

# 40 years – but what more needs doing?

**Anniversaries are often a time to celebrate and reflect. For CICRA, our 40th anniversary will be tinged with some sadness: more children are being diagnosed with IBD.**

Treatments today are much more advanced than when we started in 1978, in part due to medical research funded by CICRA supporters.

However, Crohn's and colitis remain frustrating and difficult conditions for children and their families to live with. There is still an urgent need for more research but also better care and greater understanding within society. We want children living with IBD to have the happy childhood they deserve.

Is there enough psychological support for children dealing with these long-term conditions? Do colleges and universities really understand the great potential of a child who may have been forced to miss crucial stages of their schooling? Are employers aware of the pressures faced by adults caring for a child with IBD?

We want to know what you think. We are developing our plans for next year and beyond, and we want to be sure that we are taking action on the

things that matter to you. What is the greatest challenge facing children and families affected by IBD today? What is your priority for us to focus on?

Please fill in our special survey online at [bit.ly/cicrasurvey](http://bit.ly/cicrasurvey), so we can plan for the future based on the views of the people that matter most – children living with Crohn's and colitis, and their families.

CICRA supporters have had a huge impact, making a big difference for families and children. Medical professionals caring for children with

**YOUR  
OPINION  
MATTERS**

IBD every day started their careers thanks to CICRA supporters funding their research. Families talk positively about the support they receive at CICRA information days, and from booklets and our website. You can read inspiring stories inside about families helping families, still at the heart of our work.

In celebrating our 40th anniversary, we are proud of what we've achieved and the difference we have made, but our ultimate goal is children leading full and happy lives, unaffected by IBD. We won't rest until we're no longer needed.

Very Early Onset IBD is a new arm of the traditional IBD. Paediatric gastroenterologists are seeing more and more children that fall into this category every year. Despite the ongoing research, very little is known about why this is on the rise. Having such a serious condition at an early age causes understandable concern for parents, particularly if it has taken some time to get an accurate diagnosis. CICRA is drawing on our medical experts and researchers to create much needed additional information resources for parents and families. These resources will also benefit doctors and nurses and help them support these children and their families. **We hope to have specialists in VEOIBD at our Family Information Day in Birmingham on 14th October.**

### Crohn's in Childhood Research Association

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You can find us on many social  
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username: **cicracharity**

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# Trustees' Report

## Letter from the Chair

Dear Friends

I would like to welcome to our team, Nick Posford, CICRA's new CEO. Those members who came to our last family day in Cobham will have met Nick and heard just a brief outline of his background and his aim to increase even further the support and research that CICRA has been able to give families affected by Crohn's and colitis over the last 39 years.

We are very proud of what we have achieved but very conscious that there is still much to do. With more children being diagnosed, and especially the increase in the very young, Nick will have much to start on. You will see on page 3 his first thoughts and a short summary of CICRA's past achievements. The Trustees will be working alongside Nick to help him bring our plans to fruition and are very confident that under his leadership CICRA will go from strength to strength.

We also thank Richard Hansen, our Medical Director, not only for his invaluable help at the last two family day meetings but also giving us his thoughts (page 10) on the meeting from a doctor's viewpoint. It is great to hear that he is going to work closely with Nick.

Next year we will be celebrating CICRA's 40th Anniversary but the real celebration will be if we are able to substantially increase our research and support. If you can help us achieve this, please get in touch on [support@cicra.org](mailto:support@cicra.org).

Best wishes

**Margaret Lee**

*Chair*

## Family Day in Birmingham

CICRA's next family day will be held at **'theStudio'** in **Birmingham** on **Saturday 14th October 2017**. As is usual on these days there will be something for everyone – parents can learn more about their child's condition in a relaxed atmosphere, young people can meet with others of their own age and there's entertainment for younger children. If you don't have an invite and would like more information please contact [support@cicra.org](mailto:support@cicra.org).



**Our Birmingham and Cobham meetings are sponsored by AbbVie.  
AbbVie has no input into the meeting programmes.**

## CICRA's new CEO – here for you

Ever since joining CICRA at the end of June, I have been impressed by the dedication of our supporters and volunteers, the hard work of our trustees and our small staff team, and the incredible commitment of so many researchers and healthcare professionals. Like all of them, I want to make sure every day counts.

The increasing number of children being diagnosed with Crohn's and colitis, including babies and young children with very early onset IBD, is deeply concerning. The impact of a diagnosis extends to the whole family and it is important that children, parents and siblings feel well informed and have somewhere they can turn for support.

Your views are important, and help us understand what you need and what we should prioritise. Please complete our online survey at [bit.ly/cicrasurvey](http://bit.ly/cicrasurvey) so we can create a strategy for next year and beyond.

Having previously worked for several health charities, I'm honoured to work for a charity that has achieved so much for families affected by IBD in children, as you can read below. But we mustn't rest on our past achievements, however impressive they have been.

Some things do need improving. Our website is outdated and difficult to use on mobile devices. We need to use language and images for different age ranges and we need to make more use of social media. We'll continue to need powerful images of real people



New CEO Nick Posford

and real stories about how IBD can impact childhood and families.

All of these changes will help CICRA do more top quality research, connect families and children together so they can help each other and provide up-to-date information. You can always reach me on [nickposford@cicra.org](mailto:nickposford@cicra.org) or follow me on Twitter [@nickposford](https://twitter.com/nickposford)

## Our research impact for children and young adults in ten steps

**1 Developing paediatric gastroenterology (childhood digestion and bowel) as a specialist medical area:** in 1978 there were no paediatricians specialising in Crohn's and colitis in children so CICRA set up a Fellowship Scheme and this funding helped push the specialism to be recognised.

**2 The first paediatric gastroenterology laboratory in the UK** was set up by CICRA in 1982 at St. Bartholomew's Hospital in London. This facility is now world- recognised for its excellence and has expanded and moved to laboratories at the Royal London Hospital.

**3 Many of today's leading doctors treating children and young people for IBD** had their specialist training through our research schemes.

**4 More children with Crohn's and colitis can now see an IBD specialist** because the doctors we funded previously are training a new generation of doctors.

**5 Continuing studies by three CICRA Fellows (1983–1996) led to enteral nutrition often being the first line of treatment for children.**

**6 New treatments being taken forward for clinical trials,** such as the drug Mongersen, which followed early work by a CICRA funded project in Southampton investigating the role of Smad7.

**7 Identifying an increase in the number of children and babies being diagnosed** with inflammatory bowel disease, through projects in Scotland and Southampton.

**8 Spreading CICRA-funded expertise nationally and globally.**

Our bursary awards help researchers attend events like the world's largest gastroenterology conference – Digestive Diseases Week.

**9 Through CICRA funded PhD studentships, encouraging young talented scientists to follow a career path of researching Inflammatory Bowel Disease.**

**10 50 CICRA funded scientific projects have added a wealth of knowledge** about Inflammatory Bowel Disease, including current projects on genetics, bacteria, diet, prevention, pharmaceutical options and psychological stress.

If you want a world where children with crohns and colitis can lead fulfilling lives, help keep our ground breaking research going: [cicra.org/donate](http://cicra.org/donate)

## CICRA funds mindfulness study

Last spring CICRA's Advisory Panel recommended the funding of a mindfulness-based stress management project titled 'Psychological stress and inflammation in adolescents with IBD'.

