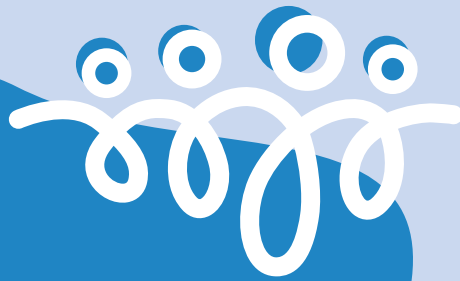


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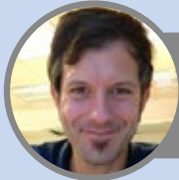
Autumn 2022



Birmingham Children's Hospital
Dr Rafeeq Muhammed



Alder Hey Children's Hospital, Liverpool
Dr Elizabeth Renji



Evelina London Children's Hospital
Dr Jochen Kammermeier



Great Ormond Street Hospital, London
Dr Kelsey Jones



Great Ormond Street Hospital, London
Dr Fevronia Kiparissi



Oxford Children's Hospital
Professor Holm Uhlig
Research Lead



Royal Hospital for Children and Young People, Edinburgh
Professor David Wilson



The Royal London Hospital
Professor Nick Croft



Royal Hospital for Children, Glasgow
Dr Richard Hansen



Cambridge Children's Hospital
Professor Matthias Zilbaur



Southampton Children's Hospital
Dr James Ashton



PIBD Coordinator
Sarah Hearn

Paediatric IBD BioResource

If you have a child/young person with IBD being cared for by one of the above specialists, please turn to pages 12-13 to hear from Professor Uhlig, two young patients and a Mum, on how you can help this very important CICRA funded project.

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Chairman’s Message



Dear Friends,

Welcome to the Autumn edition of our newsletter in which we have a number of fascinating articles, not least of which can be seen on the cover and centres pages, showing the specialists involved in this important research funded by CICRA. It is really important that children and young people join this project – there is very little involvement but a huge benefit to future research.

For many of our members and families, the first person they will come into contact with at CICRA are the dedicated staff and volunteers at our office. This small team work tirelessly to ensure that we provide support in what can be a distressing time for families. On pages 3-4 you can find out more about the people who answer the calls and emails.

It can be difficult for children and young people to express their feelings when dealing with IBD. We are lucky that our younger members provide an insight into their lives, and we thank Tom for giving us an honest, funny assessment of how he deals with his condition. And what a role model Daniel Billett has been on not giving up on your dreams. Daniel faced many problems that children are going through today but never lost hope. We also thank Louise for a parent perspective when her daughter Martha was diagnosed with Crohn’s.

CICRA doesn’t receive any government grants, so relies on donations from charitable trusts and the generosity of members, their family, and friends. Without this financial support we wouldn’t have been able to fund the training of 27 specialists to improve the management and treatment for children, fund scientific research and offer support to families. For those who have given their time to run, ride, dance, hold sweet sales, sell plants etc., we offer our sincere thanks, and never forget those who are unable to fundraise but give regular generous donations. We are extremely grateful; this has helped so much. Please keep up the support so that we can continue to fund our vital research and support programmes.

Best wishes,

Graham Lee



Meet the Team

Having been through a very unsettling and difficult couple of years the CICRA office is now back on track and, due to the increase in the amount of young people being diagnosed with IBD, we are receiving more calls for support than ever. For this reason, we thought it was time to introduce 'the team' who are here to help families through some of the most difficult times. We cannot give medical advice but can help with explanations, school problems, practical day to day problems and more. Please do not hesitate to get in touch if you think we can help.

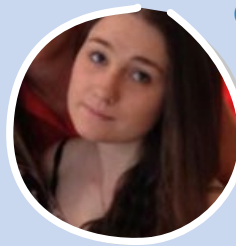


Jayne Boyd-Bell

I joined CICRA back in 2013 and for many years looked after the membership, E-Pals, supported hospitals with our Parent Packs and organised our Family Information Days.

I'm married to David and have three-daughters and four beautiful grandchildren. My youngest daughter was diagnosed with Ulcerative Colitis when she was 13 and had a tough time, she is now 26 and doing really well. When I chat to parents on the telephone, I always think back and try and offer the level of support that I was so grateful for when Eliza was poorly, missed a lot of school or when I just needed to talk to someone who understood how I was feeling as a mum. I'm always happy to chat to parents to offer information and support.

I now work part-time and look after our wonderful members and their fundraising activities, make applications to grant making trusts for donations and organise our popular Family Information Days. One of the most rewarding parts of my job is still chatting and supporting parents on the telephone.



Courtney Coleman

I started volunteering at the CICRA office in 2019 to administer the Christmas draw and help with Christmas card orders. Since then, I have become a permanent member of the team and now work part time.

I live with my parents, Anne & Simon. Simon has been involved with CICRA from the start and has been a trustee for over 10 years. When I get the time, I enjoy socialising with friends and family and editing photos and videos.

My responsibilities have grown over the past three years. I am happy to help wherever I can, but one of my main roles is looking after membership. Applications for membership come to me. I try to deal with them as quickly as I can, so people receive as soon as possible the information they need to help and support them. I also look after parent packs and our wonderful e-pals scheme.





Tammy Migliaccio

Hi - I'm the newest member of the CICRA team. I started temping with CICRA in April 2021 and so enjoyed working here that I then joined as a part-time permanent staff member in December 2021.

I'm married to Nick - we have a son and I have two stepchildren (now adults from Nick's first marriage). Although I don't have family members with IBD - I do have friends who live with IBD. I too am always happy to chat with parents to offer support and information. My colleagues have a wealth of information and anything I'm unable to advise on - I can turn to them for support, and they are sure to have some ideas or suggestions that I can then in turn pass onto families.

My role at CICRA is varied - School Support Queries is my one role - having prior experience in the school sector serves me well and enables me to help and advise where I can on the school front. I also work with the Accounts Team, help with sending letters of thanks for the generous donations that come in and am in the process of updating our Collection Box Records. Recently I've taken over keeping note of our wonderful Facebook Fundraiser's ensuring they are acknowledged and know how much the CICRA Charity appreciates their support. And I'm assisting in the production and collation of materials for our twice-yearly newsletters.

