

# the insider

autumn 2018



advice for  
school and  
college

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our fabulous  
fundraisers  
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**cicra**   
better lives for children with crohns and colitis

> **Make Some Noise for CICRA**  
on 5th October page 4





## message from the Chair

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#### Dear Friends,

Welcome to the second issue of our 'new look' newsletter. We hope you find lots to interest you but would welcome your feedback. Too much research or not enough, too much fundraising or not enough? Would a questions and answers page for parents and one for children be of interest? We will include a feedback form with this newsletter and look forward to ideas on what YOU would like to see in future newsletters. Of course, if you lose the form, but think of something later on, please let us know anytime and we will do our best to feature it.

On the 7th July we were pleased to welcome many parents and children to the meeting in Leicester, which you can read about on the opposite page. At this meeting, although she couldn't be there, we officially welcomed Sally McNaught, mother of a son with IBD, to our Trustee board. Sally was co-opted to the board last November but had to wait until the AGM to make that official. We still have a vacancy for a Trustee so if you could get to an evening meeting in London (from 6pm), approximately every six weeks, and would be interested in knowing more please email [margaretlee@cicra.org](mailto:margaretlee@cicra.org) or telephone 020 8949 6209.

In the middle of a heatwave we have been putting the finishing touches to our Christmas Card Brochure. Yes, it's that time of year again when we clear the shelves to make way for around 50,000 cards, ever hopeful that we have chosen something to

suit everybody. Like most things, even Christmas Cards change with the fashion but we try to keep up to date with them. On a fundraising note this is something that most people can help us with - even if it is only by buying a couple of packs. Taken that some shops selling charity cards give back just 10%, it make sense to buy from us as 50% on the sale of every pack will go directly to the charity account to help maintain and expand our research and support programmes. Essentially this is a fundraising event carried out by Trustees, with help from the occasional volunteer, therefore, other than the suppliers cost of the cards, nothing else is taken out from the amount paid by you.

I take this opportunity, early I know, to send Season's Greetings and very best wishes for a healthy 2019.

Best wishes

Margaret Lee, Chair of the Trustees

**50% of the price of every pack goes directly to CICRA to help maintain and expand our work.**



# 40th anniversary family day

On a lovely summer day, marred only by clashing with the England/Sweden football quarter-final (which we managed to get round) we had our 40th anniversary meeting in a perfect setting at the University of Leicester, thanks to Trustee Paul Cooper who sourced this venue.

As a registered charity, part of our legal requirement is to have an Annual General Meeting once a year. As this takes up a very short time (no more than ½ hour) we combine this with the summer meeting. Trustee Graham Lee started the day by giving a short presentation of the Trustees Report and Accounts. A copy of this can be seen on our website. If you would like a paper copy please contact the office.

Our Medical Director, Dr Richard Hansen then introduced our first two speakers, Jonathan Fallman aged 26, diagnosed with Crohn's at 13, and Mansi age 13, diagnosed with Crohn's at 10. Jonathan gave his first talk to a CICRA audience at the age

**"The talks were informative, but it really helped talking to other families who have been through similar experiences and sharing information on treatment, side effects, behaviour etc."**

of 16 and it was very heartening to hear how well he had coped since. Having been able to talk about his condition to his school friends he emphasised how much their support had helped, especially at exam time. University had given him many and varied choices but also fears. One of these being 'relationships' which are often a dread for young people but rarely spoken about. It was encouraging to hear from Jonathan

how, to his surprise, his condition hadn't made any difference and he is now very happily settled.

A very confident Mansi spoke about the psychological issues she has faced from being bullied at school, which had affected her mental health, and how cognitive behavioural therapy had helped. Mansi's advice: "If you feel down or anxious, talk to someone".

Chaired by Prof. Ian Sanderson, a panel of experts in childhood IBD, Dr Kate Blakeley, Dr Fiona Cameron, Dr Nick Croft, Dr Ieuan Davies and Dr Rob Heuschkel answered questions put by the audience, including mental health, cannabis oil and autism. This became a very interesting session during which time the children of 11+ were enjoying themselves and building self confidence in a creative workshop with Rachel Cole-Wilkin, otherwise known as the 'loo lady'. The very young ones joined volunteers Amy and Luke for a craft

and lego session. To close the morning CEO, Nick Posford, gave a short talk and showed a video of 40 years of CICRA.

Lunchtime in these lovely surroundings gave an opportunity for parents and children to mix and share stories with each other, members of the medical profession, CICRA trustees and staff. Thanks go to our volunteers, Sarah and Eliza, and Trustee Rod Mitchell for



**"We got such a lot out of the meeting and now feel part of something rather than feeling isolated."**

manning the merchandise stalls.

An afternoon panel session took as the theme 'The Way Ahead'. This was chaired by Dr Nick Croft with Dr Protima Amon, Dr Tracy Coelho, Dr Richard Hanson and Professor Ian Sanderson giving the audience their thoughts on what the next ten years of IBD research would look like. Patient specific treatments, triggers, improved MRI, ultra sound, diet, less invasive diagnostic techniques and complimentary therapies were all discussed.

In this 40th Anniversary year, Life President Professor John Walker-Smith, shared his experiences of many years of caring for children with IBD and the early days of CICRA. Small discussion groups, covering various aspects of IBD, and headed up by the medical professionals, ended a very full day. We thank them all and everybody who helped make this day so informative and memorable.

**Margaret Lee**





# giving children with IBD their childhood back



Nick Posford,  
Chief Executive, CICRA

Our project will give practical and emotional support to children living with IBD and their families

In July, a film crew from Global's Make Some Noise came to our 40th anniversary family day in Leicester. They recorded some footage of the day, and filmed one of our young speakers, Mansi, talking about the impact of inflammatory bowel disease (IBD) on her mental

health, and how she overcame difficult times through therapy and meeting other young people. They also talked to Liz Graham, who as mum to Joanne, has been at her daughter's side through the rollercoaster ups and downs of IBD. These two stories feature in a film about CICRA for Global's Make Some Noise, an annual fundraising appeal supporting small and brilliant charities across the UK which help youngsters and their families living with illness, disability or lack of opportunity.

The big day for this appeal is 5th October where major national radio stations including Radio X, Classic FM and Heart join together to fundraise and CICRA is one of the benefitting charities for 2018.

Our project – which they hope to fund for up to two years – focusses on providing direct support to children with IBD and their families to help them deal with the impact of Crohn's and colitis. A diagnosis of IBD can be a knock-out punch

for children and families because it impacts their lives in so many ways: the physical aspects intersect with social taboos and confidence; growth and development can be delayed at a crucial time; long periods of hospital stays and overwhelming fatigue can mean large chunks of school are missed. Some parents give up work to care for their child and take them to medical appointments. Our project will give practical and emotional support to children living with IBD

## Make Some Noise Day is 5th October

to get involved go to  
[www.makesomenoise.com](http://www.makesomenoise.com)

and their families, so they can cope with a long-term condition.

To those who come to CICRA for information and support, the psychological issues are often more important than the physical. Lack of understanding about IBD can create anxiety and emotional distress.



## Sophie's epic journey

Hi, my name is Sophie, I'm 27 and I'm a Social Media Editor at Global. Like many of you reading this, I harbour invisible illnesses - Crohns Disease, OFG (Orofacial granulomatosis) and IBS. It's been a 19-year journey which has so far taught me a lot about life, my strength of character and of course, the complicated world of IBD! You can read my full story on the CICRA website later this month.