Dr Jackie Doyle, who is overseeing the study, came along to the CICRA meeting in Cardiff to demonstrate what they were doing and to explain what they hoped to gain from this research. The audience were really interested and some very good questions were asked by younger members. *Below is Jackie's first report.*

In spring of last year, our team was over the moon to learn that CICRA had agreed to support us in undertaking a two-year project to evaluate our mindfulness-based stress reduction groups in young people with IBD. These groups had been running at UCLH for a number of years, with excellent feedback but up until

CICRA's support, we did not have the resources to examine whether the intervention truly improves quality of life.

So what is mindfulness? In our work with young people, we are inviting them to become more aware of their bodies, thoughts and feelings. At first

glance, this may not seem such a good idea if you are feeling unwell or are in pain. Most of us surely want to push away these experiences?

However, often when difficulties arise we react not only to the current situation but our memories of the past and worries for the future. This can in fact make the current situation even worse and sometimes we don't even realise that this is happening.

### Tools and techniques

In the groups that we are running, we are teaching young people a range of tools and techniques to develop a better awareness of this process, so that when difficulties or health problems arise, they are easier to cope with. This is all done in a group format as we believe that getting support from peers and reducing isolation is crucial.

The project began in earnest in April 2017 and since this time the team has been busy meeting with young people in the gastroenterology clinics at UCLH, happily wearing their CICRA t-shirts. The research is a randomised waiting list control trial which means that everyone recruited to the study gets the chance to be part of the groups, although at different stages.

Pictured left is Megan Hitchcock, Psychology Research Assistant, holding the first randomisation envelope, which was a very exciting moment for us all. We have now recruited 30 of the 85 participants needed for the project and have almost finished the first group involving some amazing young people.

We would like to take the opportunity to thank CICRA once again for providing the funding for this research.



*Megan holding the first randomisation envelope*

## Set up a CICRA Family Fund today!

'The recruitment team have been in the adolescent gastroenterology clinic on Tuesday afternoons where they have been busily recruiting young people. I popped in this week just before the first mindfulness group was set to begin and was pleased to see a real buzz in clinic and the team were engaging, and chatting to potential candidates for the up and coming groups.'

**Dr Jackie Doyle**  
(Clinical Psychologist)

'It's been a real joy seeing the recruitment team at our weekly team meetings with their CICRA t-shirts on and heading off to clinic with CICRA merchandise in hand.'

**Professor Deborah Christie**  
(Consultant Clinical Psychologist)



**CICRA was started by families to help other families. Our amazing community of supporters and fundraisers are often members of, or friends with, a family with a child or young adult living with Crohn's Disease or ulcerative colitis.**

Relatives and friends are inspired by the courage of children and are keen to support them. Family funds are CICRA's way of recognising your phenomenal support and showing just what an amazing difference a group of people can make – changing the world for others.

It is simple and easy to set up a Family Fund – just let us know what you want to call it and any supporters we should link to it. You may wish to call it after the family name or the specific name of the person the fund is supporting such as the West Family Fund or the John West Fund.

Where data is available, we can add up previous donations to give a current total and any fundraiser who supports the fund can be told what the running total is so they can see how their support adds to a bigger pot. We can also give you lots of ideas on how to make the most of your fund.

### **Your family's impact for other families**

A total of £500 covers the cost of seven families attending a CICRA information day to hear from medical experts about IBD, treatments and



copied. They also give children and their families the chance to meet with others in similar situations.

An amazing total of £2,000 could help provide essential laboratory equipment to one of CICRA's researchers as they help us to understand more about the causes of IBD and identify possible future treatments to help hundreds of families.

**Set up your family fund today!**  
Email [fundraising@cicra.org](mailto:fundraising@cicra.org) or call 020 8949 6209. We'll add up your previous support and start helping others get the help they need today and in the future.

Getting to university is a challenge for any aspiring student but especially when your childhood is disrupted by Crohn's or colitis. Three young adults write about achieving their ambitions despite the obstacles they have faced. IBD can impact academic results before and during university but institutions have many means of support for students with particular needs, from accommodation to academic support. If you're at university or planning to go, you have a right to help from student services.

## DON'T LET IBD STOP YOU

**Georgia Lack was diagnosed at 13 with ulcerative colitis and feels her experience gave her strength for the future.**

“ Within the space of three weeks, I was taken into hospital and underwent an emergency operation to remove my colon, leaving me with a stoma bag. I had a further three lots of invasive surgery to form an internal pouch. At the time, university seemed a long way away – GCSEs to think about first, and even though I missed a great deal of school in years 9 and 10, I was determined to succeed.

One of my favourite phrases is “you only know how strong you are when being strong is the only choice you have”. The lessons I learnt – from trying to explain the stoma bag to airport security, to having to wait an agonising three months before playing sport again, were invaluable in making me a stronger person. If you can deal with having a bag at 13, you can deal with anything university throws at you – from fresher's flu and hungover lectures to sports team initiations and all-nighters in the library!

**Emily Fairbrother has taken a different route to her degree studies.**

“ Having hidden how ill I was to my parents, I was admitted into Derby Children's Hospital in summer 2005. Growing up I felt very embarrassed by the fact I couldn't predict when I would need to go to the toilet or what would set me off into a flare up. I always tried to keep up with others my age and not let the disease affect



Georgia

me or my social life. I would often be told by my doctor and parents to take it easy!

During my A Levels I had a series of complications that led to surgery. I now have a new-found confidence and love my scar as it is part of me and my journey. I was unable to apply for university as I had no predicted grades due to all the time absent from school. I did want to work in education but did not know what the best route for me would be.

I started as an apprentice and I am now a Lead Teaching Assistant with students who have behavioural, social and emotional difficulties. My workplace is a great support as I have had many colonoscopies, MRIs, surgeries and regular infusions of Infiximab.

# FOLLOWING YOUR DREAMS!

I started my Psychology degree with The Open University in 2016, three years after my A Levels. I am aiming to gain accreditation by the British Psychological Society – but my grades need to be of a high standard all the way through my degree. I was wary of informing the student teams and my tutors about my Crohn's as I didn't want them to single me out from the other students as different. My tutors have been incredibly understanding and have even given additional one-to-one tutorials.

A good thing about the Open University is that a lot of the teaching is online, meaning if I am fatigued due to my disease, I have been able to still attend tutorials from the comfort of my bed through Skype. I have been known to study in the bathroom when my symptoms have been bad! I may be taking a different route to others but I hope to achieve my goals and have accepted it will take a little longer to get there.



Emily

**Karina Punia struggled to control her symptoms for 16 years but persistence and dedication has seen her achieve something remarkable.**



Sixteen years ago, aged 6, I first experienced my symptoms. After a year of misdiagnosis, I was finally told I had ulcerative colitis, a disease with no cure. Abdominal pain and extreme fatigue, courses of high dose steroids led to rapid weight gain and numerous unkind comments from onlookers at school. Trials of immunosuppressants, herbal remedies and anti-inflammatories meant I was on 32 tablets a day. Desperate for remission, I tolerated dairy and gluten free diets, weekly blood tests and frequent colonoscopies. This became part of my everyday life.

