

# the insider

spring 2019

one family,  
two children  
with IBD

the Rolt family  
tell their stories



cicra   
better lives for children with crohns and colitis

inside >

All the ways we can help you, from school to transition

Steroids - friend or foe?

NEW: ask the doc: is IBD inherited and can cannabis oil help?



## message from the Chair

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**ERRATUM:** In the last issue, an article on schools stated "If your child is out of school for three consecutive weeks, begin to discuss home tuition." Government guidance stipulates that the fifteen days can be cumulative not just consecutive.

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Dear Friends

I am pleased to report that 2018 was a very good year financially for CICRA. Support from fundraising organised by members, their families and friends was around the same level as previous years for which we are very grateful. Family and Company Trusts showed a record amount of grants thanks to Jayne Boyd-Bell who painstakingly completes the formal applications for these. Although there is a sadness to receiving legacies, this year was exceptional in that four estates were settled in which we were a named beneficiary. Thank you to all the families who, through their loss, have helped to give our income this boost.

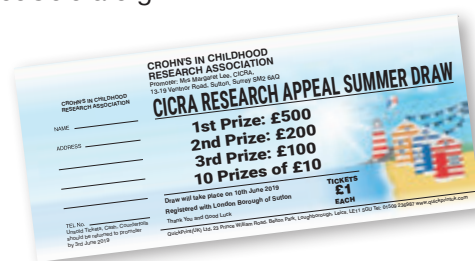
Thank you to all of those who sent feedback as to what you would like to see in future newsletters. We were grateful for such a large response and by far and away the most popular was an 'Ask the Doctor' page so we are introducing in this issue three questions from Family Day meetings. Stories from the youngsters are always popular but from the feedback received, stories from parents would also be of interest so we are including an article from Finn's Mum Sarah Brown, who spoke so movingly at the Oxford Family Day. We will include other topics in future newsletters. To continue our 'Ask the Doctor' page we need your questions so please either send an email to [support@cicra.org](mailto:support@cicra.org) with 'newsletter question' as the subject heading or if you are returning draw tickets please just jot your question on a note and enclose it with the tickets in the stamped addressed envelope.

While on the subject of draw tickets we really appreciate the support we receive for the Summer Draw. Once again any funds raised will be restricted to funding research so do please help if you can to try and ensure a brighter, healthier future for all children with IBD. We do understand, however, that some people choose, or are unable to help in this way. If you do not wish to receive tickets could you please either email [support@cicra.org](mailto:support@cicra.org) or ring the office and let us know your name and address so that we can take you off the database list.

The Trustees are currently recruiting new Trustees and hope to have some news for you soon but if you are interested and would like to receive a leaflet on becoming a Trustee please email me on [margretlee@cicra.org](mailto:margretlee@cicra.org)

Very best wishes  
for 2019

Margaret Lee





# special sessions

## highlight of family days



Nick Posford,  
Chief Executive, CICRA



At the final two, of our five, family days in 2019, we had sessions looking at areas of concern for families. At the Maidstone meeting IBD nurse specialist Mary Brennan from Cambridge, took the lead on a group discussion covering transition, education and support. Concerns were expressed by families that some schools fail their pupils who have IBD by not providing support, for instance, when frequently needing the toilet during exams. This means the overall transition to adulthood can be problematic and a smooth, phased move to adult services within the NHS becomes even more important. In this context, inspirational Team GB athlete Arthur Leech and Sophie Austin from Global's Make Some Noise told their stories about diagnosis and how they dealt with IBD as young people. Their achievements as young adults, despite the seriousness of their condition, showed how the challenges of IBD can be overcome. Arthur and Sophie joined discussion groups with teenagers later in the day.

Our Oxford family day saw Professor Holm Uhlig host a session for parents of children with Very Early Onset IBD (defined as IBD diagnosed before the age of 6). The session questions and answers will help to guide the content being developed for our forthcoming booklet on VEOIBD.

Professor Uhlig also spoke to a packed room of around 160 members about the cause of IBD possibly involving the combination of genetic and environmental factors affecting the immune system, and how research is helping to find ways to treat this. Professor Uhlig then joined our panel of experts answering the all important questions from members. We also heard from

Hamish Sharp who is hoping to go on to study medicine later this year and is currently working in the CICRA office covering for Laura Doyle, who is on maternity leave. Zak Caton, who has performed on the West End stage, had no problem in taking to the CICRA stage to tell the audience about how he has dealt with his IBD. This was followed by Sarah Brown's moving story of the journey her family and her son have gone through as a result of having a diagnosis of VEOIBD. You can read Sarah and Zak's story later in this newsletter.

We also had two very interesting discussion groups for teenagers at both events, including a split by gender at Oxford to encourage open conversation about some of the more intimate aspects of IBD from forming relationships to telling the difference between period pains and IBD pain. These have encouraged us to develop more workshops to build confidence in young people with Crohn's and colitis. Many members left the meeting feeling less isolated having met other parents and children in a similar situation.

### **new support worker - coming soon!**

Since its formation CICRA has offered support and understanding to parents and children by way of those who have either nursed children with IBD or parents of children with IBD. Thanks to funding from Global's Make Some Noise we are recruiting a Family Support Worker to boost this vital service. Our website and social media will announce when they start.



# Finn's story

Sarah Brown spoke at our Oxford family day in 2018 about her family's experience of having a child, Finn, with Very Early Onset IBD.



the Brown family

I live in Northamptonshire with my husband, Drew, and our two children, Elsie, 8, and Finn, 6. Finn was diagnosed with IBD two years ago, when he had just turned 4. It was a long road to diagnosis, but Finn's symptoms started as a baby. We saw some lovely Paediatricians, but his symptoms were not attributed to IBD for a long time and became conflated with a cow's milk protein intolerance he had as a baby. Prior to Finn's diagnosis, we had very little awareness or understanding of Inflammatory Bowel Disease (IBD). Drew and I are both Primary school teachers but, even so, we had not come across IBD in children before. There is no IBD in either of our families, so this was a strange, unexpected

and scary place to find ourselves in. Every person's IBD seems so unique, but I am sure many other parents will be able to relate to some of our experiences.

## **Oh my! Finn did not sleep.**

Finn was born in 2012. His older sister, Elsie, had been born two years earlier. First time around, we had been blessed with a baby who started to sleep through the night from around 6 weeks; we all enjoyed 12 hour snooze-filled nights, as well as regular, long, daytime naps.... We only truly realised how remarkable Elsie's sleeping ability was when Finn arrived. Oh my! Finn did not sleep. He cried. He initially had trouble feeding thanks to a tongue-tie but, even when this was resolved, he

found it very hard to settle and seemed in a lot of distress, a lot of the time. He would forcefully regurgitate feeds and was very difficult to console. Because he was so sick and empty after feeds, he was hungry and wanted to feed again almost straight away. His poo was very frequent and runny... We were in a continuous feed-sick-feed-poo cycle, with very little rest on anyone's part. It was, in short, exhausting.

