



# the insider

spring 2022

## Jubilee celebrations

In this Jubilee Year what better way to celebrate than to fundraise to help children with a lifelong condition. Our aim is a childhood free from Crohn's and Colitis (Inflammatory Bowel Disease). There are many ways in which you can raise funds to help CICRA bring that day forward and here are a few ideas.

### Bake, eat and make a difference!

Hold a bake sale, tea party or cupcake competition with family and friends

### Bank Holiday BBQ or Picnic

Enjoy socialising with friends and family, include a raffle or games such a guess the .... number of sweets in jar or name of teddy

### Table/Garage Sale

Sell unwanted toys, books etc. from a table in the front garden

### Open Garden

Open your garden to friends, family and neighbours and sell tea/coffee and cake.

### School fundraiser

Nominate CICRA to benefit from a non-uniform day at school or college

### Family Fun-Day

Games, competitions, face-painting, food stalls, pamper area, raffle and children's fancy dress competition – the possibilities are endless!

### Quiz for CICRA

Ask friends, family, neighbours or colleagues to take part in a fun quiz with a 'Royal' round, don't forget to charge a fee for each team and donate the proceeds to CICRA

### Best foot forward!

Join one of the CICRA sponsored runs email: [fundraising@circra.org](mailto:fundraising@circra.org)

## We can support your fundraising with

Ideas & advice | Posters | Balloons | Cake toppers | Collection boxes  
Leaflets about how IBD affects the lives of children | Banners & table cloths  
Get in touch with our friendly team – 020 8949 6209 | [fundraising@circra.org](mailto:fundraising@circra.org)

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

## CONTENTS

Message from the Chair	2
Trustee report	3
Mini-MARVEL study	4-5
Little things that make a big difference	6
Ask the doctor	7
Young people's questions	8-9
Digital health passport	10
IBD research survey	11
Research	12-13
Alex   Personal story	14
Family Funds	15
Hannah   Personal story	16
Fundraising 'Drive' at golf club	17
Our amazing supporters	18-21
In loving memory	22
Raffle & 200+ Club winners	23

Life President Professor J Walker-Smith	Hon. Awards Advisory Panel Professor I Sanderson (Chair) Professor S Ennis Dr J Epstein Dr R Heuschkel Professor T T MacDonald Dr S Protheroe Dr N Thapar Prof. H Uhlig Prof. D Wilson
Trustees Mr G Lee (Chair) Mr S Coleman Mr P Cooper Mr N Gooding Mrs M Lee MBE Ms C Malloy Mrs N Pitney-Hall Dr P Smith	Staff Jayne Boyd-Bell Tammy Migliaccio Courtney Coleman
Hon. Clinical Directors Dr K Blakeley Dr J Epstein	

The views and opinions expressed by the contributors are not necessarily those of the Association or the editor. This publication provides information only. Unless otherwise stated, the authors have no medical qualifications whatsoever. CICRA and its officers can accept no responsibility for any errors or omissions. Medical advice should always be sought on any specific matter.

CICRA is the operating name of Crohn's in Childhood Research Association, a registered charity in England & Wales, number 278212, and in Scotland, number SC040700 | the insider is published by CICRA | Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey SM2 6AQ  
020 8949 6209 | support@cicra.org | cicra.org

## Editors Comments

Welcome to our latest newsletter. We hope that there is something here to interest everybody.

Did you know that in the 1920's there were only about 11 cases of children with UC in the whole world? Read more in Ask the Doctor, page 5

We are delighted to feature on pages 14 and 16 inspirational stories from two young people with very positive attitudes to their illness. Alex, having been forced by Crohn's to change his hobby, has now possibly found an enjoyable career path.

We have included some cartoons with a simpler explanation of IBD for our young children and do hope that it may help when parents are trying to explain to their children what is happening to them. CICRA owns the copyright to these cartoons but we were pleased to agree, when asked, if one of them could be used to front up a study in the Netherlands. The usual acknowledgement to CICRA helps to spread the word.

CICRA's research funding has once again helped to push paediatric IBD forward as you will read on page 12/13 when Professor Ordóñez-Morán was awarded a prestigious grant to continue the research funded initially by CICRA. We are always pleased to report on research and on pages 4/5 we feature the Mini MARVEL study being led by Professor David Wilson in Edinburgh. We hope to bring further reports as the study progresses.

If you are a parent, please spend just 5-10 minutes completing the survey on page 11 and encourage the young people to do the same. Researchers really do need, and appreciate, having views and input from the patients, and their parents, to help improve the management of IBD.

Also a very short survey being carried out at Lancaster University on page 5 may shed some light on how/why/where IBD occurs.

Lastly if there is anything that you would like to see in future newsletters, please let us know by sending a note to the office at Pat Shaw House or emailing support@cicra.org



# Message from the Chair



The past two years have been difficult for us all. Here the Chair of CICRA looks at the impact the pandemic has had on CICRA and the children we help.

Over the last two years, like so many other charities, CICRA has suffered from the effects of coronavirus. Apart from the staff shortage and interruption to the daily routines we had to face the fact that with all the restrictions there would be certain things that we couldn't do or offer our members. Having to work from home was not easy. With so little resources and dealing with a variety of administrative jobs, as well as the support and fundraising side, the staff and Trustees needed to be together working as a team in one office, sharing ideas and bouncing new ideas off each other.

However, in saying that I am pleased to report that apart from the odd times when there has been a slight delay in certain areas, they have managed, with extra time and effort from everybody, particularly Jayne, to keep on top of everything. We are now in quite a good position to look forward to the year ahead and hopefully do even more to try and boost research while offering support where we can.

We have missed not being able to have our popular Information Days for parents and children but now that things are returning to normal, we are hoping to start planning these again very soon.

**As we don't receive any government grants our fundraising is an essential part of our plans**

Over the 43 years that CICRA has been supporting families of children and young people with Crohn's disease and Ulcerative Colitis, the age of onset has been reducing. We know that, in the field of medicine, these numbers are very small but it is very important for the families concerned that we try and create an awareness that babies and toddlers can be affected. For this reason, we took up an opportunity, with funding given for this purpose, to distribute a leaflet to 5000 GP surgeries, detailing what support we, as a small charity, can offer to the families. In doing so, we hope that even if the leaflet is not kept, the title of 'Babies and Toddlers with IBD' will be remembered.

