



# the insider

autumn 2019

## CD Treat:

solid food - a promising improvement to the liquid diet

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

**inside** >

inspirational stories from young people with IBD  
cake sales and fundraising mark World IBD Day  
family support workshops and London family IBD info day

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## message from the Chair

Dear Friends

Another newsletter, and hope on the horizon thanks to our clinicians and scientists. As funders of research CICRA is small, but our research has definitely improved the lives of young people with IBD and it is therefore vital that we continue to fund innovative research projects.

Apart from providing a training programme for clinicians who treat children with IBD (see the report on Dr Marco Gasparetto, page 8) the research on the CD-Treat was funded by CICRA initially and co-funded with Crohn's and Colitis UK and Catherine McEwan Foundation since. Dr Konstantinos Gerasimidis and the team have secured £900,000 from an American Trust which will take this research forward and bring hope of less drug treatment to control Crohn's disease in children and young people. This research followed on from the liquid diet, a first line of treatment for children since the late 80s which came about from CICRA's nine year funding. If a solid food can be produced, with the same effect as the liquid diet, this will be a big step forward for children with Crohn's, both medically and socially.

We wish Dr Gerasimidis, Dr Vaios Svolos, Professor Richard Russell and our Medical Director, Dr Richard Hansen and their team every success, and look forward to further news. Dr Hansen will be giving a report on this at the London Family Information Day (see page 9)

Margaret Lee





# Glasgow University secure £900,000 for CD-Treat project



A liquid-only diet using special milkshakes and taken without any other food for 8 weeks, also known as exclusive enteral nutrition (EEN) is the best initial treatment for children with Crohn's disease with active symptoms. This liquid diet is successful in about 8 out of 10 children with Crohn's disease, but it is a fairly restrictive treatment to follow and often requires feeding directly in the stomach, using a tube passed via the nose.

Previous research by Dr Konstantinos Gerasimidis from the University of Glasgow, Professor Richard Russell and Dr Richard Hansen from the Royal Hospital for Children in Glasgow, and co-funded by CICRA, showed that this liquid diet works by changing the populations of bacteria resident within our gut (the gut microbiome) and affecting their function.

It is therefore possible to utilise the science and knowledge we have about the liquid diet to develop new effective dietary therapies that are more acceptable and tolerable for people with Crohn's disease. A new dietary therapy that works as well as the liquid diet, but does not involve stopping all normal food would be more socially acceptable and appealing to most people with CD, as the same research team has shown recently in a questionnaire survey.

Dr Vaios Svolos, a former postgraduate student and current researcher, along with Dr Gerasimidis and his team, have recently developed a food-based diet using everyday foods (also known as CD-TREAT). The aim was

that this novel diet will work as well as the liquid diet. In a study published in the world's highest ranked journal for gut diseases and their treatment, Dr Gerasimidis and

his team have shown that CD-TREAT changes the gut bacteria and their function in healthy people in a similar way to EEN. In another study, they tested the CD-TREAT diet and the liquid-diet in rats with gut inflammation, and importantly, both diets were similar in reducing the gut inflammation seen in these rats. Currently, Dr Gerasimidis' team has been testing CD-TREAT in children with active Crohn's disease. Early data from the first five children with Crohn's disease showed that CD-TREAT diet, prepared and delivered free to the patients, improved their blood and gut disease markers. Among the five children receiving CD-TREAT, four got significantly better and three (60%) had complete resolution of their symptoms. Stool markers of gut inflammation dropped by 55% while on CD-TREAT.

Dr Gerasimidis and his clinical colleagues are optimistic that the clinical effect of CD-TREAT will be replicated with more participants in the ongoing study and will compare well with other standard drug therapies. If these initial findings are replicated, doctors, nurses and dietitians might be able in the future to decrease or replace toxic and expensive drugs for some patients.

An example day's menu in the CD-TREAT diet for a 15-year-old boy with Crohn's disease included the following foods (all lactose and gluten-free):

- **Breakfast:** full-fat milk, rice-based breakfast cereal, and apple juice
- **Lunch:** white bread, cheddar, and cream cheese; lettuce, peeled cucumber, and chicken with rice soup
- **Dinner:** grilled salmon, mashed potatoes, cheese sauce
- **Snacks:** pineapple juice, peeled apple, rice pudding



Video of the CD-TREAT paper abstract  
<http://bit.ly/CDTreat>





# IBD rollercoaster for Eliza

Many of you will know, or will have spoken to Jayne Boyd-Bell. Below is Jayne's story of her daughter Eliza's journey which we think will give much hope to many young people, and their parents.

Eliza is the youngest of our three daughters and it came as a complete shock when she was diagnosed with Ulcerative Colitis aged 13. It was a disease we knew very little about, and up until that point didn't know it could affect children. A steep learning curve and the IBD roller coaster journey began!

There is not an easy age to be diagnosed with IBD, it's tough at any age. Eliza was treated with a cocktail of drugs that made her sick, tired and anxious. She hated steroids and the way they changed her appearance, they made her self-conscious and affected the way she felt. I often wondered if her behaviour was the steroids or she was just a typical stroppy teenager. Her sisters were great and got her through the difficult days with humour and laughter. There were the usual sisterly fall-outs but that's just a normal part of our family life.

She struggled to attend school and 20+ trips to the toilet became the daily norm. She missed most of Year 8 & 9 which in turn affected her friendships and social life, she didn't want to tell anyone that she had a chronic bowel condition. She found it hard to see her friends having outings and sleepovers without her and posting pictures and comments on social media. Her dad and I juggled work, family life, hospital appointments and getting her to school as best we could.

When she was 15, we were all knocked sideways

when her doctors said she needed urgent surgery to remove her large bowel. She had three big operations over the course of a year and had to live with a stoma whilst waiting for her J-Pouch to work. We sat in a daze asking questions and not quite believing what was happening. Eliza was upset and asked if she would be able to have children after the surgery and to our absolute horror the surgeon said probably not because of the large amount of scarring and adhesions that could be left after major abdominal surgery. As parents we were at a complete loss as how to reassure our beautiful daughter that it would be OK, and her life would go as she'd planned.

**"Mum I can't believe it, I've actually done it. I never thought I would be lucky enough and this would happen for me."**

She coped with the surgery amazingly well and by the time she had the stoma reversed she was used to it and her life had found a new normal. She left school, got a job, went on a girl's holiday, met her boyfriend (they've now been together 6 years), learnt to drive and generally enjoyed being well.

As she got older and her relationship with Ronan became more serious the issue of having children came up from time to time. She'd ask me if I thought she'd be able to have children and how much they would have to save to pay for IVF, it broke my heart thinking that she may never have the family she so desperately wanted.

Life carried on as normal when out of the blue last November Eliza and Ronan arrived looking very happy





and announced they had news... We literally couldn't believe it when they announced Eliza was PREGNANT and the baby was due at the beginning of July!!! We were all beyond excited and in shock, they were having a baby!