Many, many trips to GPs followed and we were sent away with, 'It's just a bit of colic', which then became, 'Just a bit of reflux'. I floated the idea of allergies/intolerance as at the time my baby niece had been found to be dairy intolerant, but this idea was



dismissed... It was only when a health visitor came to our house and saw first-hand the typical violent and alarming projectile vomit in action that she raised concerns with our doctor about the difficulties we were facing. Finn was never underweight, so he always appeared to others to be thriving. After 6 months of exclusive breastfeeding, we began introducing some solids. A bowl of cereal with a dash of cow's milk produced raised red bumps all over Finn's face within hours. I visited another GP and she agreed that it would be wise for me and Finn to exclude all dairy from our diets for 2 weeks and observe the results.

### road to diagnosis

The results proved to be dramatic – the eczema that had covered Finn's head disappeared within days and the vomiting stopped. He even started to settle and sleep (a bit!). Hallelujah! At last. Finn was referred to a Paediatrician at our local hospital (which was then Northampton). He advised excluding dairy with a slow, managed reintroduction later.

Finn was discharged from the Paediatrician at 12 months, as the vomiting had mostly resolved and he was growing and gaining weight. However, his bowel movements – slimy and frequent – continued to be concerning. The first time I noticed blood in Finn's stool was at 18 months. His frequent, leaky nappies were mucousy and were now streaked with blood. Alarmed, I took him to another GP, who said it was, 'Just one of those things'. It turned out that it wasn't a one-off. We had more nappies that were jelly-like and, again, streaked with blood. This continued and, confusingly, seemed to have little correlation to foods eaten. Over the course of several more GP visits, I pressed to go back to the Paediatrician, who had told us to ask to go back if we had any concerns.

We were referred again, in the end, and continued to see the Paediatrician at Northampton for over a year but eventually, rather puzzled, he asked his colleagues at Leicester Royal for a second opinion – to perhaps rule out intestinal polyps or similar. Finn was under the Paediatric Gastro team at Leicester for another year before his symptoms worsened. In September 2016, I had a phone call at work from his Preschool to tell me that Finn had been to the toilet 8 times within an hour. He was experiencing frequent diarrhoea and passing blood. At our next appointment, it was decided that investigation was needed and Finn underwent a colonoscopy and endoscopy in November 2016, just after turning 4 years old.

Well – the consultant said – we didn't find any polyps.... But I did see that his entire colon is ulcerated and bled when I touched it with the scope. Have you heard of Ulcerative Colitis?

### words you never forget

I didn't know much at all about Ulcerative Colitis other than it's for life; forever. The doctors hadn't suspected IBD and we were totally unprepared for this. I didn't feel any relief at knowing what was wrong – I was stunned that there was indeed something so wrong.

At this point I have to stop and apologise – I do realise I am retelling the whole of Finn's life story so far! However, it is impossible to pinpoint exactly when his symptoms started. He always seemed to have a lot going on. I suspect he developed IBD in his first year. I was sent away from many GPs and made to feel like a neurotic mother, making a fuss. After his diagnosis, I wondered whether I should have shouted louder and made more of a fuss!

A week after his scopes, a Crohn's & Colitis UK information pack

arrived in the post, sent courtesy of the hospital but, other than that, we really felt lost and alone. We had been sent home with a diagnosis and a large bottle of Sulfasalazine, but that was it. Sadly, our hospital had no IBD nurse at that time. Another week or so on, Finn's consultant rang; biopsy results confirmed a diagnosis of Inflammatory Bowel Disease but not UC, rather Unclassified (IBDU).

### hangry steroid weeks

Just a couple of months after diagnosis, Finn had a bad flare. Over the Christmas and New Year period the symptoms recurred with a vengeance. Finn had a 6 week course of steroids and was put onto Azathioprine as these tapered off. The hangry steroid weeks were not fun and I do remember standing in my dressing gown, crushing the Prednisolone tablets every morning to mix with a little squash (these medications are not designed to be taken by children), feeling utterly bewildered by what our life had become. The amount of medicines I was administering to our little boy seemed astonishing. The steroids did the trick though, and Finn's energy returned and his symptoms settled. Starting on Azathioprine at the same time as several outbreaks of Chickenpox at Preschool meant that, in the early weeks of 2017, we seemed to be at the hospital for blood tests every week. We have long had a deal with Finn that, after a blood test, he can choose a magazine as a treat. This deal was made before his diagnosis – if only we had known the hundreds of pounds on Cbeebies magazines this would end up costing us!

His Preschool staff were amazing and really supported us as a family through those difficult months following diagnosis as we adjusted to all the changes for Finn and for us as a family.





# Finn's story continued

## new beginnings

Finn starting school was a big step and one I was very apprehensive about. His Primary school is small, at just over 100 pupils, he has a big sister there and I even teach there part-time! Even so, I certainly felt extremely protective and anxious about the changes ahead. Armed with three sides of A4 paper I had written and a bundle of leaflets, we asked for a meeting with Finn's Headteacher, Reception teacher and teaching assistant in the summer term before he started school. I feel this was really important to properly explain his condition, medicines, diet and special considerations (such as the importance of sunscreen for example, and of course - access to a toilet).

Two years on from diagnosis, our new normal is one of blood tests, hospital visits, medicines and dietary vigilance. Nothing is spontaneous! That big bottle of Sulfasalazine comes everywhere with us and, although I know we should try not to let his condition prevent us from doing all the things we otherwise would, there is always a small voice in my head worried about the effects of the Azathioprine and his risk of infection, which can limit where we go and what we do. IBD has happened to our whole family – there are so many ways we have been affected. Elsie is still so young too and has found it hard to understand all the time and attention Finn gets. His latest scopes were on the day of his

first school sports day, which of course was disappointing for Finn, but also meant that Mum and Dad weren't there to watch Elsie in her races. Whereas I had once anticipated a fuller return to work, my work is now very part-time and fits around making sure Finn's days are not longer than the school day, as he gets so tired, and so that I can take him to his many hospital appointments. I think it is fair to say that, as parents, Drew and I both feel somewhat detached from other parents and families at times and the worry can be overwhelming and all-consuming.

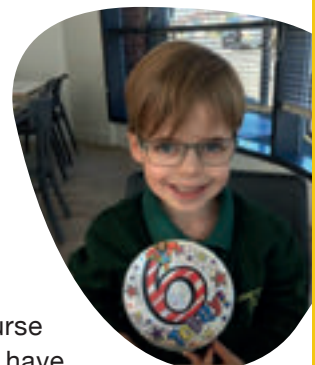
Finn's latest scopes still show some ulceration to the colon and his diagnosis remains that of IBDU. In addition, Finn was found to have an allergic disorder of the oesophagus – eosinophilic oesophagitis – which means another daily medicine, more dietary tweaks and further tests to come...

## looking ahead?

There have been scary times – like Finn being admitted to hospital to be checked for sepsis when he had an infection a year ago – and there have been calmer times, when we have felt optimistic and more accepting of Finn's IBD. There is a sadness to hearing a four-year-old child able to roll off the words 'Sulfasalazine' and 'Azathioprine' with such ease. There is never a good time to be diagnosed with IBD. I know there are many changes and challenges to come. Starting Primary school was a major milestone and I'm sure moving on to Secondary school will be even bigger.