As we don't receive any government grants our fundraising is an essential part of our plans and we thank our members for the regular donations we receive as well as the wonderful fundraising events organised by

members featured on pages 18-21. This support has been greatly appreciated and helped us no end. We are proud to be known as prudent, using our income wisely and always keeping in mind our top priority – children with IBD. We hope that In this Jubilee year we will be able to keep up the momentum and have some celebrations of our own to put funds into the CICRA research pot.

Graham Lee, Chair of CICRA



# The Mini-MARVEL study

A new UK study of treatment of paediatric ulcerative colitis



Although CICRA are not funding the Mini MARVEL study we are pleased to be able to report on this important research being carried out in Edinburgh under the direction of Professor David Wilson, one of CICRA's medical advisors

Currently, many IBD drug treatments are very strong and are aimed at suppressing the immune system. Steroid courses are often needed but these have lots of side effects and are strongly disliked by many children and young people.

## Are there alternatives to chronic immunosuppression?

Nutritional therapy is a way to repair and heal the gut damaged by Crohn's disease (CD) and that goes beyond just blocking inflammation (by chronic immunosuppression using thiopurines and biologics). Unfortunately there is no such therapy currently for ulcerative colitis (UC) when anti-inflammatories (mesalazine) do not work or stop working, or frequent steroid courses are needed.

Recent discoveries by Dr Gwo-tzer Ho's team at the University of Edinburgh have shown that the inflamed UC gut lining releases 'danger signals' arising from the mitochondria. These 'danger signals' attract immune cells and make inflammation worse. Mitochondria are the 'batteries' that provide energy for living cells. In the gut lining of people with UC, the mitochondria are more prone to damage which then increases the release of these danger signals. These lab studies have led to

new clinical drug trials in UC – the MARVEL trial for adults and the Mini-MARVEL trial for children and young people.

## Why are we interested in studying a mitochondrial antioxidant?

These specially altered antioxidants protect the mitochondria and have an anti-inflammatory effect. Our study hypothesis is that mitochondrial antioxidant will improve UC and allow the bowel to heal properly following a disease flare. The mitochondrial antioxidant has been shown to be safe in studies in adults with Parkinson's disease and Hepatitis C, but the Mini-MARVEL study, starting alongside the adult MARVEL study, will be the first study in children and young people.

## What is the Mini-MARVEL trial?

In the Mini-MARVEL study, children and young people with an active flare of UC will be given either mitochondrial antioxidant or placebo as an add-on therapy of a daily capsule for 24 weeks on top of an escalation in treatment. We will evaluate differences in inflammation, remission rates, further flare ups, steroid burden, quality of life and patient reported outcome measures.



## Why are you using add-on therapy?

We all think that it is wrong to conduct a paediatric IBD (PIBD) clinical trial which withholds effective treatment of IBD to one group of participants by giving placebo. In Mini-MARVEL, the trial is an add-on of mitochondrial antioxidant capsule or placebo (similarly designed capsule but with no active substance in it) onto standard treatment of UC. No-one misses out on proper adjustment of treatment.

## Why do you not just wait until the adult MARVEL study is over?

Successful new therapies in IBD which are licensed for use in adults take an average of a further 7 years to be licensed for children and young people. This is far too long to wait! The MARVEL study and Mini-MARVEL will start simultaneously as the first all ages IBD treatment trial. Mini-MARVEL will include 3 Scottish and 7 English PIBD centres.

## What is the 'all-ages' approach in IBD?

The team in Edinburgh take on the 'all-ages' scientific approach in IBD (children and young people, adults and the elderly) within their science

to medicine model. There is no current cure for IBD, so all our children with IBD will become adults with IBD. There is no treatment for adult IBD that has not been shown to work in children – nor a treatment that works in paediatric IBD that does not work for adults.

## Why study feasibility as well as effectiveness and safety in Mini-MARVEL?

There are a lack of randomised controlled trials (RCT) of new therapies for UC in children and young people. We wish to look at the feasibility of running a large placebo-controlled RCT for UC in 120 children and young people in the UK. We will analyse which factors in this trial make it easy or difficult to recruit participants and complete the trial. The Mini-MARVEL study, led by Prof David Wilson (paediatric IBD specialist in Edinburgh), will investigate this feasibility and will show whether mitochondrial antioxidant is a beneficial new drug treatment for UC in children and young people.

## Mini-MARVEL:

The paediatric trial of Mitochondrial Anti-oxidant therapy to Resolve Inflammation in Ulcerative Colitis

# Inflammatory Bowel Disease and its possible geographical influences

We aim to see if where patients live has any bearing on whether they get Crohn's disease, ulcerative colitis, or indeterminate IBD.

Our team includes Professor Jeremy Sanderson and Dr. Gaurav Agrawal from Guy's and St Thomas' NHS Foundation Trust in London, Professor Roger Pickup, Professor Peter Atkinson and Dr. Manoj Roy from Lancaster University and Dr. Glenn Rhodes from the UK Center for Ecology and Hydrology.

Our aim is to obtain data on why this disease occurs by running a simple survey. We therefore would

greatly appreciate it if you could participate in the survey and/or help publicise it further.

The survey consists of eleven questions and takes only a few minutes to complete. It is anonymous and confidential. If you do participate, please make sure you answer all of the survey questions.

Understanding more about the causes of the disease may lead to better treatments, and might even lead to potential cures.

Thank you for your participation

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



# BIG difference Little things that make a

## Information for schools

Even though schools are great they don't always really understand the condition. Our simple, easy to understand booklets for teachers and support staff clearly explain what it's like to have IBD, schools' responsibilities and how they can help.

We recommend that children with IBD have an Individual Healthcare Plan (IHP) in place at school. An IHP is a way of drawing up a plan between yourself and the school, ensuring that your child's needs are understood and well supported. Our 'Guide to school for parents and carers' will help with this.

## E-Pals

Chatting and sharing experiences with someone your own age, who knows how you feel, can really help. The 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.

## Can't Wait Card & Radar Key

Has your child ever been out and needed the toilet urgently? Or felt they couldn't go out just in case they needed the toilet? A 'Can't Wait' card helps explain the condition quickly and easily without embarrassment or confusion. A Radar Key gives access to locked clean toilets around the UK. Both are provided free of charge to CICRA members.

