the insider

autumn 2021

Back to School

CICRA has resources to help, including information for primary and secondary schools, a quick guide for teachers, and leaflets to help with exams and supporting children with medical conditions. Most are available on our website www.cicra.org or ring the office on 020 8949 6209

IBD and secondary schools

information for form teachers, year heads, pastoral staff, attendance and examinations officers

cicra
better lives for children with crohns and colitis

"If I had my arm in a plaster, people would understand."

how to help children with crohns or colitis at primary school

cicra
better lives for children with crohns and colitis

better lives for children with crohns and colitis

CICRA's vision is for a childhood unlimited by inflammatory bowel disease.

Through sensitivity, flexibility and support, schools can make a huge contribution to this goal.

If you have questions about IBD or its impact on young people, please **contact the team at CICRA** or visit our website for downloadable template letters to exam boards.

www.cicra.org | 0208 949 6209 | support@cicra.org

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better lives for children with crohns and colitis

Contents

Handing Over

Members have had messages from me concerning CICRA for a long time now and the message I have this time is that I am standing down as Chair but continuing as a Trustee and for the time being will continue to be in the office. Just prior to the AGM, the Trustees unanimously agreed that Graham should take over the role of Chair. Now that COVID is hopefully behind us we can get back to making plans and I know that Graham and the Trustees will do all they can to continue to support families and children affected by IBD and to continue to fund much needed research.

Best wishes, Margaret Lee

Message from the New Chair

Before discussing the future, I would like to thank Margaret for her efforts as Chair over many years. As you may know, Margaret was one of the original parents who founded CICRA in 1978 and since that time has been a driving force behind the charity, having seen over £9m invested in research, 25 paediatric gastroenterologists trained, and a lifeline offered to hundreds of families. It is great to know that she will be continuing in her role as a Trustee, so we are not losing her years of experience!

For those who do not know me, I am Margaret's son and the reason for her becoming involved many years ago. I have been a trustee of CICRA for many years and Vice Chair for two. I am delighted to take over the reins as Chair of CICRA. I and my fellow Trustees feel a huge responsibility to continue to take the Charity forward with its aims and objectives - supporting families and providing the funding for research into IBD.

I am glad to say that we are starting to see some signs of recovery in both charity income and the capacity of the medical community to re-start essential research programmes. However, we have also seen a significant increase in the level of support requested by families, parents and children due to the challenges that COVID has imposed on the NHS over the past 18 months. We hope that for the remainder of 2021 and moving forward into 2022 we can plan for the Charity to move forward and commit more funding for research and support programmes.

I would like to finish by thanking all of you for your efforts on behalf of CICRA during these difficult times – your continued support helps us make a big difference.

Best wishes

Graham Lee - Chair of the Trustees

In Loving Memory

Thinking of CICRA

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:

- Peter Williams - Much loved Grandad of a Crohn's sufferer. Remembered with love by all his family and friends.
- Alan Jones
- Katy Jade Sutton (Aged 31 years) – Treasured memories of a loving daughter and sister, remembered with love always.

Carol Concert – A date for your diary

Goldsmiths Choral Union

supporting cicra

better lives for children with crohns and colitis

Friday 17 December 2021
Holy Trinity, Sloane Square
Sloane Street, London SW1X 9BZ at 7.30pm

CAROLS
FOR CHOIR
AND AUDIENCE

Goldsmiths Choral Union
Stephen Jones *piano*
Edward Batting *organ*
Brian Wright *conductor*

Tickets: £20 unreserved
(Children under 12, £5) from
TICKETSOURCE 0333 666 3366
ticketsource.co.uk/gcu
choir members or
on the door

Collection to benefit cicra

goldsmithschoral.org.uk

The Goldsmiths Choral Union Carol Concerts have been bringing Christmas cheer to London audiences for well over sixty years and this year at 7.30pm on 17th December the Carol Concert will be held in aid of CICRA. There will be carols, old and new including well loved favourites for the audience to join in. The concerts are held each year in the beautiful late-Victorian church of Holy Trinity, Sloane Square. The entrance to Holy Trinity is on Sloane Street which is a 2 min walk from Sloane Square tube station. On-street parking is strictly controlled. The nearest car park is 6 mins walk away in Cadogan Place off Pont Street.

As the Goldsmiths Choral Union is London's finest independent amateur choir, tickets for these concerts are always in demand so if you are thinking of joining us we would encourage you to register your interest. When tickets become available in late October/early November you will then get priority. You can do this by sending an email to admin@cicra.org putting 'Carol Concert tickets' in the subject line and how many tickets you would like – adults £20, children under 12 - £5. When tickets become available to us, we will contact you with details of how to pay. If you are not able to email then please call the office on 020 8949 6209.

Christmas cards

With Christmas on the horizon we do hope you will check out the lovely selection of cards and extras we have on offer this year. Orders will be processed from the office. With everything done on a voluntary basis you can be sure that by buying our cards you are helping to fund and expand research and support for children and young people with IBD – not forgetting that any research helps the 'not so young' with IBD as well. New for this year we have lovely packs of 10 Assorted Greetings Cards on offer for under £1/card! (how many of us were caught out in Lockdown without a card to send?) As in previous years you can place your order by completing the enclosed form, telephoning the office on 020 8949 6209 or buying them online through the shop at www.cicra.org

Thank you for your support.

British Medical Science - A message from our President Professor John Walker-Smith

As I said in my message to CICRA during the pandemic, when the successful development of vaccines was occurring, with a very significant British Medical science contribution, this was a good time for CICRA to make appeals for support for British medical research. Since then, not only have there been many research studies concerning the clinical effectiveness and risk assessment of vaccines, but there have been notable clinical research studies concerning therapy for covid-19 infection e.g., the remarkable role of the well -known drug dexamethasone, as well as other drugs.

Whilst these clinical research studies were largely undertaken on NHS patients, these were not NHS funded studies, but University, Pharmaceutical company and Charity supported and funded studies. The vital role of the Universities of the UK and British medical charities is perhaps not well enough understood by the media and so by the general public. I believe CICRA can take up this message of the success of British clinical research studies and apply it to children with Crohn's disease and ulcerative colitis.

Great strides are being taken in this field, most notably by studies being undertaken by Dr Rob Heuschkel and Dr Matt Zilbauer at Addenbrookes Hospital in context of the University of Cambridge. I mention this because recently I made a visit to Dr Zilbauer's laboratory with Professor Alan Phillips and heard of the publication of their several important research studies. Their creation of organoids in the laboratory is an important tool for future research.

I want to wish the hard-working members of CICRA every good wish for success in their various fund-raising activities. Finally, it is nigh on 22 years since I was invited to be Life President of CICRA, and I continue to regard this as a single and unique honour

John Walker-Smith Emeritus Professor of Paediatric Gastroenterology, University of London. Life President of Crohn's in Childhood Research Association

Possible new therapeutic approaches for childhood IBD

COVID and lockdown caused problems for most charities and businesses and not least all aspects of the NHS. Scientists were deployed to help with vaccine and sanitizer production, therefore putting some of their other research projects on hold – our 3 new projects included. However, we are pleased to say that all three are now underway and below is a report on the research being carried out in Nottingham.

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

Most of the clinical trials done in IBD research are first carried out in animals and the compounds are validated afterwards in adult volunteers. These experiments do not exactly replicate children's disease and consequently many of these drugs fail to work. Paediatric patients would benefit considerably if there were better models that recapitulate their intestinal epithelium/tissue response to drug treatments.