In March 2019 along with a group of fellow fundraisers, I will be trekking the Great Wall of China in aid of Global's Make Some Noise. It's an incredible charity, run by Global, which uses Global's scale to raise money for small charities and projects across the UK. These charities are a lifeline to children and young people who are disadvantaged through circumstances such as a lack of opportunity, illness or bereavement.

I've never done anything like this before, nor have I travelled as far so it will certainly be a challenge. It'll be even more of a challenge due to having Crohns Disease, OFG and IBS. The conditions of the trek (think food, loos etc.) will greatly impact me on this challenge, and the physical toll will be tough on my energy levels which are near empty on a normal day! My diagnosis has made me even more determined to undertake this challenge and has prompted my decision to volunteer with CICRA.

For more info on Global's Make Some Noise:  
[www.MakeSomeNoise.com](http://www.MakeSomeNoise.com)

You can support Sophie's trek and Make Some Noise at  
[www.bit.ly/sophieglobal](http://www.bit.ly/sophieglobal)



Alongside our research into better treatments and an eventual cure, we are helping children live with IBD today. Our Make Some Noise project will counteract IBD's psychological impact that can exacerbate physical symptoms. To reduce the ripple effect, the support will provide children, parents and siblings with ways to deal with the emotional and practical difficulties that come from IBD and help them develop resilience and confidence to deal with negative social attitudes in education and their community.

Our Make Some Noise project includes a new role of family support worker, providing direct support for children and parents from an experienced professional, who can signpost services, listen to issues, facilitate discussions at our family days and be a 'rock' for the hard times. Drawing on the incredible voluntary support of clinical psychologists from paediatric gastroenterology teams at centres of excellence in the UK, we will also provide a range of expert authored information for our new website and available as downloads or in printed format.

With a dramatic increase in the number of children with IBD, support is increasingly difficult for NHS services that are already stretched. We want to help children and families cope while we work to change attitudes and improve the understanding of schools, young people and others. The core role of a Family Support Worker draws together elements of specialist nurse support, advice, information, counselling and youth work. This mix will give children and their families a solid source of emotional and practical support, and give them the best chance of enjoying childhood despite IBD.



# Crohn's, Ulcerative colitis, IBDU - what's in a name?



Dr Richard Hansen, CICRA Medical Director  
(Consultant Paediatric Gastroenterologist and  
Honorary Clinical Associate Professor, Glasgow  
Children's Hospital)

I wanted to write this piece specifically for those affected by 'inflammatory bowel disease type unclassified', commonly shortened to 'IBDU', but there's also a message in here for all other types of IBD too, so please stick with me. First of all, don't look at the figure... it'll spoil the story! OK, so I'm now presuming you've looked anyway? Well, try to forget it. We'll get to that, but first I need to tell a couple of stories... Our understanding of IBD probably started with the first description of a type of IBD in 1884 – The English physician Sir Samuel Wilks defined Ulcerative colitis (UC) in a paper titled 'On the morbid appearance of the intestine of Miss Banks', giving us our first understanding of what IBD might be and a description of what it might look like. I'm not sure how Miss Banks might have felt about this

level of publicity, and I'm delighted to say we don't take quite such a personal approach with medical discoveries these days!

Crohn's disease was actually first described by a Scottish surgeon, Sir Thomas Kennedy

Dalziel, who named it 'chronic interstitial enteritis' in 1913. My theory is that the First World War got in the way of it being recognised properly and it wasn't until a group of American physicians – Burrill Crohn, Leon Ginzburg and Gordon Oppenheimer – wrote a further paper in 1932, describing (again) the appearances of the condition, that it was given its name, and only through fluke of chance that its name was attributed to the first author by alphabetical order – Crohn, and so became Crohn's disease.

**First of all, don't look at the figure... it'll spoil the story!**

So, by now we have three descriptions of two conditions in the medical literature, but a slower moving uptake of new science than we're used to now, and a bit of uncertainty about how each was defined.

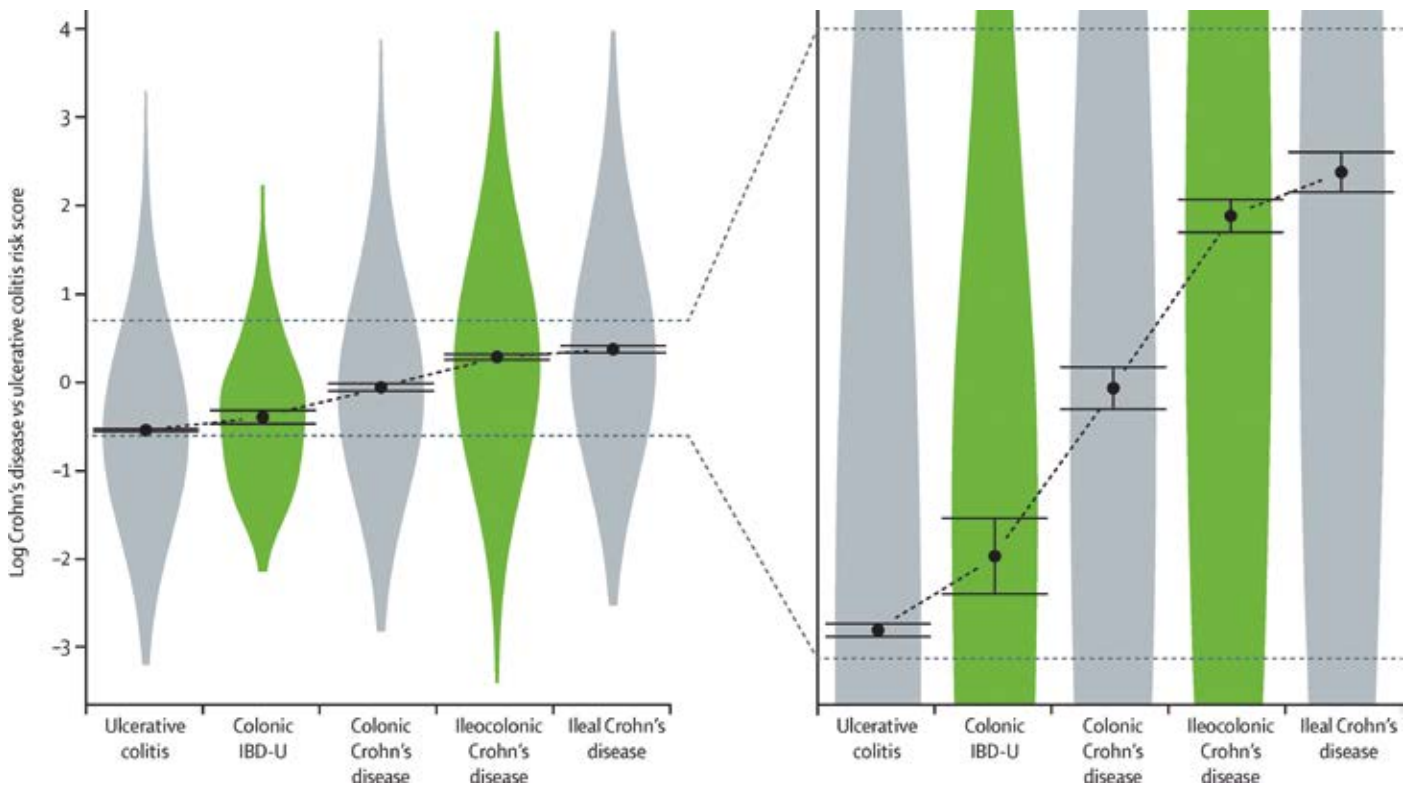
Time passed and the markers by which we began to know and define UC and Crohn's

became clearer. Indeed, another Englishman, John Lennard-Jones wrote the definitive description of how we define Crohn's disease in 1989, in a paper that still holds up today. We now think of Ulcerative colitis as a condition mainly of the colon, with inflammation from the bottom upwards in continuity, and with fairly superficial (inner lining only) inflammation. Crohn's is a little more complex, with inflammation anywhere in the gut (from mouth to bottom), often with normal and abnormal areas interspersed (so-called 'skip lesions') and sometimes involving the full lining of the gut (full thickness inflammation). IBDU arrived to fill in the gaps between these two conditions, describing disease more like UC,





**Figure** - Violin plot showing the genetic substructure of inflammatory bowel disease location



Cleynen, I, Boucher G, Jostins L, et al., Inherited determinants of Crohn's disease and ulcerative colitis phenotypes: a genetic association study, *The Lancet*, Volume 387, Issue 10014, 9–15 January 2016, pages 156-167. [https://doi.org/10.1016/S0140-6736\(15\)00465-1](https://doi.org/10.1016/S0140-6736(15)00465-1)

but with features not typically seen in that condition, for example skip lesions, however not close enough to Crohn's disease to warrant that particular label.