On the one hand, this is all Finn has ever known. On the other hand, as he grows and matures, he is starting, quite naturally, to feel the injustice and pain of being different and having this difficult

condition to deal with. He is, like all our amazing children, resilient beyond our expectations but, as parents, of course we wish he didn't have to be. We just want our boy to be the wonderful Finn he is and do all the things he loves to do – like being a Viking, brushing up on his spy techniques and fulfilling his ambition of being a rock star! CICRA's vision of a childhood unlimited by IBD is one we all long for as parents. Finn has IBD but it does not have him. He is so much more. CICRA have been there for us at our most bereft – by giving us information, support and access to the brilliant information days. We are so thankful to the field of specialists giving their time and dedication to improving the health and wellbeing of our children. We went to two information days last year and it was such a revelation and comfort to know that we are not alone. Thank you, CICRA, and I hope our story helps others to feel less alone.



# Zac's story

Zac is 13 and spoke in front of an audience of over 150 at our Oxford family day in 2018. This is his story.



**Hello, my name is Zak Caton and I am 13. I was diagnosed with Crohn's disease aged 7.**

My first symptoms started February 2012, when Norovirus went around my family and school. It was so bad my School was closed so it could be cleaned and bleached. After a while, everyone got better, except me. I still had diarrhoea and some vomiting weeks after my family got better, so my mum took me to the doctor, who suspected lactose intolerance so I went on a lactose free diet, but, after a while, I still wasn't better. The doctor then referred me to the John Radcliffe hospital in Oxford, where I had an endoscopy. The doctors found inflammation in my bowels and in the February of 2013 I was diagnosed with Crohn's disease.

My first form of treatment was a liquid diet for 6-8 weeks, which brought down inflammation a small amount. I then had 2 more

endoscopies and had 2 more liquid diets, both of which changed little. I also tried Azathioprine, which made me sick and I developed an iron deficiency. At this time I started going to a Psychiatrist to help me with anger issues that had developed. They taught me methods to handle my anger, one of which was 'lemons' which meant clenching your fists together as if you were squeezing a lemon.

Later on, I also went on Steroids, which made me bloated but did help. I was picked on at school for my bloated size, with names such as 'piggy' which didn't do much for my self esteem. I finished my steroids after a while and was taken off Azathioprine.

After a long discussion with doctors about which course of treatment to use, I was finally put on infliximab infusions. On the first infusion day I also had an iron infusion, which was painful as my Canulas kept on

getting blocked. The day after my infusion, the improvement was visibly working, so I kept on infliximab infusions and have had them ever since every 8 weeks.

Since 2014 (when I started my infusions) I have had roughly 30 infusions, and my Crohn's is now in deep remission. I can now do what I want to do, and am not held back by tiredness. Last Christmas I was on the West End stage in Her Majesty's Theatre, in a one off western show known as Troubles 'a brewin, in which I played a comedic outlaw's sidekick. I also have been on two week long scout camps, on which I did rock face climbing, canoeing and other things. I have also started my Duke of Edinburgh bronze award, in which I have started air rifling every Saturday and badminton on Fridays.

I wouldn't have got here without the help of my family, my friends, all of my doctors, all the ward nurses and the other hospital staff. Thank you.



# one family, two children with IBD

The Rolt family had no history of IBD so when both Nicola's children Luke and then Katherine were diagnosed, it was a surprise, but they have learned to adapt.



**Hi I'm Luke, I'm 16. I am studying for my A Levels. I was diagnosed with Ulcerative colitis (UC) in February 2016.**

I had been suffering symptoms for the previous 6 months. Initially I was being given antibiotics as a quick fix. I have never

been one to complain, honestly, I just assumed it would go away soon. When I started to go off my food I began to realise something was wrong. I really love food and for me not to eat, shows that something is really wrong! The symptoms finally got dealt with when I lost 9 kg over the course of the flare up. I was put on steroids, and azathioprine. This settled the symptoms down, but I suffered the side effects, such as a moon face and hot flushes. When I went back to school, to be honest, I didn't want to tell anyone I was on steroids, although I was happy to tell them I had UC.

A year later, I started to have kidney problems which could have been caused by medication or an infection. I suffered quite badly and the worst moment, was when an A&E doctor told me it was all in my head! Like I'd want to spend 5 hours sitting in A&E! It was then diagnosed by a junior doctor, as pneumonia and that really knocked me for six.

In June last year during my GCSEs, I started to suffer my first flare up since I was diagnosed. I was put on steroids which weren't working but I persisted over the summer. In a strange way, I was fortunate because the steroids were going straight through me, I didn't have to worry about my face being a beach ball. We went to Jersey for a few days and that was when things got really bad. When I got back, I was really ill, going to the toilet 28 times in a day, feeling tired, drained and in pain. I was admitted to hospital. Unfortunately, after 12 days in hospital, I was discharged even though I was still going to the loo at least ten times a day. At the end

of September I had an endoscopy, and to everyone's surprise I was re diagnosed with Crohn's. I was then put on a liquid diet for two weeks which made no difference. Fortunately, I was started on Infliximab, which was like a flip switch. I have now been on that for 3 months and touch wood, it has worked a treat. I played football for the first time in late December, when I was ill I never thought I'd play again. I have signed up with some mates, for the FA Peoples cup, this is going to be a really big deal for me to play competitive football again!

My school had been incredibly supportive, but when I had my flare up during the GCSEs, my grades were not good enough for me to return. I am now at a sixth form college, which has worked so well for me. I missed the first half term of the courses as I was so unwell but I am catching up with the support of my teachers. I hope to go to university. My aim is to become a sports journalist.

**Being 16, the hospital want me to move to adult care. This does make me anxious. How am I supposed to remember what they say in an appointment?!**

Through it all, the support of my family and friends has been so important. I am a massive Millwall fan. I have a season ticket and am a ball boy. I was really lucky, when I was ill, as the guy who organises it, got a get well soon card signed by all the players and a pair of signed shorts which definitely helped me keep going.

Being 16, the hospital want me to move to adult care. This does make me anxious, because I have never been into hospital by myself. How am I supposed to remember what they say in an appointment?! As my mum will tell you, my favourite line after a consultation is, 'so what did they say?'. Also, if I'm being dead honest I can't think of anything worse than staying on an adult ward by myself! I know CICRA have been working hard to support this process [of transition to adult care].

There are some tough times, but keeping your mind on all the things you want to do when you feel better, really do help to keep you going.







**My name is Katherine and I am 14.  
I was diagnosed with Crohn's disease  
on the 29th December 2017**

In August 2017 I started experiencing symptoms which were too similar to Luke's for comfort. On December 5th 2017 I had my first pediatric gastroenterology clinic appointment. My consultant was sure I had UC like Luke, but he would need to do a colonoscopy to check. The pain got progressively worse and no pain relief was working. I had an urgent colonoscopy on the 29th December 2017.

My consultant was very surprised to see that I had Crohn's not UC, he told me I had to go on a modulen diet in the new year (which I was dreading) We got a call saying my biopsy results were back and that I needed to start modulen immediately. Just having not very pleasant shakes every day was difficult but I was determined to drink them to make me better. It was taking the shakes to school and sitting with my friends, that was the most difficult. They would have a drink with me as they did not want to eat in front of me. They were so lovely. Modulen did not work and I became more unwell very quickly.

### **Friendship and laughter are great medicines!**

The doctors were good because they gave me an appointment quickly and I was prescribed steroids.

After a few weeks of steroids, they weren't having any effect on my Crohn's, we had been in touch with the IBD team and they were considering taking me into hospital. That weekend, I was in immense pain and went to A&E on the 3rd March 2018, I was admitted to hospital in the early hours of Sunday morning I was given high dose IV steroids. After a week, the consultant conceded they just did not work for me!

