciding on your favourite songs and creating your own desert island playlist or remixing the sound an observation machine makes- personally I think anything is an improvement. Some hospitals have various musical instruments which you can have a go at playing and learning, sometimes individually or in a group with other patients as an activity to try together. If you're struggling to sleep in hospital, soft music and relaxing sleep sounds are available to create a calm and relaxing environment to help you gently drift off to sleep.

3. Art can be really fun, even if you're like me and you're not very good at it, play specialists often have lots of arts and craft materials for you to have a go with and you never know, you might be the next Leonardo da Vinci.

4. There's no quicker way to immerse yourself in a story than by watching a movie. Sit back and relax into the world of stage and screen and experience the magic of the movies! Once the end credits begin to roll, you're in luck... the fun doesn't stop there, how about writing your own quiz to play with friends and family (or even doctors and nurses... you'd be surprised), writing your own fan fiction sequel, or drawing/ colouring a movie poster. If you do want to watch a movie or just some TV whilst you're in hospital then you can borrow a remote (often from a reception area/nurses' station), DVD player or iPad from the playroom and binge your favourite show - I know it always makes me feel better.



5. Who doesn't love a game? You can have some fun and a (friendly) competition whilst you're at it. Card games like Dobble, Top Trumps or classics like 'Rummy' and 'Cheat' can be a distraction on the ward if you're waiting for an infusion or you just have some time to spare. Playing with visiting friends or family is a perfect way to spend time together and it also gives you something to talk about. Free games on apps don't require any forward planning and are ideal for those moments in life when things take longer than you would expect, like having a blood test or picking up a prescription. Don't forget there are play specialists who can lend you iPads, games consoles and board games whilst you're in hospital. When you're feeling a bit better you can always check out the playroom and settle the score with a game of table football!

If you're bored, then don't be afraid to ask, most hospitals have plenty of things to keep you entertained so that maths worksheet can wait for another day!



ASK THE DOCTOR



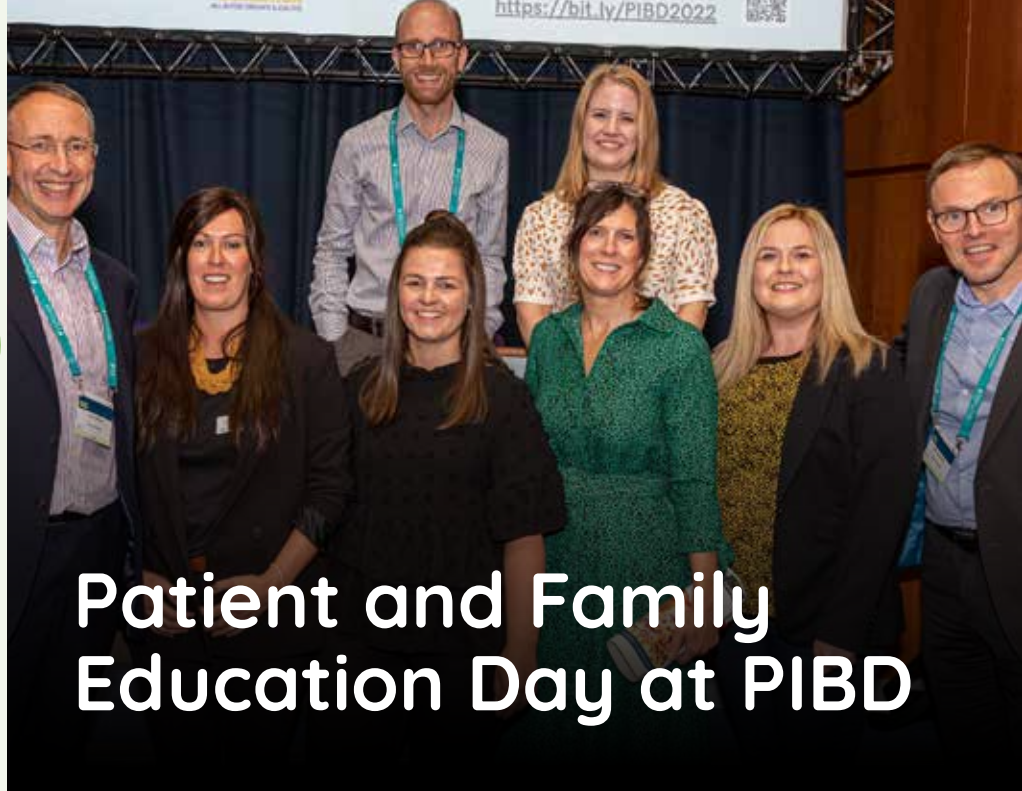
Do you have questions you'd like featured on this page? Email support@cicra.org

Ask the doctor

Could the hair loss on a 12 year old be due to being on Azathioprine?