To discover new potential treatments, we first need to optimize useful research models that recapitulate the damage done to the epithelial cells during the development of the disease. So, our project aims to develop an effective model derived from the intestinal tissue of these children and test novel therapeutic approaches without putting them at risk.

Our collaborative team composed of adult and paediatric gastroenterologists (Dr. GW Moran and Dr S Kirkham, University of Nottingham/Queens Medical Centre, Hospital of Nottingham) and biologists (Dr P Ordóñez-Morán and Dr N, Hannan, School of Medicine, University of Nottingham) have identified a way to overcome the limitations of current IBD models.

We aim to mimic the children's cellular intestinal tissue in the lab. To that end, we will collect tissue samples from patients undergoing endoscopy and we will grow these cells in plates. These cells expand 3-dimensionally, and in less than two weeks they will show very similar characteristics as they show in the human body (Figure 1). We will also collect adult biopsies to compare the responses. With this model we will be able to test novel and existing compounds for assessing epithelial damage and regeneration. This will inform us how we can improve tissue regeneration and in consequence reduce intestinal damage.

The findings from this project could potentially be translated into more effective treatments to help improve IBD patient's health.

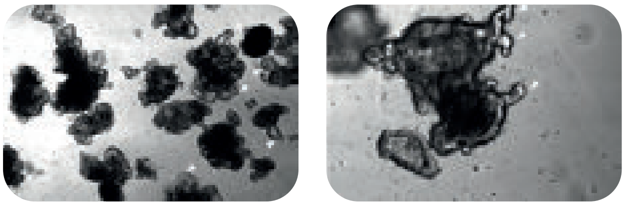


Figure 1 - Human 3D-organoids grown in the lab.

Figure 2 - Dr. M. Fischer (post funded by CICRA).

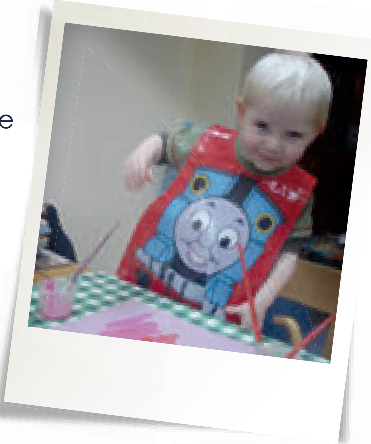
Figure 3 - Prof P Ordonez-Moran and Dr M Fischer

Oxford University project

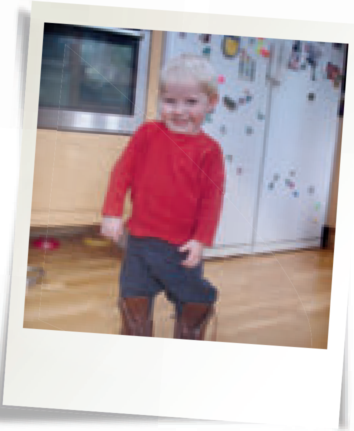
Our funding of the UK Bioresource for paediatric IBD, led by Professor Holm Uhlig at Oxford University, and involving many of the top IBD specialists has been held up by COVID but is now underway and we will be reporting on this in the next newsletter.

Oscar's journey Diagnosed at 17 months

Oscar is my third son, born eight days late weighing a very healthy 10lb 7oz! I breast fed him for the first five months and then we started weaning. Within three months he started having episodes of bloody diarrhoea. I took him to A & E and was given an appointment for the fast-track paediatric clinic. They did a number of tests, and one came back positive, entro-virus RNA, this was the reason given for his symptoms and he was discharged. After a month the symptoms came back, but now he was vomiting after eating as well. I remember taking him to the GP who said, "What do you want me to do?" All I wanted was for my baby to be better. I took a used nappy to show the GP (Pre-smart phone days!); he was referred back to the clinic, they ran tests for food allergies and intolerances, all came back negative, but as his iron levels were so low, and he was losing weight, further investigations were ordered. I got increasingly frustrated as there were so many delays; his appointment was changed from May to July - then this was again delayed until August, I knew my baby was not thriving, but no-one seemed to be doing anything to help him. This appointment was again delayed until the end of December. A seven-month delay for an appointment which was supposed to happen within 6 weeks was just too much. I had made many phone calls, during this time to try and get him seen. In the end I wrote to the hospital's chief executive complaining/explaining.

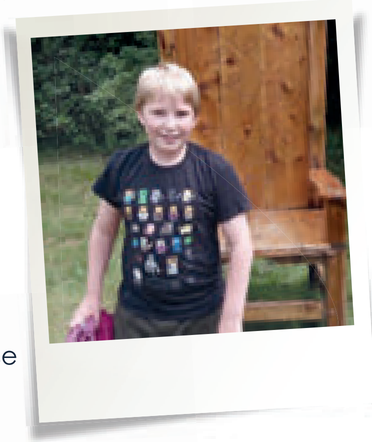


He was referred to the gastroenterology clinic for scopes. I was told it would be as soon as possible – however no appointment arrived. More phone calls followed, and they brought his appointment forward (They said it had been marked non-urgent).

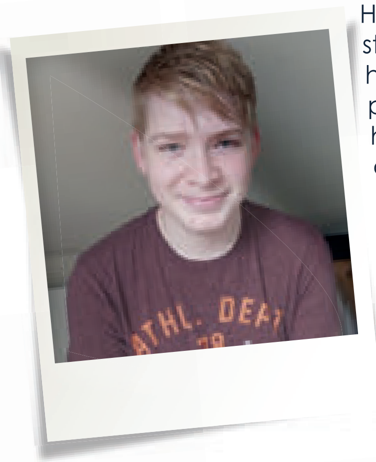


Following the scopes his consultant said there was a lot of inflammation but until the biopsies came back a final diagnosis could not be made. His consultant asked why I had not got him seen sooner! In August, he was diagnosed with Crohn's disease. I was told he was the youngest child that he had ever diagnosed. I shed a tear or two. Sadness that my son had a lifelong illness and the possible repercussions this could have and relief that at least we knew what we were dealing with. It felt like an uphill struggle to get the diagnosis, and frustrating with all of the delays from his first symptoms at six-month-old to his diagnosis at 17 months.

He was started on Sulphasalizine and steroids which helped. He grew, returning to the centiles he had been on before it all started. The medication kept all symptoms in check for several years, so much so that the consultant suggested he come off his medication. I was a little worried. It lasted for 6 months before the symptoms restarted and so did his medication.