So, what's IBDU then? Well, importantly, there's no doubt about it being inflammatory bowel disease. The unclassified doesn't relate to that at all. We used to believe that this was sort of an IBD in progress, that with time would declare itself more like either Crohn's or UC. If we look at children diagnosed with IBD in the UK, around two thirds have Crohn's disease, around one quarter UC, and around one tenth IBDU. We tend to treat IBDU similarly to UC and, on the whole, this certainly seems to work. And now we get to the figure... Isabelle Cleynen (Belgium), Gabrielle Boucher (Canada) and Luke Jostins (Oxford, England) led an international paper in *The Lancet* in 2016 looking at the genetics of IBD in nearly 30,000 people with

**So, what's IBDU then? Well, importantly, there's no doubt about it being inflammatory bowel disease.**

different types of the disease. They were able to begin separating out the spectrum of IBD, and suggested we'd be better thinking about ileal Crohn's (affecting the last part of the small bowel), colonic Crohn's, and Ulcerative colitis. Interestingly, when mapped out with IBDU and ileocolonic Crohn's (affecting the last part of the small bowel and colon), we begin to see a spectrum of IBD disease with each of these labels just waypoints from one end to the other. So, the names really are just historic and IBDU probably defines one group of people affected by a type of disease on the IBD spectrum, just as Crohn's and UC do. If we had our time over again, we may have just labelled them IBD types 1 to 5! Irrespective, the point in a name is that it tells doctors what to look for, how to treat the condition and what to expect (prognosis). This is true for all variants of IBD, it's just that one of them currently has a slightly strange name.



# it's a bug's life!

Great news for young IBD patients - Dr Protima Amon, having almost completed her 3 year CICRA funded Fellowship, will continue her fascinating work uninterrupted as a consultant, awarded during her Fellowship.

Dr Protima Amon,  
Consultant Paediatric Gastroenterologist  
Current CICRA Research Fellow at Barts & the Royal London Hospital



As a gut doctor, my main interest is inflammatory bowel disease (IBD). I have spent a lot of my working life pondering this condition and inquiring about causes, treatments and possible cures. As I approached the end of my training in 2014, a particular hot topic that was emerging was the role of gut bugs, termed microbiota in health and disease. I recall feeling very gripped by the research articles I read at the time. There was growing scientific evidence suggesting that changes in the microbiota were implicated in diseases such as diabetes, asthma, heart disease as well as IBD [Fig 1].

IBD remains one of the most extensively studied human conditions associated with the gut microbiota. It was around this time when I made one of the most life changing and rewarding decisions in my career to date. I became so interested in exploring the role of gut bacteria in childhood Crohn's disease that I decided to step into a scientific laboratory. I am grateful to CICRA for funding my research project and for giving me this opportunity to write about the research I do.

Although the cause of Crohn's disease remains elusive, the generally accepted hypothesis is that multiple factors are involved. Crohn's disease is thought to be the result of interaction of genetic, immunological and environmental factors, notably the gut microbiota [Fig.2].

With the recent advancement in next generation sequencing technologies, scientists including myself are now able to investigate the composition and dynamics of the microbial communities which mainly reside in the gut. Studies of their intestinal gut microbiota in Crohn's disease patients imply that an unbalanced microbial community composition is associated with a disturbed immune response.

**"I am excited and hopeful that my study will lead to important results which are novel."**

The results from my study are in keeping with published research, which identifies a reduced bacterial diversity in people with Crohn's disease. This reinforces the notion that gut microbiota is implicated in the cause of Crohn's disease. However, the relationship between changes in microbiota composition and disease causation remains uncertain. The challenge is to identify whether microbial imbalance is related to disease, sometimes termed "dysbiosis", and to be able to distinguish between cause and effect.

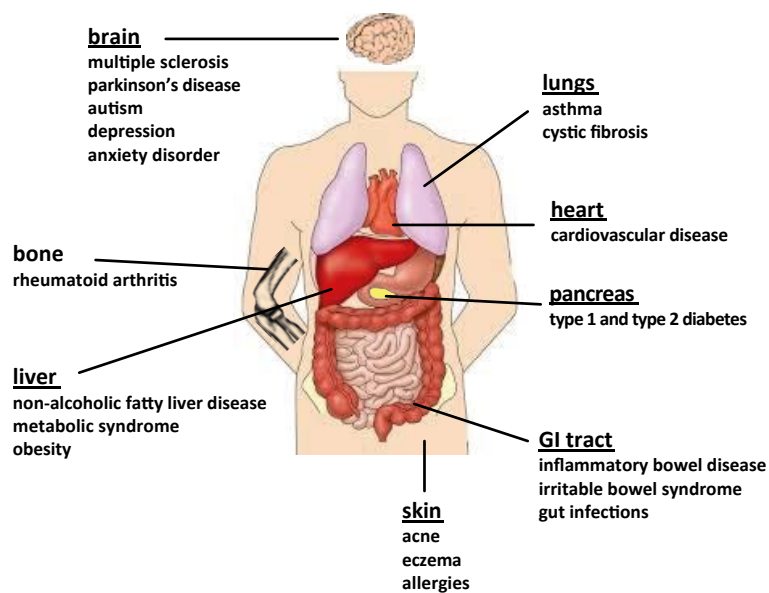
Over the course of my study, I understood this area of research is complex not just in terms of methodology but also when reporting correlation versus causation and describing diversity. In a healthy state, it is reported that humans have a very rich diversity of organisms. However, each person will have a different microbiota profile, which suggests there is no single 'healthy' microbiota composition and each person will have an individual relationship with their own microbiota. It is also known that differences between microbiota compositions exist depending on age, cultural background and geography. So far, the patterns of gut microbiota dysbiosis in Crohn's disease are inconsistent in published studies and there remains much that is not understood. So although this field is exciting and rapidly moving forward, there are plenty of challenges we face when trying to solve the enigma that is Crohn's disease.