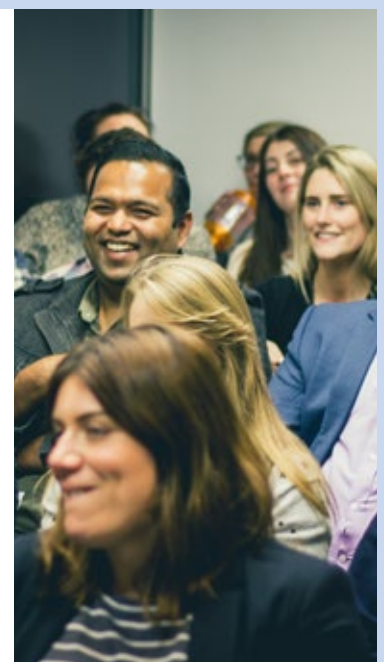


Margaret Lee

Although I am not a member of staff I am part of the very busy CICRA team endeavouring to support families of children with any form of Inflammatory Bowel Disease. The reason I am part of the team is that I am a Trustee and founder member of CICRA. I still remember how I felt when my son was diagnosed at the age of 9, one of just a handful of children diagnosed with Crohn's in the UK. We had a wonderful doctor, Professor Walker-Smith, now CICRA's President, but nobody or nowhere to turn to for practical day to day advice on how to cope, so CICRA was formed. From just a handful of children there are now 27 Centres of Excellence with specialists to treat an ever increasing number of children diagnosed with IBD. My jobs in the office are really varied but my main ones are dealing with the research applications and preparing content for leaflets, newsletter etc. but I am in the process of a slow handover. A little about me. My husband sadly passed away in 2005 but I have 5 sons, 14 grandchildren and one great grandson so never a dull moment. As some of you know, my son, so ill with Crohn's at the age of 9, is now the CICRA Chair.

Family Days

CICRA Family Days are a very important part of what we do as a charity, but we were sadly forced to suspend them during Covid. We hope we can now safely hold a Family Information Day, and with that in mind are looking to hold this in November. To ensure as many people as possible can join us we have chosen the centre of the UK and are currently trying to find a suitable venue with plenty of space so that those attending feel as comfortable as possible. A flyer enclosed with this Newsletter mailing provides further information so please complete and return the form or register your interest by emailing familyday@cicra.org and we will keep you updated by email as our plans come together. Also check for updates on the website and facebook. We look forward to seeing you.



BSPGHAN Meeting 2022

After two years of virtual meetings the 2022 Annual meeting of the British Society of Paediatric Gastroenterology, Hepatology & Nutrition took place in Birmingham in April. CICRA's Chair, Graham Lee, and Trustee, Paul Cooper, were pleased to be able to represent CICRA at this important meeting.

This was an opportunity to catch up with members of the medical profession treating and caring for children with IBD. It was clear from the amount of interest that, like us, the doctors and their teams are eager for CICRA to have Family Days again. This is a much valued way of supporting families and bringing them together to learn about IBD from the specialists in a relaxed and enjoyable day. We are grateful to have their support and will be having our first Family Day since COVID later this year.

We have reported in earlier issues of the newsletter about the Digital Health Passport for young people and we were pleased when a poster on this project by Dr Priya Narula and her team was accepted for display at the meeting giving those there the opportunity to read about the project and ask questions,

IBD UK

As founder members of this group we participated in the creation of the original IBD Standards, whilst being aware that paediatric IBD is a very small part when looking at the number of adults with IBD. While participating in the update, which was launched recently, we have tried to ensure that our small but very important paediatric patients were catered for. We are pleased to know that there are changes to some of the surveys to better reflect whether the answers are from parents or children and how these results are shown age wise. We will continue to do our best for our small patients.



PIBD 2022 Patient and Family Education Day - Saturday 10th September 10:15am - 4pm

Children and young people with IBD and their families are warmly invited to attend the 'PIBD 2022 Patient and Family Education Day', a free event (including lunch, and refreshments) being held during the global PIBD 2022 Symposium at Edinburgh International Conference Centre (EICC). This is an amazing opportunity for children and young people and their families living with IBD to share experiences, connect and find support from others who are in a similar position and who understand what they are going through. Given the unique global nature of our PIBD 2022 symposium we will have a mixture of Scottish, UK and international PIBD experts such as Professor Anne Griffiths from Toronto and Professor Marla Dubinsky from New York at this event. All these experts will be available for informal discussions as well as giving cutting-edge updates. Come to hear about and discuss vital topics including managing the disease, optimising current treatments, new treatments, the many aspects of living with the disease (including coping with pain and the psychological burdens of PIBD), and the latest IBD research.

For further information and to view the event programme or register for the event, please see the Eventbrite listing: <https://bit.ly/PIBD2022>



Sometimes it is the little things that make a **BIG** difference

Telephone Support

If you would like to speak with somebody who understands what it's like to have a child with Crohn's Disease or Ulcerative Colitis, please call us on **0208 949 6209**. We cannot give medical advice but have experienced staff, trustees and volunteers who have long time knowledge in caring for children with IBD.



Can't Wait Card

This useful card, which bears the name and photograph of the child with IBD, can be invaluable when urgent toilet facilities are required. To obtain a 'Can't Wait' card and Radar key, giving access to disabled toilets, please send a passport style photograph and full name of the child to membership@bicra.org. Parents will need to be registered with CICRA before a card can be issued – please register at www.bicra.org/how-we-can-help/membership/, email membership@bicra.org or call **020 8949 6209**



Parent Packs

We provide **Parent Packs** to hospitals across the UK for families who have a child newly diagnosed with IBD. The packs contain easy to understand information for children, parents and teachers, as well as practical advice on living with IBD.



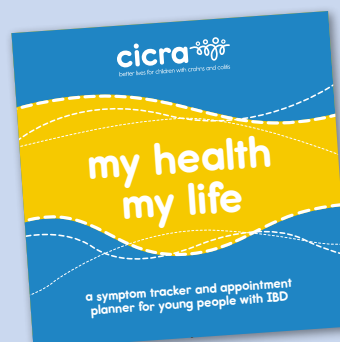
If you didn't receive a pack please email support@bicra.org or telephone **0208 949 6209**

Helpful Resources for School

Living with IBD can be tough. Our **Parent Guide and Exam Support Leaflet** resources are available to provide you with some help when it comes to understanding and setting up a Healthcare Plan for your child at school or if needing support during exams. Please call in on **020 8949 6209**, email: support@bicra.org or write to us at: **CICRA, Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey SM2 6AQ** to request copies.