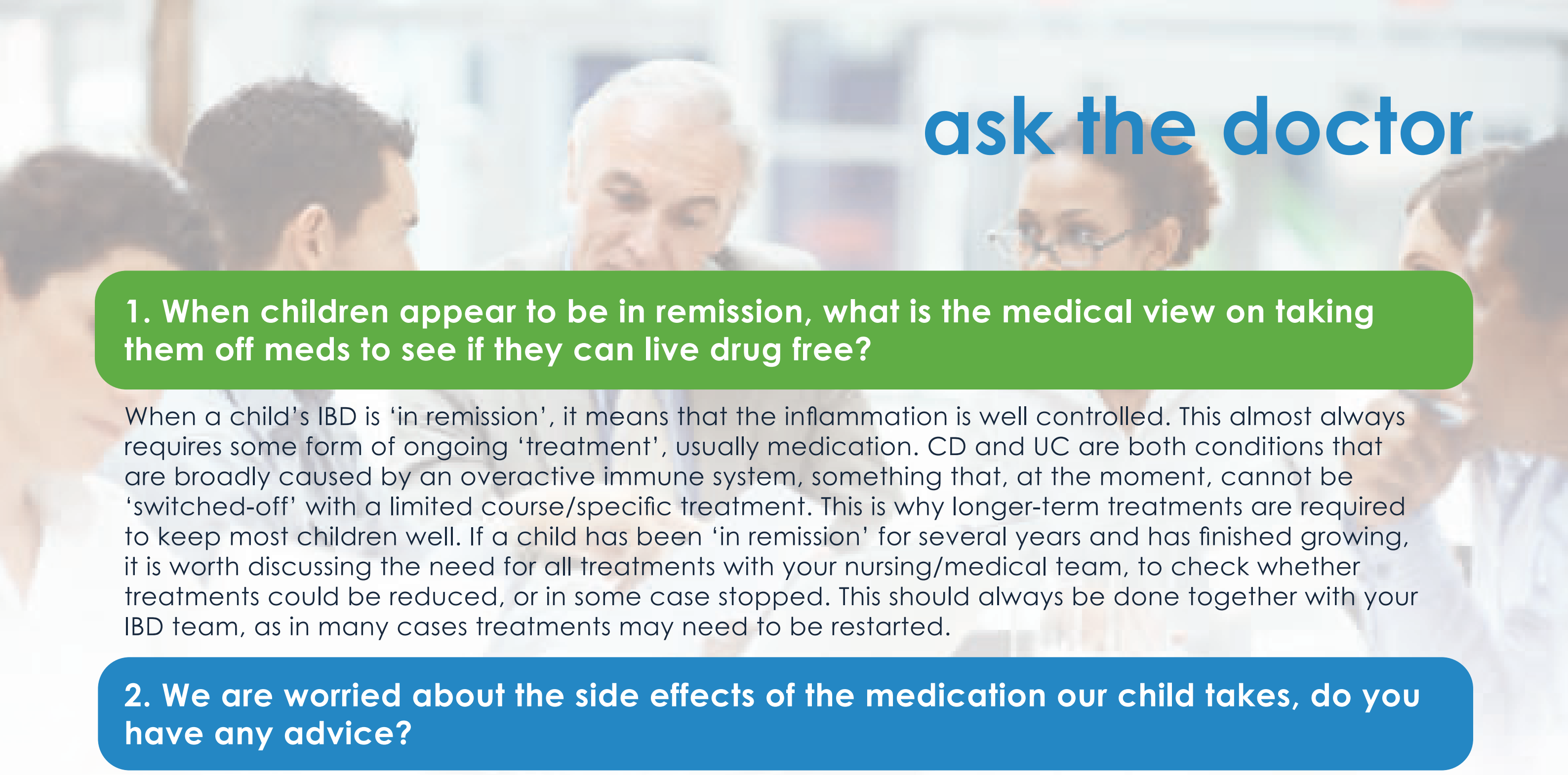
His primary school was very supportive, a member of staff also had Crohn's so there was a good level of understanding, he took his medication at school. Secondary school was fine too as he had virtually no time off, he chose to not do his medicine there as he didn't want to be different to the other students – I'm pretty sure not many of them know he has Crohn's.



He is now 16, he has had several mild relapses treated with doses of steroids he was also started on Azathioprine which was really scary, having read on-line about the possible side effects. However, it has pretty much kept him well with no side effects. Stressful times increase his symptoms, like when he was taking his GCSEs (this summer). He does everything he wants to do and for him it is a normal life.

In the words of 16-year-old Oscar: 'I was more or less born with Crohn's. It hasn't affected me in a massive way. I don't know life without it. The only difference is I take medicine and go to the hospital sometimes.'

More children are being diagnosed with IBD at a young age now, but at one time it was very rare. Diagnosis has improved no end over recent years, helped by the 25 childhood IBD specialists who received their training through the CICRA funded 3-year Fellowship scheme. We would hope that no other parents would have to go through the worrying time that Oscar's did.



ask the doctor

1. When children appear to be in remission, what is the medical view on taking them off meds to see if they can live drug free?

When a child's IBD is 'in remission', it means that the inflammation is well controlled. This almost always requires some form of ongoing 'treatment', usually medication. CD and UC are both conditions that are broadly caused by an overactive immune system, something that, at the moment, cannot be 'switched-off' with a limited course/specific treatment. This is why longer-term treatments are required to keep most children well. If a child has been 'in remission' for several years and has finished growing, it is worth discussing the need for all treatments with your nursing/medical team, to check whether treatments could be reduced, or in some case stopped. This should always be done together with your IBD team, as in many cases treatments may need to be restarted.

2. We are worried about the side effects of the medication our child takes, do you have any advice?

Almost all medications have side-effects. The type and severity of side-effects of course very much depend on the type/class of medications your child is taking. Anti-inflammatory medications generally have least side-effects, whilst immune-suppressants and biologics can have more significant side-effects that require more active monitoring. It is important to understand the risks (and the benefits!) of each treatment before it is started, so that everyone is clear about what to look out for and how side-effects can be minimised. Detailed discussion with your IBD team is important to make the best use of each treatment.

3. My child has IBDU, are children usually eventually diagnosed with Crohn's or UC? Is IBDU a common condition and why is it difficult to decide if its Crohn's or Colitis?

IBD-Unclassified is a label that is mostly used by pathologists (doctors who look at endoscopic biopsies under a microscope), when the typical features of either CD or UC are not present. Pathologists like to be accurate in their reporting, so that a label of IBD-U makes the clinical team keep an open mind on the diagnosis, whilst also being able to consider treatment options for both conditions. When there are features of both conditions in a single set of biopsies, this can (but does not always) change to a more formal diagnosis of CD or UC over time. Now that many children have upper endoscopies at the time of diagnosis, inflammation on biopsies from the stomach and upper small bowel can mean that a diagnosis of UC (textbooks say there 'should' only be inflammation in the colon) is not completely accurate.

4. My 14-year-old daughter is in remission from ulcerative colitis and is taking salofalk (Mesalazine). While I have seen information saying that she isn't at any higher risk than other people of severe Covid-19 illness, I haven't seen information to say whether or not Covid-19 could affect her IBD. i.e. if she caught covid 19, could this result in a deterioration of her IBD or could it trigger a flare up?

There is no published information to answer that question at present. In theory, any viral infection or systemic upset of any kind can trigger a relapse of IBD. In our clinical experience though, we are simply not seeing it. Perhaps people are getting flares of their IBD with Covid infection at home but if they are, it isn't severe enough for them to contact us and certainly not to be admitted to hospital. I suspect it is either a non-issue, or a minor one. Our experience and evidence is mounting, and it all suggests that people with IBD (who aren't on steroids) are at no increased risk, either of catching Covid, or of having severe Covid, or of Covid upsetting their IBD.