Moreover, we do not yet have a cure for Crohn's disease and the treatment options are limited, particularly in children. Most children require treatment over the long term and the current medical therapies that include corticosteroids, 5-aminosalicylates, antibiotics and potent immunosuppressive drugs have significant side effects. Exclusive enteral nutrition (EEN) is

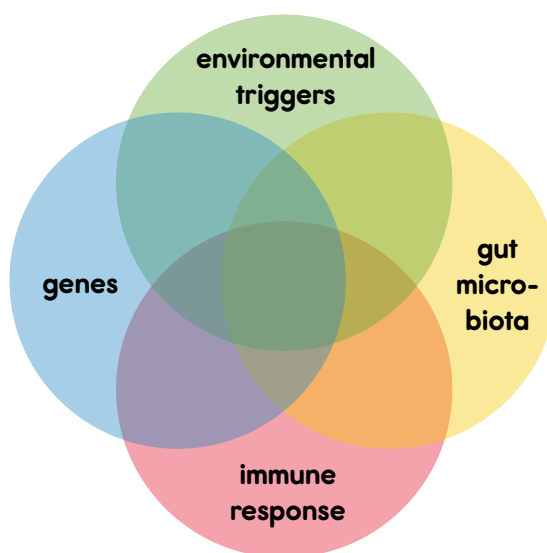




**Fig. 1: Human diseases associated with alterations in gut microbiota.**



**Fig.2: The interaction of multiple factors thought to cause Crohn's disease.**



recommended as induction therapy for active paediatric Crohn's disease in UK and across Europe. Enteral nutrition involves the administration of a liquid diet formulation, which is either elemental or polymeric formula. Enteral diet has strong anti-inflammatory effects when given exclusively for 6-8 weeks, without any additional foods. This treatment is our most effective therapy, in terms of safety and efficacy, but we still do not completely understand how enteral nutrition works and what impact it has on the gut microbiota. This is a particular focus in my current research project.

I am testing the hypothesis that EEN effects are primary on microbiota and not secondary to inflammation. There have been some research studies which suggest changes in the microbiota as a possible mechanism of action of EEN. In the work I am doing, I propose that EEN is efficacious by altering microbial diversity and community membership in Crohn's disease patients.

I feel very privileged to have the opportunity to combine my clinical interest with a scientific career. The work balance is constantly evolving and can be tough at times. However, I am excited and hopeful that my study will lead to important results which are novel (e.g., changes in microbiota are a result of EEN and not an effect of inflammation). In addition, the description of specific changes in certain microbial species at disease onset and following EEN may offer clues to disease causation and have potential therapeutic implications in the future. If changes in the microbiota are associated with remission, future studies will try to maintain that microbiota with the possibility of achieving long-term remission in children with Crohn's disease.





## top tips

- keep the school updated; following diagnosis make an appointment with the head of year or SENCO. If you have not got a letter to support your child's medical and educational needs, bring the endoscopy report or a clinic letter to show the diagnosis
- bring the teacher support information from CICRA to the appointment
- bring this article
- ensure the healthcare plan / your child's medical needs are reviewed every year and discussed at each parents' evening and updated if your child has a significant flare. If your child has a long period of remission, people will forget they have IBD – after all no one can see it!
- discuss additional support for exams early even if your child is in remission (many schools want letters of support in February; having 'a support plan in place that is never used is much less stressful than trying to get support at an already stressful time.



# school and college advice for parents from a specialist nurse



By Mary Brennan, RGN/RSCN/BSc  
Clinical Nurse Specialist Paediatric Gastroenterology

You or your child can decide who to tell that your child has inflammatory bowel disease (IBD) (Crohn's disease, Ulcerative colitis or IBD unclassified). However, to ensure your child receives the right support in school and to ensure they achieve their academic potential despite their long term condition, I encourage them to tell a minimum of two people: the SENCO and their head of year. These two can put a healthcare plan in place to support your child's medical and educational needs.

IBD can be embarrassing to talk about, hence your child may not want everyone to know – at least in the beginning when they are first diagnosed. I tell the young people in my care to take their time telling everyone, especially while they are trying to get their heads around the fact they have IBD themselves. As friendship groups change during adolescence I advise they only tell their closest friend or friends. I also advise to start with a simple explanation – ie, I have a problem with my belly/tummy which the hospital is helping to make better.

For the teachers, it is important they know that IBD is a relapsing/remitting condition for which currently there

is no cure. The majority of teachers are very supportive once they understand the condition but think of the size of your child's school and there may be only one to four children with IBD. Therefore, you will need to revisit the condition and its treatment as it changes. It may be worth thinking about having a noticeboard raising awareness of IBD or using a school event to highlight the condition (and if your child is happy to, profiling their personal experience).

**CICRA has booklets on IBD for primary and secondary schools, as well as a foldable handout for class teachers with all the key facts they need to know. You can also find example letters on our website at [cicra.org/schools](http://cicra.org/schools)**

If you don't know already who your child's IBD nurse is, find out and ask them to support you and your child in ensuring the right support is in place for your child. If your child is unfortunate and does not have an IBD Nurse, ask their consultant or GP to write a letter of support outlining your child's needs. CICRA can provide you with some example letters that can be adapted, but please ask the healthcare professional to make the letter as individual to your child as possible – ie, if they need additional time to eat or calorie-laden snacks rather than the healthy options as they are struggling to gain weight.

If your child is out of school for three consecutive weeks, begin to discuss home tuition with a view to your child being re-integrated on a phased return as soon as possible – do not forget their socialisation is important.



# early diagnosis and the multi-disciplinary team

Dr Anna Pigott is a Consultant Paediatric Gastroenterologist at University Hospitals of North Midlands

Why is early diagnosis important? Well you might think that's obvious. The sooner a child or young person is diagnosed, the sooner they can get treated. But there's a bit more to it than that. We know that if you are diagnosed earlier with IBD, there is a lower chance that you will need stronger treatments (such as Infliximab, which needs to be given via a drip) or an operation. We also know that children and young people who are diagnosed earlier tend to have their growth affected less. When the body is unwell and isn't getting the right nutrition (eg in Crohn's disease), then initially our weight will reduce; if this goes on for a longer period of time, the rate children or young people grow in height also gets affected. Young people who have IBD should have their growth plotted regularly on a growth chart to check on how it's progressing. Your doctor or dietitian will be happy to show you a growth chart.

When the body is healing and the IBD is under control it does

have some capacity to 'catch up' on the growing it didn't do as effectively when the body was ill. When I was a junior doctor in my first job working in paediatric gastroenterology, I remember seeing a quiet boy; when he came back for review after receiving a course of treatment, I was astounded to

**Young people who have IBD should have their growth plotted regularly on a growth chart.**

see he had transformed into a loud, swearsy teenager! Seeing this boy's transformation was one of the things that inspired me to follow a career in paediatric gastroenterology. It was amazing the difference treatments could make (although I'm not sure the boy's parents felt the same way)!

When a young person has IBD around the time when puberty usually starts, puberty can be

delayed. Although in an ideal world, the body should grow when it was intended to, the body detects that it isn't healthy and often puts puberty on hold until things are better. This is why paediatric gastroenterologists are keen to make sure that we get young people as healthy as possible while they are going through puberty. Doctors may do some special examinations when we are trying to work out if young people are entering puberty, such as measuring testicle size. We appreciate this is a bit embarrassing, but it can give doctors a good indication of whether we need to ramp up treatment to make sure the body grows to its full potential at this crucial time.

People often wonder if their disease should have been diagnosed earlier. This is difficult, particularly in Crohn's disease as often the symptoms start off mildly with tiredness or a bit of tummy ache, gradually becoming worse.





We know that lots of people, whether children or adults, have their symptoms for a long time before they even visit their own doctor (GP). People often look for information elsewhere as the symptoms can seem embarrassing. I was surprised to hear that the biggest unexpected rise in ‘hits’ on the NHS Choices website was when Sam Faiers from TOWIE explained she had Crohn’s disease. She says she had her symptoms for a long time before finally getting diagnosed.

About a quarter of young people had symptoms of IBD for up to a year before visiting their doctor. For adults, it can be even worse. A study showed that is not unusual for people to have symptoms for over 10 years before getting a diagnosis.