Symptom Impact Tracker

Keeping a record of how you feel between hospital appointments can be tricky. Our easy-to-use **Symptom Impact Tracker** helps keep a record of how you feel physically and mentally. It can be handed to your IBD nurse or doctor at appointments. Overall, it should help you feel more confident in managing the condition.



Ask the doctor

For this issue we have given the page over to questions from the children

Do you have questions you'd like featured on these pages? Email support@icra.org

Q What happens to my blood after they take a blood test?

You probably saw that your blood was squirted from the syringe into small tubes. The tubes have different coloured labels on them. Your name, your hospital number and the date are written onto all the tubes so that people will know that it is your blood. It looks like a lot of blood but you have much more than that left inside you so it is quite safe. The coloured tubes go to different parts of the laboratory so that all sorts of tests can be done. Some go to the haematology department for a "full blood count" to see whether you are anaemic etc. Some to the biochemistry department to test how well parts of your body are working eg your kidneys and liver. Some are such complicated tests that they take a long time to do and have to go to another specialist laboratory. The results go on to a computer so your doctor can find them as soon as they are ready.

Q Ever since I first had my Crohn's I get really tired, can you tell me why this is please?

It is a bit complicated, but I think it is because Crohn's disease is due to inflammation all over the body. That is why your blood tests show raised "inflammatory markers" such as ESR and CRP. Think how you feel when you have a head cold: The inflammation is in your nose and throat, but you will be feverish and feel weak all over. Another reason to feel tired would be if you were anaemic especially if the amount of iron in your blood was low.

Q How do the doctors know what's wrong with me?

They work like detectives. They collect up all the clues and then see if they can put them together like a jigsaw puzzle. They use a process which goes like this: **History:** This is the story of your illness. They will ask you and your parents about symptoms (what you and they have noticed such as tummy ache, losing weight, mouth ulcers etc). They will also want to know everything about you and your family, such as what illnesses you and they have

had before, who knows you best, where you go to school and everything which helps them understand you better. They will want to know what tests and treatments you have had and what you have been told already about your illness. **Examination.** You will have been weighed, measured and examined all over, even the bits of you that are feeling well. **Investigations.** This means blood tests, X-rays, scans and endoscopy etc which will have been explained to you. You and your parents have to agree to these tests (consent) and you will be told the results. **Diagnosis.** This is the jigsaw puzzle. Some doctors who are more experienced (have seen lots of children like you before) are better at making a diagnosis. Sometimes, I am afraid, they cannot be certain straight away and you will have to wait while they do more tests or discuss you with other doctors to see if they can work out the puzzle of what is wrong with you. However, the doctors will have nearly worked it out so that you can start your treatment as soon as possible.



Explanations for the younger ones

What can I eat?

When children (and adults) have Crohn's or Colitis they often don't want to eat. Sometimes they just don't feel hungry or perhaps it gives them tummy ache. If this happens to you try not to worry too much because later on, when the doctors make you better, you will probably be able to eat and drink everything you want.

Some children have allergies, which means that you won't be able to have some foods but a dietician at the hospital will be able to help you and your parents with what you can eat and what you have to avoid.

Sometime children have to have a special drink (like a milkshake) and if you have to have this you may not be able to eat anything else for about six weeks, but if it makes you better then you will soon start to feel hungry and be able to enjoy all your usual foods.

Remember, we all need to eat healthy food to give us the energy to do all the things that we want to do.



Medicines for children with IBD

Almost every day the doctors learn more about how Crohn's and Colitis affect children and the treatments are improving all the time.

There are several different types of medicine and tablets that the doctors can give you. They will have looked at the results of all the tests that you have had done before deciding which one they think will make you better. Sometimes you will need to have an enteral diet which means that you drink a special drink which gives you all the things that food contains but in a form that your tummy will find very easy to digest. It is like a milkshake and comes in lots of different flavours – so you can choose your favourite.

Some children can drink it from their favourite cup but others need to have it sent straight down to their tummy. If you have to have this the nurses will put a very tiny tube up your nose and down to your tummy. This doesn't sound very nice but lots of tiny children have this done and sometimes they like to put the tube up their nose themselves. This is a very special fine tube so that it doesn't hurt.

Sometimes you may have to have a medicine put into your arm. You usually have to go to hospital every few weeks for this but there will be doctors and nurses there to look after you and you won't have to stay in. Sometimes it can be done at home. Before the medicine is put into your arm the nurses will put a cream on so that it won't hurt.





Tom's story

Hi, I'm Tom. I first shared my Crohn's story in 2019 at a family information day. I was diagnosed when I was 8 years old and have tried lots of different things to get my condition under control, not there yet, but I believe one day I will find the magic bullet that will make my life easier.

In 2019 I had just started on infliximab, and was optimistic. I was also about to transfer to senior school. Initially I felt a little better with infliximab but after a while, things started to go downhill again. My consultant decided to 'bin' that drug and try another...I then went onto adalimumab. It hurt when it was injected into my leg, it stung, and I hated it! I was proud of myself though as I had learnt to say its name, despite it not really helping me too much! I went for another MRI scan and felt like James Bond himself going into that tunnel. I also had an ultrasound scan - still no baby!

Neither showed anything much so it was agreed I should go into hospital for a few days. I was quite skinny again and eating little, I had not grown, and my shoe size remained the same for ages. At Bristol Children's hospital mum stayed with me and the nurses monitored everything that went into and came out of my body- lucky them! I had many more blood tests -you would think I am a pin cushion! I did

bowel prep for yet more scopes which is grim.

Before the procedure mum promised me a sharing box of chicken nuggets and a coke which I made sure I got! The scopes told us that my Crohn's was still active and Dr Wiskin wanted me to go on some shakes to support my nutrition and more steroids. I find shakes hard to drink, so I agreed to let the nurses try and get a feeding

Within a few days I started to feel better, and this continued until I was weaned off, and then it was down that rollercoaster again.

tube down (first time not good). I had medicine to help me relax and it made me more funny than usual! I was skipping through the ward at one point and making everyone laugh by talking in different accents! Despite laughing and feeling very 'high' it was still not possible for them to get the tube down so I decided to drink the stuff instead. A dietician introduced me to another shake ...and they are really delicious - where have they been all my life! I was able to drink this, they are sooo much better!

I went home from hospital with my shake boxes and steroids.