St. Georges Hospital in London were amazing and kept a close eye on Eliza throughout her pregnancy. Looking for information on what's normal in pregnancy with a J-pouch was tricky as there is not much information out there. After a discussion with her doctors a caesarean section was planned for the 27th June and her surgeon agreed to attend in case there were any complications with her J-pouch or bowel.

31 weeks into her pregnancy Eliza started to feel unwell and was admitted to hospital where she was monitored closely and given steroids for the baby's lungs.

On the 14th May 2019 at 10:29pm baby Freddie arrived safely at 32 weeks weighing 4lb 2oz. The team looking after Eliza decided on a natural delivery because the baby was so small and there would be minimal risk of damage to her J-Pouch. Whilst the baby was whisked off with his daddy to the Special Care Baby Unit, I sat with Eliza whilst she was being checked and she looked at me and said "Mum I can't believe it, I've actually done it. I never thought I would be lucky enough and this would happen for me". I just sat and cried.

Baby Freddie is doing well and at the end of July weighed 9lb and is an absolute joy to his mummy, daddy, aunties and very proud grandparents.

## What is a J-Pouch?

The ileoanal pouch is a surgical procedure option for ulcerative colitis patients who need to have their large intestine (colon) removed.

An ileoanal pouch or (J Pouch) is an internal pouch formed of small intestine. This pouch provides a storage place for stool in the absence of the large intestine.

The anal sphincter muscles assist in holding in the stool. Then several times a day, stool is passed through the anus in the normal way.



Eliza is happy to answer questions on her pregnancy J-Pouch experience.

Alternatively, if you have a J-Pouch and would like to be put in touch with other young people in a similar situation, please let us know.

E-mail Jayne at: [support@cicra.org](mailto:support@cicra.org)







# IBD and university: how technology can help

**Leaving home and going to university is a challenge for many young people. Liam, 22, was diagnosed with Ulcerative colitis in the middle of his second year but is now back on track thanks to a supportive consultant, new technology, and being open about his condition**

Liam, despite having to defer part of his studies, has just passed his 2nd year at Portsmouth University, where he studies economics

Liam said “In February 2018, I started to feel ill. I thought I had an upset stomach, the GP took some samples, but it seemed to clear up. Then my Nan passed away, and my health rapidly declined. I lost 17 kilos in six weeks - from 13.5 to 11 stone.”

A colonoscopy on 27 April 2018, a date etched in his memory, confirmed that Liam had Ulcerative colitis “I was physically & mentally overwhelmed by the diagnosis” and spent the next week in East Surrey Hospital on treatment. This didn’t work well so while changing his treatment, Dr Azhar Ansari asked Liam to use the Patient Knows Best\* (PKB) digital personal health record. Liam credits the online

system with giving him easy virtual access to his healthcare team and allowing early intervention to prevent problems from developing into more serious ones.

The PKB systems logs blood tests and other results and gives an explanation of what they mean for him personally. It also allows Liam to track his symptoms so the team can react to any red flags. Being able to communicate without leaving home is a real bonus.

When feeling unwell again, Liam’s medications were adjusted in consultation with Dr Ansari via the system. He also uses PKB on his phone in his appointments with his Portsmouth GP, where he gets repeat prescriptions. He can show changes in his medication and the interpretations of blood tests via the platform.

Liam has made some changes to his lifestyle. He doesn’t drink alcohol but can now eat what he likes. His strength is returning, so he is back clay pigeon and rifle shooting. He has also returned to his summer job in Caterham.

“I’ve got back to normal life, apart from the fatigue. But if I’m drained, I have a reset day.

Liam is looking to the future. ‘I consider myself fortunate. I’m looking forward to my final year now and graduation and hopefully a career in corporate finance.’

\*PKB is a digital health record used by some NHS hospitals in the UK. It is also one of the platforms being used in an NHS England pilot called the Local Health and Care Record Exemplars. It is hoped that the outcomes of the pilot will help develop digital health records for everyone in England, in line with the NHS plan. Digital health records are also being developed in Scotland, Wales and Northern Ireland.

## Liam’s top tips for young people with IBD starting university or higher education:

- embrace being classed as a student with a disability and accept all the help that comes with it
- ask to sit exams in a separate room and take breaks to use the toilet without affecting the time limit
- ask for software to record lectures if your fatigue means you are too tired to take notes
- speak to your lecturers individually to explain your condition and how it might affect you as it fluctuates over time
- have a rest day if you feel drained, realise what you can and can’t do and listen to your body
- be open about IBD with academic and support staff, arrange a meeting with your head of year and any other staff that may need informing and explain the condition and how it affects you
- take all the support on offer. And if you do get ill - don’t worry about it. Get your health back on track so you can fully concentrate on your studies



# more support for families

"I had a lovely chat with Laura! She's really friendly and super easy to talk to."

Joanne

Laura Palmer has joined CICRA as our new family support worker, thanks to funding from Global's Make Some Noise. Laura is here to provide confidential support to parents, carers, young people with IBD and siblings. Later this year, Laura will be running some new, fun events for young people with IBD, to help them make new friends and become more confident about managing their condition.



## About Laura

I am very excited about the opportunities this role brings and look forward to working with as many of you as possible.

My background for the last 12 years has been one of family support. I have lots of ideas about things that may benefit families, much of which has come about through already speaking to a number of parents and young people with IBD, which has been so insightful and informative, thank you!

Please get in touch if you would be interested in exploring the idea of setting up a support/social group for children/young people or young adults affected by IBD in your local area. There's no commitment, but your thoughts are so helpful!

Share your stories, ideas and opinions in relation to developing the service, or if you just want to say 'Hello!' I would love to hear from you! The most important thing for me is ensuring that families remain at the heart of everything we do, both families already known to CICRA and those we are yet to reach.

Whether you have been CICRA members for a while or you have a recent diagnosis of IBD, whatever your situation, you can get in touch for Laura's help with:

- supporting parents/carers and young people affected by IBD on a regular or occasional basis depending what you need
- offering advice/support around specific issues, (but not medical) or to provide ongoing emotional support over the telephone or online
- helping find local services that may be available to support you
- liaising with schools to ensure they are supporting you/your child as effectively as they can
- advocating for you with professionals where there may be misunderstanding of the impact of IBD or your family's needs
- understanding your experiences and working with hospitals/other professionals to ensure that we are continually improving the support CICRA offers to families living with IBD
- workshops and support groups for families both online and in some locations face to face – Newcastle (Sat 5 Oct), East Anglia (Mon 21 Oct: half term), Belfast (Sat 2 Nov) and Cardiff (Sat 30 Nov). Please register: [www.cicra.org/workshops](http://www.cicra.org/workshops)

The support on offer is not restricted to any one thing. Whatever your challenges, worries or questions, please get in touch. If Laura can't help directly, she will find a way of getting the information/support you need, it is often out there if not always easy to find!