I try to get the message out to local family doctors that children and young people can get IBD as well as adults, along with some of the symptoms and changes in blood

tests that can indicate that a referral to a specialist is needed.

In 2009, CICRA worked with Crohn’s and Colitis UK and professionals working in IBD to put together the IBD Standards Document. This has now been mostly replaced by the NICE (National Institute for Health and Care

**About a quarter of young people had symptoms of IBD for up to a year before visiting their doctor.**

Excellence) guidelines for managing IBD, but it set out the standards that people (adults or children) should get a referral promptly if IBD is suspected and be contacted within 2 weeks. Children should be seen by a paediatric specialist within 4 weeks from referral by their GP (or sooner if necessary). If endoscopy is required this should happen within 6 weeks of referral from a family doctor. It is

true to say that this doesn’t always happen, as sometimes the signs and symptoms or the tests don’t immediately flag that somebody has IBD. The IBD Standards also state that people who have IBD should be cared for by a multi-disciplinary team.

It is important that any flare-up of a young person’s IBD is diagnosed and treated quickly. Families are often much more aware when a flare-up happens that they need to talk to their team, as they’ve been looking out for the symptoms the person had before they got diagnosed. The benefits of diagnosing flare-ups quickly are the same as at initial diagnosis. When doctors know early that a flare-up is happening, they can often (but not always) manage this by increasing a dose of an existing medication, or add another medicine in, without the need for more complicated treatments. Children and young people who have their flare-ups treated early are less likely to take time off school, >>>





and less likely to have their growth affected.

If you think your child might be having a flare-up, it's time to talk to one of the multi-disciplinary team. The team are your team of experts, and can help work out if your child is experiencing a flare-up or not.

The multi-disciplinary team are different health professionals who between them should be able to deal with all the issues that IBD can raise. The key members of the team are doctors (who may include a local paediatrician with an interest in IBD) specialist nurse, dietitian and psychologist.

Specialist nurses are often the person to call when you think your child may be having a flare-up. I like to think I'm a pretty approachable person, but somehow our specialist nurses have that knack of finding out the information that I don't always get to hear about – perhaps that someone is struggling to remember to take their medications as regularly as they know they should. They often have more time than doctors to talk about issues that may be affecting the family. They are a great

source of information and practical advice: after all, they've met lots of families in the same position and can pass on hints, tips and advice. They can also have a chat with school teachers and school nurses to help explain what IBD is and how it may affect your child.

### The key members of the team are doctors, specialist nurse, dietitian and psychologist.

Specialist dietitians are important in managing IBD. For young people with Crohn's disease, they will explain if a young person needs to have exclusive enteral feeds/liquid diet, and how to follow it. They are important for young people with Ulcerative colitis as well, making sure that young people have an adequate iron intake. Calcium intake is also important to get assessed if the young person is taking steroids medication, to ensure the bones are protected.

Psychologists can be really useful members of the team. They can help

deal with anxiety about adjusting to life with IBD, or around having tests. If a young person needs surgery, they can help prepare for that too.

There are lots of other professionals that may get involved with treating IBD. We sometimes need to involve eye specialists (ophthalmologists), joint specialists (rheumatologists), specialist pharmacists, surgeons and pathologists (who look at the biopsies after an endoscopy). Radiologists are specialist doctors who help interpret and perform X-ray tests like MRIs and ultrasound scans. You might also meet ward nurses and play specialists if your child needs to stay in hospital.

Your child should feel supported by the professionals who are there to help you manage living with IBD. Do feel free to 'phone a friend' if your family needs help. It is usually easy to reassure someone when there is a little query, we always prefer to know about problems when they are little, before they turn into bigger ones!



# all change!

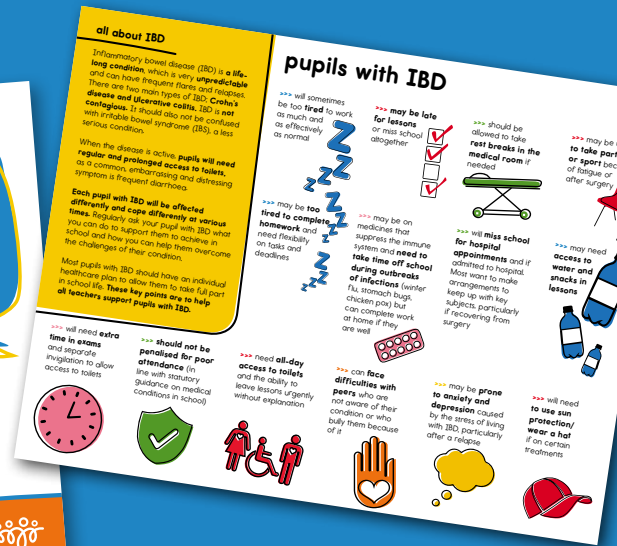
## parents guide

We are also revamping our popular parents guide to help parents following a diagnosis.

As part of our bold strategy introduced in the most recent edition of **the insider**, CICRA has been busy behind the scenes creating some new literature to benefit children and young people with Crohn's and colitis.

## schools booklets

These new booklets have been developed in consultation with children, teachers and parents, including at two of our family days this year. It was felt that there would be real value in having specific leaflets for the two main stages of schooling – primary and secondary – and then an additional one pager to give to each subject teacher in secondary.

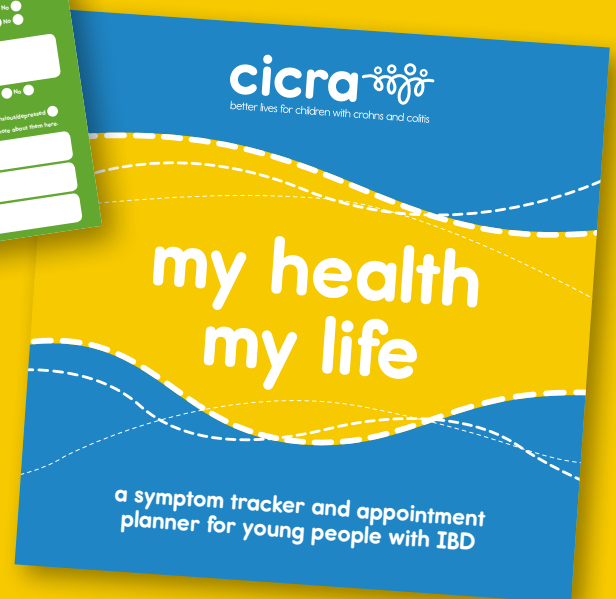


If you would be interested in receiving any of the new items on these pages, please contact the office on [support@cicra.org](mailto:support@cicra.org) or 020 8949 6209



## symptom impact tracker

The tracker is designed to give an overview of how you feel, physically and mentally. We hope that it will help to equip young people as they approach transition from paediatric to adult services. It was developed with the input of medical professionals, parents and young people, including attendees at our Bristol and Sheffield information days. Transition is a challenging process where practical realities do not always match official guidance. We hope this symptom tracker helps young people become more confident about managing their condition.



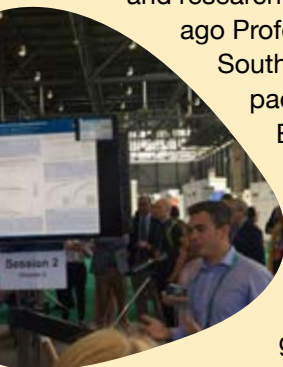
# improving the future for children with IBD around the world

CICRA supports medical professionals to research new ways of managing IBD and present their findings at international conferences to share ideas with the international community. We have reports from two researchers whose attendance at conferences was made possible by CICRA funding.