## 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.

## Telephone Support

If you would like to speak to somebody who understands what it's like to have a child with Crohn's Disease or Ulcerative Colitis, please call us on 020 8949 6209. We cannot give medical advice but have experienced staff, trustees and volunteers who have long time knowledge in caring for children with IBD.

## Family Days

Our IBD Family Information Days offer an opportunity to share experiences and connect with other families in a similar position. This can be an extremely powerful and validating experience which helps young people feel less alone in the challenges they face. The Family Information Days provide an opportunity to meet with and hear from a team of experienced medical professionals, with a chance to ask questions and learn more about the condition in a friendly and supportive environment.

Our IBD Family Information Days have been paused due to the pandemic, however we are very much looking forward to restarting the meetings as soon as we can. A number of factors will influence our decision on when the right time is to get back to 'normal'. Keeping you and your family safe is paramount, another factor is the meetings rely on the support of medical professionals who are still working under massive pressure within the NHS.

## 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.



To find out more phone **020 8949 6209**  
or email [support@cicra.org](mailto:support@cicra.org)



# Ask the doctor

This is your page to ask questions of our specialists.

Do you have questions you'd like featured on these pages? Email [support@cicra.org](mailto:support@cicra.org)

**Q** My daughter is scheduled to start infliximab in January, less than 6 months after diagnosis. We have run out of other options.

**We have an information sheet that details that after 12 months on infliximab only 29% of UC patients are in remission. This doesn't seem very high! Are the figure for children any better?"**

The short answer is yes, the figures are a bit better in children, and the response to infliximab also tends to be better when it is started earlier in the course of the illness. It is also important to understand that there are different ways of defining remission. The figure of 29% would refer to 'histological remission'. That is, if you did a colonoscopy the biopsies would show no signs of UC at all. This is a very stringent definition of remission, and although we do strive for it, this is often not fully achievable for most people with IBD. Other, less stringent, definitions of remission include 'endoscopic remission' (colonoscopy looks normal to the naked eye), 'serological remission' (normal blood results) and 'clinical remission' (no symptoms). If you were to include those definitions of remission, you would get over 50% 'remission' with infliximab. If you include all types of remission and 'response' as well (ie the condition improves but doesn't completely resolve) then you would get at least a 75% response rate to infliximab. These figures would improve again if other treatments are combined with infliximab (azathioprine, mesalazine, etc). So the 29% figure does seem a bit negative, and in practice does not reflect the situation we see for children with UC, for most of whom infliximab is an effective treatment.

**Q** There appears to have been a big increase in the 70s of Crohn's Disease and there is talk about triggers, multiple triggers and genetic predisposition. Are there any statistical studies to identify what may be the cause and the reason for the sudden increase in the 70s?

If you look at the situation in the 1920s there were only about 11 cases of Ulcerative Colitis in children in the whole world. In the 1960s in Sweden they were describing many cases of Ulcerative Colitis, but in Sweden now the dominant clinical pattern is Crohn's Disease. It seems to be Ulcerative Colitis in adults then Crohn's Disease in adults, then Ulcerative Colitis in children, then Crohn's Disease in children. There is a correlate with affluence and prosperity and the history of paediatric gastroenterology. In the late 60s the first text book in the United States highlighted Crohn's Disease and yet we in Britain in the early 70s had hardly seen it

It is unlikely that our genetic make-up has changed over the last 40 odd years but there are other illnesses that have become more frequent such as allergies, asthma, eczema, hayfever and food intolerances. It may well be that with environmental changes, more antibiotic use, changes in diet, so called "clean child" hypothesis, we are not exposed to the same amount of parasites or bacterial infections early in life – all that has changed dramatically over the last 30/40 years and is likely to be related to the way we live, in addition to the genetic makeup and the trigger we have. We know there are differences north to south in developing countries and east to

west, so there is a lesser incidence of Inflammatory Bowel Disease in the former eastern European countries but that is changing as their lifestyle becomes more like our own.

**Q** Is diet one of the important lifestyle factors?

Diet and inflammatory bowel disease is a fascinating topic and one that's had a real resurgence in recent years. It's important to explain that there's a big difference between what we learn about how diet is linked to an increased risk of developing IBD and diets that might be used to treat the conditions, particularly Crohn's disease. There are clear links between western diet, and perhaps consumption of meat, with the development of IBD, however no diet has been proven to cause IBD and many people consume these diets without developing the condition. Distinct from this, we've known since the early 1980s that we can treat Crohn's disease with liquid-only exclusion diets but our recently developed understanding of how these change populations of gut bacteria has led to a proliferation of dietary research seeking to replicate this treatment success but with more normal foods. It's hard to predict whether this will lead to diet as a long-term therapy or whether this will remain something used for short courses to achieve remission while we try to maintain this with other therapies. In ulcerative colitis, sadly, there are limited options for diet as therapy at the moment.





# Young people's questions

## Why do all the doctors use long words and do you need to know long words to be a doctor?

In the old days people had to study Latin at University to study to be doctors so it was natural that the medical words were made from Latin or Greek. However, there are other good reasons to have long words. If you have a long word it can describe exactly what you want to say. If it is made from one language, such as Greek or Latin then doctors in other countries can understand the medical language.

We call it "**Medispeak**". Languages are fun. If you can speak Italian, which is like Latin, or modern Greek (or have friends or a teacher to ask) you can work out the long words like Gastroenterology.

This is from Latin - "Gastro-" = stomach, "entero-" = bowels and "ology-" = study.

So it means what it says, the study of the stomach and intestines, which is why gastroenterologists know about Crohn's disease and Ulcerative Colitis.

Paediatrician This is mainly from Greek which has its own alphabet.

"Paed-" is from a word that sounds like "pethi" = child,

"iatr-" comes from a word that sounds like "iatros" = doctor and

"ician" is actually from Latin and means someone who does it.

So, paediatrician means a doctor who specialises in children's illnesses.