## Don't struggle on your own because you think you have to!

You can connect with Laura in whichever way works best:

☎ 020 8949 6209

✉ [laurapalmer@cicra.org](mailto:laurapalmer@cicra.org)

📱 / 📷 @LauraPalmerCICRA

**Laura is usually available Tuesday to Friday, 10am-3pm and Monday and Thursday evenings, 7-9pm, and can also arrange specific appointments outside these times**



# congratulations to Dr Marco Gasparetto



*For the last three years Dr Marco Gasparetto has received training in research and clinical expertise from his supervisors, Dr Rob Heuschkel and Dr Matt Zilbauer, in the Paediatric Gastroenterology Unit at Addenbrookes Hospital, Cambridge. On completion of his CICRA Fellowship, Marco was offered a consultancy at the Royal London Hospital.*

Many members will have met Marco at Family Days and we thank him for willingly giving up his Saturdays to come along to meetings at various locations around the UK. Marco is already booked for the next London meeting in November (see opposite page) In addition Marco ran the Cambridge Half Marathon in 2018 to raise funds for CICRA and has promised to run in the Royal Parks Half Marathon in October 2019. Many thanks Marco.

**Research training:** During his fellowship Marco has gained substantial expertise in translational research focussed on the development of a disease prognostic biomarker for children diagnosed with IBD. Briefly, he was involved in recruiting children to the study and purifying CD8+ T-cells from a peripheral blood sample. A major aspect of Marco's research activities

was to perform bioinformatic analyses of the generated datasets. In this area he gained major expertise and was fortunate to collaborate with, and get support from, some leading bioinformaticians based in Cambridge, further highlighting the quality of his research training.

Marco has presented his work on several national and international meetings including oral presentations at the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and the British Society of Gastroenterology, Hepatology and Nutrition (BSPGHAN) annual meetings. A manuscript containing the main findings, and on which Marco is the first author, has been submitted to *Gastroenterology*, a leading medical journal.

**We very much look forward to monitoring his future career, which we have no doubt will be very bright.**

**Summary of findings:** Based on the findings, the conclusion is that the previously reported CD8+ T-cell based, disease prognostic signature does not seem to be present in children and hence is of limited value as a disease prognostic biomarker. Interpretation of these

findings include that they may reflect differences in disease pathogenesis between adult and paediatric onset IBD – a very important finding.

**Clinical training:** As a CICRA fellow in the Paediatric Gastroenterology department, Marco gained extensive experience in the diagnosis, treatment and management of children suffering from IBD. He was an essential part of a very busy service and participated in all aspects. Furthermore he contributed towards the centre joining the Improve Care Now (ICN) network and formed an important link between the clinical and research team.

A note from his supervisors: "In summary, Marco's time as a CICRA funded fellow was highly successful in all aspects. Although we were of course sad to see him leave we were delighted for him that he managed to be appointed as a locum consultant in one of the biggest centres in the UK. We very much look forward to monitoring his future career, which we have no doubt will be very bright.

We would like to express our sincere gratitude to CICRA, trustees and donors for supporting Marco's fellowship. We believe this played a critical role in Marco's development as a future leader in paediatric IBD."





# we return to London with a match winning programme

Family Information Days are a very important part of our support programme.

London was where it all started, when we just had one event a year. That has now grown to four events a year, and as it is nearly 5 years since we last visited the city, we are pleased to announce that we will be back in November at a very exciting venue – The Kia Oval cricket ground.

## Programme

We have already set to work on putting an interesting programme in place, and are extremely grateful to have had doctors and specialists from all the main London centres offer their help and support for the day.

The feedback received from members and medical professionals attending previous events has been extremely positive. Whilst the prime objective is to provide you with information and the opportunity to ask questions, many doctors and consultants have said how much they gain from taking part in talks and our informal discussion groups.

For our young people, there will be their own discussions groups, and also a 'team building' session and tours of the behind the scenes facilities at the Oval ground (small charge will apply for tours).

Lunch and refreshments will be provided.

## Travel

The Oval is a very easy place to get to – just a 5-minute train journey from Waterloo, there are also two Underground stations close to the ground, and many bus services also stop nearby.

## Book in advance

From the initial responses already received, this is going to be a very popular event, so please do get your places booked as soon as possible as there will be a limit to the number of people we are able to accommodate. (Places must be booked in advance).



Saturday  
16th November 2019  
10am until 4pm

### For everyone

- Listen to young people talk about living with Crohn's and colitis
- Meet and chat to other families in a similar situation
- Listen to short talks from specialists who treat children with IBD
- Followed by specialist led discussion groups

### For young people

- Friendly and fun activities
- Activity session
- Tour of the cricket ground (charge may apply)
- Circus skills and balloon modelling workshop (for under 11's)

### For parents

A chance to ask questions directly to specialists who treat children with IBD on subjects which include:

- Living & Coping with IBD
- The Importance of Diet & Nutrition
- The latest in Research
- Early Onset & VEOIBD
- Supporting children with IBD in school
- Tests, Medication & Surgery



For more information, or to book your place, please contact Jayne at: [support@cicra.org](mailto:support@cicra.org)





# ask the doctor

This is your page to ask questions of our specialists. This issue, three different doctors answer questions about IBD prevalence, treatment and infections.

**My daughter is on infliximab and azathioprine and I'm wondering how careful do we have to be around catching infection? Is it essential to miss school if infections are doing the rounds? My friends and family are aware to stay away if they are unwell or have chickenpox, measles or shingles. Does this spread to all the family? Should we all steer clear of people who have infections?**

Azathioprine and infliximab is a common combination of treatment and only rarely, in my experience, leads to significant serious infection

We routinely test children's chickenpox antibodies before starting immunosuppression to be aware of the risk of infection as this can be very infectious and could be a risk for children on Azathioprine. If there are no antibodies, then contact with open chickenpox should be avoided (although this can be difficult in

the early stages of disease). Antibodies for other infections (e.g. measles) can be measured (or should be present if vaccinated).

We do not advise missing school to avoid infections, as regular monitoring of blood tests should ensure that adequate numbers of immune blood cells should be present to deal with normal childhood infections.

By Dr Rob Heuschkel, Consultant Paediatric Gastroenterologist, Addenbrookes Hospital, Cambridge



## How is IBD treated?

There are broadly two types of treatments for IBD, the treatments that get you better and the treatments that keep you better. We always have to remember with inflammatory bowel disease that to keep someone better you have to have made them better first.

In Crohn's disease, the mainstay of treatment in children across Europe and Australasia and parts of Canada involves a liquid only diet called exclusive enteral nutrition (EEN) which people take for 6-8 weeks. Probably the longer the course, the more effective the therapy. It is a challenging course because you have to take liquid only diet for 8 weeks with no other food. However, we know that it switches off inflammation and helps heal the bowel in 4 out of 5 people. If you come off that and back on

to a normal diet, most people will flare again within a year. We don't think that diet works for Ulcerative colitis. We've got very limited information about diet and Ulcerative colitis so the main treatments are a medicine that is quite similar to aspirin for the colon, usually mesalazine (sometimes known as 5-ASA or 5-aminosalicylic acid) or steroid treatments which depress the immune system.