After spending 11 days on the children's ward (where I have to say, the nurses and doctors looked after me so well) I was sent home, I was put on a new infusion medication, infliximab.

Thankfully, that has been working well for me and I have regular infusions. I still suffer with joint pain and tiredness, but I am feeling better.

I am lucky to have my family and friends to support me. My school friends always check up on me to make sure I am okay. I have also met some friends while having my infusions at hospital, this is nice because we share our stories and text each other to make sure we are all okay! Friendship and laughter are great medicines!





**Luke and Katherine were always so healthy. 100% attendance, barely a day off school.**

There was no history of IBD in our family so Luke being diagnosed with UC was a surprise.

The diagnosis in many ways was a relief, after the months of him being unwell. Watching him in pain, tired, and losing weight, was so worrying.

Luke was thirteen when his symptoms started, and just before her 13th birthday, Katherine started having similar symptoms. I took her to the GP, Luke's diagnosis took nearly five months, but because of the family history, the GP sent a stool sample for a faecal calprotectin test and this confirmed inflammation. At Christmas 2017 Katherine was diagnosed with Crohn's. The Consultant was surprised, he had felt that as Luke had UC Katherine would have the same.

Just as I was coming to terms with the fact they both had IBD, Luke had his first flare up. We now have family trips to hospital for both Luke and Katherine to have their Infliximab infusions. Crohn's has just become part of our lives.

**We have family trips to hospital for both Luke and Katherine to have their Infliximab infusions. Crohn's has just become part of our lives.**

It has been a tough couple of years but a positive outlook has helped us all. We have kept ourselves informed and have researched to help us to understand more about IBD. Talking helps a lot! The support of family, friends and our community has been so important. The children's schools have been understanding and supported them. CICRA information for schools, has really helped with this, as staff are given really clear information on their needs. Their friends have been amazing, wanting to understand and support them. I am a teacher and without the support of my headteacher, I do not know how I would have managed. She has given me all the time I needed whilst the children were admitted to hospital and for all their appointments.

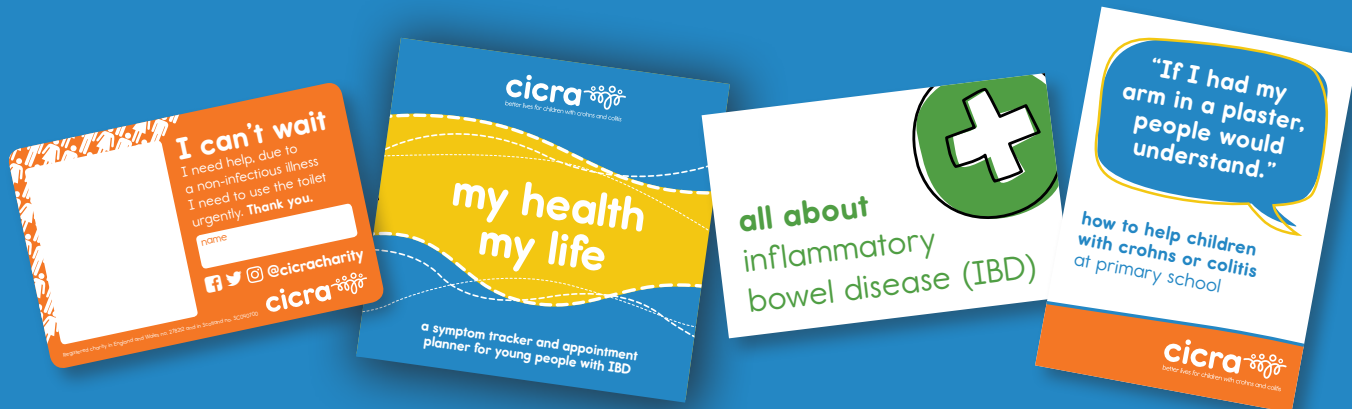
The IBD team has been important. An IBD nurse, who both the children and I can contact has been vital. There have been some amazing doctors and nurses along the way who have made it so much easier.

I am so proud to have two strong, resilient and positive children. They have been so open and honest about their illness. They have been lucky enough to share their stories as CICRA media volunteers. We visited Smooth radio last summer as part of Global's Make Some noise and a Paediatric conference earlier this year to give a patient perspective. Opportunities that Crohn's has opened up for them.

My advice to other parents. Talk about it! Keep positive and know that there are people out there going through the same thing.







# sometimes it's the little things that make a **BIG** difference

## e-pals

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 IBD (collectively known as IBD) who range in age from 7-20 years old. They understand what it's like to have IBD and the importance of not feeling you're on your own.

"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 knows exactly what it's like!"

## can't wait card

Have you ever been out and needed the toilet urgently? Or felt you couldn't go out just in-case you might need the toilet? A 'Can't Wait' card helps explain the condition quickly and easily without embarrassment or confusion. An NKS Radar Key gives access to locked clean toilets around the UK.

"Having the Can't Wait card & Radar key gives me great piece of mind when I go out, just knowing it's there if I need it".

## symptom impact tracker

Keeping a record of how you feel between hospital appointments can be tricky. Our easy to use Symptom Impact Tracker helps you 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 your condition.

"The symptom tracker has been brilliant for both me and my consultant. I've been using it a lot and it saves all the questioning in clinic appointments".

## information for schools

Sometimes even though schools are great they don't really understand the condition. Our simple, easy to understand booklets for teachers clearly explain what it's like to have IBD, schools' responsibilities and how they can help. We also have factsheets for practical help with exams and how schools should support children with chronic medical conditions.

"All the info we have been given we have found invaluable, especially the teachers leaflet. The school had never had a child with IBD before and they found it really useful".

## family days

Our IBD Family Information Days offer an opportunity to share experiences and connect with other people 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 days also provide an opportunity to meet with and hear from a team of experienced professionals, where there will be space to ask questions and learn more about coping with the challenges of IBD in a friendly and supportive environment. Meetings in 2019 are scheduled to take place in Plymouth (23rd March), Newcastle (6th July), Glasgow (date tba) and London (date tba).

"Wow, an informative, interesting and supportive day. Both my mum & I came away feeling more positive about managing this frustrating condition."

If you would like to find out more about the support CICRA offers children with IBD including E-Pals, the Symptom Impact Tracker, information for schools, the 'Can't Wait' card or NKS Radar Key please get in touch with Jayne at the CICRA office.

**Telephone: 020 8949 6209**

**E-mail: [support@bicra.org](mailto:support@bicra.org)**





# steroids – friend or foe?



Dr Rob Heuschkel, Service Lead for Paediatric Gastroenterology and Divisional Director for Women's & Children's Services at Addenbrookes Hospital, Cambridge

Before the arrival of corticosteroids in the 1950s, a diagnosis of Ulcerative colitis was fatal in up to 2 in 3 patients. The use of steroids (along with better surgery) dramatically reduced this mortality - more or less overnight - to about 1 in 100!

Since then steroids have had increasingly bad press – some justified, some not.

Steroids still remain a highly effective treatment to induce a disease remission in acute Crohn's disease and Ulcerative colitis - up to 80% of children respond. The fact that there are now several alternative treatments available makes steroids no less effective. This is increasingly ignored, given the worry about their side-effects and the huge studies on new biologic agents, which often imply that steroids no longer have a role in managing IBD.