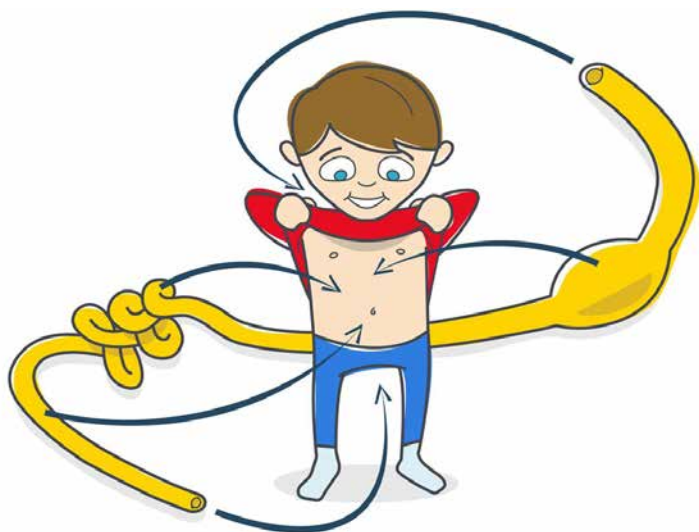
## What is IBD?

IBD stands for Inflammatory Bowel Disease and this means a group of illnesses that are very similar and are often treated in a similar way. The three main illnesses in this group are Crohn's Disease, Ulcerative Colitis and IBDU.

If one doctor says you have Crohn's disease and another doctor calls it inflammatory bowel disease it doesn't mean that you have more than one illness. Although one doctor may call it by its real name and another doctor by its group name, the doctors treating you will know exactly which illness you have so you don't need to worry. The same thing applies if you have Ulcerative Colitis or IBDU.

IBD happens when the long tube in your body doesn't work properly and becomes inflamed and sore. The different names for IBD will depend on where the soreness is and what this looks like when the doctors examine you.

Any of these illnesses can give you pain in your tummy and make you feel very poorly. Children with UC will find they need to go to the toilet a lot more. However, you won't always feel unwell. Medicine will make you feel better and you will be able to do the things you want to but it may take a little while to find the right medicine. Sometimes you may have what is known as a 'flare' when the pain comes back again and you may need to have more tests and a different medicine.



## What causes IBD?

We do not know yet and that is why doctors and scientists are doing a lot of research. What we do know is that it is not due to anything you, or your family, have done or anything you have eaten. You cannot catch IBD from anybody else and you cannot give it to anybody either. Sometimes though there may be other members of the family with IBD – it could be a parent, grandparent, sister, brother, aunt or uncle. The doctors don't know yet why this happens.



## Why me?

When children have an illness that lasts for a long time they can sometimes get very fed up and angry and wonder what they have done to deserve this. The fact is that they haven't done anything to make it happen.

Lots of children have illnesses. Some things can be seen very easily like children who can't walk properly but it is sometimes hard with IBD, because it is all inside your body and your friends may think you are making a fuss over nothing. This can be very hurtful. It is okay to tell them that you are not well and that your illness is invisible.

If you are worried or fed up tell your parents, carers or doctor just how you feel. You don't have to worry about getting the right words just say whatever comes into your head – they will understand and you will probably feel a whole lot better.

When you have IBD the main thing to remember is that you will not feel ill all the time. The doctors will be able to give you something to make you feel better and when you are well you will be able to join in with your friends and do all the things that they are doing.



# Creating a digital health passport for young people with IBD

You may remember that recently CICRA members were invited to complete a survey to help a group, headed up by Dr Priya Narula from Sheffield Children's Hospital. The survey was to hear the views of the young people on their digital requirements when reaching transition to adult services. Below is a report on the progress of this project.

When young people with inflammatory bowel disease (IBD) are about 16 years old, they need to move their healthcare to adult health services. Adult health services are very different from children's health services, and young people need to be prepared. However, many health

services do not have the resources to prepare young people for adult services well enough. This can mean that some young people become very poorly.

We would like to design a version of an existing mobile app that will give young people 24/7 access to information about IBD and a way to track their symptoms. The app is called the Digital Health Passport (DHP) and has been created by a small company called Tiny Medical Apps.

In January and February 2021, CICRA partnered with Sheffield Children's NHS Foundation Trust and NIHR Children and Young People MedTech Co-operative to carry out a survey. This survey aimed to understand the views and requirements of young people with IBD and their parents/carers regarding the development of the DHP for IBD. Twenty-five young people with IBD and ninety-three parents from across the UK completed the survey. Young

people and parents/carers rated the idea of the DHP very highly. Young people and parents/carers thought the DHP would be useful for easy access to health records, symptom tracking, appointment notifications, information about IBD, information about moving to adult services, and information about research studies.

Based on this survey, the project team have applied for research funding to carry out a nine-month project to co-design the DHP for IBD. To do this, we will ask young people with IBD, parents/carers of young people with IBD, and health professionals who work with young people with IBD to take part in two workshops to tell us how to design the DHP for IBD. By the end of this project, we will have developed a live version of the DHP that meets the needs of young people with IBD, their parents/carers, and health professionals.



To find out more about NIHR Children and Young People MedTech Co-operative, please visit their website:  
[www.cypmedtech.nihr.ac.uk](http://www.cypmedtech.nihr.ac.uk)





# Help set the research agenda for young people with inflammatory bowel disease

A group of patients, carers, healthcare professionals, and researchers are collaborating on a project that aims to identify the top 10 research priorities for digital technology in adolescents and young persons with inflammatory bowel disease (IBD).

The project team have created a short survey to identify as many unanswered questions as possible.

The survey only takes 5-10 minutes to complete and is open to the following groups:

- A young person under 25 years with IBD;
- A parent or carer of a young person with IBD; or
- A health professional working with young people with IBD.

This Priority Setting Partnership (PSP) is a collaboration between the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSGHAN), British Society of Gastroenterology (BSG), the James Lind Alliance (JLA), and NIHR Children and Young People MedTech Co-operative.