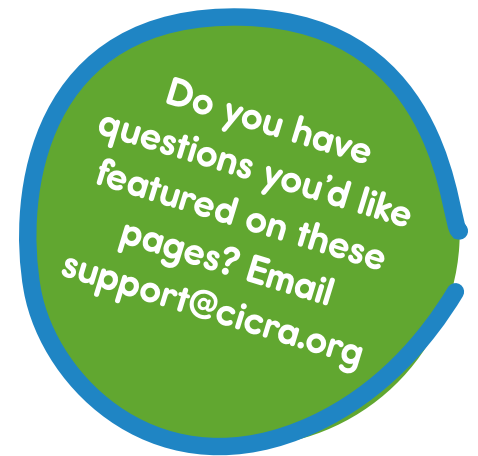
Once we get someone into remission it's important that we keep them there. We try and do that with as minimum an amount of treatment as we can, but often that involves medications that dampen down the immune system. There are a variety of those that we can use depending on the age and stage of disease and how bad things have been. We monitor for things like faecal

## How common is IBD?

We've just presented work at this year's professional association meetings, that has been submitted for publication in the journals, showing that in Scotland we have got the highest rate of new patients under 16 worldwide, except for Israel. Scotland is right up there with Scandinavia and Canada but what is most important, for the first time, we've clearly documented the number of patients in our clinical services with inflammatory bowel disease (IBD). That is all patients both in paediatric clinics and in adult clinics as well.

We've done this work with our adult colleagues in the Lothian area of Scotland. All ages with IBD is up

to 0.8% of the population, so 1 in 125 people in Lothian in Scotland have IBD. The vast majority of these are adults, some that were diagnosed in childhood. We've also shown that the number of existing patients in Scotland is the highest ever published in the world. Our colleagues in Wessex are also looking at this epidemiology and I think they will show similar figures. They may not be quite as high as Scotland because there's a very clear north/south gradient in Europe; the more northerly you go, the higher your chances of



calprotectin, watch for symptoms or keep an eye on blood tests so we can try and identify disease activity coming back before it starts to impact on someone.

By Dr Richard Hansen,  
Consultant Paediatric  
Gastroenterologist & Honorary  
Clinical Associate Professor,  
Glasgow Children's Hospital



developing the condition. We even see that in Scotland. Patients in the north, Shetlands and Orkney and Highlands are more likely to develop IBD than the central belt of Scotland.

By Professor David  
Wilson, Department  
of Paediatric  
Gastroenterology and  
Nutrition, Child Life  
and Health, University  
Of Edinburgh



You can watch Dr Richard Hansen and Professor David Wilson, talk about IBD on our new video library: [cicra.org/videos](http://cicra.org/videos)







we receive  
no government  
funding

# help us help children

There are many simple and easy ways you can help, it's often the little things that make a BIG difference.

## Set up a regular donation

A monthly/annual gift, no matter how small, makes a huge difference to what we, as a small charity, can do.

## Give a single donation

As and when you can.

## Join the 200+ Club

For only 50p a week (£26 a year) you get the chance to win a monthly cash prize and at the same time help fund research into childhood IBD.

## Corporate and Charitable Trust donations

Many Charitable Trusts and Foundations only consider a grant application if the charity has been recommended or put forward by someone with a connection, can you help?

## Recommend CICRA for 'Charity of the Year' with your employer

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

## Use Easyfundraising or AmazonSmile

Once registered every time you make a purchase CICRA receive a donation based on what you spend at absolutely no cost to you.

## Recycle your inkjet cartridges at Recycle4charity

We receive £1 for every inkjet donated.

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

### £5 could provide a Symptom Impact Tracker for two children

Our easy to use Symptom Impact Tracker helps children keep a record of how they feel physically and mentally.

### £10 could pay for three children to receive our information for schools

Our easy to understand booklets help teachers understand how they can support children with IBD so they don't miss out on their education or achieving their academic potential.

### £20 could provide a Can't Wait card & Radar Key for four children

Cards and keys are supplied to children with IBD to help them gain access to toilet facilities when they need them most.

### £30 could provide six Parent Packs & Support cards to hospital clinics across the UK

Parent Packs & Support Cards are supplied to hospitals across the UK to support families after diagnosis. Each pack contains vital information for children, parents and schools.

### £50 could help fund vital Medical Research

Advances in research mean more personalised treatments for children with IBD can be prescribed, limiting the side effects.



# it's good to talk

Sometimes we all need a bit of help and it's good to talk, especially to someone who knows exactly how we feel. Here are three ways to support others dealing with IBD.

## E-Pals, for children and teenagers with Crohn's, colitis or IBDU (age 8-22 years)

Children with IBD can often feel isolated and alone. The nature of the condition means they miss a lot of school, and friends just don't understand how they feel. The support of someone their own age, in a similar situation can be surprisingly positive and valuable.

The E-pals are children and teenagers with Crohn's, colitis or IBDU who chat and share experiences by e-mail. It doesn't matter if the children are newly diagnosed or had the condition for some time, chatting to someone who understands can be supportive and fun!

**"Being part of the E-pals means a lot to me because it enables me to chat with other young people who are going through the same thing as me."**

*Katy who has Ulcerative colitis*

## Very Early Onset IBD (VEOIBD)

for parents whose children are under 9 years old.

The challenges facing parents with younger children can be very different to those with teenagers – weaning, potty training, nursery, starting school, medication and how to explain the condition can all be daunting. Sharing your thoughts, questions and tips with other parents in a similar situation can be beneficial and reassuring.



## Stoma & J-Pouch

for parents and children/teenagers.

Surgery can be daunting for both children and parents. Practical tips and advice from someone who has 'been there' can be useful when recovering from surgery and coping with the practicalities of a stoma or pouch. Chatting to someone who knows how you feel can be reassuring and positive.

If you have a stoma or J-Pouch (or your child has) and you are happy to support other people, please get in touch. If your child is facing surgery and you would like support from other families, we can help.



If you would like to join or find out more about our E-mail support groups E-Pals, Stoma & J-Pouch or Early Onset & VEOIBD, please contact Jayne: **support@cicra.org** or call the office on **020 8949 6209**



# “things change, they always do”

Hannah Sewell is 16 and is being treated for Crohn's disease. Here she tells us about growing up with IBD.