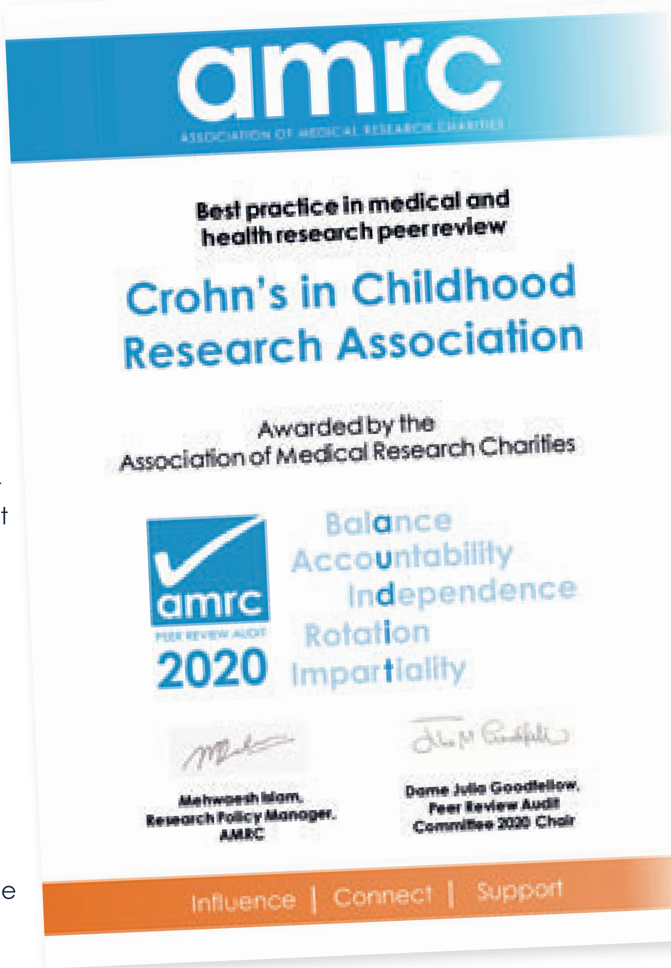
All questions are answered by our team of medical advisors

An important 'tick' for CICRA

CICRA has once again passed a 5-year audit by the Association for Medical Research Charities (AMRC) allowing continued use of the AMRC tick. This is the third audit carried out by the AMRC and CICRA has passed all three. These audits consider all aspects of the process used by their members for awarding research grants and signify good quality peer review.

In the early days CICRA, along with NACC (now CCUK) and other gastro charities, were not able to join the AMRC due to insufficient spend on research. Under the guidance of the late Professor John Lennard-Jones, the Association of Gastroenterology Research Charities (AGRC) was set up and regular meetings held at the BDF offices (now GUTS UK). The combined funding of the AGRC allowed it to be accepted as an associated member of the AMRC. Eventually the research spend for each charity was enough for them to become a member in their own name.

CICRA has been very fortunate to have had a Medical Advisory Panel (MAP) made up of both scientific and clinical experts in IBD and we would like to thank them all, both past and present, for giving freely of their time to help us ensure wise funding. Under the AMRC guidelines, each funding application must also be graded by 2-3 independent external referees, either from this country or abroad. We thank the many experts we have called on to do this and their willingness to help.


amrc

ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Best practice in medical and
health research peer review

Crohn's in Childhood
Research Association

Awarded by the
Association of Medical Research Charities

amrc
PEER REVIEW AUDIT
2020

Balance
Accountability
Independence
Rotation
Impartiality

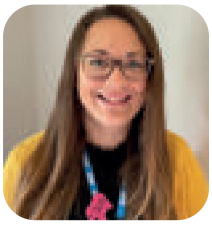
Mehwaesh Islam,
Research Policy Manager,
AMRC

Dame Julia Goodfellow,
Peer Review Audit
Committee 2020 Chair

Influence | Connect | Support

The advice from all our experts has ensured good quality research and brought about better management and treatments for children with IBD but there is still a lot to do and we will be calling on our experts again soon.

How does the stigma of having IBD impact young people?



A CICRA funded research project, led by Dr Annabel David, Senior Clinical Psychologist at the Oxford Children's Hospital, will hopefully give us some of the answers and better ways of supporting these children. Her first report on this project is below:

The research aims to better understand the impact of health-related stigma for young people with IBD. Working in collaboration with Dr Kate Muse at the University of Gloucestershire, the team began by reviewing previous literature exploring what it is like to experience stigma, from the perspective of individuals living with the disease. By drawing together a range of first-hand accounts, the review provided insight into when, how, and why different forms of stigma impacted people with IBD. Many individuals perceived stigma (such as thinking that others might think badly of them because they have IBD), but far less experienced any enacted stigma (such as being treated unfairly because of having IBD). The level of stigma that individuals perceived changed over time, related to disease activity and social and physical environments. There were also a number of factors that protected individuals from stigma impacting on their view of themselves or their psychosocial wellbeing. Adjustment to living with IBD (acceptance of the illness and being able to see it as just one part of their identity) and the development of adaptive coping skills were important processes. This shows the importance of individuals with IBD seeking psychological help to support them to live well with IBD. Furthermore, family and friends encouraging open discussions about living with IBD led to individuals feeling supported and more connected to important others. Peer support, for example through attending groups for people with IBD, was also identified as beneficial. Given the additional burden stigma places on people with IBD, it is vital to raise public awareness and understanding to help change the way people think about and act towards individuals with IBD. The majority of research in this area has been conducted with adults. Therefore, the next step for the researchers is to recruit young people to complete questionnaires and be interviewed about their experiences of living with IBD, and any experiences of stigma and its effect. It is hoped that this further understanding, specifically about young people, will help shape the psychological support offered to young people and the development of targeted campaigns to reduce stigma.

Congratulations
Dr Daniel Brice PhD

Our congratulations to Dr Daniel Brice, the latest CICRA funded student to be awarded his PhD. Daniel spent 3 years at the University of Aberdeen working in the laboratory of Dr Mairi McLean (Senior Clinical Lecturer and Consultant in Gastroenterology) researching interleukin (IL)-27 as a potential treatment for inflammatory bowel disease (IBD). His report is below:.

IL-27 is a cytokine (a soluble mediator of inflammation) that has previously been shown to have profound anti-inflammatory effect on cells of the immune system, promote the resolution of inflammation, and healing of the intestinal barrier in experimentally induced colitis in mice. The mechanisms by which IL-27 promotes healing of the intestinal barrier had not been investigated and formed the basis for my research.

The first layer of the intestinal barrier, the epithelium, is our first line of defence in isolating the contents of the intestine from the underlying tissue. Disruption of the epithelial barrier and increased transit of the contents of the intestine (increased permeability) to the underlying tissue has been implicated in IBD. Using cutting edge human patient derived organoid cultures (complex 3D mucosal structures that resemble the tissue they are taken from) my research has defined some of the mechanisms by which IL-27 promotes healing of the epithelial barrier. To control the movement of molecules from the intestine to the underlying tissues epithelial cells are joined together by tight junctions, these junctions form pores between the cells which vary in diameter to restrict or allow transit of molecules. A 'leaky' more permeable barrier has been implicated in the onset and progression of IBD, under inflammatory conditions my research has shown that the presence of IL-27 changes the expression of genes responsible for tight junction composition, reducing permeability and enhancing the barrier function.

As well as forming a physical barrier the epithelium also produces chemical mediators that prevent micro-organisms (bacteria, virus, fungi etc.,) from infiltrating the epithelium and underlying tissues. IL-27 has been shown to increase the expression of genes responsible for the mucus barrier and anti-microbial peptides (proteins that kill or restrict the movement of microbes). Importantly, using cell culture models of epithelial wounding IL-27 has been shown to increase the proliferation of epithelial cells and promote the healing of epithelial barrier.

IL-27 represents a promising new therapeutic strategy for the treatment of IBD and the results of my research will be published shortly. Furthermore, Dr. McLean is continuing the research and additional studies are underway to better define the effects of IL-27 on other cells of the immune system, the results of which may provide further evidence for the development of IL-27 as a new therapeutic in the treatment of IBD.

Youngsters

Getting involved

CICRA is your charity, dedicated to improving the lives of children and young people with any form of inflammatory Bowel Disease (IBD), so if you have Chron's, Colitis or IBDU you may like to chat and share experiences with others of your own age who understand what you are going through. Join in, get involved, make new friends and keep in touch by emailing support@cicra.org

Crohn's or Colitis – any questions?

Share your story – it will help!

Any tips or suggestions for others?