Steroids appeared to be the only drug that made the real difference stopping my symptoms to my dismay, which only meant that the torture from those who did not understand my invisible illness did not cease. I was hospitalised twice in the space of a year, given seven blood transfusions and my school absences increased, but this only made me more determined.

Finally, feeling as though my symptoms were settling, I persevered with my GCSEs and had iron infusions once a week during my exams as my anaemia continued to leave me feeling weak. I refused to fall behind and let my illness take control of my future so I took revision cards with me to the hospital whenever I needed to attend. Even during these tough times, I didn't apply for extenuating



circumstances or special support as I didn't want my disease to give me special allowances. I was driven to work hard to do my best.

Having a chronic illness is terrifying and unpredictable. I never knew when a flare up would come to haunt me and I was left living in fear. My doctors and nurses always did their best to ensure I received the care I needed and this inspired me. I fought my way through education since primary school to get the best grades I possibly could, and from this achieved my ultimate goal of getting into medical school. I have now completed my third year as a Cardiff medic and with two more years to go, I cannot wait to help others the way the NHS and the healthcare professionals within it helped me recover.



Karina

## The Hub Challenge

*Francesca, aged 12, attended the recent CICRA Family Day at Cobham and, during the morning while the adults were listening to the presentations from the doctors, the young people joined in a Hub Challenge. Here are Francesca's thoughts.*

During the Cobham family day, CICRA arranged a new activity called Hub Challenge, for the children. Hub Challenge is designed to help people to work in teams, have fun and encourage their confidence. We were split into groups, randomly and the staff explained the types of challenges we would be doing.

Each challenge's details were written on a card. Once a card had been selected, each team then had a few minutes to talk through how they were going to achieve the challenge. Everyone had a chance to give their view. After a few tries, my team managed to achieve our first challenge. Each team member had a chance to select a challenge card. Overall, we completed about



*Young people taking part in the hub challenge at the Family Information Day*

seven different challenges during the workshop.

However the challenge wasn't over yet, we were then asked to rate each challenge in different ways e.g.

'teamwork factor'. So again we worked in our teams to decide the ratings jointly. The Hub Challenge event was a real ice breaker as most of the children didn't know each other beforehand. There were girls and boys of different age groups in each team and the challenges really helped us all get to know each other better.

In the afternoon, we were split into groups by our age this time. I joined the teenage group. We had a chance to meet in small groups with specialist doctors and nurses who know all about IBD. We asked questions about our illnesses and discuss any worries we have, away from our parents.

I enjoyed the whole day, the hotel was really nice, the food delicious and I made lots of new friends who understand all about my condition. It's great to know I'm not alone! Thank you CICRA for organising such a great event – I can't wait for the next one!

## Natalia's story

*Natalia gave an excellent talk at the Cobham meeting telling the audience of her journey with Crohn's and we print below her story which shows her courage in battling two disabling conditions.*

Hi, my name is Natalia. I am 18 years old. I am severely sight impaired and suffer from Crohn's Disease.

Eight years ago, at the age of ten, I began to experience a reduced appetite, abdominal pains, bleeding and severe fatigue. However, by the time I was correctly diagnosed with Crohn's Disease, a year had passed, but I was successfully treated with

steroids, azathioprine and a modulen feed which I took orally for three months. This was a really challenging time for me but I eventually went into remission in 2012.

In 2012 and feeling relatively stable, I developed a passion for indoor rowing through my school rowing club and, with the support of my rowing coach, I competed at the

British Indoor Rowing Championships in March 2012 alongside the Polish Paralympic team. To my absolute delight, I won a gold medal and later that year was also announced the winner of another gold medal at the South of England Indoor Rowing Championships. I was so very happy.

However, this was all short-lived and by January 2013, I had a serious relapse. Despite trialling various therapies such as infliximab and newer biologics including vedolizumab, my condition in March 2016 seriously deteriorated. In accordance with my



Grateful thanks to AbbVie and Dr Falk for supporting our Cobham meeting



consultant's advice, I submitted myself for surgery and had an ileostomy which resulted in a stoma.

Crohn's Disease has had a huge impact on my education and social well-being. However, I maintain my sense of humour and have even given my stoma a name – but I'm not telling you what I've called it!

In my experience, it is vitally important to have consultants who are supportive and understand the daily challenges of life that Crohn's Disease presents. My doctors have shown strong empathy in their dealings with me and have been a huge source of strength and optimism. My parents

and siblings have also been very supportive.

It is also important in the school and college environment for teachers and staff to have an awareness and understanding of chronic conditions such as Crohn's. Much to my dismay, some teachers at my school still fail to realise or understand the impact of my condition. I have had to face, amongst other things, very insensitive remarks such as that I should find the energy to study and that if I cannot cope with my A levels, how will I cope at uni. However, my parents, consultants and I persevere in our attempts to educate the school as to how unpredictable Crohn's Disease can be and the impact

that it can have on my daily life. Indeed, I made a presentation to the school staff on World IBD Day. This, I think, has made a small difference.

I also take this opportunity to pay great tribute to charities like CICRA for the vital work that they do and the research that they fund into IBD.

I remain determined to confront my illnesses and to progress in my life. I cling onto the hope that one day the cause of IBD will be established and a complete cure then found.

Thank you for reading my story.

Natalia.

# Views from the Doc!

Following recent Family Days in Edinburgh and Cobham, CICRA's Hon. Medical Director Dr Richard Hansen discusses some of the issues raised that relate to his experiences and CICRA's use of social media.

### *Family days and IBD: A view from the other side of the consulting room!*

The amount of energy, time and money that CICRA puts into supporting family days is significant. Attendance is always good and families both enjoy and gain from attending. I was struck by the level of expertise we were able to present at both the recent Edinburgh and Cobham meetings – each had the participation of at least two Professors of Paediatric Gastroenterology, 3-4 other NHS Consultants with expertise associated with IBD, and also experts related to nutrition, psychology and research.

#### **International-level expert faculty**

In short, we were able to present an international-level expert faculty at these meetings for free. It should be said that each of the professionals who attends these meetings does so entirely unpaid, in their own time, and out of kindness to the IBD community. For this, we thank them, as we couldn't run the family days in their current format without them.

What does this participation "give back" to the professionals themselves though? From my own experience, I often learn more about IBD and what it really is from family days.

The gloves are off, so-to-speak, and the truth emerges – what people



*Dr Richard Hansen*

think about IBD; what questions they ask about IBD, its causes and treatments; and, perhaps most importantly, what children and teenagers with IBD have to put up with – socially, physically, mentally, medically, spiritually, etc.

#### **Needs of families**

There's only ever so much we can explore with families in pressurised 10-15 minute appointment slots, so this additional time to boost our understanding is priceless. I believe and hope that family days make me a better, more caring and more holistic physician in addition to meeting the needs of the families themselves.

In short, see you at the next one!

### *The future of CICRA and social media*

On a related note, we explored what more CICRA could do with our audience in Cobham. The fairly unanimous response from our young members was "more social media", so we're listening.



With Nick as the new CEO, and my own enthusiastic (albeit older person) engagement with social media, we aim to do more and be more on Twitter and Facebook, but also to explore new channels on YouTube and Instagram to reach out in new and different ways.