A Hair loss in IBD can of course be due to the IBD itself, and it is commoner in my experience for people with uncontrolled IBD to lose hair, than as a side effect of azathioprine. Very often the hair will regrow even if the person stays on the azathioprine. Other causes of hair loss should be ruled out (eg iron deficiency). Of course, if the hair loss is severe, they may want to discuss with their IBD team whether it is worth considering stopping the azathioprine or changing it to a different medication. This would also help answer the question whether the hair loss is truly due to the azathioprine.

Medical Advisor



Patient and Family Education Day at PIBD

PIBD 2022, the only global stand-alone meeting for paediatric IBD, was held on 7-10 Sept in the Edinburgh International Conference Centre (EICC). This was the 6th symposia and the 1st held in the UK. The feedback has been stunningly good, on the very high scientific and educational quality, and on how fantastic it was to meet again as a global PIBD community - 476 attended from 5 continents and 46 countries (176 from the UK).

On the Saturday the Edinburgh PIBD team organised a Patient and Family Education Day, offering free admission to all PIBD communities in the UK and Ireland. This was a hugely important part of PIBD 2022 due to the pandemic-induced difficulties for charities serving our PIBD community in not being able to have their traditional patient and family meetings. We wish to thank CICRA, CCUK and the Catherine McEwan Foundation for publicity and financial support. 170 people enjoyed a great day together on the Saturday including charities, speakers and IBD professionals. Highlights of the day included talks by Prof. Maria Dubinsky (New York) and Anne Griffiths (Toronto). Joining them were Dr Lyndsay Hughes (Senior Lecturer in Health Psychology, King's College London) and Dr Sarah Gordon, Edinburgh. Personal stories shared by a young person with IBD and a father of two sons with IBD were as popular as ever. Fun activities were provided for the children while others had the opportunity to chat at charity stands, network, gain information, share stories and a rare opportunity to speak 1:1 with local, national and global IBD experts during two informal chat sessions. Feedback on the day was hugely enthusiastic, and certainly has continued to be so.



Might 'First Milk' help Crohn's?

A big "shout out" and thank you to all the children and young people who took part in the study!

Professor Stephen Allen and his team at Alder Hey in Liverpool have completed the first part of this 'First Milk' study, supported by the National Institute of Health Research (NIHR), and are now ready to start planning a larger study to see if there are possible health benefits of daily First Milk in Crohn's Disease. At the CICRA meeting in Nottingham Dr Jeng Cheng and Cennet Tezgel joined us to explain a little more about what they are doing and carried out some taste testing with the audience.

What is "First Milk"?

"First Milk" is produced by cows for their newborn calves (also called "bovine colostrum"). It has many naturally occurring factors that may reduce gut inflammation and infection and repair the gut lining in Crohn's.

What did we do?

Twenty-three children and young people aged 8-17 years with Crohn's disease took a glass of either First Milk or a 'dummy' milk (placebo) every day for 6 weeks (blinded phase). After that, everyone received the First Milk for the following 6 weeks (open phase).

What did we find out?

- 75% of children and young people taking First Milk and 81% taking placebo completed the first 6-week blinded phase
- 58% of children and young people were able to take First Milk daily for 3 months
- Most children and young people were able to take First Milk every day
- Some children and young people preferred First Milk over other nutritional supplements

We were pleased that many of the children and young people were able to take First Milk daily for up to 3 months.

What's next?

Now we know that many children and young people can take First Milk every day, we are planning to do a larger study to work out the possible health benefits of daily First Milk in Crohn's disease.

Where can I find out more?

You can read about the study here: <https://www.mdpi.com/2072-6643/14/21/4598>

Who funded the research?

The National Institute for Health and Care Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0816-20020). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Who can I contact for further information?

E mail: researchsponsorship@alderhey.nhs.uk citing "Grant Reference Number PB-PG-0816-20020".

Contributed by Prof Steve Allen, Alder Hey Children's NHS Foundation Trust, Eaton Road, Liverpool, on behalf of the study team.



What is a CICRA Research Fellowship?

A question we have been asked many times so, as we are about to advertise another Fellowship, we thought we should explain how important it has been to fund these positions over 45 years and the need to continue.

Until the 1970's when children were first seen with Crohn's it was thought to be a condition only affecting adults. Obviously, the gastroenterologists treating adults could help with treating children but, because of its effect on growth and development, it was essential that these children were under the care of a paediatrician.

Our Life President, Professor John Walker-Smith, working as a Consultant Paediatrician at St. Bartholomew's Hospital in London, was the person treating these early cases and, when needed, sought advice from a very experienced Consultant Gastroenterologist at Barts the late Sir Anthony Dawson. It was obvious that with the sudden unremitting number of children being diagnosed that specialists were needed. At this time parents learned that a junior doctor, Dr Colin Campbell, who had been helping Professor Walker-Smith treat these children, was having to move on when his one year private grant expired. Feeling almost despair the parents decided to set up a charity for Crohn's to try and keep the grant going.