Within a few days I started to feel better, and this continued until I was weaned off, and then it was down that rollercoaster again. This time the consultant decided to 'bin' adalimumab and put me onto 'ustekinumab' 8-weekly. Another name to learn!! I have been on this for just over a year now but I'm still not how I want to be, I still suffer with awful fatigue, aching joints, tummy pain, lots of loo trips etc.. I inject this drug every 4 weeks at home now, I do it myself and my dad makes a funny face every time- he thinks I am very brave.

My education is suffering due to my health, I have not been to school this academic year, I can't get up and moving in the mornings to get to school for an 8.40am start. I struggle with my confidence in doing things by myself without family support and some days I feel rubbish. My school are now applying for an EHCP for me on medical grounds to secure additional support on a more long-term basis.

All that said, it's not all negative...I do have good times too...I recently went to a river locally with my sister and enjoyed an hour jumping into the water in my wetsuit and swimming with my dog, I have joined army cadets (which I wanted to do from an early age), and I now have a new pet...a bearded dragon called Yoda.





A Self-Compassion Intervention for Parents of Children with IBD



Annie Wray, Trainee Clinical Psychologist,
University of Sheffield

Parenting a child with inflammatory bowel disease (IBD) may be stressful and emotionally challenging at times. However, there is limited research exploring the experiences of parents of children with IBD and how this group may be supported in practice.

One way in which parents may be supported in this context is through self-compassion interventions. Self-compassion has been defined in relation to three main components: self-kindness; common humanity; and mindfulness. Existing research has shown the benefits of self-compassion in the context of chronic health conditions and challenging parenting situations.

We therefore conducted a randomised controlled trial which investigated the effectiveness of a brief online self-compassion intervention for parents of children with IBD. The intervention involved reflecting and expressing compassion to oneself in relation to a recent challenging parenting event. With support from CICRA, 159 parents of children with IBD were recruited to take part in the study, which ran between April and December

2021. Participants were randomised to either the intervention or a control group, completing outcome measures before, immediately after the intervention, and two weeks after daily engagement in the intervention.

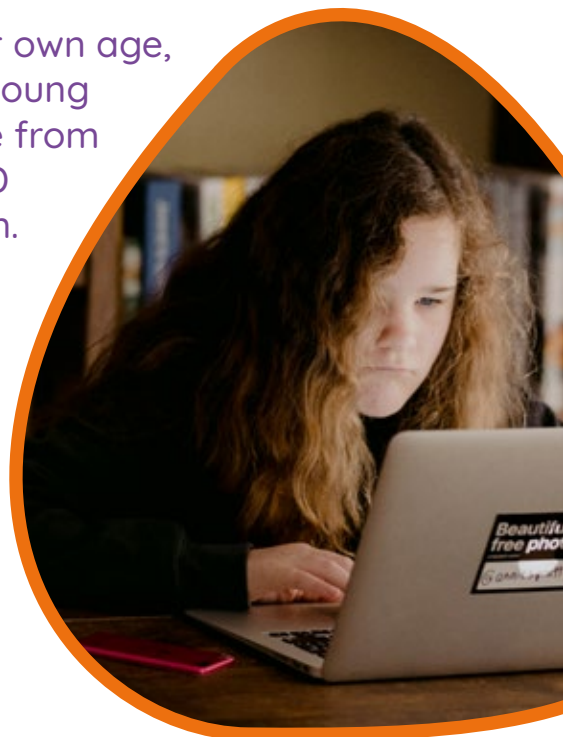
Findings suggest that the self-compassion intervention effectively increased self-compassion and reduced distress, but not shame, immediately following the intervention. Repeated engagement in the intervention had no effect on longer-term measures of self-compassion or parental stress. Significant drop-out and several methodological limitations mean that these latter findings cannot be confidently applied to all and further studies are needed. Nonetheless, this study is the first to explore a brief self-compassion intervention for parents of children with IBD, and findings suggest that this may be a helpful and accessible way to support parents in the immediate moment. Future research and clinical practice in IBD should seek to understand and support the wellbeing of parents alongside their children.



E Pal friends

Chatting and sharing experiences with someone your own age, who knows how you feel, can really help. E-Pals are young people with Crohn's, Colitis, or IBDU who range in age from 8-22 years. They understand what it's like to have IBD and the importance of not feeling you're on your own. We asked parents and the young people to give us their feedback on whether the scheme was helpful. Here are a few of their answers.

- Thank you and everyone else for making my time in the scheme great, I really appreciate all the support I have gained from it!
- Emma is really enjoying being an E-pal. She, and the friends she has made, have their own WhatsApp group, and each time someone new reaches out, they get added to the group. It's lovely they all keep each other's spirits up and are there to support each other.
- I'm so grateful - she gets so much out of the e-pals scheme.
- I think it's been absolutely brilliant my daughter has a small group of friends who "chat" and knowing that she's not the only one certainly helps mentally especially when treatment doesn't work.
- I appreciate hearing that other children are having the same experiences as my daughter and she's not on her own.
- I've made 3 great friends from e-pals and I love they can relate to me and I can relate to them!
- E-Pals has been great for getting to know people and feeling part of a group who experience similar things rather than being alone.
- The best thing about it is the community I get the chance to be a part of.
- We think the concept of e-pals is great. I think if you don't have IBD then it's hard to understand the impacts on your life so it's a good idea for the children to compare notes on what helps etc
- I have loved being a part of it and have made loads of new friends. The best thing about e-pals is being able to talk to people who understand me.



We are always on the lookout for inspiring stories about your journey with Crohn's, Ulcerative Colitis or IBD for our social media and Newsletters. If you feel you would like to share the highs and lows of your story with others, please submit your story and photo's to: support@icra.org



The Paediatric and Young People's IBD (PIBD) BioResource

We are very pleased to bring you this first report of the PIBD BioResource project headed up by Professor Holm Uhlig at Oxford and funded by CICRA. This project had a delayed start due to COVID but once things eased, Sarah Hearn was brought in as co-ordinator to liaise with all the busy IBD specialists involved in this project. It has now got off to a very good start. We all want to understand what happens when IBD appears, but for that to happen young people need to help the doctors and scientists. By joining this study, they can. Our thanks to Holm, Sarah, all the specialists involved and to CICRA member Sarah Brown for representing the parents/patients.