**Hello, I'm Hannah. So, a little bit about me now and what I'm like and what I do so you get an idea before I dive into my story and what I've been through to get here. So, to start with I am 16 and I'm just finishing my first year of 6th**

**form where I have been studying Psychology, English Language and history A-levels.**

I am 16 and just starting my second year of sixth form where I am studying Psychology, English Language and History A-levels. I'm hoping to train to be a paediatric nurse. I also have a little part time job at a stage school where I help teach kids dancing, singing, drama and gymnastics, as performing arts is a massive hobby of mine. I am a little bit of a geek and love being on Xbox and watching Disney and superhero movies. Even though I sound like your normal teenager I'm slightly different because I also have Crohn's.

A few years ago, I was invited to a CICRA family day when I was about 13 and I was going through a really hard time. I remember being sat with my mam listening to two other people's stories and thinking I hope someday I can tell people how far I've come. I was a totally different person then, I was still figuring out how to deal with being 'poorly' and I still am!

Things change, they always do. To a lot of people my age a big change would be moving school or changing friend group but to us big changes can be new medication, a new treatment plan, so we have that little bit extra on our plate. It isn't as scary as it may seem. It took me a while to realise that, but you have to take every day in your stride, and I wish I realised this when I was younger.

When I was about 9, I started getting a lot of pain in my side and had been in and out of the doctors for them to tell me it was growing pains or it was 'nothing to worry

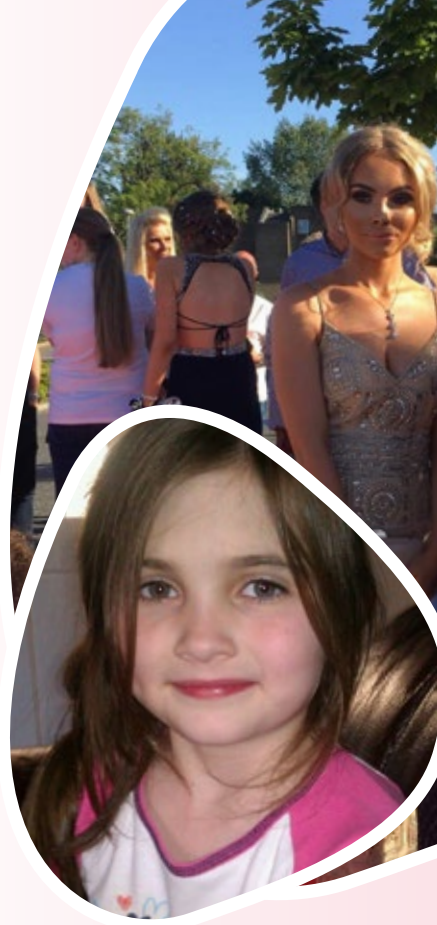
about'. One doctor, however, was worried and sent me for a scan and in that scan, I became extremely ill so ended up getting admitted at Sunderland. I then got blue lighted into the RVI in Newcastle for an emergency kidney operation. My kidney was the size of a beach ball! You could imagine how big that would have been on tiny me. My tube got twisted and that made me stay in hospital for a lot longer than expected because the toxins that they were meant to be draining were instead coming back inside of me and working their way to my heart. Luckily it was caught before it became anything serious.

**I then came home to a lovely letter saying that my foetal calprotectin level was something along the lines of 32,250...**

I then came home to a lovely letter saying that my faecal calprotectin level was something along the lines of 32,250. The normal is between 0-250 so I was slightly off! I got took back to hospital.

I have undetermined colitis so we don't know if I have Crohn's or colitis but I am treated for Crohn's. For two years I was in and out, getting scans and tests to try and figure out which one. The scans were possibly the worst part for me because I hated drinking the prep to the point where I developed a genuine phobia and got sent to counselling as even someone mentioning the prep would lead to me having a panic attack. Diagnosis was the worst for me, I was so young and all of a sudden I'm being told all of these things. It was mentally draining as well as being physically draining because of the amount of pain I was in and the amount of medication and tests I had to go through.

The first few years were the hardest, I had steroids for a long time but they started to make me a lot worse and I became steroid responsive but steroid dependent. The steroids led to me having temporary diabetes







which was a massive issue as I was developing something else which had to be monitored. I was then on methotrexate injections which resulted in me feeling quite low and down which was a very hard thing to have to go through. I was always a very happy, bubbly, talkative person and all of a sudden, I just changed massively and I really struggled. I wouldn't go into school or go out with friends so that was another medication I got took off and then I got moved on to infliximab infusions and with the help of azathioprine I have never been better. There's been

one hiccup in the 4 years

I have been on but it was easily fixed by putting the infusion over two hours and not one. Now I know that Infliximab won't work for everyone like it has for me but I had to go through so many treatments before we got to this stage, this was a last resort so if right now your medication isn't working, just think there's always another option and always another route your doctors can try.

I've had my fair share of side effects: the dreaded moonface, hair thinning, fatigue and nausea. Sometimes the side effects can be just as bad as the condition itself. You can easily lose sight of goals and aspirations and switch to self-pity mode. There have been many times where I have just wanted to say I give in and cry in my room and not want to see or talk to anyone, especially when I was younger. I basically missed year 7 and 8 of school and that was hard as I loved school and loved being with my friends and I think being in and out of hospital and being around adults 24/7 sort of made me mature a lot quicker than other people my age so when I went back to school it was a massive change as I didn't see the point in the silly games people were playing and I wasn't interested in a lot of stuff they did either. But I think some of me not joining in was because of how cautious I was because of my medication. I am so grateful to my friends and family for always supporting me through it all and making sure I didn't sit and lock myself away.

I have achieved a lot of things that I thought at one point I never could. Since I was little my dream was to sing on a big stage. I actually remember sitting crying in hospital as I missed the school talent show auditions because I was admitted. if only I could then have fast forwarded

to now. Last summer I had the chance to perform at Sunderland Empire which was a dream come true. But other things I've still managed to achieve despite the hospital stuff is things like being made head girl at my school, passing my GCSE's despite the amount of school missed, starting my A-levels, going to countless amounts of gigs, going out with my friends, going to parties.

Now as odd as this may seem being poorly has also presented me with opportunities. I've been in the pilot for an ITV show called kids with camera: life on the ward. This TV show asked me to film my life and everything I did and my treatment and the final cut was amazing and the show got aired because of my pilot. They wanted me to be the 'feature child' for all the episodes but I dropped out because I was too scared and at the time was embarrassed because I didn't want people knowing about my condition. Passing up on that is one of my biggest regrets.

**I've had my fair share of side effects the dreaded moon face, hair thinning, fatigue and nausea to name a few of the many.**

I also got the chance to go to Orlando Florida with a charity called Dream Flight. I am so grateful to have been able to experience it and it did change me as a person. They take 190 seriously ill and disabled children to Orlando Florida for free. The children get nominated by their doctors and nurses and out of the thousands of nominations they narrow it down to about 20 kids per region. My nurse and my gastro team nominated me

to go and I was lucky enough to be selected. I actually found out I was going while I was admitted so as you can imagine that cheered me right up. The holiday is meant to be a respite for us all to feel like 'normal kids' for ten days and honestly it was the most amazing experience. I made lifelong friends on that trip and have memories that will last a life time. The full experience was something I will never forgot and made me realise I wasn't in this alone. It taught me how to be a bit more independent and gave me the confidence I needed to be able to talk about having a health condition and be able to deal with it in day to day life.