When setting up, much help and

valuable advice was received from Professor Walker-Smith, Sir Anthony, Dr Campbell and the Dean of Barts Hospital. With their fundraising hats on the parents managed to raise something like £8,000 in the first year which was then about the equivalent of a paediatrician's annual salary. The suggestion was that, under the direction of Professor Walker-Smith. The Trustees could invest this and future money in the training of a qualified paediatrician to specialise in gastroenterology, hence the CICRA Research Fellowship was set up. Since those early days we now have Ulcerative Colitis, IBDO and VEOIBD to add to lists of children needing their specialist skills.

Professor Walker-Smith worked tirelessly to advocate and promote the necessity for paediatric gastroenterologists to treat children with gastroenterological disorders. His endeavours came to fruition when Paediatric Gastroenterology was classified as a sub speciality of Paediatrics in its own right.

The photographs opposite were taken a long time ago, and many are now Professors, but we feel sure that some of our members will recognise these specialists and have much to thank them for. They all trained under the CICRA Fellowship Scheme to become IBD specialists and have cared for and managed children's treatment - without them where would we have been? Their skills have enabled, and are enabling, most children with IBD to go into adulthood looking forward to having a healthier life than they may have expected. We are also grateful to these Doctors for the support and advice they give CICRA.

The funding of these Fellowships continues and with an ever-increasing number of children being diagnosed the need to train specialists today is as important as it was when we started. We are hoping to raise with our [justgiving.com/campaign/cicra-45th](https://www.justgiving.com/campaign/cicra-45th) enough to cover at least one year of the cost of the three year training of a further Fellow which will allow CICRA to put more funds into basic research.

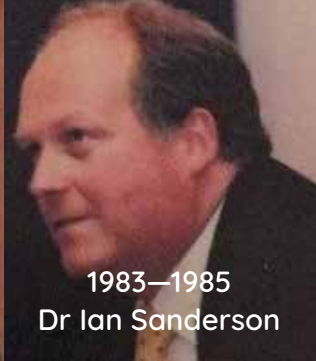




1979—1980
Dr John Douglas



1981—1983
Dr Sonny Chong



1983—1985
Dr Ian Sanderson



1985—1986
Dr Lisa Lipson



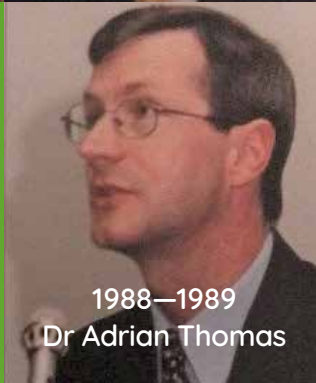
45
years
1978 - 2023
research & support



1987—1990
Dr Mark Evans



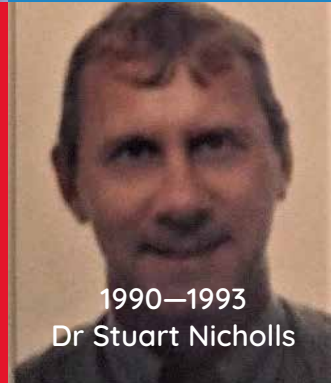
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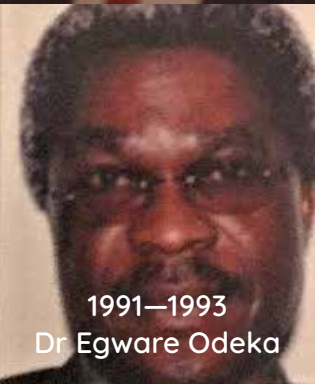
1988—1989
Dr Adrian Thomas



1989—1990
Dr F Sagher



1990—1993
Dr Stuart Nicholls



1991—1993
Dr Egware Odeka



1993—1995
Dr Mark Beattie



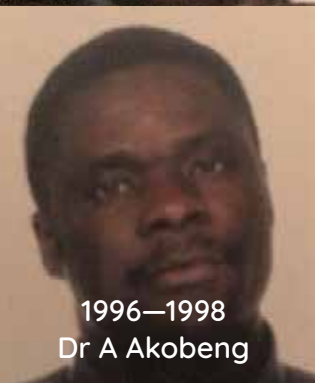
1994—1996
Dr Adubaker Elbadri



1995—1997
Dr John Fell



45
years
1978 - 2023
research & support



1996—1998
Dr A Akobeng



1997—1999
Dr Rob Heuschkel



2000—2001
Dr Kay Dryhurst



2001—2002
Dr Andrew
Sawzcenko



2001—2003
Dr Ronald Bremner



45
years
1978 - 2023
research & support



2005—2008
Dr Ed Giles



2006—2009
Dr Jenny Epstein



2006—2008
Dr Sanjay Lala



2011—2012
Dr Tony Wiskin



2013—2015
Dr Fiona Cameron



2013—2016
Dr Tracy Coelho



2015—2018
Dr Protima Amon
(Deb)



2016—2019
Dr Marco
Gasparetto



45
years
1978 - 2023
research & support

Family Holidays

With thanks to IBD Nurse specialist Kay Greveson for this article.