For more information and to complete the survey, please visit:  
[cypmedtech.nihr.ac.uk/  
digital-technology-ibd-ppsp/](https://cypmedtech.nihr.ac.uk/digital-technology-ibd-ppsp/)

Scan the QR code to go straight to the survey



If you have any questions, please email the project coordinator: [cypmedtech@nihr.ac.uk](mailto:cypmedtech@nihr.ac.uk)





Assistant Professor Ordóñez-Morán's team

Dr Marlies Fischer (Research technician)  
a position funded by CICRA

# Congratulations

## to Asst Professor Ordóñez-Morán

In March 2019 CICRA awarded Dr Paloma Ordóñez-Morán at Nottingham University a £50,000 one-year grant. As happened to so many other research projects there were delays caused by the outbreak of the Coronavirus epidemic. However, despite this, Dr Moran and her group were able to produce very promising preliminary data. This enabled her to apply, and receive, a prestigious MRC award of £750,000 over three years.

During this time Dr Moran wrote a revision manuscript of "Intestinal organoid models" which was published in a prestigious Bioengineering journal Acta Biomaterialia and in which CICRA's support was acknowledged

We were delighted to hear that once again our funding has helped to push Paediatric IBD research forward.



# Optimization of effective models to test novel therapeutic approaches for paediatric IBD patients



The project funded by CICRA since February 2021 to Ordóñez-Morán's group & collaborators (School of Medicine, University of Nottingham) has recently been awarded the competitive New Investigator Research Grant from the Medical Research Council, UK Research and Innovation. They will be supported with £750 K during 3 years, <https://www.ukri.org/councils/mrc/guidance-for-applicants/types-of-funding-we-offer/new-investigator-research-grant/>. These new funds will allow the group to continue studying IBD paediatric models in vitro and allow them to test new compounds that could be potentially used in the clinics. The group will begin a new collaboration with the Beatson Institute, University of Glasgow and the new research grant will support two more positions in IBD research. First, a research technician and second, a postdoctoral scientist for 3 years. In addition, the group has also been awarded the Early Career Development Award from GUTS UK (£15k, 1 year).

Thanks to these awards IBD research will advance to understand better the disease. The findings could potentially be translated into more effective treatments to help improve IBD paediatric and adult patient's health.

The group, that during this last year has acquired relevant data supported by CICRA funds, will continue studying why the inflamed intestinal tissue fails to repair during chronic inflammation. To this end, they will study the intestinal stem cell population which is responsible for tissue repair. In their project, they aim to discover novel effective approaches for treating IBD patients by inactivating a protein, recently discovered, that has a relevant role in chronic inflammation. They will use Ulcerative Colitis human samples cultured in an in vitro innovative 3D organoid model that will help to understand the mechanism driving the disease forward and how to improve tissue repair in patient's tissue.

## More research news coming next issue

The Paediatric IBD Resource project, being carried under the direction of Professor Holm Uhlig in Oxford is well under way. There will be a full report in the next newsletter.



# Alex's past, present and future



With a lack of strength and energy due to Alex's Crohn's he turned to archaeology as a new hobby, and it seems likely it might just turn into a future career.

When I was diagnosed with Crohn's Disease in 2016, I lost weight rapidly, reaching around 31kg at the age of 13. I was an active child, I liked sports and activities, and so when I became very ill, I found the diagnosis hard to deal with. I used to play in a local junior football team as well as swim in my free time, which I had to give up then because of my health. Soon, I found myself wanting to do another

hobby, but I didn't have the energy or strength. My mum and I searched for activities that wouldn't be so strenuous, and we came across a local archaeology club. I always had a fascination with history and leapt at the idea of becoming involved with the club, without any prior knowledge of what archaeology really entailed. Although I missed playing football at weekends and swimming laps of a pool, archaeology provided me with a different outlet, something which engaged my mind and body without being too energetic. Over time, I had treatment with various medications and my health started to improve. I carried on pursuing archaeology, as I found the subject so engaging and fun.

In better health currently (although not completely in remission) I still attend the club, volunteering there as a

'Young Leader'. I could have gone back to the old sports I once loved but I had developed such a strong connection with the field of archaeology, made some great memories and found so many fascinating artefacts that there was not a thought in my mind about leaving. I have even decided to study Ancient History and Archaeology at university after leaving sixth form this year.

I remember one time, helping with an excavation on a Roman Villa in Folkestone, I was still quite ill and very thin. I was unsure of whether to go, as it was quite a long trip and I didn't think I would be able to cope. I found it in me to go, and despite my worry, I had an incredible time. My club has always been inclusive and encouraging and made sure all of my requirements had been sorted.

We went onto Folkestone beach to 'Mudlark', finding artefacts on the surface of the sand, and taking them back up to the villa to be reviewed by the professionals. At this point, I was quite worn out, as my Crohn's made me fatigued very easily. In my bag of finds, an archaeologist pointed out a piece of Roman amphora (wine jar) which I had thought was generic rock or building material. Still, this is my most treasured find, as it reminds me that I was strong enough to step out of my comfort zone and do something incredible.



Me age 12



# Family funds

**This is a great way of motivating family and friends to fundraise for CICRA. Just use the family reference when sending donations and we will add it to your Family Fund to give you a running total.**

CICRA was started in 1978 by parents of children with Crohn's disease in an effort to create awareness that this condition was being diagnosed for the first time in children. One year later having had help with fundraising from families, friends and schools, the Trustees were able to fund their first research project at the Queen Elizabeth Hospital for children in Hackney.

We are grateful to still receive support from families of those affected, but as there are now so many ways to receive donations it is becoming harder for us to link these to a particular person/family. Many members like to know how much has been raised in total by their circle of family and friends so to help us do this we are setting up Family Funds.

Please note that no fundraising appeals will be sent to family or friends unless they are registered with us for free membership, in which case they will receive all mailings, either by post or email, depending on their choice. Members can unsubscribe or change the way they would like to hear from us at any time. Newsletters, sent twice a year, give updates on the work of the charity and importantly reports from researchers on how projects funded by CICRA are progressing.

If you would like to know how much is raised to support your family member, please choose a name,, perhaps the family name, or a name of your choice, and let us know by email or phone. We will add a reference number. All we need then is for whoever pays in the donation, and by whatever means, to give this reference so that this can be added to their Family Fund.

Over the years, with help from the families affected, we have been able to expand our research programme and really make a huge difference to the treatment and understanding of the condition in children, as well as increasing our support for the families affected. Family Funds are CICRA's way of recognising this wonderful support and showing what a difference a small group of supporters can make. Wherever possible, we will add up all previous donations to give a current total.