The bad press around steroids comes almost exclusively from their longer-term use (more than about 6 months). Steroids do have a long list of side-effects – amongst others these include negative effects on growth, bone strength, blood sugar control, skin and body shape. Many of these are particularly difficult for children – yet the clinical benefit of achieving a rapid disease remission frequently outweighs these mostly short-lived and reversible side-effects.

Steroids do affect the way the body controls sugar. The body's own stress hormone 'cortisol' mobilizes sugar in readiness for oncoming 'stress'. This hormone is blocked by taking corticosteroids. In almost all patients

who stop their steroids, the body goes back to normal sugar control. However, if steroids are continued for a very prolonged period, particularly in older people, the pancreas' ability to produce insulin and control sugar levels may not recover. Then blood sugar may remain too high and a patient would require treatment of this resulting 'diabetes'. Such instances are exceedingly rare in children with IBD, as they are young and generally have only limited steroid exposure.

There is now widespread agreement that the use of steroids should be minimized as far as possible, particularly during phases of rapid growth in puberty. There are several steroid-sparing strategies available

to children with IBD. These begin with trying to use nutritional treatment in Crohn's disease, as well as trying non-steroid anti-inflammatories to maintain remission in mild to moderate IBD. For inflammation that is a more severe / widespread at diagnosis, it is now commonplace to use an immunosuppressant (e.g. azathioprine) very early on in the disease as this has

been shown to reduce the need for multiple / prolonged steroid courses. Later on, care is also taken to reassess where inflammation recurs, as timely and judicious use of surgery also reduces the need for more prolonged courses of steroids.

So.....steroids still play an important part in the management of IBD in children, yet they should not be used as a long-term 'maintenance' treatment and the aim should always be to 'wean' them down and stop their use – if necessary by using a 'steroid-sparing' alternative. Steroids remain a valuable 'friend' if used wisely, yet they can become a 'foe' if used to excess.

**Steroids have  
had increasingly  
bad press – some  
justified, some not.**



# Congratulations - Dr Kirsty Hooper

CICRA funded Kirsty researches a new therapeutic strategy for the treatment of IBD

CICRA-funded PhD student Kirsty Hooper, working on a collaborative project led by Dr Craig Stevens (Edinburgh Napier University) and Dr Paul Henderson (Royal Hospital for Sick Children, Edinburgh), recently completed her research project to evaluate the effect of current IBD drugs on autophagy and to investigate how they work.

Genetic studies have identified a strong association of genes linked to autophagy with Crohn's disease (CD), and further research suggests that autophagy does not function properly in some CD patients. Autophagy is a process that occurs in cells where, among other things, it plays an essential role in the body's innate immune response. This response is our first line of defence and is required for the detection and destruction of potentially harmful microorganisms (bacteria, virus, fungi). This theme of an abnormal immune response to microorganisms is in keeping with a

long-standing interest in the role of bacteria in CD.

Kirsty's results, soon to be published in the journal *Inflammatory Bowel Diseases*, show that the drug azathioprine strongly increases the level of autophagy in cells. In addition azathioprine was also able to help clear certain strains of *Escherichia coli* (that have been linked to CD), and also reduced the inflammation caused by this bacteria. Azathioprine also significantly increased autophagy in white blood cells (our body's main type of immune cell). Importantly, in cells from patients with genetic mutation in one of the major risk factor genes for CD, azathioprine was still able to induce autophagy.

Kirsty's results also show that azathioprine induces autophagy via mechanisms involving stimulation of another process: the unfolded protein response (UPR). This is important for regulating how

proteins are processed within cells. Genetic studies have identified several UPR genes associated with IBD and breakdown of the UPR pathways has been strongly linked to development of disease. Taken altogether, Kirsty's results suggest that stimulation of both autophagy and the UPR may contribute to the therapeutic effect of azathioprine.

Changing the process of autophagy in combination with the UPR represents a promising new therapeutic strategy for the treatment of IBD, and the study team have recently published a review article summarising the known interactions between these pathways, also in the journal *Inflammatory Bowel Diseases*. Furthermore, additional studies are now underway to better understand how drugs like azathioprine regulate these converging pathways, and results may pave the way for development of a new generation of drugs.





# the doctor will see you now

You requested an “ask the doctor” page so to start things off we asked our medical director, Dr Richard Hansen, to answer some questions from the recent Maidstone and Oxford meetings.

## We have no family history of IBD, how did my child get it?

IBD is not a genetic condition in the same way as cystic fibrosis or Huntington’s disease, where a specific gene leads to biological change/defect and this manifests as a disease. In cystic fibrosis the sufferer needs two defective genes (one from each parent) to impact on their production of a membrane channel, with the net effect being a tendency to chronic chest infections and blockages of the gut and pancreas. This is called autosomal recessive inheritance. In Huntington’s, an abnormal protein is formed that causes damage and death of brain cells. One defective gene is all that is needed (from either parent). This is called autosomal dominant inheritance. Even in the situation where one child born to carrier parents has cystic fibrosis, the risk of a further sibling being affected is 1 in 4. Both copies of the gene have to be defective and each gene has a 1 in 2 chance of being normal or defective. In a dominant condition like Huntington’s, where one parent is affected, the risk is 1 in 2 as only one defective gene is needed. (I won’t explore two parents each with a dominant

condition, as the situation isn’t a common one.) So, even from this basic genetic explanation it’s clear that “more” genetic conditions still result in affected and unaffected cases in the same family. When we look at IBD, the risk of developing the disease in an unaffected twin when the other twin is diagnosed is around 1/3. This is in genetically identical individuals, highlighting the importance of the environment in the development of IBD. Whilst there are some rarer forms of IBD that follow a more classical autosomal recessive form of inheritance, and tend to occur very early in life, this is not true for the more conventionally understood forms of IBD. Our current understanding of the cause of most IBD revolves around a triad of genetics, the immune system, and the environment. We have identified multiple genes within the population that can increase the risk of developing IBD, but for every sufferer with a gene, thousands of other people carry the same gene and aren’t affected by the disease at all. Most of these genes point to how the immune system identifies and responds

to infection, particularly within the gut. These discoveries led to a renewed focus on the bacteria that live within each of us (called the microbiome). Changes in the bacterial species present in the gut can be seen in all forms of IBD and at all stages of the disease. Fundamentally, we now believe that IBD is what happens when the immune system can’t respond appropriately to stimulation or challenge from bacteria within the gut. A lot of interest is now exploring how we might alter the bacteria rather than the immune system, but our current approaches to treating IBD tend to revolve around rebalancing the immune system’s response by diminishing its function.

So, many families have a first member with IBD and no previous family history, and other families have multiple affected members. We’re understanding more about this every year, but for now we can think of IBD as a combination of the person’s genetics, their immune system, and their environment, particularly their microbiome.