Live (attenuated) vaccinations

- Oral Polio
- Measles, mumps and rubella (MMR)
- Chickenpox
- Yellow Fever
- Cholera (oral version also available as inactive)
- Oral Typhoid (injectable version is inactive)
- BCG Flumist (nasal flu vaccine only)
- Rotavirus (used in infants only)

The time of year has come where many people are now planning their summer holiday. Travel forms part of maintaining a balanced quality of life and overseas travel is becoming more common, with people venturing further afield to more exotic and adventurous places. Having a diagnosis of Crohn's disease or Ulcerative Colitis should not restrict people from travelling overseas but if your child has IBD the idea of planning a trip to a foreign country; uncertainties about changes in food and access to toilet facilities may often feel daunting. Careful planning of your holiday and consideration of key issues that may cause problems will ensure your trip goes as smoothly as possible.

The main problems travellers with inflammatory bowel disease may face are often caused by a flare of IBD symptoms, acquiring infectious diseases that are common to the destination and availability of healthcare and medicines whilst abroad. Issues such as changes in diet and forgetting to take an adequate supply of medication can all add to the risk. The following information describes some important considerations prior to your trip:

Vaccinations

If your child is receiving immunosuppressive medication (such as corticosteroids, azathioprine, mercaptopurine, infliximab or humira), they may have an increased risk of

catching some vaccine-preventable infections but their immune system may also have a lesser response to some vaccinations. If your child is taking any of the medications previously mentioned, it is important to be aware that they should not have 'live' vaccinations (shown above) as their immune system will be a little weaker than normal. You should plan at least six weeks ahead of your trip to ensure you have enough time to obtain travel advice from your IBD clinic and local GP/ travel clinic so that you are armed with the appropriate education and resources for your child to stay healthy during your journey.

Travel insurance

Travel insurance is extremely important but something that many people may overlook or perhaps obtain with inadequate cover for their IBD. It is a good idea to shop around and get a good deal as some insurers have lower premiums than others. As a general rule, insurance premiums will be higher if your child has recently had surgery or has been hospitalised by a flare up of their symptoms.

Age, travel destination and other medical conditions will also influence premiums. Travel after 12 months of surgery or admission to hospital will generally incur lower premiums. CICRA has a useful information sheet on insurance which provides names of some insurers who have been recommended by members.





IBD Passport Travel website

During my work as an IBD nurse, I found that patients were often not aware of where to obtain accurate advice to help them travel with IBD and they often received conflicting advice from their GP and IBD clinic. As a result of this I have developed a nonprofit online travel resource called IBD Passport (www.ibdpassport.com).

IBD Passport is the first website of its kind and aims to provide evidence-based, accurate and reputable information gathered from national and international IBD guidelines, published research, government publications and patient organisations to provide no-nonsense IBD-specific travel information for individuals planning to travel with IBD healthcare professionals advising patients.

Most of the information of the website can be viewed without registering but to see the country-specific information and IBD Centre listings on the interactive map a short, free registration is required.

Information available on the website includes:

Vaccination advice • Interactive world-map with country-specific advice • Details of IBD centres globally which have registered with the site • Practical advice for planning your trip • Obtaining travel insurance • Obtaining healthcare overseas • Travel after surgery and with a stoma • Diet and travel • Managing travellers diarrhoea

It's easy to register

ibdpassport.com

✉ info@ibdpassport.com

🐦 [@ibdpassport](https://twitter.com/ibdpassport)

1. It is better to travel when your child's IBD is stable. This will prevent the risk of a flare-up and also reduce your insurance premiums.
2. If you have any worries about your child visiting a certain country do ask the advice of your IBD Nurse or member of the team.
3. Obtain a letter from your specialist outlining your child's medical history and medication to take on your trip.
4. Consider your travel destination. Different countries will carry different risks and need more preparation. Take into consideration your child's current health and the facilities available in the country you are visiting.
5. Does your child need any vaccinations before your trip? These may be needed up to eight weeks before you travel so plan ahead. Your child may be taking medication that prevents them from having some vaccinations so you should check this out with your IBD nurse specialist/member of the gastroenterology team.
6. Ensure you take an adequate supply of medication with you.
7. If your child is on medication that needs to be kept cold, does your accommodation have an in-room fridge?
8. Choose accommodation to suit you. Does it have a private or shared bathroom? If shared, is the bathroom on the same floor?
9. Pack your medication and any medical supplies in an 'emergency travel kit'. Pack this in your hand luggage and check with the airline for any product restrictions.





