the insider

Spring 2017

children and young adults with crohns and colitis

Excellent research funded by CICRA

The Paediatric Gastroenterology Department of Southampton General Hospital and the linked laboratories, under the direction of Professors Mark Beattie and Sarah Ennis, are carrying out some excellent research.

CICRA is very proud to be closely associated with this unit having funded both Fellowships and PhD studentships to help bring about the success that they are having. A paper published recently at Genome Medicine is now available as a video – very exciting times.

This paper identified a new gene in IBD and was a result of a collaboration between Sarah Ennis and a group at Stanford University. Gaia Andreoletti (CICRA funded PhD student in Sarah's lab) and Sarah were joint first and last authors. Professor Mark Beattie was a co-author.

L-R: Professor Sarah Ennis, Dr Tracy Coelho and Dr Gaia Andreoletti

The teams discovered a new set of mutations that could explain why certain people have inflammatory bowel disease. While the mutations are rare, they point to an important role for a family of so-called chaperone proteins, which help other proteins fold properly in cells, and offer new ways to treat the disease.

However, there is still a lot of research to be done. Scientists have identified more than 160 spots in the genome where variants can increase the risk of developing the disease but they still explain just a fraction of the genetic contribution so we must continue to support IBD research.

Over her time as a PhD student, Gaia has attended and shared her research at several national and international conferences and won many awards.

You can be sure it will continue and that Gaia having accepted a new postdoctoral position at the University of California, Berkeley, USA will still be collaborating. Gaia now holds an important position at the centre of an international IBD network that plays a major role in the scientific evaluation of state-of-the-art informatic tools in genomics, standardizing their application and defining parameters for accurate prediction.

Another member of the team, Dr Tracy Coelho, has just completed his CICRA Fellowship and was offered, and accepted, a permanent position – an unusual and rare opportunity, obviously acknowledging his worth.

There will be more updates in later newsletters.

Help celebrate our 40th anniversary

In 2018 CICRA will be celebrating its 40th Anniversary. We are hoping to arrange many events, not only to celebrate, but to raise a record amount for research. If you have any suggestions on the best way to mark this event to help everybody with Crohn's or Colitis but in particular our very special young people please contact the office. We would love to hear from you.

CICRA

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Trustees Report

Letter from the Chair

Dear Friends

Last year was definitely one to remember for the CICRA team. Hanging over us from Christmas 2015 was the knowledge that we had to leave Parkgate House in September 2016. With office hunting causing highs and lows through to late June, when we found an office in Pat Shaw House, it was difficult to concentrate on our most important job of supporting families affected by IBD, and finding the funds to maintain the research and support programmes – but this we did.

Our family information day meetings, held in Cardiff, Manchester and Cambridge were all very well attended and from the feedback we received they were much appreciated. We have many people to thank for the success of these days and especially members of the medical profession who, on an honorary basis, so willingly give up their Saturday to join us on these days. It wouldn't happen without them and we are grateful.

Unfortunately due to the location of the new office we have lost two of our most loyal and valuable volunteers – Rosemary Thornton and Maggie Bates. Maggie, who some will remember nursed the early cases of IBD as Sister Lucas, Senior Sister at Barts Hospital. Maggie has been helping CICRA since around 1985 and Rosemary came to us as a part-time typist, around 1989. In 1992 Rosemary decided that she would like to continuing doing the same job, two days a week, but as a volunteer. She did this until the move. We have been very fortunate to have had Rosemary and Maggie's help for so long and we are hoping to still see them but on a less regular basis in the future. We also hope that they will be joining us for the family day in July so that we can thank them properly.

Next year is the charity's 40th anniversary. We are hoping that we will be able to arrange events to celebrate and, in doing so, raise a substantial sum for research. We are making our lists now and if you are thinking of having a 40th fundraising event for CICRA please let us know on fundraising@cicra.org.

With very best wishes and many thanks to our supporters.

Margaret Lee
Chair

Dates for your diary

After a successful day in Edinburgh, Cobham, Surrey will be our next stop for an IBD Family Information Day on **1st July** followed by a meeting in **Bristol** on **14th October** (TBC). If you would more information about joining us on either of these days please email **support@cicra.org** or ring Jayne on **020 8949 6209**.

Medical Director handover

For the last four years we have been very fortunate to have had Dr Nick Croft, from Barts & the Royal Hospital in London, as CICRA's Medical Director.