Join E Pals and make new friends

Send us a poem

Over 16? – be a member in your own right

E-PALS.

Although IBD is on the increase in children and young people it is not unusual to feel you are the only one with the illness. Through E-Pals, we aim to reduce this sense of isolation. Of course, it is important that all children and young people involved with E-Pals feel comfortable with their 'on-line' friends. We have therefore put together a Code of Conduct when joining that we ask all parents, children and young people to abide by.

Chatting and sharing experiences with someone your own age, who knows how you feel, can really help. The CICRA E-Pals are young people with Crohn's, Colitis or IBDU (collectively known as IBD) who range in age from 8-22 years old. They understand what it's like to have IBD, the importance of not feeling alone and being able to chat about their interests, as well as IBD.

"The E-pals has been great for me, it meant as soon as I was diagnosed, I was able to talk to people who knew what I was going through. I've felt so much better chatting to other children because it makes you feel like you're not alone. Parents try their hardest to understand but it's so much better talking to someone your own age who know exactly what it's like!"

90 children are currently enjoying being part of E-Pals and new people are always welcome, the list is broadly speaking, split into 4 age groups.

If you're interested, just email: support@cicra.org

Youngsters

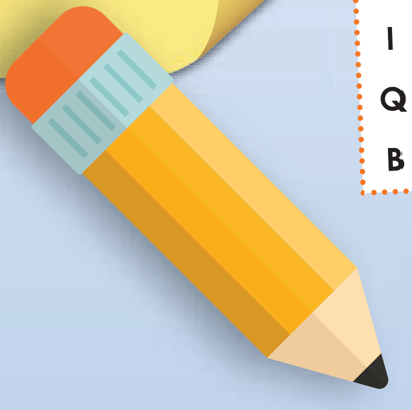
Lacey laments with a little help from Nanny Mandy

Crohn's and me!
I.B.D was such a shock, another name for the illness I got.
I'd been ill two years, what could this be, the pain that drains the life out of me?
Eating was out, so the weight it fell off, I had no colour and used the bathroom A LOT!!
My family concerned lots of tests followed, rightly so as my eyes hollowed.
We were given a name, It's Crohn's disease, this thing inside that's hurting me.
It's been a month now and we've started the race, steroids, infusions were all put in place.
I'm not going to lie I worried a lot, knowledge is good with this illness I've got, so I read the books and searched it online and learned quite a bit on the great Crohn's grapevine.
Now weeks have passed but I live day by day, cos the way that I am, why I'm feeling this way? The pills and needles I accept they are needed its part of the plan for my life going on. Until the day I feel better and I'm feeling strong, my trust in their hands through the journey I'm on.
The doctors and nurses are becoming my friends and I need them all there until each setback ends.
They all keep me safe, and they do it with smiles, as they set up machines and they fiddle with dials, the X-rays and scans are all done with care, if I'm worried at all I know that they're there. They talk me right through it beginning to end with letters and calls until I'm on the mend.
I am the fighter the one with the Crohn's, I am just twelve, but I try not to moan.
This is my journey of Crohn's and me, but they told me I'd never be totally free.
This is my story for you all to read, spreading the name of Crohn's disease, I take the bad with the good and don't give up hope as this is the way that allows me to cope, thanks to the staff of the NHS I live for the day when my pain is less. I want to thank you from my heart and my soul., please read this story, it needs to be told. My name is Lacey, I'm just twelve years old, the bad days are hell, but the good days are gold.

CICRA Word Search

Time for a little fun!!

In the puzzle are hidden different words relating to holidays and travel. You will find them all listed below the grid. Just cross them off the list as you see them.



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R	A	I	V	E	N	U	U	U	T	D	F	X	T	I	I
Y	L	D	R	E	C	E	I	G	A	U	C	S	I	P	N
F	R	R	I	T	R	W	S	N	O	Q	I	U	N	A	B
Q	U	T	N	L	I	S	E	A	B	A	T	B	A	S	K
C	U	E	N	O	O	C	E	L	L	R	Y	P	T	S	Q
R	Y	J	D	U	I	H	K	A	G	R	L	Q	I	E	F
Q	W	T	S	T	O	T	B	E	S	I	W	Y	O	N	U
T	R	A	P	E	D	C	A	E	T	V	U	D	N	G	F
I	S	L	A	N	D	H	T	C	A	E	A	I	P	E	B
Q	G	Q	N	T	T	C	Q	G	A	C	B	A	W	R	X
B	K	Q	B	Q	N	W	Z	H	V	V	H	O	B	S	U

ARRIVE
AIRPORT
PLANE
OVERSEAS
BUS
BEACH
VACATION
TICKET
CRUISE
CITY
BOAT
TRAIN
DESTINATION
CURRENCY
COUNTRY
ISLAND
FLIGHT
DEPART
PASSENGER
LANGUAGE
HOLIDAY

Looking to the future………. CICRA Family Days

One our main goals alongside funding our very important IBD Research, has always been to provide members with as much information support and advice as we possibly can, and for many people that has been at least partly achieved through our very popular Family Days. These events are a very important part of the service we provide to our Members, and it was with very much regret that we had to cancel all our planned events in 2020 due to the Covid outbreak. Likewise, 2021 has also seen us unable to make any firm plans for meetings, and despite us mentioning in the last edition of 'The Insider' that we hoped to resume 'service as normal' in the latter part of 2021, things right now, don't look terribly positive.

There are a number of factors that will influence our decision with regards to when is the right time to get back to 'normal'. The safety of you and your family is paramount, and a recent straw poll amongst our Facebook users indicated that many with immune-suppressed children would be unhappy about gathering in an enclosed space at the current time. Another major factor is that we rely on the support of a number of medical professionals to attend, and they are still working under massive pressures within the NHS. Further issues with availability and the current considerably increased costs of suitable venues also need to be considered.

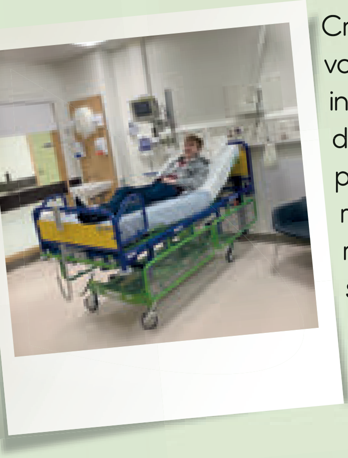
We should say that the 'CICRA Team' are as keen as many of you are, to get back to holding our Family Days, and the situation in constantly being reviewed, but sadly, even when it does look like the time is right and everyone is happy to meet up again for one of these large events, they cannot be organised overnight. Regrettably therefore it seems fairly unlikely that there will be any Family Days in 2021, but who can predict what the future holds! If things do suddenly improve in the Autumn, we may be able to try and put an event together at short notice and in a much simpler format than usual. Fingers crossed that 2022 is 'normal', and we can get back to a full programme, when we would very much hope to be organising Family Days in Liverpool, Cardiff, Glasgow, Belfast and somewhere in Central England. Please keep a look out on our website and social media pages for up-to-date information on plans for these events, or contact Jayne at the CICRA office.

It is always an absolute pleasure to meet so many of you at these special days, and we know how much adults and youngsters who attend get from the experience hence why we are so keen to try and get them back up and running just as soon as we possibly can, but, we cannot stress enough, that this must be in an environment that ensures the safety of everyone, especially our Children & Young People living and coping with IBD. We look forward to having the pleasure of welcoming you to a 'Cicra Family Day' in the not too distant future, and thank you once again for your patience

With Best Wishes

Paul Cooper (Trustee)

Jan’s Story...