The last decade has seen major progress in the understanding of inflammatory bowel disease (IBD), in particular major progress in the understanding of genetic causes, how the immune system works in patients with inflammatory bowel disease, and a number of new treatments becoming available, or are close to the market, for paediatric patients with inflammatory bowel disease.

Nevertheless, we are still far away from completely understanding the disease. Some of the seemingly simple questions that parents and patients ask are difficult to answer: What causes Crohn's and Colitis? What makes symptoms worse in one patient compared to another? Why do certain treatments work for some children but not others? What new treatments can be developed for children with IBD?

One lesson from all the research over the last decade is that real progress can be made

when research centres join forces to try and understand the epidemiology and mechanisms of paediatric inflammatory bowel disease, aimed at developing new therapies.

In order to expedite the research into paediatric inflammatory bowel disease, the Paediatric Inflammatory Bowel Disease (PIBD) BioResource study aims to recruit paediatric IBD patients within the UK to investigate key questions that are important for children and young people with IBD. The PIBD BioResource aims to speed up research advances in paediatric Crohn's and Colitis so that current and future children with IBD can benefit sooner.

The PIBD BioResource is part of a larger project, the NIHR BioResource which supports research in IBD as well as many other disease areas. Thousands of adult volunteers with IBD from all over the country have already agreed that blood



samples and information about their health may be collected and stored in the IBD BioResource. The PIBD BioResource aims to recruit paediatric IBD patients, including 150 newly onset, to establish an overall resource of 5,000 patients with paediatric onset disease.

Children and young people who are being seen under the care of gastroenterology consultants at particular hospitals in the UK will be considered for the PIBD BioResource. Those who wish to participate will provide blood or saliva, biopsy, and stool samples as well as health and lifestyle data. The PIBD BioResource is led by Professor Holm Uhlig and co-ordinated by Sarah Hearn at the University of Oxford and is being closely aligned with the adult IBD BioResource led by Professor Miles Parkes from Cambridge. The initial set of participating hospitals are on the front cover of this newsletter.

The setting up of the PIBD BioResource was only possible because of the support of CICRA, parents and patients who contributed by reading draft versions of the report and information forms and commenting on the project. The strong integration of CICRA in the project is illustrated by a CICRA representative who joined investigator meetings and a parent representative Sarah Brown who joined all investigator meetings to discuss progress.

From Sarah Brown (parent/patient representative):

“When our son was diagnosed with IBDU, aged 4, I felt fairly hopeless for a long time, and I found it difficult to come to terms with this difficult condition. The establishment of a PIBD Bioresource should give every patient and parent hope. The aims of understanding more about PIBD and using this knowledge to inform treatment will see better outcomes for children. I have seen the amazing teamwork of the UK’s top paediatric gastroenterologists actively working together to realise these aims. I am privileged to hear presentations by expert researchers in the field at our monthly meetings; obviously the science is way beyond me (I mean, way beyond me - turns out GCSE Science only gets you so far!), but I cannot stress enough how heartening it is to see the detail of research and the collaboration that is going on. I don’t need

to understand the science to know how great it is that centres are gathering, analysing, and sharing data in pursuit of greater understanding.

We will definitely consent to participation and would encourage other families to do the same. There are no additional invasive procedures (our children already have enough of those to deal with); it will only involve giving samples already taken in routine procedures, along with completing some lifestyle and health questionnaires.

It is a privilege to be a tiny part of this important project. As parents, it gives us hope - something that can evade us on the challenging journey that follows a diagnosis of IBD

From the patient’s perspective, Finn Brown, says, “I don’t mind giving a bit of extra blood when I go for my blood tests if it helps doctors to know more about IBD.”

In Oxford in April 2022 the first patient was recruited to this project and said: “I am eight years old and I have had Crohn’s disease since I was two - but this has never stopped me from doing whatever I wanted to do or achieve! Which means you can keep going too! Don’t stop doing what you must - keep going!

Crohn’s disease is not comfortable at all when you get tenesmus and terrible when your poo gets slimy, bloody and turns liquid- so it is really important to do more research to cure this disease. But don’t worry we can hopefully cure this- all we need is you to join the **NIHR BioResource project.**”

With joint efforts of the UK research community, the contribution of parents and patients and the support of CICRA this project will allow us to better understand IBD and identify the best treatment options available for children and young people with this condition. Importantly, this paediatric research network has already contributed to some relevant outcomes since several of the investigators and patient representatives contributed to guidelines how to use genetics in inflammatory bowel disease. We will use the CICRA newsletter to update on progress.



Martha's Journey

Here is Martha's story as told by her Mum Louise.



We became concerned about Martha when the school nurse did her measurements when she was in Year 6. They showed Martha was very underweight and small for her age. My husband and I thought it was just family genes as we were both small ourselves as children. However, during the summer of 2019, Martha became increasingly unwell - complaining about tummy ache and constantly racing to the toilet. Her appetite was very small and she was noticeably thinner and shorter than her friends.

Martha's condition came to a head during the first term of Year 7. What should have been a very exciting and enjoyable entry into secondary school education became a stressful, worrying and confusing period for Martha and us as family. Our energetic, fun-loving, outgoing little girl was quiet, tearful and in pain. We were thankful she became open about what she was experiencing, including passing blood and the level of discomfort she was in. It resulted in us taking urgent action with our GP - Martha and I have since discussed the importance of her being honest and open with us as parents - a huge lesson as a family.

Initially our GP thought that Martha's symptoms were because of her starting secondary school - the usual stresses and anxieties. But I was thankful she decided to trigger several assessments including a faecal calprotectin test on Martha's stool sample. This showed

Our energetic, fun-loving, outgoing little girl was quiet, tearful and in pain.

very high results in terms of inflammation markers and as a result, the process of diagnosing Martha commenced. Martha's bloods always looked stable, so this faecal calprotectin test remains a critical indicator for her condition 3 years on...

Martha was diagnosed with Crohn's disease following a colonoscopy and endoscopy in November 2019. She started treatment through exclusive enteral nutrition via a nasogastric tube but with limited success, was put on steroid treatment during the height of the pandemic and lockdown. We were able to monitor her weight gain and progress carefully with us all being at home together and with the help of Azathioprine and subsequently, regular Amgevita injections, Martha's condition has gradually improved.