Awesome Facebook Fundraisers

We are pleased to announce that our wonderful Facebook Fundraisers have raised another amazing £1,405!

A very big 'thank you' to:

Wendy Garwell, Emma Lou, Sarah Bownes, Frances Greyfié de Bellecombe, Gillian McAllister, Sarah Hoyle, Andrea Nickey Williams, Louise Abigail Street, Melissa Christian, Nikki Herbert, Anna Batchelor, Chelsea Naylor, Kirstin Lea Greenslade, Helen Russell, Emma Gordon Gillary and Amanda Muñoz

Your help is greatly appreciated.



Molly has her own surprise prom

Molly's poor school attendance record, due to her hospital appointments meant that she wouldn't be allowed to go to her school leaving prom. Outraged by this her family and local community arranged her own

Left disappointed and upset when it was confirmed that her poor school attendance record meant that she wouldn't be allowed to go to her school leaving prom, Molly's Mum recalls thinking that this was not fair - her poor attendance was due entirely to being diagnosed with Crohn's and having to attend hospital every six weeks for infusion treatment through a drip. Also some days the effects of having Crohn's and the medication meant that a full day at school was too demanding for Molly.

In the space of about five weeks, Molly's parents rallied together a private prom at the local pub with thanks and help from the landlord, who went 'above and beyond' to make sure Molly could still have the prom she had dreamt of since seeing her big sister go to her prom 10 years ago.

Customers of the pub helped raise £600 to fund the majority of the event, which was held on the same night as the school prom. It came after pub staff made the decision that as a 'community pub' they wanted to do what they could to support Molly while raising awareness of Crohn's disease.

Purple decorations adorned a private function room which welcomed 40 guests including some of Molly's musical theatre friends. An awards plaque and a presentation slideshow of Molly's memories up until age 16 awaited her. She thought she was off to a photoshoot in her prom dress.

Molly, a musical theatre student, described the surprise as 'magical' I was thinking we were going home and eating pizza and watching some Disney movies but that's not what happened at all" 'I'm really happy. It's really nice.'



Our amazing supporters!

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



Big chop, big bucks!

9-year-old Eddie was diagnosed with Crohn's disease in 2021. To help raise awareness and to support CICRA Eddie decided to grow his hair. It needed to be 30cm as he wanted to donate it to The Little Princess Trust - who provide free real hair wigs to children and young people, who have lost their own hair through cancer treatment or other conditions.

On the 25th January 2023 Eddie finally reached his 30cm target and went for the cut. With the support of family and friends Eddie managed to raise £4,727.25

He has now become a celebrity; with the local Croyley news reporting on Eddie's fabulous achievements and is being featured on their You Tube channel too.

A truly inspiring and dedicated young man who set himself a challenge and saw it through; raising awareness and funds for CICRA, we are so grateful Eddie - a big thank you.

Raised
£4,727

Amazing dancers and amazing fundraisers

We thank Alison Johnston and her fantastic ladies for their ongoing support.

A total of £984.50 raised in 2022 from the weekly class, monthly raffle, donation box, sale of cards, fantastic shoe bags and trinket boxes made by some of the ladies - there seems to be no end of talents in the group! A big thank you from us all.

Raised
£985

Ironman Challenge

We would like to thank Christian Beckworth for raising £1,480.00 by completing an ironman Challenge.

Having a cousin recently diagnosed with Crohn's, Christian has seen the effects the condition has had on a loved one, so decided to challenge himself to the Ironman. This consisted of a 2.4 miles swim, a 112-mile bicycle ride and a 26.22-mile marathon run. Christian trained for almost a year to be able to compete, with some of the training sessions taking up to 7 hours in a day.

We thank Christian for this incredible feat of endurance and am sure his cousin was very proud.

Raised
£1,480





Great North Run

Daniel Meddes, Cindy Lowthian, Laura Buckman, Louise Wright and Simon Burchell all took on the Great North run in September to raise funds for CICRA.

Daniel had run the race in 2019 for CICRA so it was nice to see he was challenging himself again, this time he raised an impressive £516.

Laura raised £425 and promoted awareness of the condition along with the event on her Instagram account, even taking part in a radio interview; we thank you for going above and beyond for CICRA. Laura's partner also ran on a ballot place, we are sure that racing each other helped, plus the support of Laura's parents along the way.

Cindy ran the event for her daughter Felicity who has Crohn's and raised a fantastic £711.

Due to illness **Sarah Brown** was unable to run the GNR but **Simon Burchell**, her brother-in-law stepped in and took on the challenge, raising a huge £726.25.

Louise Wright took on the challenge and raised a massive £1,451 Louise told us:-

I can honestly say after starting couch to 5k in February there were times I never thought we'd make it and I think it might have been one of the hardest things I've ever done. I am so proud of how much we've raised for you though; I know in research terms it's a drop in ocean but every little helps!