I just want to leave you with the best advice I can give. When you feel low or sad write down everything that is getting you down then write next to each of those things how you can sort it or what you can do positive from that. Set goals and aims for yourself so you're constantly striving to do better. Always remember that you have always got someone to talk to no matter what. You are never alone in any of this there is always going to be someone who is there and cares even if you don't know it.

There's always a light at the end of the tunnel even if it seems to go on forever!



# family information days

So far this year we have had two of our Family Information Days in Plymouth and Newcastle. At the Plymouth event Thomas Baker, a young person with IBD, spoke about his experiences. Below is his story in his own words.

**Massive thanks** to all the young people who have showed great confidence speaking at our events this year!  
Cecile Belcher, Geoge Budden  
Hamish Sharp, Hannah Sewell  
and Flynn Taylor

Hello. My name is Thomas and I am 11 yrs old. I live with my Mum, Dad, older sister Rowenna and my best friend, Chewie-my dog, here in Plymouth.

I was diagnosed with crohns disease nearly 3 years ago when I was 8 yrs old. It started with me losing weight, having tummy pains and feeling and being sick. I was having too many trips to the toilet(which were not pleasant, if you know what I mean!). I was being sick sometimes 6 or 7 times a day.

I tried a dairy free diet but my sister got to eat **Easter eggs** when I couldn't! I tried gluten free foods too as my Aunty is a coeliac. I didnt like that! The bread was like cardboard.

Mum and Dad took me to the GP over and over again but no one knew what was wrong. I went to Exeter Nuffield hospital for an ultrasound scan to see if anything was lurking inside. The gel was a bit cold for my liking but the good news was **I wasn't pregnant!** The scan didn't show anything.

Next I had an MRI. That was cool! I felt like **James Bond!** That didn't really show anything either.

After more GP visits I saw my Plymouth Consultant- Dr Broad. He then wrote to Dr Wiskin in Bristol to ask if I could have an endoscopy and colonoscopy.

I was worried about being put to sleep but I watched a video about it which made me feel a bit better. Well, who would be happy about having a tube down your throat and up your **(cough,cough!)**. Not nice!!

We went to Bristol and stayed in a hotel to do the bowel prep the day before. Bowel prep is **DISGUSTING** and you can only eat orange jelly! After the procedure we saw photos of my **beautiful digestive system** but it wasn't very beautiful. I had lots of ulcers and crohns was diagnosed. It was mainly in my stomach.

Afterwards I was starving and I had the **2 biggest sausage baps ever!** My parents also bought me a new bike, so that was a good outcome.

I had to go on a liquid only diet for 8 weeks **(so boy, did I deserve that bike!)**. I had modulen to heal my body and I couldn't eat anything except foxs glacier mints and full sugar gum. Modulen is **YUCK!** It was hard.

I took omeprazole and azathioprine too. After a short time I felt better, I stopped being sick, I gained weight and was happier and healthier. I could swim, ride my bike, play football and cricket again. Even going to the loo was 'normal' **and I wasn't used to that!**

Life was good for some time, then I started to flare again and Dr Broad gave me some steroids. Ive had steroids twice now and they make me better and build my muscles... BUT when I stop them, I get poorly again.

Now I'm trying a new drug - infliximab. I have this as an infusion into my hand or arm every 6-8 weeks at hospital. It's a full day there but it's not so bad- 1 full day of my ipad or phone **without my parents moaning at me to get off a screen!** I get sweets to take too, and sometimes a day off school (but my mum tries to book it in the holidays!).

Crohn's is tough, but Ive had fun times with it too. I take part in the Plymouth Walkits, I have helped organise a 'Crazy for Crohns' day at my school, Ive been to 'Pig Racing' and I have raised lots of money for Crohns and Colitis and Cicra. I have penpals who have Crohn's like me.

I think there will be a cure for Crohn's soon because lots of research is being done. I have lots to look forward to so there has to be! I will keep fighting!! I'm off to Senior school in September and I'm looking forward to the new challenges that brings. When I am 12, I want to join army cadets.

Thanks for listening to me and hearing about my crohns journey.

Our next Family Information Day will be in London on November 16th.

Dates for next year are yet to be confirmed. We hope to hold events in Cardiff, Glasgow, Belfast and Liverpool.

To reserve a place, or find out more email [support@cicra.org](mailto:support@cicra.org)





# happy retirement, Dorrie!

Here we celebrate fundraiser Dorrie Mottram, who over the years has raised over £82,000 for children with IBD.

A wonderful fundraiser who many CICRA members will have heard of over the years, especially in the West Sussex area, is taking a well earned rest after raising, with a group of loyal friends, over £82,000 for CICRA. As always, Dorrie is reluctant to take credit for the wonderful fundraising events that have been organised in her village of Hassocks, but without her continued efforts CICRA and its research programme would have been much poorer.

It all started at the end of 1989 when Dorrie's son Kevin was diagnosed with Crohn's disease. Together with friends, who had a family member suffering from the same illness, they organised coffee mornings and musical events. These events were not only very enjoyable and successful they gave valuable publicity to local communities of this serious illness that was still little heard of in the early 1990's.

The last coffee morning was held in 2005 but the very popular 'Summer Variety' concerts continued every year, the last being in June 2018. CICRA is extremely grateful to those who gave their time freely to help, including the Friends & Neighbours Group and everybody involved in the concerts, whether it was in the production itself, behind stage or front of house. Also to the Hassocks Community for supporting the table sales and filling the Adastra Hall for the concerts. Dorrie is adamant that in all her fundraising she has just been the leader of a group of people but without a wonderful leader, this local CICRA Group would not have been active for such a long time. Dorrie avoids all personal publicity but on behalf of all children with IBD, and their families, I convey our most sincere thanks and wish her a healthy and happy retirement from fundraising.

Margaret Lee



## Thank you to all of you who go the extra mile

We regularly receive generous support in the form of a single donation, a regular standing order or Direct Debit, an extra gift sent with draw tickets or added to Christmas card orders. We would like to thank everybody, too numerous to list, who have contributed in this way. You can be sure that your generosity is very much appreciated and helps make a big difference to children with IBD.





# running for children with IBD

## go Laura, go!

Laura McNaught completed the Edinburgh Running Festival (5K) in her personal record time of 33 minutes and 24 seconds – she has every reason to feel pleased with herself. Laura raised over £300 to help improve the quality of life for her brother Mark and many others.



## Callum Noble

Thanks to the keen efforts of Callum Noble at the Brighton Marathon, CICRA was awarded over £500 through sponsorship, thanks in particular to the pupils, staff and family members of Upton Junior School.