We are still on the journey to get Martha in remission and are monitoring her progress on the two drugs she is currently on, but it continues to be a challenge at times. We are hopeful and trust we are in great hands with her consultants and IBD team but are learning resilience and a positive attitude are crucial. As parents, we are incredibly proud of how Martha has coped during the last 3 years and know she will continue to manage her condition with strength and courage moving forward. We hope IBD and Crohn's disease will increasingly benefit from much needed research and funding in the future to help children like Martha lead a disease-free life.



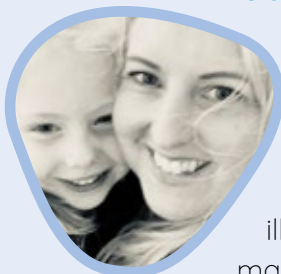
Awesome Facebook Fundraisers

We are pleased to announce that our wonderful Facebook Fundraisers have raised an amazing £1,934

Members will be receiving a certificate and letter of thanks. If we don't have contact details please be sure that we greatly appreciate our fundraisers and their family and friends who support them.

We thank Laura and Kirsty for expanding their reasons for raising funds and we are pleased that we were able to be of help.

Laura Woolliscroft's



"A few months ago our darling girl Harriet was diagnosed with Crohn's disease at just 8 years old. This is a chronic illness which will have to be managed for the rest of her life.

Harriet is currently on week 7 of an 8 week exclusive enteral nutrition treatment whereby she has not been able to eat any food and has taken all her nutrients through a special drink. As she comes to the end of this treatment we have created this fundraiser to raise money for a charity which has supported us during this overwhelming diagnosis and will continue to support Harriet on her journey. We are so very proud of Harriet who has been incredibly brave and still continues to smile through it all. If you could donate a few pounds it would mean the world to Harriet

(and distract her from the thought of Easter eggs)
Thank you."

A big thank you to
Gail Crampton
Emma Jane, Hayley Holmes,
Casey James, Serena
Garratt, Tim Tillberg, Luci
Zanutto Geraldine Prosser,
Clare Tovey, Victor Pashko,
Andrea Shuff, Alisha
Strange, Sarah Dan

Kirsty Elizabeth



"I've been thinking long and hard about which charity I want to support this year for my birthday as so many mean so much to me, however, as 2022 marks 25 years since my diagnosis of Ulcerative Colitis, I thought it only right that I choose CICRA.

I didn't understand my diagnosis in 1997. My brother didn't understand my diagnosis in 1997. My parents didn't understand my diagnosis in 1997, but we were signposted to this charity and they provided invaluable information around IBD that helped, not only us as a family, but my school teachers. We were able to start having conversations around support I would need at school and a better understanding of the condition, medications etc.

My IBD journey is still ongoing and for some it is unfortunately just starting and I never want someone newly diagnosed, especially as a child, to feel like they have no one to turn to, or that they are all alone in this world with their IBD diagnosis.

Anything you can donate would be greatly appreciated, however, I understand times are hard and I'll genuinely be happy that you've taken the time to read all this text and expand your knowledge of IBD and help raise awareness of this ghastly invisible illness."

Monies raised are used wisely to fund research into Inflammatory Bowel Disease and supporting children and their families.



Fishguard Man's Space Agency Work Reaches for the Stars



A Fishguard man is reaching for the stars, having been made a Fellow of the European Space Agency (ESA) despite battling a debilitating illness which caused him to lose a third of his body weight and put him a year behind in his schooling.

Dr Daniel Billett, a former pupil of Holy Name School Fishguard and Netherwood School Saundersfoot, was made a fellow of the ESA after being offered the post of senior research assistant at Saskachewen University, Canada.

His studies involve using the Canadian Super DARN Radar Array, a global network of scientific radars monitoring conditions in the near-earth space environment.

The radars allow researchers to observe how space weather conditions affect the earth.

Daniel reports to the European Space Agency on a bimonthly basis as well as regularly attending talks at conferences worldwide on behalf of the agency.

Daniel's route into space included A levels at Pembrokeshire College before going on to study for a Masters degree in Astrophysics at Aberystwyth University.

"I actually only just got the A levels needed to go to Uni in Aberystwyth, after needing to do an extra year," said Daniel.

"I don't think most of my teachers in Pembrokeshire thought I would get super far, but Dr Helen Coomer at Pembrokeshire College always stood out as someone very supportive and encouraging."

University was followed by a PhD at Lancaster University where he wrote a thesis entitled The Great Space Weather Washing Machine and was given the Dean's award for excellence.

Although he has skyrocketed to the top of his field, it hasn't all been plain sailing; at the age of 14 Daniel was diagnosed with Crohn's Disease. Over the next four years he spent extensive periods in hospital and lost a third of his body weight in just six months.

Daniel still suffers from Crohn's, which is incurable and had to take three months off from his PhD to recover from surgery.

"It will always be an uphill battle when you feel held back because you're sick," said Daniel. "I feel lucky that I've gotten the opportunities I've gotten."

"I've found that colleges and universities are getting much better at accommodating people with health conditions, whether that's extra time off or even a free laptop. It's never been easier to go after the things you're most interested in."

With acknowledgement to Becky Hotchin, Senior Reporter at www.westerntelegraph.co.uk

Our amazing supporters!

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



Whitefield Golf Club

CICRA was chosen as Charity of the Year by members of the Whitefield Golf Club and we were delighted to receive £3,390 from a Sunday morning competition in March. Further charity events are planned for later in the year. Our sincere thanks go to Martin Sluckis and Linda Baynard for all their help in organising this and to the members for their generosity.

Raised
£3,390

London Vitality 10k

On the 2nd May this year Sarah & Chris Collins decided to raise money for CICRA by taking part in the London Vitality 10k after their daughter Amber was diagnosed with Crohn's in October 2021. Sarah said the first few moments after Amber's diagnosis were filled with worry, heartbreak and anxiety, just not knowing what the future would hold. We hope things are improving for Amber and thank you for the £996 which will go towards trying to find some of the answers to give these children a healthier future.

Raised
£996

In the same race were Holly Whitehorn and her mum Jo May. Holly is only 16-years old and wanted to take part as her sister has IBD. She said "The race was amazing! I loved the way everyone was cheering us on! It was very special to us too as my sister Caitlin was diagnosed in 2021! I'm so glad I raised money for such a good cause!" Holly and her Mum raised £328 for which we are so grateful.