We would very much value specific feedback on what you'd like to see on social media, and if you have ideas or content for our YouTube channel in particular, do get in touch.

#### **Respect for privacy**

We're mindful of not leaving permanent and potentially embarrassing footprints behind for our younger members though, so whilst we do want to encourage people to "talk about poo" and get our messages out in terms of the impact of IBD, we also want to respect the privacy of the young people at the heart of this.

We have some ideas on how best to do this, but it's early days yet...

Anyway, do please get in touch to tell us what you think and how best we can use social media for your benefit!

## Thoughts of a 'Mum' attending a CICRA Family Day for the first time

**Hi, I'm Elliott's mum. He was diagnosed with Crohn's in January 2016 aged 14. He's had nine surgical procedures to date and has a second seton in situ to help drain fistulas, as well as all the drugs he's on and eight-weekly infusions in London – we are still reeling from it all.**

We had the opportunity to go to an IBD meeting with CICRA. I'm a member of this wonderful charity on behalf of Elliott. Sadly he has kept himself to himself since being diagnosed plus he hasn't been back to school either!

So after having a horrible infusion the day before, I had said to him that we didn't have to go to the meeting as everything in our life is about Crohn's and there will always be another time! But he knew myself and my husband wanted to go, so bless him we did!

It was held at the Hilton Hotel in Cobham which was a lovely venue – no hospital wards, needles, nurses or drugs involved! On arrival we were

checked in and given a bag with CICRA and the day's itinerary info inside, plus sticky name tags too!

The day was filled with guest speakers such as surgeons, dieticians, consultants and the charity members and three of the young adult members giving us an insight into their lives and how they cope with Crohn's/colitis.

The morning talks were incredibly interesting. The young adults were very brave sharing their life stories with everyone and we were humbled by their honesty!

The professionals were split up into rooms, which allowed us, the parents,

to have a question time with them. There had also been some activities put in place for the younger children to get together who were kindly helped by the older ones!

To sum up the day, it felt very relaxed, very informative and as parents it was so beneficial talking and listening to other parents about their lives and how they try to cope with this disease. For our son who has become a hermit and not able to open up, it has allowed him to see that he's not on his own. He was able to speak to others like himself in various stages of Crohn's/colitis which has made him stronger and he has made friends via a Facebook group.

Oh yes! There was also a raffle and goodies for sale including t-shirts with the CICRA logo on to give us a chance to give back for the excellent day! So I would hugely recommend going along to the next meeting. We will be!

Marion Baker

**Aisha Jesani, age 9, writes about the hub challenge at the Cobham Family Day**

On my way to Cicra, I felt excited to meet other children with similar conditions to me. I found the other children's stories interesting. When I was doing the hub challenge I had fun with my team mates and I really enjoyed the activities, because the challenges were a great way to make new friends. If I went again I would like to see more children doing speeches on how it's like living with their condition.

by Aisha Jesani

## I've made really good friends

14-year-old Brooke is newly diagnosed and was happy to tell us about her reaction to being diagnosed with ulcerative colitis, IBS and coeliac disease.

Hi, I'm Brooke and I'm 14 years old. I live with my mum, dad, twin sister Abbie and my dog Rico. I first started showing signs of being ill in September 2016.

It wasn't anything huge and didn't seem significant at the time. I started struggling to eat and feeling full easily but I was losing a lot of weight. I was tired most of the time, which I had assumed was down to going back to school. I only became concerned when in October there started to be blood in my poo. Originally, I kept quiet, mainly because I had never had any health problems before so it didn't seem likely that it was anything to worry about. After a few weeks, it hadn't stopped and it was getting worse so I told my mum and we got a doctor's appointment.

There were a lot of appointments where I got pain killers because I was also getting stomach pain, but the doctor was unsure of what was wrong. I ended up being booked in for a colonoscopy which was weird. I didn't mind not eating before it but afterwards I felt unwell and disgusting. Not long after that they let us know that I had ulcerative colitis, irritable bowel syndrome and coeliac disease.

It was a bit of a shock to the system, but my family adjusted alright. My grandma has ulcerative colitis and my nana had coeliac disease so we knew a bit about both. I had a course of steroids which managed to get it under control and I had a lot of other medication. This was a struggle to begin with because I couldn't take tablets but now it doesn't faze me.



Brooke (right) with her twin sister Abbie

“

It was great to be able to talk to others of a similar age

”

My school was great at accommodating anything I needed so I was back in quite quickly. Friends didn't really understand what it was at all but they

were supportive nonetheless. With all the support I was getting I slowly got better and I was in remission for around five months. In this time, I did Walk It 2017 which was an event hosted by Crohn's and Colitis UK. Me and my family raised around £600.

In June I was having arguments with my friends and the stress was getting to me. I felt quite isolated because I had things to deal with which my friends couldn't understand. During this time the blood came back. I'm not sure whether the arguments caused my flare up or not but it happened at the same time.

I was admitted into hospital for eight days while I was on IV steroids and it was a difficult time for me but I still had a lot of support from my family, and I got better again with the help of new and stronger medication. My biggest worry at the time (which sounds stupid) was that I really didn't want to miss The Vamps concert. I'm a huge fan and I was really determined to get there which I thankfully did.

Not long after my original diagnosis I was contacted by CICRA and I joined E-Pals. It was great to be able to talk to others of a similar age who are going through the same thing as you. I've made some really good friends through it such as Amy, Emma and Anna to name a few. It's always nice to hear how they're doing and to have the opportunity to support each other.

**If you have a story to tell, as a child or a parent, please let us know – [support@cicra.org](mailto:support@cicra.org)**

## YOUNG PEOPLE'S PUZZLES

Congratulations to all those who submitted the correct answer of 'hedwig' in the last Wordsearch and to the winner: **Abigail Cooper**.

### Summer Crossword

Once you have placed all the words, the shaded squares will give you another word to do with summer.

### Minibeasts Word Scramble

Unscramble the letters and when you

have found them all, the shaded squares will give you another minibeast.

Simply send us either **one** or **two shaded words**, along with your **name, age** and **contact details**, either by email to: [groups@cicra.org](mailto:groups@cicra.org) or by post to **CICRA, Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey, SM2 6AQ**. The lucky winner will receive a pack of CICRA merchandise.

This competition is open to all of our young members up to the age of 18 years.