## Robert Muncaster

Robert Muncaster ran the Sunderland 10K and raised £155. Great achievement and good practice for a bigger run next time...?

## you can run for CICRA too!

**We have places for runners in two fabulous half marathons in Cambridge and London for March 2020.**

- Unforgettable journeys through incredible cities
- Both are flat courses – great for first timers or those of you looking for a PB
- Cambridge Half Marathon is one of the UK's biggest running events, with 10,000 runners
- Entering The Vitality Big Half in London gives you free access to The Vitality Big Festival to relax afterwards with your family and friends.

Get in touch on [fundraising@bicra.org](mailto:fundraising@bicra.org) or call us on **020 8949 6209** to book your place or ask us to find an event to suit your location and interest!



## autumn serenade...

...was organised by the Inner Wheel Club of Wellingborough Hatton in Northamptonshire on Saturday, 4th May as a fundraising evening in aid of CICRA as part of the President's chosen charity fund for her year. Nick Posford came to give a most interesting talk about CICRA's work in November 2018 and members of the club were keen to support it in some way.

A lovely time was had by all in an autumn-time decorated hall with bright CICRA balloons, as a musical serenade was provided by local singers, Jonathan Reynolds and his son, James. They brought along two of their singing pupils to add delight to the programme as CICRA is a charity working for young people and children. That was an especially nice touch, and Jessie and Lily were simply amazing!

The programme consisted of a great mix of music from swing to musicals and popular hits of today. A delicious buffet supper was served in the middle of the evening and by the end we let our own Robbie Williams entertain us!

Everyone had great fun and a total of £657.37 was raised for CICRA so we were very pleased indeed by the support on the night. The club's total amount raised for CICRA will be sent when the Presidential year ends. We hope our contribution will make a little difference to CICRA's terrific work.





**Raised  
£7,000!!**

## pedal power

In March, Iolo Edwards rode an incredible 100 miles from his home in Merthyr Tydfil to Brean Sands in Somerset, over 2 days with members of Dowlais RFC, where Iolo previously played scrum half in the junior section. He raised nearly £7000 split between CICRA and Noah's Ark Children's Hospital. Having suffered with acute severe Ulcerative colitis in 2018 and requiring life saving surgery, Iolo went on to impress Sir Richard Branson when bumping into him on holiday in Spain, with his own stoma bag designs because he found the ones offered were either old-fashioned or designed for young children. Iolo told Richard about his other business ventures too and the world-famous serial entrepreneur and philanthropist was inspired to share his three best pieces of advice for young and aspiring entrepreneurs.

Thank you for all your support Iolo - we think you're amazing!



**Raised  
£1,000!!**

## question time!

Jill Fanner and her friends in Dundee ran a great quiz night at their local pub and exceeded their target by raising over £1000 for CICRA – fantastic team work!

**A quiz night is a great way to raise money, and get your friends and wider community together for some friendly rivalry!**



## crafty Ruby

A huge thank you to Ruby who has been another inspiring young person who after a lengthy spell in hospital wanted to help other children suffering from IBD. Ruby has spent time creating amazingly neat and accurate Hama-Bead figures. Not stopping there this enterprising young lady travelled from door to door selling them and raising £80. Fantastically enterprising



**Raised  
£250!!**

## if you don't ask...

Gail Crampton, helped by daughter Isabelle, operated a raffle in their local corner shop and raised nearly £50. Every little helps says Gail and then managed to persuade her employer, Holland and Barrett, to donate £250. Thank you, Gail

## open house art

Yvonne Law opened her beautiful garden to others and hosted an art event raising over £300 for CICRA.

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

## talented bunch

Sixth formers, at Hailsham Community College (Academy Trust), whom I have termed as 'The Fundraising Angels' organised an event called, "Teacher's Got Talent Concert – This One's for You." As you might well imagine the teachers performed and they raised a grand total of £497.61 for CICRA. Sounds great fun and they must all have a great deal of talent!

## the three peaks

A team from Camozzi Automation Ltd, including CICRA supporter Lee Hargrave, braved the 3 Peaks Challenge and raised a fantastic sum of £1062.50 for CICRA. Hope that they felt rejuvenated after that challenge!

**Raised  
£1062!!**



# cake feasts

across the country to mark World IBD Day



## it's a family affair at Mala Dance School

At 13, Clare Wagstaff (now Beesley), a budding ballet star, was lying in a hospital bed at St. Bartholomew's Hospital London, having been given the news that she had Crohn's disease. These were still early days of seeing children with any form of IBD and Clare's parents, Angela and Tony, were beginning to think that Clare's hopes of making dance her career, had been dashed.

However, Clare had other ideas. With excellent care from the team at St Bartholomew's, headed up by our Life President, Professor John Walker-Smith, her mind was made up. Despite the ups and downs of having Crohn's disease, she would continue to follow her dream. Having been told by a GP that there wasn't a doctor in the country who would approve of her going to dance college, Clare will always be grateful to Professor Walker-Smith for sending a letter stating that she deserved to be given the chance to do her training at college. The rest is history.

Angela and Tony were not to know just how involved they would become in this dream. Clare now has a very successful dance school, with 4 studios and 280 students. Family support is the key with husband Craig, and Angela and Tony always on hand, particularly if Clare has a Crohn's flare. Unfortunately, Angela and Tony's family are one of the rare families who have more than one

child with Crohn's. Their 2nd daughter Lisa was diagnosed as an adult and 3rd daughter Heidi has a kidney disease which is linked to Crohn's. They all cope really well and all three have children. Angela and Tony feel very blessed to have a close family with 11 grandchildren. Two of Lisa's little ones Alannah 6 and Xander 4 are keeping up the family tradition by learning ballet, tap and modern with their Auntie Clare.

Some long term CICRA members may remember a very upbeat Clare coming to a Family Day at Bart's quite late in her first pregnancy, to talk about how far she had got with her dream. Isabelle is now 19, followed by Madeline, 15 and Oscar 12. Clare and the family are an inspiration on how to get as much as possible out of life whilst coping with fluctuating Crohn's disease.

We are very grateful to Clare, Angela, Judy and Catia for recently organising a Cake Sale at the Mala Dance School, raising £200 for CICRA, and to Madeline who made some very tasty cup cakes to go with those kindly donated by parents of the Mala students. Mala Dance are very grateful for this support and of course to the wonderful children for eating the cakes!

Margaret Lee







## Mufti and muffins!

Harry Steart and his school raised a massive £702.50 by selling cakes and the school wore non-uniform. Great work Harry and many thanks to mum Natalie for encouraging the school to support CICRA!

**Raised  
£702!!**



## marathon of traybakes

Lisa Baugh and friends (x5 separate events) hence termed "Isla's Cake Sale Relay" presented lots of fun raising £278.50. This cake sale marathon was assisted by the Baugh and Sturgess families Beaus lemonade stand, Daniel Owen & Norwegian Log Buildings. Isla is pictured below



## spread the word at work

**Raised  
£214!!**

CICRA member Paul Welton left a copy of the latest newsletter in the staff room at work. As a direct consequence Emma Barber and Andy Long of Gilberts (Blackpool) Ltd organised a cake sale and raised £214 for CICRA. Brilliant what a newsletter can do!!