Raised
£328

Sewing Course

Long-time supporter Trish Walker is a member of the Exeter Quilters who have supported CICRA over many years. Trish started supporting the charity when her daughter Sarah was diagnosed with Crohn's Disease in 2009 and has been running courses and passing the fees on to CICRA. **What a lovely way to raise funds. Thanks Trish.**

Raised
£197.50





Raised
£1,115

Elliott & Kirsten Beard's 2022 Challenge

Elliott was diagnosed with Crohn's Disease in 2020 age 15. He said "CICRA helped me cope with the many challenges caused by Crohn's and because they helped me I wanted to raise some money." He had the wonderful idea to walk the West Highland Way (96 miles from Milngavie to Fort Willian) with his mum Kirsten in April of this year.

Kirsten then decided to challenge herself by completing a 47-mile race around Lake Windermere in 24-hours with her pal Sarah.

She said "it's been brilliant raising money with Elliott, its helped his confidence raising money, and telling people about IBD was really empowering for him. It was great doing something together and for him to feel like he was helping me rather than vice versa!!" **How good to hear that Elliott benefitted as well as CICRA great idea. Thank you both.**

Kate Bryans

Kate's daughter Hannah was diagnosed with Crohn's in 2020 when she was 10. Kate decided to sell unwanted items to raise money for CICRA. **Well done Kate, we have probably all got 'unwanted items' lurking in our cupboards - just a fundraising thought !**

Sonia just keeps on Tri-ing!

Raised
£784

Sonia Perkins decided to take part in the Grantham Springs Triathlon on the 3rd April after her good friend Claire Coate's son was diagnosed with IBD. She said she felt so helpless watching Ben and his family coping with the diagnosis she had to do something positive.



Raised
£125.72

Watford Grammar School for Girls

A special thank you to Year-9 who supported CICRA with a sweet sale, scrunchie sale and valentine's day event. **We hope you all had a lovely day and thank you all.**

Raised
£100





Raised
£2,438

Dorrie Mottram

Dorrie has been fundraising for CICRA since 1989 when her son Kevin was diagnosed with Crohn's Disease. We have featured Dorrie in the newsletter many times before because, with help from her group of friends in West Sussex she has raised in excess of £84,000 and is still adding to CICRA's research pot. How amazing that CICRA has been helped so much from what started with Dorrie having a coffee morning at her house.

Raised
£524

Aunty Kelly's 100 miles for Daisy

Aunty Kelly is an incredibly proud aunt to her resilient, caring and happy-go-lucky niece who was diagnosed with IBDU in November 2020. She says "the courage and strength Daisy has shown in fighting this disease has been amazing and despite her suffering she smiles through it all. I am honoured to be running 100 miles for a charity that is vital in helping children like Daisy manage their IBD." On the 7th May 2022 Kelly ran 100 miles from Richmond in London to Oxford along the Thames Path. We are sure that Daisy is proud of you too Kelly. Our grateful thanks for such an amazing amount raised for CICRA.



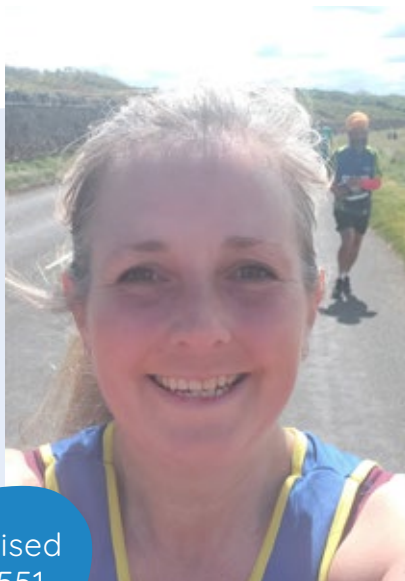
Raised
£3,000

London Marathon

Huge thanks to Eileen Stewart, Tom Parsons and Vicky Jones who all took part in the Virtual London Marathon in 2021 and collectively raised over £3,000. They each have a son with IBD; we are sure Matthew, William and Brandon are super proud of your achievements.

Claire Coats

Claire is Ben's mum and along with Sonia decided to raise some money for CICRA. She took part in the Edinburgh Marathon splitting the money raised between CICRA and the Children's Liver Disease Foundation, we were very grateful to receive £551. Ben is 12 years old and was diagnosed with IBDU in February 2021.



Raised
£551





Raised
£5,019

Kerrie Stoner

Kerrie's son Jye was diagnosed with Crohn's Disease in February 2020. He is super proud of his mum who organised both a Black & White Charity Ball and a Leisure Centre Funday over the weekend of 12th & 13th March. A massive total of £5,019 was raised which will be split equally between CICRA and the Cystic Fibrosis Warriors. The leisure Centre Funday was well supported with spinnathon, aquafit, danceathon, totally shredded, wall climbing and dance workshops – a great day was had by all and children with IBD or Cystic Fibrosis were the beneficiaries. **Well done Kerrie**

Raised
£1,378

Louise Culshaw



I wanted to raise money for CICRA when I decided to do the Manchester 10k as the charity have been incredibly supportive of Martha and also we as family since her Crohn's

diagnosis in 2019. CICRA have provided support and guidance both in the early days of us understanding more about Martha's condition as well as during the more confusing periods of supporting her such as during the pandemic. Martha has formed a lovely friendship group through CICRA's E-Pals programme, and she has benefitted from reading the materials and newsletters from the charity about children with a similar condition to her own. We are incredibly grateful to CICRA and the important work they do supporting families like our own. **Thank you Louise. You can read Martha's story on page 14**



Raised
£520

The Law Family

The wonderful green fingered Law family once again opened their garden for a plant sale raising £520. Patrina, son Torin and the rest of the family have been supporting CICRA since 2018 when Torin was diagnosed with Crohn's Disease. Patrina has also set herself up as a public collection site for Recycle4Charity and already raised £28.85 from recycled ink cartridges. **Thanks once again for everything. We hope you have time to enjoy your own garden.**





Raised
£2,417

Alison Johnston and her line dancing ladies

Big thanks to Alison and her line dancing ladies for their continued support. £418 raised this year from her weekly class, monthly raffle and donation box... keep on dancing ladies!

Raised
£418

Run, Simon, Run!