Crohn’s Disease first entered our vocabulary for the very first time in 2013, when my son, Toby, was diagnosed, aged 9. He had been poorly for a year before, with mysterious weight loss, fatigue and missing lots of school. He then suddenly developed an extremely painful perianal abscess, which eventually required emergency surgery and led to the shock diagnosis of his Crohn’s Disease

Fast forward 8 years and he’s now 16, currently tackling his GCSE assessments to complete Year 11 at school and hoping to go into the 6th Form in September. He’s had a 50% attendance for each school year in between, but has somehow managed to keep up with the majority of his schoolwork. He has dropped 2 subjects to lighten the load, but is bravely tackling everything else at the moment, with school helpfully providing an invigilator for him to complete the assessments formally at home.

Over the years, he has tried all the various treatments available, but never achieved remission. Chronic fatigue has robbed him of his energy, his social opportunities and any enjoyment of sport. Relentless side-effects of medication have made him feel regularly sick and steroids have also dangerously added Adrenal Insufficiency into his diagnosis. He has endured several long exclusion diets, yet continues to be underweight, pale and malnourished. He has learned to self-inject weekly and 8-weekly medication endless times. He needed to ‘shield’ for a whole year during Covid, missing so much of his school, teenage fun, but actually finding staying at home the most comfortable place to be.

Just last week he has coped with scans and a colonoscopy in hospital, in between his exam schedule, to now face the very tough decision of surgery this summer. This will be to remove part of his bowel and have a temporary ileostomy formed, to allow his bowel some time to possibly heal over the coming year. He is hoping this will make him feel better and give him the chance to enjoy 6th form, before then wanting to head off to University.

Crohn's has been a very unwelcome guest in our home, who just stubbornly refuses to ever pack up and leave. Crohn's has also been a thief, a cheat and a nasty bully. Crohn’s has been the cause of many battles, arguments, appointments and tears. But despite this, we have tried very hard to accept and accommodate Crohn’s into our lives. CICRA have always been very helpful and we have learnt so much through our telephone enquiries, their website and attending Family Information Days.

My son is socially shy, but fiercely determined. He amazes me with his resilience and calmness to deal with what Crohn’s choose to throw at him on a daily basis. He is learning to stand up to this bully, to prove Crohn's wrong and to succeed despite the odds being stacked against him.

I’m proud to be beside my son, as his Mum, on this tough journey. His wonderful sense of humour makes me laugh every day. His adaptability and acceptance is something I learn from and admire. He has strengths and talents that far exceed any weaknesses and I’m very proud of the adult he is suddenly becoming. He is a very talented photographer, scientist, mathematician, computer expert, gadget fixer and F1 fan. He used his camera to take lockdown doorstep photos for our neighbours last year, raising £600 for CICRA on World IBD Day 2020. This was an ingenious idea of his, amongst the lockdown restrictions, which gave him a great photo-editing project to do at home, along with a huge confidence boost.

I do hate Crohn’s and everything about it, but I love my son so much, much more. This love and admiration will never be defeated, even as our long battle with Crohn’s very much continues.

Update from a very proud Mum... Toby had his surgery and made an amazing recovery. He is now in 6th form, feeling much better and coping well with his ileostomy.

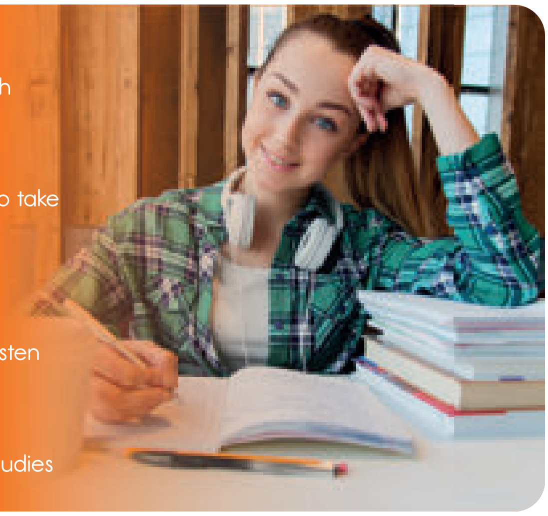
Toby

Schools

To ensure children with Crohn's or Colitis receive the right support in school and reach their academic potential, despite IBD, it is important that the SENCO and all staff know of the problems associated with Crohn's and Colitis. An Individual Health Plan (IHP)should be put in place at the start, even if your child is in remission at the time. A plan that is never needed is much less stressful than trying to get support during a relapse or hospitalisation. CICRA has resources to help, including information for primary and secondary schools, a quick guide for teachers, help with exams, supporting children with medical conditions and a letter than can be personalised for your child. Most are available on our website www.cicra.org or ring the office on 020 8949 6209 for more details.

Tips for those going to college or university

- be open about IBD with academic and support staff, arrange a meeting with your head of year and any other staff and speak with them individually if necessary, explaining how IBD affects you
- ask for software to record lectures if your fatigue means you are too tired to take notes
- ask to sit exams in a separate room and take breaks to use the toilet without affecting the time limit
- have a rest day if you feel drained, realise what you can and can't do and listen to your body
- take all the support on offer. If you have a flare, get help straight away to shorten the time to being well again and able to fully concentrate on your studies



Claire - A Mum's poem for World IBD Day

As I watch you sleeping, holding back my tears I try to breathe away the day's worries and fears.
It shouldn't be this way. It just feels so wrong. I ask myself how you can be so strong.
Facing each new day with that sense of hope, then the pain hits and you wonder how you'll cope.
Tasks "normal" people do on a daily basis, require you to put on one of your brave faces.
Feeling the fatigue but hiding it so well. Still talking and smiling when you must want to yell.
Crying out for others to try and understand what you have to endure, we can't count on one hand.
Diarrhoea and bleeding, feeling tender and sore, joint pain and breathlessness, to name a couple more.
Sometimes nausea and constipation Not to mention
the embarrassment of the situation. In the bathroom
waiting for the pain to subside, then carrying on when
you just want to hide. Anxiety, depression, worries
and stress. Wondering how you got caught in this
mess. Please know, as parents, we constantly pray
that we could swap places and take your pain away.
But until that time comes, what gets us through Is the
overwhelming sense of pride we have for you. Although
at times you may feel alone. We'll never leave your
side, even when you've grown. So please reach out to
others, whether far or near who are going through the
same and understand your fear. May us parents stick
together, as only we can see the challenges we face
raising a child with IBD.

Claire and daughter

Give more for research without cost to you

We are very grateful for all donations either as single or regular payments and for the Gift Aid declarations allowing us to reclaim 25% on every £1 donated. Below is a reminder of the rules governing Gift Aid, If you haven't already done so and would like us to make a claim on your donation, or there has been a change in your circumstances since you made the declaration, please email support@cicra.org or ring the office 020 8949 6209

What is Gift Aid?

Gift Aid gives CICRA an extra 25p for every £1 you donate. Gift Aid is an income tax relief designed to benefit charities such as CICRA. If you're a UK taxpayer, Gift Aid increases the value of your charity donations by 25% because CICRA can reclaim the basic rate of tax on your gift at no extra cost to you.

How does Gift Aid work?

The process is really simple; all you need to do is fill out a Gift Aid Declaration form and CICRA will be able to claim 25% on every donation until you ask us to stop. If you want CICRA to claim Gift Aid on just a single donation you can put that in writing, either when sending the donation or later, remembering to add your name, address and postcode.

Am I eligible for Gift Aid?