With the help of a John Earnshaw Award and two CICRA bursary grants, the excellent research being carried out at Southampton Hospital, under the direction of Professor Mark Beattie and Professor Sarah Ennis, was presented at the European Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) meeting in Geneva, in May this year.

The ESPGHAN conference is the largest annual gathering for paediatric IBD specialist doctors, nurses and dietitians, with the common purpose of learning about the latest research (both clinical and scientific), promoting collaboration between PIBD centres, and presenting cutting-edge work from hospitals and universities. Everyone's overall goal is to improve the care of children and young people with Crohn's and colitis.

Although comparatively a small amount when looking at the cost of research generally, the impact that CICRA's research funding has had over many years could be seen at this meeting. Professor Mark Beattie, a former CICRA Research Fellow, Professor Sarah Ennis, supported by CICRA for many years, and Dr Tracy Coelho, a very recent CICRA Fellow, were there to present the research from Southampton, together with Dr James Ashton and research nurse Rachel Haggarty. Some 20 years ago Professor Tom MacDonald transferred to Southampton to set up a research unit for paediatric gastroenterology. Professor Mark Beattie joined him and so began CICRA's involvement with Southampton. Professor MacDonald eventually returned to London and Professors Beattie and Ennis have continued to expand this excellent paediatric gastroenterology unit.



## Below is a report of the ESPGHAN meeting from Dr James Ashton

*"As a doctor training to become a specialist in paediatric IBD at Southampton Children's Hospital, and additionally a current PhD student looking at the interaction between genetics and the environment in PIBD at the University of Southampton, it is always a privilege to attend these conferences. This year, we were fortunate enough to have five pieces of work accepted from Southampton for presentation at ESPGHAN 2018. CICRA have provided invaluable funding and support to our research group in Southampton over many years.*

**"In Southampton, we are hugely thankful to the generous donations from CICRA that make a lot of PIBD research possible."**

*This year, we heard about such international studies as the H2020 PIBDnet safety registry, the interim results from the GROWTH CD study, and the new treatments (including new biological therapies) that are currently in development. There was also a series of talks on the considerable achievements and advances during the 50 years of ESPGHAN's work on PIBD and what we hoped for in the next 50 years.*

*The work in Southampton is led by Professor Mark Beattie, Professor Sarah Ennis and Professor Tony Williams and is supported by the Southampton Children's Hospital, University of Southampton and the Southampton NIHR biomedical research centre. The presentations centred on topics such as the role of the immune system in PIBD, autoimmune disease in the family history of patients with PIBD, perspectives of patients, parents and professionals on maintenance enteral nutrition, and a new genetic score for assessing the impact of mutations to a gene in a single patient with PIBD. CICRA has provided funding for members of our team (myself, consultant Dr Tracy Coelho and research nurse Rachel Haggarty) to attend the conference in Geneva, present this work*





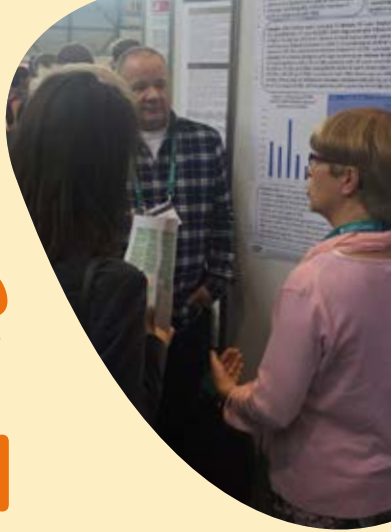
# future the world

and finding a cure. They often  
international IBD community. Here we  
possible by CICRA funding.

*and learn about the latest worldwide advances in  
PIBD research and care.*

*Attending a conference such as ESPGHAN  
reconfirms the commitment of our clinical and  
research teams to understand what causes Crohn's  
disease and Ulcerative colitis and move towards  
personalised, precision therapy for children and  
young people with these conditions. The presence  
of international experts, researchers presenting  
novel work and >4500 delegates is a fantastic  
opportunity to learn, meet new like-minded  
people and promote the importance of improving  
treatments, management and care for children and  
young people with Crohn's and colitis.*

*In Southampton, we are hugely thankful to the  
generous donations from CICRA that make a lot  
of PIBD research possible and allowed us to share  
our work, promoting the continued learning and  
development of our team. We look forward to  
continuing to work closely with CICRA, children/  
young people and other researchers to advance  
paediatric IBD care forward."*



**CICRA PhD  
student  
Daniel Brice**

## researching a potential new treatment

From very early days, CICRA has been very fortunate to have had great clinicians and scientists willing to serve as medical advisors. In addition to coming along to our family information days, their annual commitment to CICRA at the time of granting research awards has been invaluable. Two years ago, along with others, we received an application from Dr Mairi McLean at Aberdeen University to support a PhD studentship. This research was ranked highly and a 3-year grant was awarded to Dr McLean who appointed Daniel Brice to carry out the research for his PhD project. As can be seen from Daniel's report below he was invited to present his work at a BSG meeting signifying another very good recommendation for funding from our advisors.

*"The British Society of Gastroenterology (BSG) conference was held in an exceptionally sunny Liverpool bringing together over 2,200 delegates including international expert speakers, specialist IBD doctors, and scientists to present the latest research and promote collaboration to further care and outcomes for people with IBD.*

*As a PhD student at the University of Aberdeen in the lab of Dr Mairi McLean it was a fantastic opportunity for me to attend the conference and I was awarded the opportunity to present my research as a poster presentation. The research I presented detailed how inflammation of the gut impairs its function as a barrier and how a potential new treatment may be beneficial in restoring this vital function.*

*At the conference I was able listen to many respected speakers in the field of IBD research and the opportunity to learn and gain feedback on my work and learn from other IBD researchers was of immense value. The BSG launched its new research strategy in which it committed to encourage and support health, academic and science sectors to collaborate and work with patients to improve outcomes.*

*There were many great presentations on IBD including research looking at the role of the immune system, genetics and the environment in IBD and how these can influence patient response to treatment and outcomes.*

*My work in Aberdeen focuses on a potential new treatment for IBD and has only been possible thanks to the generosity of CICRA, its members and supporters. CICRA funding made it possible for me to attend the conference and present my work and learn about the advances in IBD research and clinical management around the UK and the world. I am incredibly thankful to CICRA for their donations that make my research possible and look forward to working with CICRA in the future."*



# Amelia's story

## In January 2016, my story began.

I was a happy, normal 10-year-old girl, just like my friends. Suddenly I started to feel unwell and people were making comments like, "You look a bit pale", "Are you feeling OK?" or "Do you need to sit down?" Everyone started to get worried about me as I kept feeling really dizzy, having severe stomach pain and lost 10kg in a few months, dropping to my weight when I was 7 years old. After numerous appointments for the same symptoms, I had puzzled everyone, leading to a trip to the local hospital for an investigation. Not quite as exciting or fun as one from Sherlock Holmes, but it helped. Test results came back, and I was referred to a consultant gastroenterologist. My consultant ran even more tests and eventually, in October 2016, I was diagnosed with Crohn's disease.

When I was told about my diagnosis, I felt a whole mix of emotions and had so many questions. I had never heard of Crohn's before but fortunately my mum had a friend with it. Worry filled my mind, I thought that I had just caught a bad bug to begin with. I was also relieved that I finally had a diagnosis but knew I had a long road ahead of me. My mum and I researched Crohn's and read other stories from young people like me. Before I read these, I felt alone because none of my friends knew what it was like to be me.