➔ **Set up your family fund today! Email [support@cicra.org](mailto:support@cicra.org) or call 020 8949 6209 with the name you have chosen, and we will do the rest.**

**"I am fundraising for Hamish, Connie and a cure"**





# Well done Hannah

I'm Hannah, I'm 11 years old. I love reading, playing the Saxophone and cuddling my pet rabbits. I was diagnosed with Crohn's when I was nine, in the February just before the pandemic. I started to get ill in the December. The doctors found I was anaemic and underweight. I was in and out of hospital for a bit, when they did a colonoscopy I was diagnosed with Crohn's. I went on the polymeric diet (just milkshakes) for 8 weeks, it was not easy, but my friends helped me. I mixed the chocolate and the banana flavours to make Choc-nana!

Unfortunately, I had to take steroids as well, now I take azathioprine, allopurinol, omeprazole and salofalk. My friends are good at reminding me to take my salofalk at school.

My teacher read the Crohn's and Colitis cats book to my school friends (it's a free book produced by Crohn's and Colitis UK). In the book it refers to Crohn's as a naughty cat and it helped me to know that it is not my fault when my Crohn's flares, we blame the cat! The book helped my friends to understand that I have an invisible condition and they sometimes ask me how my 'cat' is and I reply "I've only got pet rabbits"!

At the start of year 5, my doctors told me I couldn't go to school because I was taking another course of steroids. I did lots of zooms with my teachers and friends, which was fun. Then I started Infliximab infusions. I used to hate blood tests,

but a nurse at the hospital called Steve helped me understand what was happening, so I became more confident and calmer, now I don't mind having blood tests or cannulas. I've been having Infliximab infusions for just over a year now and they have made me really well. I go to hospital for a day every 6 weeks for the infusion. It can be a bit boring, but I don't mind because all the nurses are kind. I get to miss a day of school and have treats from M&S (their croissants and fruit salad are the best!).

**I also went on a residential with school even though I had to take all my medicines with me.**

For about the first year after I was diagnosed I had lots of stays in hospital, until they found the right medicines for me. However, my Crohn's hasn't stopped me from doing much. I decided to do the grammar school exam with only 3 months to revise. They let me do the exam on my own in the afternoon, so I was allowed to go to the toilet without losing time. I passed the exam and am hoping to go to grammar school in September. I also went on a residential with school even though I had to take all my medicines with me. My mum was more worried than I was!

Last year we raised some money for CICRA. I did a bake sale for Captain Tom's 100, so we baked 100 cupcakes and 100 cookies and sold them on our drive. We have also been selling second-hand books and toys etc. Overall, we have raised over £1,000 and are planning another bake sale this year.



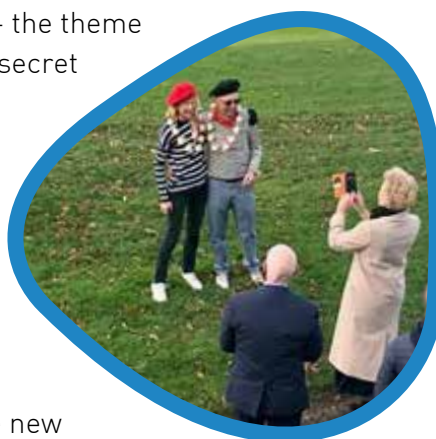


# Great fundraising 'drive' from the Rochester & Cobham Park Golf Club

In early November, our trustee Chloe Malloy attended a charity event at the Rochester & Cobham Park Golf Club, who have very kindly chosen CICRA to be their charity of the year in support of friends and family members with IBD.

A tradition at the golf club is for the in-coming Captains of the Club to take part in a themed 'Drive-in' – the theme decided by the captains and kept a guarded secret until the day. To our surprise (and much enjoyment!), Club Captain Mike Breton and Lady Captain Sally Ferrers cycled up the 18th fairway dressed as French onion sellers, to applause and laughter as the members gathered on the balcony to watch them drive a golf ball off the 18th tee.

The French theme was a fun nod to Mike's Gallic surname. Shortly after their cycle, the new Captains had to drive (hit) a golf ball as far as possible from the tee. Prior to the Drive-in and on the day, members of the club had been asked to guess the length of each of their drives for £1 a go. The distances were measured and the two winners who guessed correctly were presented with their share of the kitty – which they promptly donated to CICRA!



Following the Drive-in was a lovely lunch, and an opportunity to share with the club members a little more about the great work CICRA do. We were delighted to raise an impressive £400 on the day!



Over the festive period CICRA Christmas cards were sold to members raising an impressive £238.55 and our charity buckets remain dotted around the clubhouse for donations from both members and guests.

The Club have an exciting programme of fundraising activities planned for the rest of the year including ladies selling Mulligans (free shots) to players at the Ladies Invitation Golf Day. The Captain's Charity Day which takes place on the 14th May is a golf competition with club members competing in teams of all men, all ladies or mixed. All money raised after expenses goes to CICRA. In August the Club hosts an Open Team Golf Charity Day which is open to all golfers who have a recognised golf handicap. The day is usually well supported and players stay for a meal and prize giving, as well as having the opportunity to bid on some interesting auction prizes.

Raised to date  
£3,475

**Do you work for a business, or belong to a club that could nominate CICRA as their Charity of the Year?**

- Work colleagues or fellow club members will be inspired to raise money and make a real difference to the lives of children with IBD
- Money spent on vital research and support programmes
- Raises awareness of how IBD impacts children's lives
- Raises awareness of CICRA's work

Our grateful thanks also go to Martin Sluckis who we have just heard has kindly nominated CICRA as Charity of the Year 2022 at the Whitefield Golf Club in Manchester. We will be reporting on this in a later edition.



# Our amazing supporters!

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



Raised £377.12

## Hair Cut

Maya Moreira: Now 12-years old, was diagnosed with Crohn's in 2019. Since her diagnoses she has dealt with stomach pain, fatigue, weight loss, lots of hospital appointments, many tests and different medication and treatments. Maya joined the E-Pals and has enjoyed chatting to other children with IBD, she soon realised she wasn't on her own! Maya decided she would like to raise some money for CICRA by cutting her long hair which she had been growing for years. She donated the money to CICRA and her hair to the Little Princess Trusts who make wigs for children.