## What are the risks of developing bowel cancer when receiving biological infusions to treat IBD?

Great question! Most of the families with a member on biologic drugs (infliximab or adalimumab usually) will be aware of the increased risk of cancer attributed to these drugs. This is one of the trickiest things for IBD doctors and nurses to address, trying to explain or describe this risk in a way that makes some sense. I tend to use two different approaches in my own practice- first explaining the “see-saw” of risk and benefit, trying to remove consideration of risks/side-effects on their own and to ensure that these are seen against the hopeful benefits of therapy... healing the bowel, gaining weight, avoiding surgery, returning to school, etc. This is the only way to get some context about risk and to understand the whole picture. The other thing I tend to do is explain how this risk comes about- immunosuppressants reduce the function of the immune system. That’s their job. I like to call this “turning down the volume” of the immune system, which still does its usual job on immunosuppressant drugs but slightly slower and with slightly less capacity than normal... meaning “normal” infections can take a little longer to resolve or might be a bit worse in severity than with a fully functioning immune system. Thankfully, despite using immunosuppression frequently in IBD, severe and life-threatening infections during treatment are very rare. The other job the immune system does is to monitor our own body cells, eliminating those that look abnormal. This is an important step in preventing cancers before they can even develop and is called immune surveillance. It’s probably here that the increased cancer risk attributed to some immunosuppressant therapies comes from. If immunosuppressants work by turning down the volume of the immune system, this will have an impact on its normal job, notably in fighting infection and

in immune surveillance. The net effect will be more infections that are worse in severity and last longer plus a small increase in cancers compared to the general population. Again, understanding all of this has to include considering the effect or benefit of the therapy and the alternatives available. This is the part that needs an understanding of the bigger picture.

So, let’s put some meat on the bones of the risk side of this discussion. I’ll do so with reference to two scientific papers. First, Kopylov and colleagues looked at 41,176 adult IBD patients in a Canadian database to explore drugs prescribed and cancers diagnosed. 19,852 were eligible to analyse against the questions the researchers were interested in. This particular study did identify an increased risk of non-melanoma skin cancers in patients receiving immunomodulator medicines for more than 5 years, but found no increase in melanoma skin cancer or colorectal cancer associated with IBD immunosuppressant therapies. Remember, colorectal cancer is very much an adult diagnosis, so no finding in a large adult study is very reassuring for paediatric practice where the rates of this type of cancer are already vanishingly low. Second, Hyams and colleagues published an international paediatric experience paper, looking at 5766 children being followed for long-term outcomes of IBD. In total 15 patients developed a cancer. 8 were leukaemia or lymphoma and 7 were of other assorted types. None was a colorectal cancer. Numbers like this are hard to comprehend on an individual basis, particularly when there is a baseline risk in the normal population. The authors helpfully included a table to help stratify risk a little better. The expected rate of

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

cancer in the general (US) population of a similar age was 2.2 in 10,000 patients in a year. This rate increased to 2.4 with biologics alone, to 5.2 with thiopurine drugs (azathioprine and mercaptopurine) and to 7.0 with a combination of biologics and thiopurines. So whilst there is indeed an increased risk of cancer associated with drugs used to treat IBD, colorectal cancer isn’t one of them... to the best of our knowledge. This makes sense, as the pathway to colorectal cancer involves inflammation of the gut lining leading to cell changes and ultimately cancer. Controlling inflammation with immunosuppressant drugs is arguably more likely to reduce than increase this risk, but exploring all of this in a medical condition where inflammation in the bowel is a crucial feature is a difficult undertaking. The types of cancers seen on IBD therapy seem to involve the immune system more than other organs, but are still rare. Weighing up this risk for an individual must take into account the benefits of the therapy being used and the alternatives possible. This is a discussion to be had between individual families and their IBD teams. Hopefully this answer has given some reassurance and information for such discussions.

→ Kopylov U, et al. <https://academic.oup.com/ibdjournal/article/21/8/1847/4602940>

→ Hyams JS, et al. [https://www.gastrojournal.org/article/S0016-5085\(17\)30148-8/abstract](https://www.gastrojournal.org/article/S0016-5085(17)30148-8/abstract)



## Is there any evidence that cannabis oil (cannabidiol) is useful with UC?

This is a hot topic and seems to come up often at family days. It's easy to see why- most people understand what cannabis is as a drug, and there's been a huge amount of press recently about the availability of cannabis-derived drugs for the treatment of difficult epilepsy. There's two things to cover before we get to the evidence in IBD. Firstly the catch-all term of 'cannabis oil' encompasses a lot of different products with varying amounts and types of active ingredients, some legal and some not legal (depending on tetrahydrocannabinol content). So not all cannabis oil is equivalent to all others. Secondly, testing specific compounds and their usefulness within a specific medical condition is tricky, time consuming, and usually very expensive. So generalising any data from one product to a whole class of products or their derivatives is hugely difficult.

The standard way to look for evidence of effect in any drug-based therapy in medicine is by comparing it head-to-head in a trial with either a dummy product (placebo) or a competitor. The comparator is known as a control and so this is known as a control trial. To eliminate bias in testing, the best way to do so is to blind

both the patient receiving the therapy and the doctor/researcher assessing the impact. If this doesn't happen, the patient might perceive benefit or side-effects that are not actually caused by the drug (placebo effect). The observer may subconsciously assess benefit as a result of wanting to see a benefit in their patient. So in a good quality study, blinding can be single-blind or double-blind, depending on who knows what's been assessed. One final comment is that to assess something fairly, the chances of receiving the test drug or the control product should be left up to chance and not decided based on disease severity or who came to clinic on Thursday. The way to do this is by randomising the treatment received. So the gold standard test is a double-blind, placebo-controlled randomised study. It often amazes me that people will see a news item or blog piece on a therapy and immediately look at whether it's possible to start the treatment or not. All patients, families and healthcare providers should look first for the highest quality of evidence and for double-blind, placebo-controlled randomised studies. If this isn't present, important questions should be asked about why. This is how infliximab came to

transform IBD care for thousands of sufferers worldwide for instance.

So, let's take this approach to cannabis and UC... in fact, the Cochrane collaboration already did this for us in November, identifying one double-blind, placebo-controlled randomised study and another placebo-controlled randomised study with issues related to blinding because of the psychoactive effects of the product being tested. I should say, Cochrane seeks to provide an even higher level of evidence for medical treatment by bringing together the results of all studies published on a topic, combining their results if possible. Their conclusion?

"The effects of cannabis and cannabidiol on UC are uncertain, thus no firm conclusions regarding the efficacy and safety of cannabis or cannabidiol in adults with active UC can be drawn. There is no evidence for cannabis or cannabinoid use for maintenance of remission in UC. Further studies with a larger number of patients are required to assess the effects of cannabis in UC patients with active and quiescent disease. Different doses of cannabis and routes of administration should be investigated. Lastly, follow-up is needed to assess the long term safety outcomes of frequent cannabis use."

I can't say fairer than that. Is there an argument for testing cannabis products in IBD? Absolutely, but it's important it's done in a robust and scientific manner. Until then, the jury's out.

➔ [https://www.cochrane.org/CD012954/IBD\\_cannabis-and-cannabis-oil-treatment-ulcerative-colitis](https://www.cochrane.org/CD012954/IBD_cannabis-and-cannabis-oil-treatment-ulcerative-colitis)





# working together for research

CICRA Research Fellows were well represented at the BSPGHAN annual meeting.



Dr Sue Protheroe  
President of BSPGHAN



Margaret Lee,  
Chair and founding member, CICRA

A great moment for CICRA representatives, Nick Posford, Paul Cooper and myself to be at the Annual Meeting of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), when Dr Sue Protheroe, one of CICRA's Medical Advisors, took over as President from CICRA's former Medical Director, Professor Nick Croft.