For a charity to claim Gift Aid on your donation you must first have paid UK Income or Capital Gains Tax that financial year. The tax you pay must be equivalent to the amount of Gift Aid the charity will reclaim on your donation that tax year, (and will be claimed by other charities and CASCs). I understand that if I pay less Income Tax or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

What if I pay higher rate tax?

If you're a higher rate taxpayer, you can claim additional tax benefits for the donations you make to charity, which you can keep or pass on to CICRA. Simply indicate how much you've donated when completing your tax self assessment form.

Notes:

a. You can cancel a Gift Aid declaration at any time by notifying the CICRA office.

b. It is essential that you notify the CICRA office if you change your name or address while the declaration is still in force.

c. Remember to notify the CICRA office if you no longer pay an amount of income tax and/or capital gains tax at least equal to the tax that is claimed on all your charitable donations in the tax year.

d. If you are unsure whether your donations qualify for Gift Aid tax relief, please contact the CICRA office or ask your local tax office for leaflet IR113 Gift Aid

Registered with
FUNDRAISING
REGULATOR

Can't Wait Card

Don't forget your **'Can't Wait'** card.

This useful card, which bears the name and photograph of the young person with Crohn's or Colitis, can be invaluable when urgent toilet facilities are required. To obtain a **'Can't Wait'** card, please send a head and shoulders photograph together with the name of the person to: courtney@cicra.org. We **are able** to crop a photograph if necessary.

NKS Radar Keys are issued in conjunction with our Can't Wait' card. The key gives access to locked public toilets around the country. The keys are only available for people who require the use of a toilet for a heath condition or disability.

Please note that we only issue 'Can't Wait' cards and NKS Radar Keys to CICRA members who have given full details on a membership form. If you have any questions, please phone us on 0208 949 6209.

fundraising

Andrew Convery - Scotland's Virtual Kiltwalk 2021 23rd, 24th & 25th April 2021

Raised £702!

Andrew and team 'Hawd Oan the Noo' (Michelle, Jacqueline, Jennifer & Sophie) raised an impressive £702 by taking part in the Virtual Kiltwalk at the end of April. The team raised £428 in sponsorship and the Hunter Foundation generously topped this up to the £702 we received.

Imogen Tickner - 100,000 steps in 2-weeks

Raised £318!

Imogen is 13 years old and has UC, she decided to organise a fundraising activity as part of her year-8 curriculum. After lots of discussion with mum and dad she decided to walk an impressive 100,000 steps in 2-weeks. She completed the challenge and raised £318.75 for CICRA.

Trudy Smith - Trudy's Fundraiser for IBD Day

Raised £231!

Trudy's eldest son Khan is 16 and was diagnosed with Crohn's in December 2020 mid-pandemic and mid-GCSE's. She wanted to raise money for CICRA to help with the support we offer families and to fund much needed research, she set up a JustGiving page which she shared with family, friends and colleagues and asked if they could donate.

Jo Hooper & Ella Wilkes

Raised £312!

Jo and Ella are both members of the Halterworth Harriers, along with fellow runners they decided to cover 123 miles over the May Bank Holiday weekend and raised an impressive £312.50

Andrea Shuff - Walked 186 miles in 91 days

Raised £271!

This year marks 20-years since Andrea was diagnosed with IBD. She decided to take on a 186-mile virtual trek through Canada in 91 days. Over the last 20-years Andrea has had periods of flares and remission and in 2017 had to have surgery. She says 'CICRA provided amazing support for me and my family through the diagnosis period and for many years after which we are grateful for'.

Terry Fletcher, Cotswold Way

Raised £435!

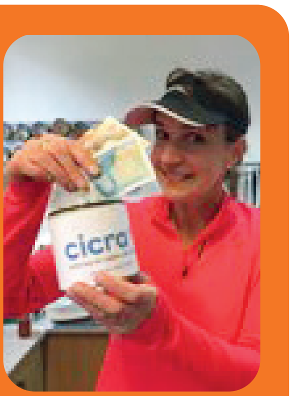
Terry is 73 years young and was inspired to take on a personal challenge by Joanne Chilcott who has supported the charity over many years. Terry took on the Cotswold Way which is a 100km challenge over 2 days. He started at 9am on Saturday and finished on Sunday just after 5pm. Terry raised an impressive £435

POUR Moi?

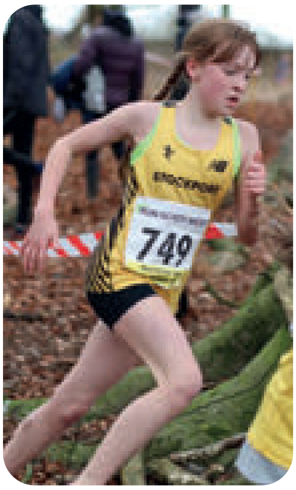
We were grateful to receive £162 from Pour Moi at the beginning of the year from their #getyourwiggleon campaign

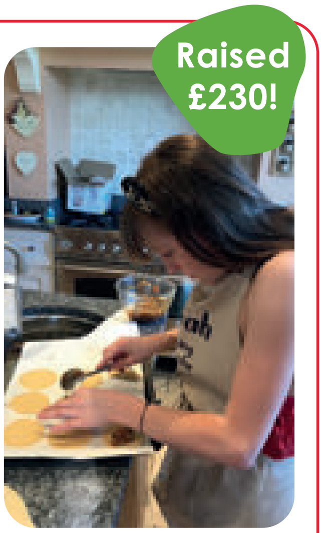
Raised £787!

Katie Parsons - 50km in February



Katie had Covid-19 at the beginning of January 2020 and says she didn't exercise at all for the rest of the month. After so much time locked down, she wanted to get active again and so set herself the challenge to run 50km in a month. CICRA is a charity close to her heart as her eldest son was diagnosed with Crohn's disease aged 12, in 2016. She says, 'having the information that CICRA provided helped us to get our heads around what seemed at the time like a scary unknown future. We were aware that 2020 was a difficult year financially for charities, so I linked my running challenge to raising some money for CICRA. I know that to dedicated runners 50km isn't very far but it was just the right challenge for me... I was slow at first but having publicised the challenge I'd set myself I felt I had to keep going - even during the snowy weeks! Personally, it felt great to be out exercising again, and I was absolutely blown away by people's generosity. My son shared his story on my facebook page as part of my advertising and that really helped people to understand what an impact this illness can have even though everything looks fine on the outside.'





Raised £230!

Lucy Jones - School sport event & village bake off challenge

Lucy is a young CICRA member who has Crohn's Disease. She recently raised an amazing £230 for the Charity at a school sports event and by organising a Bake-Off Challenge in her village.

Susan Ravenhill - London Vitality 10k Sunday 11th July 2021

Raised £578!

Susan decided to run the Vitality 10k for CICRA because she wanted to give something back. Despite a last-minute change of venue and feeling a little apprehensive Susan completed the course in a fantastic 1-hour and 15mins. Susan said 'CICRA were a great support when Emily was diagnosed with Indeterminate Colitis and we had lots of questions about the condition and treatments. We are amazed at our daughter's strength and courage with everything she has been through and were grateful to be able to give something back.'

The Bryans family - Captain Toms 100 fundraiser.

Raised £336!

Kate, Hannah & Rebecca raised an amazing £336 by baking 100 cupcakes and cookies to sell to friends and neighbours from a stall at the end of their cul-de-sac. The family are also selling unwanted books, cd's & DVD's through facebook and Zifit.

fundraising

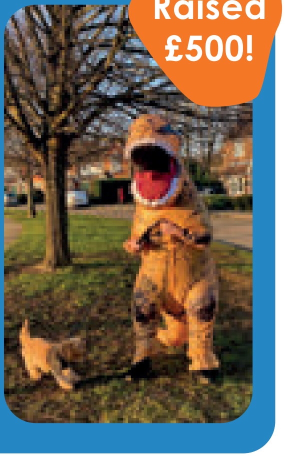

Kelly Taylor - Captain Tom's 100 Reading 100 books

Raised £330!