A huge thank you to Simon Jarvis who took on his second half marathon in six months. Despite being struck down with Covid-19 two weeks before the Cambridge Half Marathon on Sunday 6th March he managed to complete the course in a fantastic time and raise £684 for CICRA. Simon also took part in the London Vitality Big Half in August 2021 and raised £1,733 to help children with IBD. Simon's 5-year-old daughter Betty was diagnosed with Ulcerative Colitis in 2020. We are sure Betty is super proud of her Daddy for raising such a great amount of money for CICRA.

Raised
£2,030



London/Essex Ride 100

After a 2-year hiatus Ryan Frood joined over 20,000 riders taking part in the world's greatest cycling festival which had returned with a new 100-mile route on closed roads around London and out into the Essex countryside. Ryan suffers from Crohn's and knows first-hand the negative impact it can have on someone's life, he said "anything I can do to help a charity supporting the lives of children with the illness is very important to me." We are very grateful to Ryan for raising such a huge amount

Raised
£3,018

Another supporter Hassan Uddin took to the road for the Ride London to raise funds for CICRA. In his words "I have family that have been affected with the disease, I looked into what CICRA does as a charity how it supports children and families with Crohn's and Colitis and it inspired me to raise money by taking part in Ride London. Many thanks Hassan so pleased that you thought of CICRA, it is much appreciated

Raised
£341



London Vitality Big Half

Mark Euesdon, Ellie Sadler and Steve Fowler all took to the road in the London Vitality Big Half to raise funds for CICRA. Following Mark's son Kam's diagnosis, he was admitted to hospital for 10 days and put on a liquid diet for 2-months. Mark says Kam has been an absolute trooper and he is incredibly proud of him as he endures countless blood tests and injections with no complaints.



Collection Boxes

We are currently in the process of updating our collection box records. Certificates and letters of thanks are being sent out to those who have raised amazing amounts of monies both big and small over the years for the CICRA Charity. Your support means the world to us and monies are wisely used to fund continued research into Inflammatory Bowel Disease and in supporting children and their families.

To our lovely members who have CICRA collection boxes in their home or arrange for a local shop, pub, leisure centre etc. to have a box, we are delighted to say a further **£1,038** has been raised from Collection Boxes from **Jan-June 2022**. Our grateful thanks go to:

- Julie Jones (The Murenger House)
- Ann Donohoe (Home)
- Timothy Brosnan (Hobson & Son Worthing Ltd)
- Mrs Q Chen
- B McKinney (Pub)
- Simon Owen/Rob Keir (Cauliflower Group Ltd)
- Natalie Baldev (Berkshire College of Agriculture)
- Sharon Grose/Adam Seal (A & J Seal Family Butchers)

If you hold collection boxes and your circumstances have changed and you no longer wish to have them. We would ask if you would be kind enough to notify us and return them to us – we are happy to send out a prepaid postage bag for you to send them back to us.

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



Family Funds

Are a great way of motivating family and friends to fundraise for CICRA. Simply set up a Family Fund with us and use a family reference (this can be your family name or a name of your choice). Use this reference when sending donations and we will know to add it to your Family Fund. Should you wish to receive a total of funds raised to date we can let you know who has donated and the total amount raised by all but will not separately advise of individual payments. Simply send us a request via email: **admin@bicra.org** or phone in on **0208 949 6209**.

No fundraising appeals will be sent to family or friends unless they are registered with us as members. Our members are able to unsubscribe or change the way they would like to hear from us at any time.

We are excited to say we have a few Family Funds in place now and so far an amazing amount of **£800** has been raised to date! This just goes to show what a difference a small group of supporters can make.

Our grateful thanks go out to all those who have generously donated to the Family Funds for the CICRA Charity.



In loving memory

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:

Jean Goakes

Jean was a Grandma to three Crohn's/ Ulcerative Colitis sufferers who was dearly loved by all who knew her.
Brian Goakes & Family

Edward Bell (Ed)

Treasured memories. Until we meet again.
Heart heavy, mournful.
Sun sitting, bee watching, calm.
Release, rest in peace.
Margaret, Susan, Kevin, Chris, Alex, Jared, Ian, Karen, Erin, Ken and Lynn xx

Mrs Yvonne Anne-Marie Medcraft

Nanna and Great Nanna of Crohn's sufferers remembered with love and a smile by all her family and friends.



AmazonSmile is a simple and automatic way for you to support CICRA every time you shop, at no cost to you. When you shop at smile.amazon.co.uk, you'll find the exact same low prices, vast selection and convenient shopping experience as amazon.co.uk, with the added bonus that Amazon will donate a portion of the purchase price to children with IBD.

www.smile.amazon.co.uk/ch/278212-0



Easyfundraising is the UK's largest charity shopping fundraising site. Thanks to our members, CICRA has benefitted by almost £5,000 with no cost to our members, or to CICRA. When you do your shopping please remember that easyfundraising is partnered with many of the largest retailers and businesses who give a small percentage of their cost to chosen charities through his simple scheme.

Summer Draw

On Tuesday 14th June the Summer Draw took place in the CICRA office. Marcie Regelous, Resources Director from the Sutton Housing Association, drew the three winners listed below.

Below are the winners

| Prize | Ticket No. | Name |
|-------|------------|-----------------------|
| £500 | 54324 | Betsy Morrison, Derby |
| £250 | 60990 | Katie Coe, |
| £100 | 49961 | Carole Wollen |

Many thanks to members who either bought tickets themselves or sold tickets to support this draw during another difficult year. We are very grateful for your support and 100% of the funds raised will go towards the funding of new research into inflammatory bowel disease.

Margaret Lee (Promoter) 30.6.22

Christmas Cards Available NOW

By buying CICRA cards and encouraging family and friends to do the same, you will be helping to find answers to this debilitating condition, affecting an increasing number of children. **For each pack sold 50% of the cost will go towards our research and support programmes.**

We look forward to receiving your orders.



Order at www.cicra.org/shop

If you would like brochures to pass around family and friends then ring **020 8949 6209** or email: support@cicra.org

cicra 
better lives for children with crohns and colitis

Mapping IBD Across the UK

Are you living with #IBD in the UK? Does where you live influence #Crohns and #Colitis?

Researchers from Lancaster University and gastroenterologists from Guy's & St Thomas' Hospital are looking for people with IBD to take part in a short survey to find out if there are geographic patterns.

More than 3,700 people have participated in the survey so far.

IF YOU HAVE NOT PARTICIPATED IN THE STUDY BEFORE,
you can support it with your participation and sharing.

<https://wp.lancs.ac.uk/ibdsurvey/>