Over the three days we were pleased to see many former CICRA Fellows, all Paediatric Gastroenterology Consultants and all still caring for children in their IBD clinics. We were especially pleased to see Dr Egware Odeka, whose three year Training Fellowship we funded at Manchester Children's Hospital back in 1991.

Five CICRA bursary grants had been awarded to young health professionals to enable them to attend this important meeting, including Marco Gasperatto, who has just completed his three year CICRA

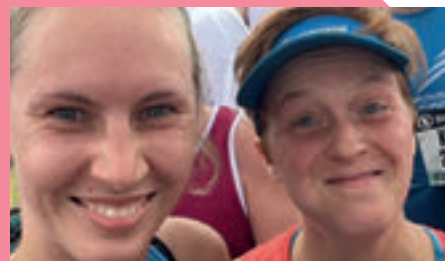
Fellowship at Addenbrookes Hospital, Cambridge. We were especially pleased to be able to support Neil Chanchlani, a clinician currently studying IBD pharmacogenetics at Exeter. Neil has won many awards for his work and as rarely happens, two of his papers were accepted for presentation at the meeting. We are very pleased to say that Neil will be joining us at our next Family Information Day in Plymouth.

This really is an important meeting for CICRA, and showcases the impact that the funding on research and specialist training for young doctors has made on Paediatric Gastroenterology. Many children with IBD today benefit directly from the CICRA Training scheme by being under the care of these specialists. We are extremely grateful for the dedication that CICRA Fellows bring to their profession.





# running for research



## Great North Run 2018

We had three runners in the Great North Run in September 2018. Thank you to Paul Glistler, Nora Hine and Becky Haft for taking part in this world-renowned event and raising valuable funds for CICRA.

If you would like to run for CICRA this year, we have 5 spaces available! Please email [fundraising@cicra.org](mailto:fundraising@cicra.org)

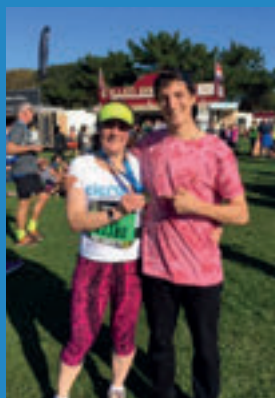


## Cardiff Half Marathon

We were lucky enough to have four runners in the Cardiff Half Marathon. The combined total from these dedicated runners was an incredible £1270! Our thanks go out to Caroline Prosser, Abbie Delaney, Katherine Webster and Joanne Chilcott-Lawson

## running all over the place

Jamie Lee Hood and his team (Chris Kidd, Craig Mullen, Stephen Burns, Andrew Dunn, Stephen Samson) took part in the Festival of Running held by West Lothian Run and raised £450 for CICRA. Huge thank you to them all for their efforts!



Last year Joanne Hooper took part in the Great South Run raising a total of £529. She ran for CICRA as her "eldest son's girlfriend and her brother both have Crohn's"

Thank you to Pauline Woods for running the Bournemouth Half Marathon for her son and raising £195!



## getting muddy

Thank you to Ella Wilks and company who completed a 5K Tough Mudder raising £222!

Josh Chambers was diagnosed with Ulcerative Colitis when he was 11. Last year he decided to do a Wild Warriors 5K Mud Run and raised £475. Thank you Josh!





## garden party

"We opened the garden during the afternoon of 4th August 2018 for friends to visit our new garden makeover. Tea/coffee/cold drinks were served along with cakes and biscuits. I had the CICRA collection container on the table and people came and went throughout the day and were very generous and added to it. I also received a few donations at a later date from those that weren't able to come. The final total collected was £220. My daughter suffers from Crohn's disease and has daily medication. She was first diagnosed when she was just 12 years old and shortly after we started fundraising for CICRA. My daughter is now 28 and between us we raise funds for two IBD charities: CICRA and Crohn's & Colitis UK." A big thank you to Val and Craig Hutchinson for their Garden Open Day.

**Raised  
£220!!**

## picking up a racquet

Our CEO Nick was honoured to pick up a cheque from Woking Lawn Tennis & Croquet Club for an incredible £3325.64. The club members supported long term CICRA members Bill and Anne Wood-Roe in fundraising for children with Crohn's and colitis with several events during 2018. We are very grateful to all who donated and the many volunteers who helped sell Christmas cards, organise a fancy dress day and who baked an incredible CICRA-themed Xmas cake!



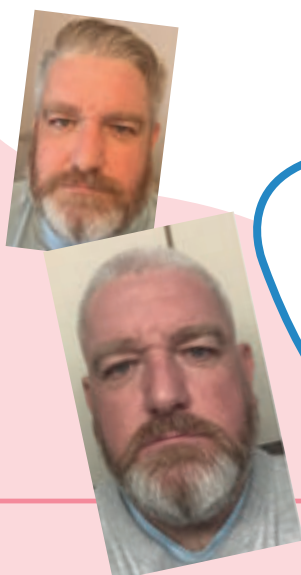
## dip in the sea

Longe Côte UK got together on New Year's Day and braved the cold waters for a 'splish splash' in the sea. Thank you to all those who took part and helped to raise £168.



## braving the shave

On the 15th of August, Jason Sanderson shaved his head raising £520 on his Facebook Fundraising page. Here are the before and after pictures!



Jason used Facebook Fundraising to raise money. Find out more about this on the back page of this issue

## pounds for pampering

Thank you to Emily Fairbrother, who raised £100 by holding a pamper session. She is qualified in manicures and pedicures, and a friend did the participants' hair.







## festive fundraising

Over IBD Awareness Week and the Christmas period we had 22 fundraising events and we raised an amazing £3503.89!

On Saturday 1st December Leanne Early, her daughter Emmy and her niece Nell held a Christmas Fayre to raise funds for CICRA. They had stalls, a raffle, a DJ, face painting and more, raising a phenomenal £1015.79.

Ruth Victoria was diagnosed with Crohn's when she was 14 years old. Last year she decided to run the Singapore Half Marathon for CICRA (despite the 29-degree heat)! Thank you to Ruth for raising £580!

During this period, we also had 6 CICRA Cake Sales raising £551.37 and we would like to thank Shirley Glover, Patrina Law, Mick McCormick, Katy Broome, Liz Gardiner, Jackie Chater and Joanne Bingham for all their help.

Louise Grieg raised £60 by raffling a Christmas hamper at her salon, Louise Grieg Hair Design. A big thank you to Louise!

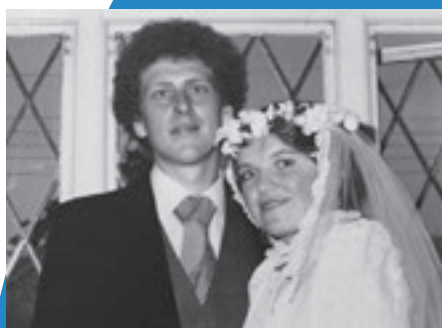


**raised  
£1,015!!**



## Finchfield hockey

Finchfield Hockey Club agreed that Gail Crampton and family could fundraise at an event being held at the club. Almost £300 was raised – thank you so much!