## Weekly Line Dancing Class & Monthly Raffle

Alison's daughter Amy now 28-years old was diagnosed with Crohn's Disease when she was 15. Alison has been a long-time supporter of the Charity. A fabulous photo of Alison and her very generous line dancing ladies (Alison bottom right, black t-shirt).

"This is a photo of my Friday Line dance class. I also have a Monday and Thursday class from which donations are made. We have a raffle on the last Friday of each month to raise money and a collection box too. I would like to personally thank each and every one of my dancers for their generosity. Alison x"



Raised £5,458 to date

## Ella Wilkes & Jo Hooper

Throughout September & October Ella & Jo ran in a number of events to raise money for CICRA.

- Southampton 10km – 5th Sept
- Romsey 5 – 19th Sept
- Great South Run - 19th Sept
- Great South Run – 17th Oct
- 5km Fun Run – 11th Sept
- Clarendon Relay Marathon – 3rd Oct
- Forest 10-mile trail run – 31st Oct

Raised £996

## Craft Table

Jenny & Peter Hay are long standing members of CICRA, they took a table at a local craft sale and sold stained-glass items, wooden pens and paintings.

Raised £115



## Virtual Christmas cards

Roger Isaacs

Raised  
£502.50

## Donated fuel allowance

Rod Evans

Raised  
£300

## Watford Grammar School

Year-9 students organised a football shootout and non-uniform day

Raised  
£152.72

## Charitable sewing course

Trish is a member of the Exeter Quilters and has supported CICRA with her charitable sewing course since her daughter Sarah was diagnosed with Crohn's Disease in 2009. The sewing group consists of ladies who bring their sewing projects (cushions, blinds, curtains, quilts etc.) and meet once a week when they can. The group has recently restarted after being paused during the pandemic.

Trish says the sewing mornings are a real joy and she has made some good friends whilst sharing life's ups and downs over sewing, tea and laughter.

Raised  
£21,000  
to date

## Cambridge Half Marathon

Nine amazing runners took part in the half marathon around the beautiful city of Cambridge, passing countless historic landmarks along with way including two iconic colleges of the University of Cambridge.

Caroline Lea – Son Freddie was diagnosed with UC aged 13 in 2020, 2-weeks before he started dance school 140-miles away from home.

Finlay Wood – Fin was diagnosed with UC in 2020 aged 17, he is still learning about the condition and decided to do something positive and take on a challenge by running 13.1 miles.

Nic Elvidge – Daughter Katherine was diagnosed with IBD just after her first birthday. He says she deals with the illness with immense amount of bravery, love and gratitude for those who care for her.

Nic Rayward & Jon Wallis – Their sons' friend Raffy was diagnosed with Crohn's just after his 8th birthday.

Sam Lodge – Sam was diagnosed with Crohn's when he was 9-years old. He decided to run to prove to himself that even if you do suffer from IBD, you can do anything!

Stefan Latter – Son Ben was diagnosed with UC/Proctitis at the age of 15. Stefan said running for CICRA was an amazing experience and it filled me and my family with pride raising so much money.

Richard Pallet – 11-year-old daughter Jessica was diagnosed with UC in 2018

Fiona Blackwell – 13-year-old daughter Emily has UC

Raised  
£14,276

## North-West Tough Mudder Challenge

Max Espley: In 2020, Max's young cousin was diagnosed with Crohn's Disease and has spent a lot of time in hospital. He decided to take on a personal challenge in support of his cousin.

Raised  
£339

## Christmas Wreath Making

Joanne Chilcott: Long time CICRA supporter Joanne Chilcott raised an amazing £800 running a wreath making workshop in December. Joanne has two children with Crohn's.

Raised  
£800

## Pub Fundraiser

Sarah Hoyle: Together with her daughter Faith organised a successful fundraiser at their local pub. Faith is 12 years old and was diagnosed with UC in August 2020.

Raised  
£124





Raised  
£6,605

## Ironman 70.3 challenge

Scott signed up to do 'Ironman 70.3' after his niece Izzy was diagnosed with IBD at 16-months old in January 2021. Training for the event took 9-months and huge amounts of resilience and determination with early morning sea swims, runs and bike rides – sometimes more than once a day!

The challenge involved a 1,900m swim, followed by a 56-mile cycle and finishing off with a half marathon, Scott finished in an amazing 6-hours and 11-mins and placed 773rd out of 1474 competitors - a truly wonderful achievement.

His sister Rebecca (Izzy's mum) said it was a very emotional and moving day for the whole family, and they are all incredibly proud of him and what he achieved. Izzy loved clapping all the competitors as they came past and gave her uncle Scott a big cuddle at the finish line.

## London Marathon

October saw two contenders for the London Marathon:

David Lemer not put off by the outcome of his 2014 run which ended at mile 22 with a collapse, hospitalisation, and an uncomfortably placed thermometer!! He was back out there raising money for CICRA (the Crohn's in Childhood Research Association). A cause he tells us is very close to his family's hearts.

Fiona Lawson-Best ran for her father, sister, and Aunt. And her niece and nephew - both were diagnosed at 13 years old with Crohn's. Fiona finds her niece and nephew's courage inspiring in their battle against this invisible disease. And feels CICRA's support has been invaluable. She runs to raise awareness of the condition and do all that she can to fund research to find a cure.

Raised  
£8,687.78

## Great North Run

This iconic event celebrated its delayed 40th anniversary in 2021 after being cancelled in 2020 due to the coronavirus pandemic. Five fantastic runners for CICRA completed the 13.1-mile course that took them towards the River Tyne and the iconic Tyne Bridge.

Katie O'Malley – Daughter diagnosed aged 12 with Ulcerative Colitis.

Kevin Lovell – Brother of Katie O'Malley – supported his niece who has Ulcerative Colitis.

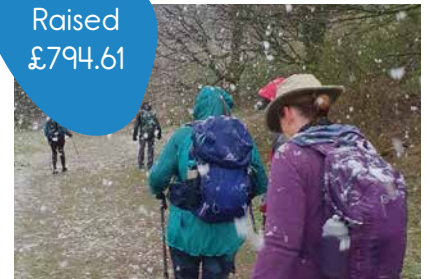
Daniel Meddes – diagnosed with Crohn's aged 13.