**ASE Global of Manchester** also organised a cake sale and raised £56.63 for CICRA – Great work!

## aren't mums amazing!?

CICRA member Tor, and son Ollie, have really taken the fundraising bull by the horns and are on a mission! Ollie's school ran a "Wear It Purple" mufti day and Ollie and Tor organised Ollie's Cake Sale in their back garden. These ventures raised £475.



**Raised  
£475!!**

Ollie is wearing the wrong T-shirt but CICRA did receive the funds!

Subsequent to this, Triumphant Tor raised hundreds by requesting donations for CICRA rather than presents in honour of her recent birthday. Tor's latest fundraising venture will be with a couple of friends, they intend to join in a local fun run to raise even more funds. We really are most grateful to Tor for her energy and drive channelled into helping CICRA.

## more cake please...

If you would like to host your own CICRA cake sale, why not kick off the festive season in style with a special cake-filled event marking Crohn's and Colitis Awareness Week, to raise vital funds to support children with IBD.

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!

Just £50 can help fund our new leaflets for schools or help young people with our symptom tracker, to help children and their families understand and cope with their condition.





## a community affair

Aaron has managed to reach beyond his direct family, and inspire those of the wider community including neighbours and the local church parishioners for his flavoursome feast of cake fare.

Parents and grandparents raised nearly £2000 for CICRA by organising cake sales and obtaining direct donations from neighbours. Thank you so much.

Aaron, pictured during one of his hospital visits.



**Raised £2,000!!**



**raised £200!!**

## garden party with sprinkles on top

Sarah and Daisy Pitt decided to hold a cake sale in their back garden. Daisy wrote her own speech and delivered it to her audience too. These tremendous efforts raised an impressive £310.20. Here is part of Daisy's inspirational speech:



## school cake success

Sarah's children, Elsie and Finn held a mufti day and cake sale at their little school, this was an excellent achievement as they raised £200.

**“Sometimes I feel a bit lonely and upset at school as my class don't really know what I have. They are always asking things like “ what do you have and what does it do?” and “will your thing go away?” and it can sometimes be a bit embarrassing to talk about it in front of them but I want to help raise awareness. My bake sale meant I can talk to people about the condition and help them to understand. CICRA has helped me lots as it means I can talk to others about how I feel. I've made some good friends on epals and they help me feel less alone. I also enjoy writing stories about children with IBD as superheroes.”**





## 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:

### James Gallacher

Uncle of a Crohn's sufferer who would have been happy to know that monies donated will go to a very worthwhile cause.

### Peggy Williams

remembered with fondest love by daughter Sian and family, Sister Gill O'Neill, Tony and Gareth.

### Gillian Allen

Beloved daughter of Mary and Ron Harraway. Loved and respected by all her colleagues and friends from all over the world.



## CICRA Summer Draw 2019

Robin Roberts, CEO of the Sutton Housing Society drew the winners of the CICRA Summer Draw on Monday 10th June 2019, at the CICRA offices, Pat Shaw House.

### Below are the winners.

Prize	Ticket No.	Name
1st Prize	02521	Mr H Arthur, Derbyshire
2nd Prize	20280	Ms D Burgess, Middlesex
3rd Prize	15535	Ms S Hancocks, W Midlands
4th Prize	05621	Mrs A Snell, Pontefract
5th Prize	48281	Mrs R Ramsden for CICRA*
6th Prize	03882	Mr R Mills. Monmouth
7th Prize	47142	J Cull, Essex
8th Prize	10663	Mr J Kyle, Cambridge*
9th Prize	35452	Mrs F Blackman*
10th Prize	02244	Mrs B Morrison, Derby
11th Prize	11662	Ms P Steven, Bucks*
12th Prize	28854	Mrs J Baskerville, Cheshire
13th Prize	32813	Mr Underwood*

\*Given back as a donation to CICRA

Many thanks to members who either bought tickets themselves or sold tickets to support this 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.

Mrs Margaret Lee, Promoter 17.7.19

## the 200+ club winner list 2018

Welcome to those of you who joined the 200+ Club recently. Your support is very much appreciated. All funds are split 50/50 between prizes and research - a real 'win-win' situation. If you are not a member yet but would like to help us raise funds by this method please ring the office on 020 8949 6209 or email [margaretlee@bicra.org](mailto:margaretlee@bicra.org) and we will send you the forms.

### January

87	T Hearn, Berkshire	£50
123	M Watson, Aberdeen	£50

### February

71	S Parsons, Swansea	£50
66	C Shipp, Sussex	£50

### March

128	G Pritchard, London	£250
79	M Bines, Kent	£75
89	M Coupe, Lancs	£75

### April

109	L Browning, Dumfries	£50
196	C Collett, Sussex	£50

### May

82	S Durman, Guernsey	£50
243	L C Smith, Cheshire	£50

### June

209	S Bramble, Conwy	£250
18	H Brady, Essex	£75
255	D Ferguson, Oxford	£75







Newcastle - Sat 5 Oct  
East Anglia - Mon 21 Oct  
Belfast - Sat 2 Nov  
Cardiff - Sat 30 Nov  
More to come, so please  
register wherever you  
may live

# workshops for young people with IBD

Being a young person isn't always easy; pressure to work hard at school, have 100% attendance, achieve good results and make big decisions about your future! Friendships can be difficult as you try to find your way through it all. As if that wasn't enough, then you are hit with a diagnosis of IBD!

At times, it may feel like nobody understands and at other times you might not want people to mention it, you just want to get on with life. The unpredictability of IBD can throw up all sorts of challenges both physically and emotionally. School and socialising aren't compatible with an IBD flare.

Whilst it is understandable to feel angry and upset with a sense that life just isn't fair, it is important to remember that there are other young people out there going through a similar thing. You're not alone!

The workshops we are offering to young people with IBD are about acknowledging that first and foremost you are a young person, you are not defined by your IBD diagnosis. There is no denying that it can make life more difficult but meeting other young people in a similar situation and sharing experiences in a relaxed environment could make you feel better.

**These events are in addition to and separate from our family IBD information days**

## The workshops are intended to help with...

- Increasing your **self confidence**
- Recognising and **managing difficult emotions** in a healthy way
- Feeling **more in control** of decisions that affect you
- Developing some **new ideas/ techniques** to help you relax
- Giving you a strong sense that you are still a young person capable of **achieving and being happy** (even if you don't get there in the same way as your peers!)

Register at [cicra.org/workshops](https://www.cicra.org/workshops)

Give Laura, our family support worker, a shout if you have any questions  
[laurapalmer@cicra.org](mailto:laurapalmer@cicra.org)