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

## 40 years on

As you will know, 2018 was CICRA's 40th year. Valued members Monica and Ian Newbery celebrated their 40th wedding anniversary the same year. They chose to fundraise for CICRA to coincide with their celebrations, raising £425. Thank you and well done to you both!







raised  
£580!!

## fundraising in tribute to friend

Inga Judge and husband Sunny went trekking at the end of December in tribute to their friend Zul. Inga is also running the Vitality Half Marathon.

“Our latest endeavour to continue Zul’s legacy as someone who had a passion ‘to give’ (he was studying to become a Human Rights lawyer and previously worked for the British Red Cross)... Accompanied by my husband Sunny Judge, I will be flying out to Zul’s birthplace, Tanzania on 28th December 2018.

This excursion involves us climbing the active volcano Ol Doinyo Lengai, known to the Maasai as the ‘Mountain of God’. We will then do further trekking in this region within the southern end of the Great Rift Valley of Eastern Africa. We will finish the trip by walking through the foothills of Mount Kilimanjaro, staying in Moshi (Zul’s birthplace) and on to the Tsavo West National Park in Kenya.”



raised  
£60!!



## amazing schools, brilliant pupils

We were delighted to benefit from several super school fundraising events, with thanks to Debs Greig and Lydgate Junior School, Catherine Lutman and The Barlow R.C. High School, Hilary Tennant, Vicky Howe and Shelton Infant School (top) and Imogen Tickner and Chipstead Valley Primary School.

Imogen (and mum Sam) came to the CICRA office (right) to present a cheque to CEO Nick for funds raised by Imogen’s school in their Christmas concerts. Imogen bravely spoke about IBD in front of the whole school and helped raise an amazing £736.77.



# Ring of Fire

## 135 miles in 37 hours

A dedicated doctor treating children with Inflammatory Bowel Disease went well beyond all expectations when he took on a hugely demanding fundraising event – the 'Ring of Fire' to raise funds for CICRA and Crohn's and Colitis UK. Dr Ieuan Davies of Cardiff said "Unlike other disabling and unpleasant conditions Crohn's disease and Ulcerative colitis are seldom discussed and the public, the press, our commissioners and the government remain largely ignorant about these horrible diseases"



"This was my Everest, I shall not try this again".

On 31 August 73 runners left Holyhead at lunchtime but only 37 finished. By circling Ynys Mon via the coastal path those who finished ran 135 miles over three stages. The multi-surface path has sharp rock, soft sand, shingle, road, dirt, marsh and fields and there is over 4000m of ascent / descent (4 times Snowdon). Averaging 4 mph the pack Dr Davies carried weighed between 3 and 5 kg. Sleeping for less than 3 hours in 2 nights and finishing in a just over 37 hours from the allowed 40 hours Dr Davies said "This event is tough, emotional but amazing, the scenery is beautiful and I have seldom felt as happy or fulfilled. This was my Everest, I shall not try this again".

## bake, eat and make a difference!

raise funds for children with IBD

Celebrate your birthday or the start of a new season with a cake-filled event to raise vital funds to support children with Crohn's and colitis. Hold one at your workplace, school or home and invite colleagues, friends and family.

Everyone bring a cake, collect a donation for every slice, pop on the kettle and indulge!

We can provide you with posters, a fundraising guide and a t-shirt for the organiser.

For more information and to register your interest email [fundraising@cicra.org](mailto:fundraising@cicra.org) or visit [cicra.org/cake](http://cicra.org/cake)



Why not mark World IBD Day on 19th May with a special CICRA bake sale?





# in 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 very grateful for donations in memory of:

## **Dot Peever**

Dearly loved by all that knew her.  
Helping this charity would have warmed her heart to help her grandchildren.

## **Georgina Mary Smith**

Loving Grandma of Crohn's sufferer.  
Remembered with love by all the family.  
The sun will come out tomorrow.

## **Ena Mary Simmons**

Great Nan of a Crohn's/Ulcerative Colitis sufferer.  
Remembered with love by all the family.

## **Mr Walter Kelly**

Grandpa of a Crohn's sufferer, fondly remembered and forever in our hearts of his family.



## corporate and trust donations

Trusts & Foundations generate funding from private income that they then donate to charitable organisations such as CICRA in the form of a grant - this is a very valuable source of funding for us. Many trusts and foundations will only consider a grant application if the charity has been recommended or put forward by someone with a connection. Can you help?

Also, could you recommend CICRA for Charity of the Year with your employer, or why not hold a bake sale at work or put on a dress down day to raise funds?

Your employer may also do payroll giving which is a flexible and tax efficient way to support us.



## winner list 2018

In reporting another good year for the 200+ Club, with half of the proceeds going back as prizes and half towards our research, we still have room for more members. If you would like to have a chance of winning a cash prize in the monthly draw, all for 50p a week, please email [support@cicra.org](mailto:support@cicra.org). Thank you for your support.

### January

15	Mrs B Morrison, Alvaston	£50
9	Mrs E Horgan, Wilmington	£50

### February

237	Mrs L Taylor, Barnstaple	£50
163	Mrs M Cotterell, Bassaleg	£50

### March

236	Mrs Chapman, Uttoxeter	£250
54	Ms O L Goldsmith, London	£75
158	Mrs C Saunders, Oxford	£75

### April

77	Mrs J Kirby, Hertfordshire	£50
88	Mrs J Allen, Suffolk	£50

### May

203	Mrs J Berry, Cheltenham	£50
103	Mrs W Dando, Caerphilly	£50

### June

59	Mrs H Siderfin, Notts	£250
109	Mrs L Browning, Dumfries	£75
154	Mrs L Ayre, London	£75

### July

6	Mrs B Govey, Enfield	£50
35	Mrs A Wagstaff, Wickford	£50

### August

64	Mrs S Sparling, Milton Keynes	£50
13	Mrs G O'Neill, Gloucester	£50

### September

147	Mrs C. McCormick, Bucks	£250
245	Mrs P Aspden, Hindley	£75
224	Mrs S McNaught, Edinburgh	£75

### October

19	Mrs S Warren, Bristol	£50
107	Ms J Fletcher, Llandeilo	£50

### November

107	Ms J Fletcher, Llandeilo	£50
7	Mrs S Clyne, Prestwich	£50

### December

104	Mrs P O'Neil, Wigan	£250
147	Mrs C McCormick, Bucks	£75
75	Mrs Cave	£75





# 3 easy ways to raise funds for CICRA

From buying your holiday to fundraising on Facebook, it's easy to help children with IBD when you're online.

1

Easyfundraising is the UK's largest charity shopping fundraising site. Thanks to our members, CICRA has benefitted by just under £3,000 with no cost to our members, or to CICRA. When you do your shopping please remember that easyfundraising is partnered with many of the largest retailers and businesses who give a small percentage of their cost to chosen charities through this simple scheme.

To sign up and raise more for CICRA go to:

[easyfundraising.org.uk/cicra/](https://easyfundraising.org.uk/cicra/)



Help us hit  
a big total,  
we are at £2915.  
Your next shop  
could make the  
difference!



2

It's easy to create a fundraiser, share it with friends and reach your goal. Why not donate your birthday to children with IBD? Or set one up to mark World IBD Day? 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 clicks without leaving Facebook

[facebook.com/fund/CICRAcharity/](https://facebook.com/fund/CICRAcharity/)



3

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