Robyn Thorburn – Son Jake diagnosed with Crohn's aged 8.

Chris Harper-Harris -

Raised  
£ 2,435

Raised  
£794.61



## Worcestershire Way

Kirsten Beard: Initially planned to take part in the Cardiff Half Marathon in October 2021 which was unfortunately postponed until March 2022. Instead she walked the Worcestershire Way, a total of 31 miles which she says was 'beautiful but brutal, both the hills and the weather!'. Kirsten's son Elliott was diagnosed with Crohn's Disease in 2020 age 15.

## Speaking fee

Sheila Jefferson donated her fee for speaking at Thirsk Probus Club

Raised  
£50





## Climbing Snowdon

Jodie Miller organised this challenge after a friend's son was diagnosed with Crohn's Disease. Along with Rio's mum Emma and two other friends Kari and Sarah they decided to climb Snowdon. Jodie said that despite seeing Rio quite poorly at times, he is a kind boy who always tries to keep a smile on his face which inspired her to take on a personal challenge and raise money for CICRA.

Raised  
£3,180

## London to Brighton Cycle Ride

Chris George

Raised  
£442

## Chase the Moon

Judith Burt: Judith was diagnosed with Crohn's in 1984 and has supported CICRA ever since. She decided to take on the couch to 5k challenge in preparation for the run, and took part in the 5k run at the Queen Elizabeth Olympic Park in December.

Raised  
£75

## Christmas Fayre

Raised  
£8,557

Lucy Schofield: Lucy's sister arranged a Christmas Fayre with proceeds being split between CICRA and Kirkwood Hospice. Lucy has been fundraising for CICRA since her daughter Nell was diagnosed with Crohn's disease in 2018.

## Cards for cash

A generous and long time supporter, Margaret Bines, whose grandson Alex features on page 14 made and sold greetings cards during lockdown.

Raised  
£120



Raised  
£185

## Knit one

Victoria's mother Isobel has been knitting dolls to raise money for CICRA. Her grandson Evan was diagnosed with Crohn's at 6-years old, she decided she wanted to do something positive to help him and other children with IBD.

## Purl one

Mrs Passmore is a grandma and long-time CICRA supporter who makes knitted items that she sells, and also sells items occasionally at car boot sales.

Raised  
£650  
to date



# 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 is most grateful for donations received in memory of:

## **Delsa Rosina Cooper**

Delsa was full of life. She had a great sense of humour, she wrote stories and poems, knitted many jumpers, made clothes, decorated wedding cakes, made wedding bouquets and painted. She was a lady full of talent. But above all this she loved children. Remembered with love by all family and friends and missed every day.

## **Please remember CICRA in your Will**

Legacies are an extremely valuable source of income for all charities and CICRA is extremely grateful for any that we receive – whether large or small.

Unexpected income such as this has helped to provide the funds to maintain and expand the research programme, improving the lives of children with Crohn's and colitis.

We will always respect the wishes of the legatee or their family if there are certain wishes as to the way the funds are used and will ensure that it is properly administered and acknowledged.

Making a will is very simple. You can do it yourself but it may save problems arising later if it is done by a solicitor or with the help of the Citizens' Advice Bureau.

If you are considering leaving something to CICRA in your will and would like the correct wording please get in touch.



## Cards that make a difference

A BIG thank you to all our members and supporters who purchased Christmas cards, we hope you'll agree we had a great selection of cards!



As we are able to keep our costs to a minimum, we are pleased to report that over 40% of the cost of each pack sold went towards maintaining and expanding our vital research and support programmes. Special thanks to Jean Gooding who once again sold cards to the residents of Birtley House Nursing Home, friends and neighbours.

If you missed out on supporting us at Christmas by buying cards, you can still buy cards for other occasions - see back page for more details.

## Christmas Draw

Our thanks as always go to all who purchased and sold tickets for the Christmas Draw. After taking out prizes and printing costs we have been able to put some £4,550 towards our ongoing research programme.

The draw took place on Tuesday December 14th at our office at Pat Shaw House, Sutton and the winning tickets were drawn by Tracey Currie from Sutton Housing Society

We are grateful for support for this fundraising event twice a year but if, for whatever reason, you do not wish to receive tickets, it would help us, and save the charity money, if you could please let us know and we will make a note of this. Please either send an email to [support@cicra.org](mailto:support@cicra.org) or ring the office on **020 8949 6209**

### Below are the winners

Prize	Ticket No.	Name
£500	52483	L. Fairbrother, Derby
£250	44145	D Ward, Plymouth
£100	41153	Linda Clinton, Shropshire

## 200+ club winner list July – December 2021

Thank you to those who have supported this fundraising effort in what has been a very difficult couple of years. Your support is very much appreciated, and we would like to make a special thank you to those who have donated back some or all of their winnings. You can be sure it is well spent on our research programme. All funds are split 50/50 between prizes and research - a real 'win-win' situation. If you have not joined yet but would like to please ring the office on 020 8949 6209 or email [support@cicra.org](mailto:support@cicra.org) and we will send you the forms.

### July

223	A Cooper, Berks	£50
167	M Khurajiam, Cheshire	£50

### August

100	A Simmons, Herts	£50
78	M Cox, Dorset	£50

### September

82	S Durman, Guernsey	£250
260	H Smallcombe, Oxford	£75
93	A Tucker, Plymouth	£75

### October

211	P Storey, Newcastle	£50
47	J Gooding, Surrey	£50

### November

43	R Adcock, Herts	£50
96	S Cook, W Sussex	£50

### December

271	H Magson, W Sussex	£250
131	A Ramsden, London	£75
166	S Morgan, Suffolk	£75





Over 50% of the cost goes towards helping children with IBD.

# Buy cards for all occasions and support us

A multi-pack of ten greetings cards for only £9.95 – cards are great quality and work out less than £1 per card!

go to [www.cicra.org/shop](http://www.cicra.org/shop)



## A little change makes a big difference

Having a CICRA collection box in your home, shop or pub makes a difference to the lives of young people with IBD. Whether it helps to funds research or just finding a friend through EPals. It all adds up.

If you would like a collection box email [admin@cicra.org](mailto:admin@cicra.org)



**Fresenius Kabi** are proud sponsors of



better lives for children with crohns and colitis