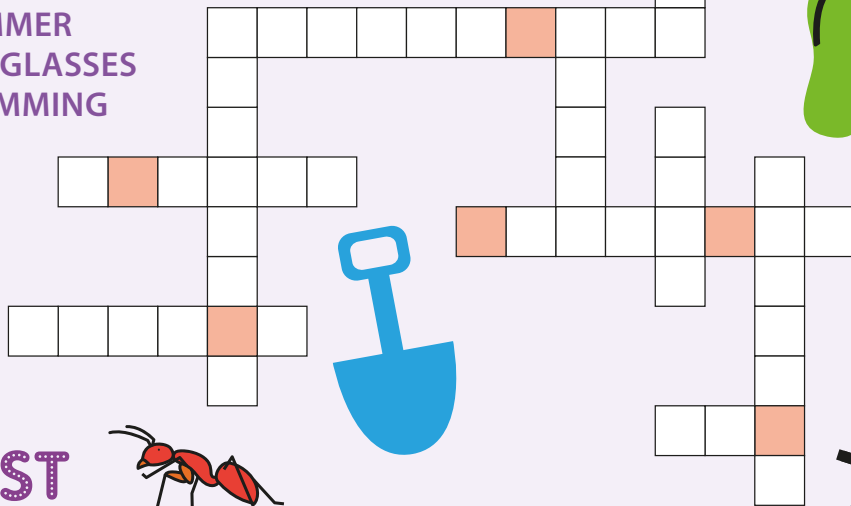
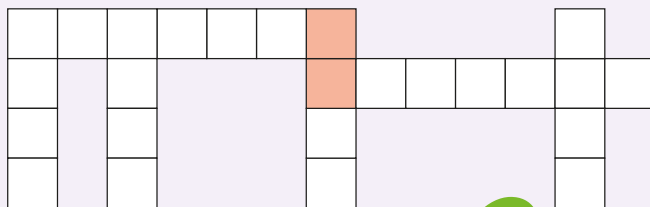
All entries must be received by **Friday 6th October**. The winning entry will be drawn and the lucky winner notified on **Monday 9th October**. **GOOD LUCK!**



### SUMMER CROSSWORD

BALL  
BIKINI  
CAMP  
CAMPING  
FAN  
HOLIDAY  
ICE CREAM  
PARK  
PICNICS  
PLAY

SHORTS  
SPADE  
SUMMER  
SUNGLASSES  
SWIMMING



### MINIBEAST WORD SCRAMBLE

TAN

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EBE

--	--	--

GUSL

--	--	--	--

MRWO

--	--	--	--	--

NLISA

--	--	--	--	--

ETLEBE

--	--	--	--	--	--

PRESDI

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TBRUEFTYL

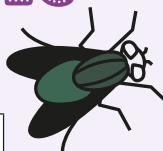
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RNGFDAYOL

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OSRAPRGSPEH

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## Getting a 'taste' of IBD



**A very important part of every medical student's training is making the decision on what particular aspect of medicine they will specialise in.**

That could be emergency medicine, cardiology, urology etc but one of the roles of the British Society of Paediatric Gastroenterology, Hepatology & Nutrition (BSPGHAN) is to encourage the doctors of the future to consider a career within the field of IBD.

BSPGHAN recently held a second 'Taster Day' for Royal College of Paediatrics & Child Health (RCPCH) trainees and junior members of the Associated Health Professionals (AHP) who are considering a career pathway within Paediatric Gastroenterology, Hepatology & Nutrition (PGHAN).

The day was held in June at the Education Centre at the Royal London Hospital in Whitechapel, and we here at CICRA were delighted to be asked to attend, along with our friends and colleagues at the Children's Liver Disease Foundation (CLDF). It was a great opportunity for the attendees to hear all about what the world of Paediatric Gastroenterology has to offer, and to meet Consultants and other esteemed health professionals already working in the field.

Indeed, it was a credit to BSPGHAN that there were so many Consultants and specialists who had taken time out to talk to the trainees about the wide variety of career opportunities that are available within the world of IBD. Sessions were offered on a full range of specialties including research,

psychology, diet, pharmacology, stomas and endoscopy.

This was a most worthwhile event for CICRA to take part in as it is very likely that some of those attending the day will be looking to us for funding in the future. Hopefully we will play an important role in helping them become the paediatric doctors and specialists in IBD for future generations.

Grateful thanks to everyone involved in this really inspirational day, especially Dr Sandhia Naik the chair of the BSPGHAN Education Committee who was instrumental in putting it all together, and whom many of you will have met at our Family Days.

**Paul Cooper, Trustee**

## St. Marks IBD Open Day – IBD in focus

**We were invited to attend an IBD open day with our advice and literature at St. Marks Hospital in Harrow (North London).**

St. Marks holds a unique position as the only hospital in the world to specialise entirely in intestinal and colorectal medicine. It's a national and international referral centre for intestinal and colorectal disorders, and recognised as a centre of excellence by the World Organisation for Digestive Endoscopy.

The morning session saw talks on the hospital's history, latest information on IBD treatments, how bowels work and

the important role of specialist nursing staff in the treatment and wellbeing of patients.

### Range of talks

The afternoon saw a further comprehensive range of talks. Of special note were Dr Yoram Inspector (Cons. Psychiatrist) who gave a fascinating insight into his work with IBD patients and offered practical tips to help cope with the 'bad days', and also a much more unusual talk by Uchu Meade (IBD Pharmacist) who was keen to emphasise what a great source of help and information your pharmacist can be to you when dealing with your IBD flare up.



We're grateful to paediatric IBD nurse Kay Crook, Tracey Tyrrell, Dr Warren Hyer, Dr Ailsa Hart, Monica Waga and the rest of the team at St. Marks for inviting CICRA to their very informative day.

**Paul Cooper, Trustee**

# Edinburgh Family Day

On an unusually sunny March day, families heard from Professor Wilson about CICRA-funded research in Scotland, Dr Rachel Brackenbridge on psychological issues, Dr Richard Hansen on new treatments, Gregor Walker on surgical options, Heather Grant on diet & nutrition and Dr Fiona Cameron on IBD services in Scotland. During the day, Professor Nick Croft stood down as CICRA's Medical Director and proudly passed the 'Crown' over to Dr Richard Hansen.

## Warm and welcoming Edinburgh Family Day

As always, youngsters were star turns with Colin Galletly talking about living with IBD and Grace Warnock (accompanied by mum Judith) 'interviewed' by Pam Rogers about her phenomenal campaign to increase awareness of hidden disabilities, especially the use of disabled toilet facilities.

Special thanks also to Michelle Nolan and Maureen Kinney who assisted!

### 15-year-old Colin spoke about his condition beginning just after his 11th birthday:

Initially blood in the toilet alerted and alarmed his parents followed by pain or discomfort. Colin was eventually diagnosed with IBDU (unclassified inflammatory bowel disease). The condition progressed and at one time Colin was taking 20 pills a day with talk of possible surgery. However an infliximab infusions resulted, so far, in a remarkable improvement

and he is currently down to 8 pills. With a suppressed immune system, unfortunately, he is more open to colds etc. and is liable to bouts of fatigue – common amongst youngsters with IBD but obviously very frustrating at this age. With his symptoms currently under control, Colin finished his talk on the positive point that others should take heart – individual treatments can help them lead a normal life despite the condition.

### Katie Veitch, age 11, has Crohn's and gives her view of the day:

First of all, I really enjoyed the presentation about hospital passports and I would love to find out more about them!

The lunch I had was delicious and I met a boy from my school who I didn't know also had Crohn's. I also sat at a table with a lady whose daughter has Crohn's and used to go to my school too!

I really enjoyed my afternoon with the entertainer, I met lots of really nice people, made lots of new friends, and played exciting games. My favourite game was dodgeball because it was quite challenging, but good fun to play!

At the end of the day, I was so happy because I won an electric toy in the



Katie Veitch

raffle and me and my brother enjoy playing with it.