Unfortunately for me, I was admitted to hospital only a few days after starting secondary school. I had two friends in my form from my primary school but everyone else was new. Unlike others, I didn't have the opportunity to make new friends in these important first weeks of school. However, my

spirits were boosted when I was in hospital and I received a card. I opened it to find a 'Get Well Soon' card signed by everyone in my form, even though they barely knew me. What was tough was going back to school after a term away. Work wasn't a problem as I had had some sent home. It was going back with an NG tube and talking about it in front of my classmates that was hard. I summoned all my courage, stood at the front of the class and explained my Crohn's. After a while, I got used to people looking at me. They were only curious because I looked a bit different.

“  
Worry filled my mind,  
I thought that I had  
just caught a bad bug  
to begin with.”

My life has changed, but not completely. I am always having appointments, trying new diets, foods and medicines and sometimes missing out on things. Knowing that I wasn't like my friends was hard although I have come to realise that everyone is unique. I'm still like my friends; I do similar things to them, go to school most of the time and most importantly, I try to have a fun, unique personality. I have learnt that I should always think positive. Some may think it weird, but I had 3 NG tubes in total and named each one: Timmy, Timmy Junior and Tilly. It just made my situation more fun. For BBC Children in Need 2016, my school dressed in a onesie or spots for the day. Accompanying my spotty t-shirt was my NG tape on Timmy covered with colourful spots

to fit in. I got lots of comments from people around school from my year and the older years – it just shows how supportive people can be.

My family have played an even bigger part in my life recently. My mum is always talking me to appointments and cheering me up. My grandparents are always willing to experiment with recipes and look after my two siblings while I am in hospital or at appointments. They have all really helped me to cope when my Crohn's is bad, and they are always there for me no matter what. Once my friends knew about my Crohn's and Timmy, they really helped me. They had a few questions obviously but they all respected me, help me with the work that I miss and don't treat me nastily or differently.

Medical care has been good, with both my consultant and dietitian being friendly and helpful. They aren't really negative, but they don't sugar coat things when they are not so good. All of the nurses at my local hospital know me well now and cheer me up when I am admitted and have helped me to overcome my fear of needles. I have tried many different medicines (at one point having 22 a day!) but you shouldn't worry. No one's IBD is the same, so some medicines will work for some people and not for others.

From having IBD, I have met quite a few new people: my consultant, my dietitian, lots of lovely nurses and doctors and other young people like me from a CICRA information day and through e-pals. Now that I know more about Crohn's, I feel better about having it. I can't really remember what it was like without IBD and all of its symptoms even though it wasn't that long ago.



# Amelia's top tips

- 1) **Stay positive!** Although life can be negative sometimes, something positive always comes out of it. I now realise how many people really do care about me and will do anything to support me if they can.
- 2) **Trust the people helping you!** Doctors have gone through so much training and know what they are doing. Don't be afraid to ask about your treatment and talk to people about how you are feeling.
- 3) **Don't let it change your life!** Although it is sensible to miss out on some opportunities because of your IBD, you should try to do as much as you can when you can. For instance, I've had to stop going to gymnastics, I now do art and have piano lessons instead.

“  
IBD shouldn't be what  
is changing your life,  
you should! ”

If you would like  
to share your story, please  
email [marketing@bicra.org](mailto:marketing@bicra.org)

## How you can help

We receive no government funding, so we can only help children with IBD because of people like you.

### fundraising booklet

CICRA cannot fund the research or provide the support that families need without fundraisers. We have developed a new fundraising booklet to help anybody who would like to help us achieve our vision of a childhood unlimited by IBD.



## be part of our running team!

Would you like to run for CICRA on Sunday 10 March 2019, in London's most exciting half-marathon, starting close to the Tower of London and finishing at the Cutty Sark?

CICRA has just five places so if you would like to take one of these and raise funds for IBD research please email [fundraising@bicra.org](mailto:fundraising@bicra.org) for more details.





## the three peaks

"In November 2017, our 11-year-old daughter, Nell, was diagnosed with Crohn's disease. Crohn's is an inflammatory disease which affects any part of the digestive system. People with Crohn's have periods of flare-ups and remission. Unfortunately, there is currently no cure.

Nell has tried various treatments and medication to try and control her symptoms and sadly we are still working with her specialist team at MidYorks and LGI to try and get her into remission.

Despite everything, Nell continues to trial various medication and treatments no matter how painful or what the side effects may be. She has amazed everyone with her bravery and is determined to get in control of this disease.

Nell's courage inspired me and 4 mates to do something to encourage her to stay strong, so we made a plan to walk The Yorkshire 3 Peaks for CICRA."

The final total for the event came in at around £5,500 – incredible! Thank you to everyone involved.

**Raised  
£5.500!!**

## 30 obstacle race course



Ian Mackinder rallied a team at work to undertake Urban Evolution Obstacle Course - 7km and 10km with obstacles. Despite having never done anything like this before, participants were keen to raise funds for CICRA in honour of Ian and Donna's daughter, Evelyn-Rose, who was diagnosed with Crohn's disease aged 10.

Thank you to Daniel, Ian, Joshua, Cheryl, Jaimie, Karl, Sophie and Luke for raising over £500!!

**Raised  
£500!!**



## a tough day of riding!

On Sunday 29th July, approximately 25,000 amateur cyclists took on a cycling challenge like no other through London and Surrey. The Prudential RideLondon-Surrey 100 began in Queen Elizabeth Olympic Park, out through London to Surrey's stunning country roads and hills before returning to the capital to finish in spectacular style on The Mall in front of Buckingham Palace.

James was CICRA's entrant this year, riding in some awful weather amongst the glorious sunshine we've been so used to this year! "It was a tough day riding in nasty weather conditions but pleased to finish and raise some money for a great cause."

## an enterprising grandmother

We know that knitting is very fashionable now and since 2014, thanks to Mrs Passmore, a knitter who regularly supports CICRA, the charity has benefitted by £1500 .

Mrs Passmore is a very proud grandmother of a grandson with UC who, despite his illness, finished his university course and went to New Zealand for further study.

Mrs Passmore not only knits anything from baby clothes to fashionable cushion covers she also makes and sells cards. We are very grateful for this enterprising lady who helps CICRA in her own special way.

For more fundraising stories and inspiration, please visit our 'new look' website: [www.cicra.org](http://www.cicra.org)



# three incredible ladies making a difference

CICRA has many long-term regular fundraisers. Unfortunately, we don't have space to thank them publicly for every event they organise, but we would like to acknowledge here the work of three very regular supporters, all doing something they enjoy and helping IBD research at the same time.

What would we have done without **Jax Martin-Betts and Cumnor House School**. From a School Christmas Bazaar £24,000, a personal donation from a parent of £30,000, and year after year the proceeds from auctioning a different themed quilt, made by the children at the school, and supervised by Jax. This year alone the quilt raised £1000. Not content with that, Jax decided a few years ago to organise a tennis tournament for parents, this

year raising £1430. The next step was a 'Kids Tennis Tournament' this year raising £555.

**Trish Walker** gives weekly sewing lessons to enthusiasts eager to learn this very rewarding craft. Each quarter Trish donates all the fees to CICRA – so far this year £1,367. A very welcome boost to our funds.

Around four years ago, **Alison Johnston** wrote to say that we would be receiving monthly funds

from her line dancing club. So far, this year alone, Alison has sent us nearly £1000.

**What a wonderful contribution these three ladies make towards our aim of helping as many families as possible affected by IBD, and while waiting for the cure, to help children and young people lead as normal a life as possible. Thank you all so very much.**

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

## more of our amazing supporters!



### Mongol Rally

Sean Williams and James Murray took off on an epic adventure on 13th July, travelling from Mochrum in Scotland to Mongolia in a tiny 11 engine car. They have so far raised nearly £5,000 to be shared between us and two other charities.