From Friday 30th April to Monday 3rd May, Kelly along with sons Theo and Dexter read 100 books to raise money for CICRA. Theo was diagnosed with Ulcerative Colitis in March and Kelly said 'CICRA are such an amazing charity giving great support to parents'. The boys really enjoyed the challenge but mum said reading 100 books was harder than expected and at the end the total stack of books weighed the same amount as Theo down to the last pound!

Lucy Machen

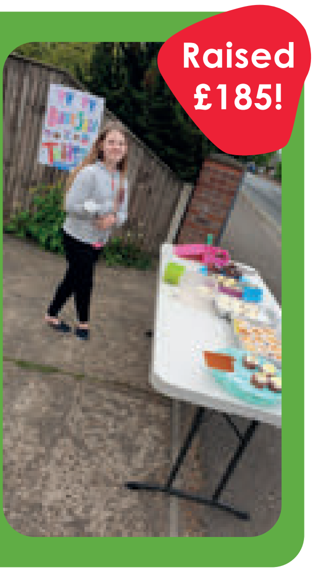
Raised £500!



Lucy's husband had a challenge at work for best dog walking photo for a team building competition. He decided to dress as a Dinosaur and take the family dog Winnie for a walk. We are delighted to report he won £500 that his employer Numis Securities donated to CICRA.

Ellie Liles - Bake sale

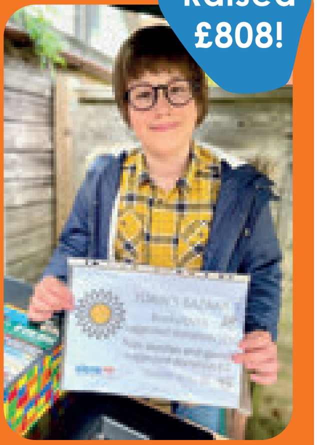
Raised £185!



Ellie is 11 years old and was diagnosed with UC in December 2020. She decided to help CICRA by organising a bake sale and raising £185. She is planning another fundraising event later in the year, she intends to walk, run or cycle 100 miles in a month – good luck Ellie!

The Law Family - Open garden event May 2021

Raised £808!



The Law family along with friends and neighbours opened their gardens to raise funds for CICRA and their local food bank. We received an amazing £808! A great day was had by all with teas, coffees, plants, jams and marmalade all sold on the day to raise money. Torin who has Crohn's sold old toys and games to add to the total raised on the day. We are very grateful to everyone who opened their gardens, £808 is a wonderful amount of money and will enable us to help children with IBD by investing in research to find better treatments and an eventual cure - Thank you.

Jim Tanner on behalf of DAZN

Raised £267!

Organised a score predictions game for the Euros and raised money for two charities one of which was CICRA, we received £267.50

cycling

Nick Powell - Smethwick Challenge 29th – 31st May

Raised £6,689!

Nick took part in the Smethwick Cycle Challenge to raise much needed funds for CICRA. The Smethwick Challenge is in its 27th year and takes place on the 29th, 30th & 31st May, it involves cycling 156 miles in very challenging conditions along the Grand Union Canal from London to Birmingham. Nick's daughter Aimee was diagnosed with Ulcerative Colitis 2-years ago when she was 11. Nick was joined on the challenge by a fantastic group of friends who are all raised money for CICRA. Our thanks go to Andy, Ant, Paul, Trevor, John, Winky, Jerry, Rich, Brian, Lee, Steve, Nick, Rich, Jim and Chris. A massive thank you for raising £6,689

5 easy ways to raise funds for CICRA

without cost to you or CICRA

1

Raised to date £4,300

easyfundraising
feel good shopping

Easyfundraising is the UK's largest charity shopping fundraising site Thanks to our members, CICRA has benefitted by over £4,300 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.

Thank you to all those of you who have remembered CICRA when shopping online – this is a great help

2

facebook

It's easy to create a fundraiser, share it with friends and reach your goal. Why not donate your birthday to children with IBD?
You can easily create a fundraiser for CICRA, share it with your friends and encourage them to help you raise money on Facebook. People can donate to your fundraiser in just a few clickswithout leaving Facebook

Facebook.com/fund/CICRAcharity/

3

Over £3,000 Raised to date

amazonsmile
You shop. Amazon gives.

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

4

ziffit.com

Turn unwanted stuff into charity donations with ZIFFIT
Did you have a 'lockdown turnout'? Don't know what to do with the unwanted goods?
Perhaps Ziffit can help. This is a free web and app service, that instantly values books, games, DVDs and CDs and the trade value can be donated directly to CICRA via Virgin Moneygiving. A quick and easy way for you to raise funds.

www.ziffit.com

5

Recycle 4 Charity

are always looking for ways to bring in extra funds so we joined the Recycle4charity scheme a free, easy to use ink recycling programme and also a simple way to help the environment whilst raising money for your charity.

So please remember CICRA if you have inkjet cartridges for recycling. They no longer use envelopes to send your cartridges direct. But it's still simple and easy. Simply go online to: http://www.recycle4charity.co.uk/Register/C43541.

- Follow the onscreen instructions and print your free postage label.
  Attach the label to any envelope containing your ink cartridges. And just pop them in the post – postage is already paid.

- CICRA receives up to £2 for each eligible empty inkjet cartridge recycled. If you have a business and wish to recycle any laser cartridges, please take a look at the Recycle4Charity website http://www.recycle4charity.co.uk for details of how to recycle them and for CICRA to receive a donation in return.

Many thanks for your support.

CICRA 200+ club

winner list 2021

Thank you very much for supporting our 200+ Club. Your support is very much appreciated. For 50p a week you could be in with a chance of winning a cash prize, while helping to fund research into Inflammatory Bowel Disease. Admin is carried out on a voluntary basis so all funds are split 50/50 between prizes and research - a real 'win-win' situation. If you are not a member yet but would like to help us raise funds by this method, please ring the office on 020 8949 6209 or email support@cicra.org and we will send you the forms.

January		
106	Paul Cooper	£50
207	Noreen World	£50
February		
210	James Beever	£50
24	Hazel Russell	£50
March		
177	Alison Ashe	£250
85	Myles Cooper	£75
27	Hazel Alton	£75
April		
163	Mary Cotterell	£50
47	Jean Gooding	£50
May		
149	Ann Kelly	£50
169	Tim Lack	£50
June		
193	Melinda Hayden	£250
189	Sue Mullen	£75
130	Roy Adcock	£75

CICRA Summer Draw

Once again, we thank those of you who bought or sold tickets for the Summer Draw and for the extra donations included with the payments. It was decided that for this, and future draws, we would discontinue the consolation prizes and increase the value of the 2nd prize. The Summer Draw took place on Tuesday 15th June 2021 in the CICRA office at Pat Shaw House and Xavier Pamment from the Sutton Housing Society drew the lucky tickets.

The three winners are listed below.

Prize	Tkt No.	Name
1st prize £500	59272	Ailsa Gibbs, Bournemouth
2nd prize £250	26284	Adene Stirton, Oxford
3rd prize £100	19359	Joyce Allen, Suffolk

cicra
better lives for children with crohns and colitis

The **insider** is published by
Crohn's in Childhood Research Association
Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey SM2 6AQ
Tel: **020 8949 6209** Email: **support@cicra.org** **www.cira.org**

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