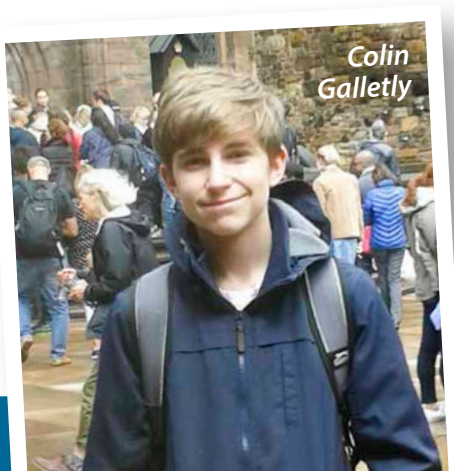
### Katie's mum, Alison, reflects on the day:

My husband and I brought Katie along and we all enjoyed it. The day was very well organised and to gather all these professionals together was quite amazing! Morning presentations were very informative and interesting. We met some parents, swapped e-mail addresses and have kept in touch. It's reassuring to know there are others out there that we can share our worries and questions with.

### Adeel Riaz & Hashir, age 9, made a long journey to be at the Edinburgh meeting necessitating an overnight stay but they thought it was worth it:

My main expectations were that Hashir could meet children with IBD so he could share his own experiences. During the children's activities Hashir popped back occasionally to tell me he was enjoying himself very much. Although mealtimes are generally a nightmare, this lunch was totally stress free. He even went back for seconds! Why can't all mealtimes at home be like this?

I got a lot out of the afternoon group discussions with other families and health professionals. It was lovely talking to other parents and sharing tips and techniques about dealing with day to day issues. My only regret is that the day was over too quickly!



Colin Galletly

## Our amazing fundraisers



**Katharine Henley** raised an outstanding **£2,500** when she completed the Thorpe Park Half Marathon at the end of February. (pictured below)



**Joanne Chilcott** continued her frequent fundraising efforts by running the Brighton Marathon in April. A fantastic achievement and another **£1,200** raised for CICRA! (pictured below)



Several members of **Nelson and Colne College** raised **£387.50** when they ran the Burnley 10k.

**Gerry Gallagher** raised **£107.50** running the Glasgow 10k in June. A well-attended event, **Michelle Del Piano, Donna Taylor** and **Claudia Singleton** all took part in the Manchester Colour Run on July 1st. Collectively, CICRA participants raised **£1,042** for this event – a massive thanks to all who fundraised for us! **Victoria Penston** ran the Derby Half Marathon and raised **£352.74**.

**Chris Dorkes** participated in the Man vs Lakes Marathon Challenge



in early July. Chris raised **£1,568.75** for CICRA. Man vs Lakes is classed as one of the most difficult marathons in the country as 90% of it is off road over the hills in Cumbria. Incredibly, due to a charitable work scheme, for every pound raised, another two pounds was donated by the St James's Place Foundation to various children's charities. (pictured above)



**Lauren Crimmins** completed an impressive abseil and raised an incredible £2,724 to split between CICRA and GOSH, to make **£1,362** for CICRA. (pictured right)

**Sarah Carroll** raised an astonishing **£1,363** for her sponsored skydive. (pictured below)



**Simeon Adams**, along with teammates **Sam, Jonny and Sarah**, took part in the Samworth Brothers Charity Challenge – and won it! The Samworth Brothers Charity challenge involves 9 hours of navigating, running, mountain biking & canoeing and other 'challenges' across the Lake district. Winners' prize money of £750, added to their fundraising of £770, gives CICRA a total of **£1,520** for their amazing efforts.





## CYCLING

**Can you ever really prepare for 300 miles on a bike? Actually, yes, it turns out you probably can, reports Oli Monks.**

The London to Paris Bike Ride is the seventh of the nine challenges I've done as part of the Nine for Nicky fundraising campaign I've been doing to raise as much money for and awareness about CICRA as I can.

The first day began in Croydon; the cycle route took us through the Kent Downs and out towards Dover for our ferry to Calais. I quickly developed a real animosity to any sort of hills or – a favourite phrase of the trip – 'undulating routes'. The day's route was 86 miles, finishing with our arrival in Calais.

The second day saw us cycle through lots of French countryside all the way to Arras. We'd been told before we set off that cycling through France was a very different experience to the UK and that is definitely true. It's a much more enjoyable cycle; drivers give you a wider berth and the roads are generally in a much better state. Most importantly though, there were far fewer hills to tackle!

The third day was a cycle from Arras to Compiègne, which meant cycling

# London–Paris for CICRA: ooh la la!



*Oli with his fellow cyclists in Paris*

through the Somme. We stopped at a number of memorials for the Allied forces and for the German soldiers. It was a poignant yet enjoyable day which left the group in a good mood ahead of what would be our last day of cycling into Paris.

By the final day, we felt we had found our groove but also felt very tired. We cycled 40 miles towards the outskirts of Paris before the roads notably changed and it felt a lot closer to the London cycling experience for the next 30

miles. My Mum, Dad, brother Nicky, and cousin Florian were there when I got to the Eiffel Tower. Nicky had flown for the first time and negotiated the challenges of travelling – with the medical needs he has – which was a huge win for the whole family and meant a lot to me.

Overall, the challenge was one of the toughest challenges I've ever done.

*Thanks to friends, family and CICRA for the support!*



**Amy James** was determined to combine her passion for cycling with her desire to raise money for CICRA – and she did just that! Amy and family completed the Dartmoor Demon and raised **£746**. (pictured left)

New member **Pradeep Krishnamurthy** rode in the Cycle Live

Nottingham event and raised an impressive **£1,140**. (pictured right)

**Adam Battersby** raised **£40** for completing the Wigan Bike Ride.



# Fundraising



**Russell Hastie** kindly nominated CICRA for his work's charity fund. Having Crohn's Disease himself, Russell wanted to help children and young adults with his nomination. As a result, Smith & Williamson donated **£2,000**.

**Paul Isaacs** organised a successful work fundraiser and donated **£180**.

CICRA received **£100** from an **HSBC** work fundraiser, facilitated by **Sally Peck**.

**River Profiles** Ltd donated **£234.55** as a result of a work fundraiser.

**Jane and Alexander Tweedie** continue to support CICRA in many ways: CICRA received donations in lieu of Christmas cards, a generous sum for Alexander's 40-year service award and **The Robertson Trust's** matched giving scheme, along with other donations and collections, totalling **£2,424** just for the few months of this year.



**Aidan Saunders** organised a cake sale at his church, raising **£524**.

**Liz and Joanne Graham** held a birthday fundraiser and raised **£250**.

Long-time supporter and fundraiser

**Maxine Armitage** raised **£257** from cake sales at the start of the year.

**Ruth Hostler** raised **£50** by putting on an afternoon tea.

**Joyce Holder** has donated **£50** and **£90** respectively, raised from cake sales at her drop-in group.

**Katie Veitch** turned her birthday party into a fundraiser and raised **£88**.

**Janet Barr** raised **£13** by selling tea and cakes.

**Margaret Davies** raised **£40** at her Aquafit class.

**Alison Johnston** continues to collect donations and put on raffles for CICRA. Alison has sent a marvellous **£705**

## Incessant Ramblers keep on go

**On 29 April 2017, Vicki Sharp (Mum to Hamish, a 13-year-old with Crohn's) and a team of six friends calling themselves the Incessant Ramblers walked 106km around the Isle of Wight to raise funds for CICRA and Crohn's and Colitis UK. Remarkably, at the end of this gruelling walk, all seven managed to cross the line together and keeping them going was the thought that they had raised well over £8,000 for research into IBD. Here is Vicki's account of this unforgettable 30 hours.**

"It was unbelievably tough, and I had to drop out at 66kms with severe diarrhoea and vomiting (over 10 times!). The medics wouldn't let me carry on through the night so I was totally devastated. However, I rallied, lay down for a couple of hours, kept some food down and re-joined the team at 86kms and walked with them for the last 20kms and then we ran over the finish line together!