Thanks to Sean and James for doing this to support children and young people with IBD.

**Raised  
£5,000!!**

### School fête

Genevieve very kindly chose to run a stall at her school fair and raise funds for CICRA in honour of her brother, Alex, who has Crohn's. Thank you both for raising £70.00 and for spreading the word!



**Raised  
£70!!**

### 25 Norwich

At only just 13, Immy is a keen cyclist and decided to complete the 25 Norwich cycle event and raise funds for CICRA. Immy completed the 25 miles in 2 hours and 7 minutes – well done on your achievement and huge thanks to you, Immy!



**Raised  
£337!!**



# Brian Oates Memorial Golf Tournament

In memory of their beloved son and brother, Brian, the Oates family organised a range of activities to raise funds. Brian died from cancer aged 54 on 3rd May 2017. He left behind a daughter Ciara, two granddaughters, his partner Moyra, his parents John and Catherine, siblings Catriona, Desmond and David, in addition to countless friends and extended family.

From his late thirties, Brian suffered quite severely from Crohn's disease which changed his life significantly. Very little of the condition was known to his family at the time of his diagnosis and Brian bravely fought and managed his condition, often keeping his suffering and discomfort hidden from his loved ones.

The main event was the Brian Oates Memorial Golf tournament, which took place on Sunday May 13th with over 60 golfers enjoying a stunning day on Stirling Golf Course.

All in all, the family is delighted that a total of £14,000 was raised for two charities: Crohn's and Colitis UK and CICRA, to help support sufferers and work towards a cure for this crippling disease.

The money was handed over on June 22nd at Stirling Golf Club to charity representatives, including CICRA trustee, Dr Deborah O'Neil, with Catherine and John Oates, Brian's parents, present, as well as Kenny Monaghan, club professional at Stirling Golf Club; Brian's sister, Catriona; sister-in-law, Tracey; and brother, David. The family would like to extend their heartfelt thanks to all who have so generously donated to this cause, and supported them over the last difficult year. They would also like to sincerely thank the staff at Stirling Golf Club for their generosity, kindness and support in hosting the Brian Oates Memorial Golf Competition and the handover event.



How fantastic is that?!

Raised £14,000!!

## CICRA 200+ club winner list 2018

If you would like the chance to win a monthly cash prize and at the same time help to fund research into childhood IBD, the 200+ Club is the one for you.

Half of the total income from this fundraising initiative is paid out as prizes and the other half helps to maintain and expand the CICRA Research Programme. These amounts, when added together with other small fundraising events, make a real difference to the amount of research we can fund each year.

If you are interested, please ring the office on 020 8949 6209 or email support@cicra.org and we will send you the forms. A big thank you to all current supporters.

January			April		
15	B Morrison, Alvaston	£50	77	J Kirby, Hertfordshire	£50
9	E Horgan, Wilmington	£50	88	J Allen, Suffolk	£50
February			May		
237	L Taylor, Barnstaple	£50	203	J Berry, Cheltenham	£50
163	M Cotterell, Bassaleg	£50	103	W Dando, Caerphilly	£50
March			June		
236	Mrs Chapman, Uttoxeter	£250	59	H Siderfin, Notts	£250
54	O Goldsmith, London	£75	109	L Browning, Dumfries	£75
158	C Saunders, Oxford	£75	154	L Ayre, London	£75



## 40th Anniversary Draw results

Ray Alder, Community Housing Services Manager from the Sutton Housing Society, drew by the winners of the 40th Anniversary Draw on Wednesday 25th July 2018, at the CICRA offices, Pat Shaw House. Below are the winners.



<b>1st prize</b>	36483	K Flanagan, Essex
<b>2nd prize</b>	38479	H Russell, Kent
<b>3rd prize</b>	20278	W Walton, Tyne & Wear
<b>4th prize</b>	04060	H Siderfin, Notts
<b>5th prize</b>	42805	O Griffen, Norfolk
<b>6th prize</b>	27740	R Wright, Northants
<b>7th prize</b>	05168	L Brasier, Kent
<b>8th prize</b>	22217	J Chilcott, Somerset
<b>9th prize</b>	18539	R Squire, Bournemouth
<b>10th prize</b>	26383	P Johnson, Derby
<b>11th prize</b>	34742	A Wagstaff, Essex
<b>12th prize</b>	33701	Mrs Reynolds, Salisbury
<b>13th prize</b>	29685	R Jones, Essex

Many thanks to members who either bought tickets themselves or sold tickets to support this special draw. 100% of the funds raised will go towards the funding of new research into inflammatory bowel disease. We don't send tickets to those who do not, for whatever reason, wish to receive them, so if you do have to return unsold tickets, please enclose your name and address so that we can make a note not to send again.





## in loving memory of our brave and courageous little boy, Jack

Always had a smile on his face throughout everything. Eternally loved and painfully missed by mummy, daddy, Callum, Kenzie, Rhys, Alfie, Jaylen and Scarlet.

We would personally like to thank CICRA for your outstanding support after losing Jack and for the information provided to educate ourselves on Jack's illness.

# 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:**

**Rex Corby Sanders** Grandad of Ben who was diagnosed with colitis aged thirteen. Remembered with love by his family and friends.

**Ann Dix** Grandmother of a Crohn's disease sufferer remembered with love by all the family and friends.

**Joyce Simmonds** Only apart from George for six months. Grandparents of Neve, a Crohn's sufferer since age seven. Greatly missed.

**Mary Boyd-Bell** Grandma of a UC sufferer. Remembered fondly by her family.

**Joan Christine Stanley** Remembered with love by her two daughters Rebecca and Jacqui, family and friends.

## in memory of Mary Weeks

Some of you reading this newsletter will remember the names of Mary and Eddie Weeks. For those who don't, this is a small tribute to Mary, a special lady who sadly died earlier this year. When CICRA was formed, Mary and Eddie had a friend whose child was really struggling with diagnosis and treatment of IBD and offered to help. Fortunately this lad recovered well and went on to live a normal life, even running marathons.

Mary and Eddie's help in those early years of raising funds was invaluable, particularly at our Summer and Christmas Fayres, jumble sales, etc. No matter what we organised, they could always be relied on to be there to help.

As Eddie was a keen stamp collector, he and Mary offered to collect and sell stamps as an extra fundraising initiative. I'm not sure that they realised at the time how

many stamps would land on their doorstep. If they weren't in I would leave several black bags of stamps as a surprise in their garage. This became a regular thing.

By sorting and putting special stamps into mounts and taking them round to stamp collecting clubs and stamp shops, they got the best price, the remainder being sold in bulk. Their efforts resulted in a continuous amount of money

being paid into the CICRA account over many years, only finishing a few years ago.

In Mary's memory, Eddie made a very valuable donation to CICRA and in his words "the one charity Mary always supported as she knew that almost all of the donation would be used for charitable intent". Thank you Eddie.

**Margaret Lee**



1978 **40** 2018  
years  
research & support

Please help  
Aaron by donating  
today and make  
a big difference  
for the little ones.

## Children with IBD deserve a happy childhood.

You can make that a reality for Aaron and many others.

Through our support for parents, we give reassurance to the whole family. Through our guides for teachers, we help make school a friendly environment. Through our work with health professionals, we set high standards of care. Through our research, we make treatments better with fewer side effects. **We get no government funding and rely entirely on donations to fund our research, information and support.**

[cicra.org/donate](https://cicra.org/donate)

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 Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey SM2 6AQ

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**FUNDRAISING  
REGULATOR**