Grace has unfortunately had to start Imflximab treatment, but it has dropped her into remission for now (fingers crossed!) so long may that continue! She seems very happy and healthy right now ultimately that is the end goal.

With the runner's own determination and the love and support of their families and friends they were able to achieve such great results, you all deserve a big thank you.

Raised
£3,829

Mountain climbing

Raised
£343

In July 2022, Emily Fairbrother decided to challenge herself and 4 friends by Climbing Mount Snowdon

Having had Crohn's from the age of 8 years old and having had many surgeries, and medications this brave lady took on the challenge and raised £343.00 for CICRA - an amazing amount!

Emily gave a lovely talk at a Family Day when she was in her late teens and with her family has been a dedicated supporter of CICRA. Well done Emily.

Gosforth Golf Club

Raised
£944

We would like to say a big thank you to Debbie Reape and the Gosforth Golf Club. Debbie nominated CICRA during her year as Ladies Captain did a great job for CICRA. Thank you Debbie.

We are very grateful to all the clubs for the support they have given CICRA in the last year. If you know of a golf club that would like to nominate CICRA as their Charity of the Year please get in touch at fundraising@cicra.org



Run for beer and cake

The 'Newtons Fraction' event in Grantham was cancelled but Darren Hobbs & Stefan Latter decided to do their own thing and ran the course on Sunday 16th October

In Darren's words:

We started at 3pm and the aim was to get it done in under 2 hours. We have a WhatsApp group called Run 4 Beer and Cake and when we told people we were running, a few chaps came along to either run it with us or offer support. It was a show of friendship and awareness of what we were trying to do. At the time of setting off, we had raised £400, but that figure has grown since.

We headed off from the Sports Ground in Grantham and took off at the intended pace. It was straightforward for the first few miles as we dodged swans along the canal towpath. At this point there were 5 of us, some seasoned runners and one trying the course for the first time. Another runner hasn't run this distance in a long time. Upon the canal tow path, we were met with another friend who wanted to run 5 miles with us and brilliantly brought welcome water.

The weather was a gift, sunny but cool. Perfect conditions. At the end of the canal path, we worked our way through Woolsthorpe-by-Belvoir and those experienced runners knew what was coming next. The first hill. I managed to trot to the top but was behind the pack. Stefan running with me all the way, which was cool of him, because he can handle hills better than I can! The others waited for me, which shows the sportsmanship of the team.

Now it's an 's' bend and a 2 mile straight stretch to recover and keep up the pace. By now legs are starting to ache as you shake off the lactic acid you've just built up. Low and behold, another group member who had just run his own 1/2 marathon in the morning had come out

in his car to blast some Guns and Roses and offer more water. Legend.

Through the village and out between the fields to Casthorpe bridge as we complete the first loop, turning right and it feels like we are carving our way through the tiny village and impending doom of the second, more inclined hill.

This bit is tough to run, you've done most of the course by now and the hill looms before you in the distance. The hill is relentless, and you can't see the top. My pace slowed so much I ended up walking until I reached the top.

Back on the gas now as we turned through Barrowby and back towards the stadium. The pace setter turns it up a notch for the last 2 miles and we complete the run with a loop round the car park. Our legend is back to greet us with a bottle of beer and some cake.

We completed it in 1 hour and 58 minutes, under the 2 hours target we set ourselves. More donations came through and we left feeling accomplished and humble at the same time. A good run on a good day for a good cause.

Thanks to the runners that joined us and the support and donations we received.

Absolute heroes.



Raised
£576





Raised
£978

Liz Daniels

Liz's grandson, Dillon, was diagnosed with Crohn's just before his 11th birthday. As Liz had grown her hair and had it cut for charity before, this was what she decided to do for CICRA, donating the hair to the Little Princess Trust. *Thank you Liz for the commitment it takes and for raising such a wonderful amount to support Crohn's.*

Joshil's Fundraiser

In March 2022 Joshil was diagnosed with Crohn's. To raise awareness about the condition the family decided to have an event at home, they put out a donation box and some leaflets.

Hinal, Joshil's mum, also started clearing out old toys, selling them online and advertising the charity on her sales listings, informing them that all proceeds raised will be donated to CICRA.

She is also hoping to get involved in some runs next year to raise more awareness.

We thank Joshil and his Mum for all their support and raising awareness, a fantastic £709 raised.

Raised
£709

Charity Craft Fair

We have Peter & Jenny Hay to thank for supporting CICRA for many years with Peter acting as Treasurer during his time as a Trustee. Their latest support was to donate part of the sales from a recent charity fair. The talented couple sold stained-glass items, wooden pens, cards and paintings – donating £100 to CICRA. *A big thank you to you both!*



Raised
£100

Coffee Morning and 12 Mile Walk

Since being diagnosed with Crohn's in 2021 Dyfan has been determined to raise funds for CICRA to help other children and families in a similar situation.