The other girls were extraordinary – one fainted and carried on, one got severe blistering which started before the 23km mark but carried on the whole way. At the end she had to go straight to A&E as her feet are totally shredded! Never seen anything like it before! Everyone else had their own crosses to bear with shin splints, ankle, joint, back and hip pain, as well as a bevy of blisters and total exhaustion,

*Vicki and her crew at the finish*



so far this year. As ever, our thanks to Alison for her continued support!

**Dean Townshend** held a very successful angling event and raised **£850**. Brilliant idea!

**Karen Pritchard** organised a fantastically successful fundraising event, raising **£2,500** to be split between two charities.

**Amanda Edgcombe** raised **£74** by collecting donations at an art exhibition.

**Joan Waldron** held an evening event called 'Bop at the Biddick', which raised £425 for CICRA.

Following the success of her Halloween fundraising event, **Rachel**

**Cartmell** had the brilliant idea of organising an Easter Egg Hunt for the community (*pictured right*), raising **£488**. What a fantastic idea for a fundraising event to get the children involved!

**Kirstie Harland** raised a wonderful **£607** following a coffee morning and Slimming World fundraiser.

With thanks to **Malcolm and Andrea Marshall, Emanay School of Dancing** raised an incredible £1,360 from their annual fundraising evening. Thanks to all involved in the success of this event.

**Caroline Barr** raised donations totalling **£271.25** for completing Dry February.



## ing on Isle of Wight walk

but the elation of crossing that line was amazing. It took us just over 30 hours – no record and far, far longer than we'd anticipated, but walking as a team of seven and staying together counted for a huge amount.

Hamish is tougher than all of us, and he inspired the team to keep going throughout. He is hugely proud of his mum! He sent us texts throughout the entire walk and wrote me the most beautiful card to take with me.

We all just wanted to thank CICRA for your very kind and personal support of us. More importantly, I wanted to thank you for all the support you give to Hamish and our family, and all the families like us who are affected by IBD. It's a hugely important job you all do and it's made dealing with the disease more bearable. Knowing that there is somewhere to go for information, for support both practical and emotional,



*A flowery moment on the 106km walk*

to get together with others who are also affected and share information (and laughter and tears) is so important. Thank you so much."

Vicki Sharp. On behalf of Emma Alleyne, Katherine Theobald, Suzie Faulkner, Ana Porfirio, Jo Harris, Karen Oliver – Team 'Incessant Ramblers'.

# Smashing fundraising by Jax

**Jax Martin-Betts** organised her usual tennis tournament this year, raising over **£1,300**. In addition she organised, for the first time, a tennis tournament for children at Ardingly College courts.

Thirty two youngsters took part and had a great time so Jax has promised to do the same next year. **£1,000** was raised on this event including a very generous donation from one of the parents of the children taking part.

The winners of the Kids CICRA Tennis Tournament were Sebastian Eaton and Bella Hodgson while Jasper Calkin and Sophie Maguire were the runners up.

Between organising tennis tournaments Jax was once again asked if she would create a Year 8 leavers' quilt at Cumnor House School, even though her son, TJ, has now left. When auctioned it raised another **£749** for CICRA and we thank Cumnor House School and the parents for their support.

*Top: Cumnor House School's incredible quilt*

*Right: Making a racquet at Ardingly College*





## ★ ★ ★ TALENT

**Adrian Lueerssen-Medina** has donated **£184.25** to CICRA from money raised from online sales of his artwork.

**Mrs MH Passmore** continues to think of CICRA when she sells her handmade knitted items, donating a further **£115** this year.

**Mrs Margaret Crawford**, sister of CICRA member **Catherine Walls** held a craft Sale and raised **£170** for CICRA.

**Heather Reid** kindly donated the proceeds raised from selling eggs – a whopping **£286.47**.

**Trish Walker** continues to support CICRA by donating her sewing course fees to CICRA, **£557** and **£462** respectively this year.

## 2+2= SCHOOL

The following school fundraisers have been held in the last six months. Many of these were on or around World IBD Day to raise awareness of the conditions.

**Natalia Baldev** gave a presentation to her school and collected money for CICRA.

**The Hessle Federation** held a successful school fundraiser and donated **£440** in May.

**Zoe Silver** collected donations of **£30** at a school fundraiser.

**£112.50** was raised by **Great Denham School** after the children had felt inspired by **Amelie Simpson** and her fundraising efforts for Bedford Hospital and CICRA. It was raised at their 'magazine launch' – an event which launched a set of magazines that the children had designed and would be sending to Bedford Hospital children's ward.

Supporting CICRA for yet another year, **Archbishop Sancroft C of E School** have held fundraising events through the year and raised **£148.80**.

**Rosie Townshend** organised a non-uniform day at **Meryfield School**, with proceeds of **£464.58** going to CICRA.

**Oakwood Primary School** raised funds for CICRA in support of **Scott Bedford** and his mum, **Stacey Keel**. **£312.17** was raised. Big thanks to everyone involved in these school fundraisers for their support.

**George Trinder** nominated CICRA to benefit from the **Dragon School** sale, which raised a total of **£1,250**.

**Jessica Jones** and her friends at **Stockport Grammar School** (pictured below) raised **£216.35** in aid of CICRA, as Jessica's sister, Lucy, has Crohn's.



## AGM Business Meeting

The 39th AGM of the charity was held on 1st July 2017 during the CICRA IBD Family Day in Cobham, Surrey. Trustee Neil Gooding provided a presentation on the work of the charity during 2016 and below is a short summary.

**Financial** – Income for 2016 was £332k, research spend £321k and Support & Information £83k. Commitment to medium to long-term research £585,000. No Trustee received any remuneration.

**Research** – During the year under review we continued to fund two Fellowships, three PhD studentships and two projects and awarded three new grants, one Fellowship, one PhD studentship and one project.

**Membership/Fundraising** – CICRA continues to offer free membership. Young adults over 16 become members in their own right. CICRA has no government funding, but applications are made to Trusts for contributions. Funds from members go towards funding Research and Support programmes.

**Support & Awareness** – We have regular contact with Paediatric IBD nurse specialists who give out our Parent Packs. “Can’t Wait” cards are very popular. There is still a rising incidence in the number of children being diagnosed, especially the early onset and we give support to all. Family information days were held in Cardiff, Manchester and Cambridge and we are indebted to

the medical staff who gave their help on a voluntary basis. The Trustees continued to work with other IBD health-related organisations in this and other countries.