Dyfan, along with family and friends, raised an amazing £3235 by walking 12 miles from Cardigan to Newport. They also held a coffee morning, and with help from local organizations who donated profits from a cake stall and bric a brac stall at a local show, helped them raise this amazing amount.

A wonderful achievement from Dyfan and a fabulous local community supporting Dyfan, we thank you all.

Raised
£3,235

London Marathon

After 7 years of trying, Rob Barry finally secured a place for the London Marathon. He knows how lucky he was to have a starting spot and as a result wanted to make the opportunity count.

His son, Joseph, diagnosed with Ulcerative Colitis in 2019 aged 10 is on his 5th line of treatment which is involving more and more hospital visits and treatment variations. Realising how hard this is for a teenager to manage alongside 'normal life', Rob wanted to raise awareness and money for two charities, CICRA and the paediatric gastroenterology team at Oxford Hospitals and of course for Joseph. *Thank you Rob, this means a lot and we are sure Joseph is very proud of you.*

Raised
£1,880



The Vitality Big Half London

The Big Half is a vibrant, inclusive half marathon with an unmissable festival atmosphere! It features a stunning 13.1-mile course that sets off by Tower Bridge in central London and finishes at the famous Cutty Sark in Greenwich. This year CICRA had two runners who wanted to experience 'The Big Half'.

Gidon Ellis ran for his daughter Ariella, who has Ulcerative Colitis and raised a fantastic £2055

Raised
£2055

Kirsty Davies ran for her son Matthew who also has Ulcerative Colitis and decided to put her 'Mum powers' to good use and raised an impressive £745.

Thank you to both families for your support, we hope you had a fantastic day and created some unforgettable memories.

Raised
£745



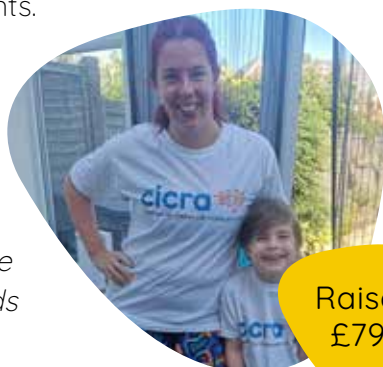
Charity Fitness Event

At one of the gyms they work at Nina Parrett and 3 other instructors put on a fitness event to raise money for a Breast Cancer charity and CICRA. This was dedicated to their friend, who was going through chemo, and Nina's 6-year-old son diagnosed with Ulcerative Colitis.

The 4 hours fitness event at which 70 people turned up for had 4 different classes, a live DJ, and a Raffle with loads of prizes donated by local businesses and residents.

An amazing time was had with everyone buzzing about it for days after.

We thank Nina and all the generous people who took part, it sounds like great fun.



Raised
£794

A Brownie always does her best

Thank you Rebecca. A fantastic way of gaining a brownie badge and continuing the family fundraising efforts. Your note says it all.

Rebecca Bryans raised £220. Her sister Hannah has IBD, so Rebecca held a cake sale with her family and sold books, cards and old toys.

Raised
£220

Inspirational Simeon

Not long after being diagnosed with Crohn's disease in 2018, 7 year old Simeon decided he wanted to be a fundraiser for CICRA and with the help of his family, friends and school has raised around £800. The recent achievement being £331 from selling craft goods made mostly by Simeon's grandparents. He was helped by sister Elsie and brother Nathaniel.

At 9 years old Simeon was put on infliximab coupled with azathioprine which has been brilliant and kept him well. Amazingly, throughout his journey he has been a diver for Sheffield Diving club.

The focus this has given him has enabled him to manage his health and his busy routine. In December 2022 he travelled to Canada to compete in his first international competition with Team England. He had the most fantastic trip and won 2 medals, a gold medal on the 3m springboard, a bronze medal on the platform and came 4th on the 1m springboard.

A massive well done from all at CICRA, a true inspiration.



Raised
£800



In loving memory

Maurice Patten

Just before Christmas we had to say a sad farewell to one of our long time supporters Maurice Patten, aged 90. Joan and Maurice, who sadly lost their son to Crohn's, aged 26 in the early days of the charity have been supporting CICRA ever since. Near to the end of his short life Richard acted as secretary of a CICRA self help group in Kent and was very active fundraising whenever he was well enough. Richard's wish was for family and friends to continue raising funds to bring hope to those diagnosed in the future. Joan and Maurice did just that. Continuing with the group all the while it was active, Joan and Maurice would help out wherever they could and with friends from the group, particularly Jill and Ray Beck, attended CICRA meetings helping out on the sales table. We remember those days well and are extremely grateful. We send our best wishes to Joan and her daughter on their sad loss and for donations in memory of Maurice.

Gertrud Kuplas

We were very sad to hear the news from Karina Sutherland that her Mother, Gertrud Kuplas, another long term supporter, had passed away. Gertrud became involved with CICRA when her son was diagnosed with Crohn's, and very generously gave CICRA financial support whenever she could. In her will Gertrud left a bequest of £50,000 to help CICRA continue funding research. We are extremely grateful for this generous gift and can assure the family that this will be spent wisely as Gertrud would have wished. We send our best wishes to the family in their sad loss of a very generous lady

Margaret Bines

We were very sad to hear that one of our amazing fundraisers had passed away after a short illness. Margaret Bines was a loving Mother and Grandmother and we featured her grandson Alex and his story in the Spring 2022 newsletter. She was really proud of the way Alex had handled his Crohn's. Despite being 91, Margaret was a very independent lady who lived alone but had a good family and neighbours and to raise funds for CICRA she made beautiful cards and crafts and sold them to others living in the flats. Margaret was very much loved, very popular and will be greatly missed by her family and friends.



Marie Coles

Another sad phone call was from Jennifer Pope to say that her Mother, another long term supporter of CICRA, had passed away and had left a small bequest to CICRA in her will. Jennifer's brother had Crohn's aged 10, in the late seventies, and her Mum supported CICRA over many years. In her will Marie left £500 to CICRA. As the will was made over 20 years ago the family decided to double the amount to £1,000 for which we are most grateful. Our thanks and best wishes go to Jennifer and her brother.

At a time of bereavement families often suggest that instead of flowers, relatives and friends may like to make a donation to charity. CICRA collection envelopes are available by contacting the office on 020 8949 6209 emailing admin@cicra.org or write to CICRA, Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey, SM2 6AQ.

CICRA is very grateful for donations received in memory of:

Gladys Sanderson (Nanny Glad)

Grandmother to a Crohn's sufferer, remembered with love and much missed by all the family and friends.

Jane Kyle

Jane will be remembered with love, and greatly missed by family and friends especially Jane's grandson who has had Crohn's disease since aged 10 but now thankfully in much better health.

Marian Thilo

A long-time supporter of CICRA who was greatly loved by family and friends and will be missed by all, especially her daughter and grandson both of whom have Crohn's.

Colonel David John Cobbett

Grandpa of Rosie Jane Cobbett who suffers from Crohn's. He will be remembered and loved by all the family.



200+ Club winners 2022

We thank members of the 200+ Club for their support during 2022 and the winners who donated some, or all, of their winnings back. This is much appreciated. If you are not a member and, for 50p a week, would like the chance of winning a cash prize, while helping to fund vital research, please ring the office on **020 8949 6209** or email **admin@cicra.org** and we will send you the forms.

January

201 Mrs Gibson-Wyer £50
132 Andrea Watkins £50

February

72 Chris Ram £50
262 B Warne £50

March

47 J Gooding £250
271 H Magson £75
225 J Clayton £75

April

151 Dr Sheasby £50
69 Mrs Montinaro £50

May

99 L Billett £50
97 A Butler £50

June

182 H Wilson £250
148 K Greatorex £75
21 V Batchelor £75

July

68 J Davey £50
52 D Willingham £50

August

95 J Cambell £50
158 C Saunders £50

September

61 B Plumb £250
223 A Cooper £75
51 H Barnes £75

October

132 A Watkins £50
140 J King £50

November

129 J Parker £50
242 P Miller £50

December

37 B Goose £250
148 K Greatorex £75
243 L Smith £75

Christmas Draw

In the CICRA office on Tuesday 12th December 2022 Michael Kilkelly from the Sutton Housing Association joined us to draw the winners of the CICRA Christmas Draw. These were as below:

Below are the winners

Prize	Ticket No.	Name
£500	063254	Lynn Philand
£250	002108	Hazel McVeigh
£100	020381	Roy Adcock

We thank all members who bought tickets themselves or sold them to support this draw and the funding of research into inflammatory bowel disease. All proceeds will be spent wisely to try and find more answers to this debilitating condition.

Collection Boxes

We are delighted to say that £1,358.02 was donated to CICRA in Collection Boxes from July 2022-Feb 2023. Our grateful thanks go to:

- Jane Tweedie (Craigellachie Filling Station)
- Gillian Robbins (Workplace)
- Julie Jones (The Murenger House)
- Alyson Chapman (T& I Bell)
- Ann Donohoe (Home)
- Brian McKinney (Pub)
- Thant Phway (SPAR GLYNCACH and Community)
- Jackie Hone (Automobile Engineering Co Ltd)
- Sarah Wooden (Home/Shop)
- Alison Johnston (Home/Dance Class)
- Mrs S P Clark
- Keren Piatt (Home)
- Justin Bennett (Café Bueno)
- Harry/Gurjit Punia (Workplace)

If you would be interested in having a collection box, or have one to return, please contact: Tammy at the office on **0208 949 6209**, or email in to **admin@cicra.org** or write in to **CICRA, Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey, SM2 6AQ.**