**Governance & Management** – Trustees met every six weeks and were responsible for determining policies, the budget and overall management. Accountants Tudor John of Epsom arranged for the Independent Examination of the 2016 accounts. Two members of staff, Jayne Boyd-Bell and Laura Doyle carried out various administrative jobs in the office overseen by Margaret Lee.

**Election of Trustees** – Two Trustees, Margaret Lee and Deborah O’Neil stood down and were re-elected.

## Working in partnership

**CICRA is a small but ambitious charity and to achieve our aims, we will always work with others whose objectives overlap with ours. As we approach our 40th year, we are delighted to be working with several national partnerships and organisations, where the influence of a united front can help bring closer the time when children lead fulfilling lives, unaffected by inflammatory bowel disease.**

**Association of Medical Research Charities:** the national membership organisation of leading medical and health research charities. They help members such as ourselves meet our charitable objectives by interpreting and influencing the regulatory, policy and research environments, and connecting members to encourage

collaboration and share learning. They support charities in delivering high-quality research to improve health and wellbeing and AMRC members support over one third of all publicly-funded medical research in the UK.

**IBD UK:** an overarching UK wide ‘strategy’ group/partnership to represent all the key organisations responsible for improving services and outcomes for people with IBD, including many charities, medical societies and support organisations. IBD UK’s overall goal is to ensure that people with IBD receive consistent, high quality, personalised care and have the best possible outcomes from their treatment.

**Crohn’s and Colitis UK:** Founded a year after CICRA as a patients’

association in 1979, they have 32,000 members across the UK and work to make life better for people of all ages with Crohn’s disease, ulcerative colitis and other forms of IBD. With support groups across the country, Crohn’s and Colitis UK campaign to increase awareness of Crohn’s Disease and ulcerative colitis among decision makers, and to improve services.

**The Toilet Consortium UK:** The overall aim of the Toilet Consortium UK is to work together to increase and improve toilet access for everyone. The consortium is a group of charities and stakeholders who are working to ensure that there are more publicly accessible toilets across the UK. The strength of our unified voice will help increase access to toilets for those in need.

# CHRISTMAS CARDS

**Cards chosen, orders placed, brochure designed, cards delivered and yes it's that time of year again – the sale of CICRA Christmas cards.**

Last year, due to the office move, we accepted help from one of our suppliers, who dealt with the despatch of all orders on our behalf. However this year we will be processing all the orders from the office. With everything done on a voluntary basis you can be sure that by buying our cards you are helping to fund and expand research and support for children and young people with IBD – not forgetting that any research helps the 'not so young' with IBD as well.

We have the cards in stock so please put your orders in early to avoid disappointment for there are

bound to be one or two that will 'fly off the shelves'. As in previous years you can place your order by completing the enclosed form, telephoning the office or going to [www.cicra.org](http://www.cicra.org) to buy them online.

If you are sending out business cards and would like to support CICRA you can obtain personalised printed cards by going to: [www.charitycardsonline.com/cicra-personalised-cards](http://www.charitycardsonline.com/cicra-personalised-cards)

Thank you for your support.



## CICRA Summer Draw 2017

**Once again we thank those of you who bought or sold tickets for the Summer Draw which took place on Saturday 1st July at a CICRA meeting for parents and children at the Hilton Hotel Cobham.**

**The Summer and Christmas Draws are all processed by Trustees so, apart from the prizes and printing of draw tickets, no expenses are taken from the funds raised.**

**This year over £3,000 was put towards research into IBD.**

*Mrs Margaret Lee MBE  
Promoter*

Prize	Ticket	Winner
1st	38042	S Chapman, Leicester
2nd	02599	Chris F, Bowhill, Scotland
3rd	00230	Mrs S Clyne, Manchester
4th	08580	C Kane, Huyton, Merseyside
5th	38217	S Green, Lincoln
6th	07055	Clare Stanley, Newport
7th	05168	Joanne Chilcott
8th	00760	Helen – donated back
9th	19327	Linda Hall, London
10th	45734	A Donohoe, Kirkcaldy
11th	00390	Unclaimed
12th	24110	Mrs K Piatt, Warrington
13th	23035	Emma Horgan, Wilmington

## 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:

- **Ann Dix** – A supporter of CICRA for 20 years. Ann is loved and missed by family and friends.
- **Phyllis Jopson** – From all the family in loving memory.
- **Christine Sybilla Wright** – Great-grandmother of Amelie Simpson, a Crohn's sufferer/CICRA fundraiser. Christine was so proud of Amelie. Remembered always with love.
- **Marjorie Carter** – A dearly loved mother and grandmother. Devoted carer of a Crohn's sufferer.
- **Kathleen Humphries** – Fondly remembered by family and friends.
- **Jo Harrison** – From the Exeter Quilters in memory of a good friend.
- **Judith Elizabeth Clarke** – Fondest love.
- **Hazel Kennedy** – Grandma of a Crohn's sufferer remembered with love by all the family and friends.
- **William Fox** – We will love you forever and pray for you always. Miss you Grandad xx.

### Bequests

We are grateful to have received a bequest from the estate of the late **Linda June Bannister**.



## Collection boxes

Grateful thanks to members who have CICRA collection boxes in their home or arrange for a local shop, pub, leisure centre etc. to have a box.

A further **£1,265.99** has been put towards research. Our thanks go to:



**Samina Ahmad**

**Mrs Pittman** – (*Auto Engineers*)

**Marie Baker**

**Janet Barr**

**Melanie Beaver** (*The Country Kitchen*)

**C Chan** (*Home*)

**Mrs S Chapman**

**S & H Davies** (*Shop*)

**Ann Donohoe** (*Home*)

**Robin Eames** (*Home*)

**Caroline Goose**

**Monica Gracey**

**Julie Jones**

**B McKinney** (*Pub*)

**Mrs Platt**

**D Robinson & Sons**

**A Ross**

**C Simpkin**

**Jane Tweedie** (*Craigellachie Filling Station*)

**Eunice Vickers** (*Sunrise Fashion*)

**J & E Whittaker**

If you would like a collection box for your home or local shop, pub etc, please contact [fundraising@cicra.org](mailto:fundraising@cicra.org).

## CICRA 200+ Club

Thank you to those of you who joined the 200+ Club following the distribution of the last newsletter.

Our numbers are now standing at 250 so how good would it be to reach the 300 and change the name to the 'CICRA 300+ Club'? The quarterly prizes are increasing in line with the

amount of members we have and as this fundraising is processed by Trustees there is nothing to cost against it and all funds are split 50/50 between prizes and research – a real 'win-win' situation. If you would like to join please contact the office on **020 8949 6209** or email [support@cicra.org](mailto:support@cicra.org) and we will send you the forms.

### CICRA 200 CLUB WINNERS Jan – June 2017

Jan	39	D Chapple, Bristol	£50	Apr	172	C Allen, Suffolk	£50
	62	A Walls, Falkirk	£50		195	P McQuade, Lincolnshire	£50
Feb	62	Andrew Walls, Falkirk	£50	May	167	M Khuraijam, Cheshire	£50
	127	Amanda Wall, Litchfield	£50		168	H Arthur, Derbyshire	£50
Mar	56	R. Thornton, London	£250	Jun	208	P Manby, Suffolk	£250
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