Apart from the help given in many other areas, members will have seen Nick chairing most of our regional meetings regardless of whatever part of the country we were in.

We reported a year ago that he was taking over as President of the British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and we now have more congratulations as Nick has recently become a Professor. We are really grateful for all the help that we have been given and wish him well for the future. We may even see him at the odd CICRA meeting – we hope so.

At the Edinburgh meeting on 25 March, Nick will be handing over the position of Medical Director to another person who has been a huge help and CICRA supporter – **Dr Richard Hansen from York Hill Children's Hospital in Glasgow**.

Many members will remember Richard's really informative but amusing talks at some of the regional meetings. The young people in particular have appreciated having some of the complexities of their condition presented in such an understandable way and we thank him for this.

Prof Nick Croft (L) and Dr Richard Hansen

We know that Richard will be a great asset to the Trustees and our work. Welcome on board Richard.

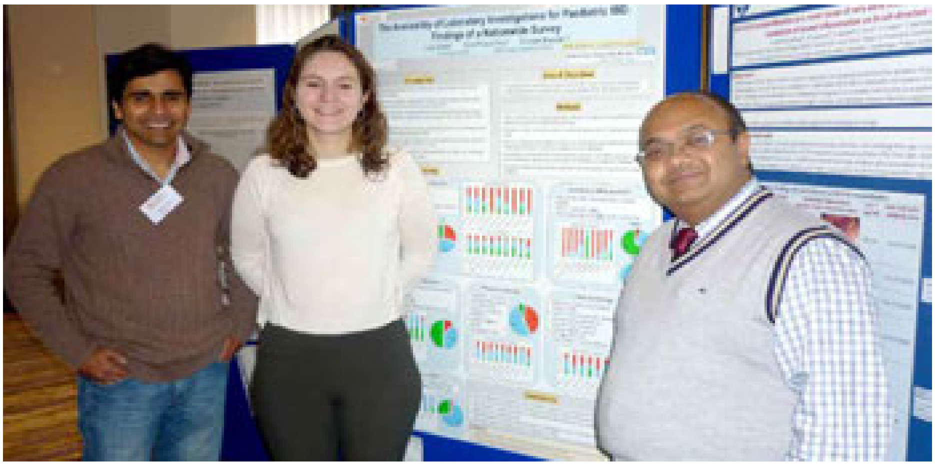
Poster of Distinction

With the support of a CICRA bursary grant, Lucy Bates, a medical student at the University of Bristol, had the opportunity to attend the BSPGHAN annual conference in 2017 to present the English nationwide survey data detailing the availability of various investigations used in the diagnosis, management and monitoring of IBD in paediatric patients.

The conference was held in Glasgow in January 2017.

Below is Lucy's report.

"The data was generated through a telephone survey of all the hospital laboratories across England providing care to children. This was done as my ESSC project in collaboration with the Department of Paediatric Gastroenterology, Bristol Royal Hospital for Children in July 2016.



L - R: Dr Dharam Basude, Lucy Bates, Dr Siba Paul

Our findings demonstrated wide regional variation regarding availability and access to investigations such as TPMT, 6-thioguanine, Infliximab serology and antibodies, ASCA. This may potentially delay the decision-making process and may have implications for management and prognosis. We demonstrated that there is need for improved access to specialist investigations in order to ensure optimal and equal care for paediatric IBD patients across England. I am grateful for CICRA's support in enabling me to attend the conference. Presenting this project as a Poster of Distinction on behalf of the Bristol team was a fantastic opportunity to share our findings and draw attention to this issue. This was also a fantastic opportunity for me as a medical student hoping to pursue a career in Paediatrics."

The MEDIC Study: Microbial effects of an Exclusion Diet In Crohn's disease

In 2015 CICRA awarded a grant to Dr Jenny Epstein, a former CICRA Research Fellow, at the Chelsea & Westminster Hospital. Jenny's project was to assess the gut microbiome in children with inflammatory bowel disease and the effects of a Crohn's-specific diet. This project is ongoing and children are still being recruited to the study. We will bring you updates in future newsletters.

Crohn's disease is an inflammatory bowel disease (IBD) of unknown cause and with no known cure which is becoming more common in children and adults. Crohn's disease causes a great deal of suffering with abdominal pain, diarrhoea, bleeding and extreme fatigue. The gut microbiota are different in children with Crohn's disease compared to those without, and the bacteria in the gut are believed to play a role in the development of the disease.

Crohn's disease is treated with immune suppressing medications with potentially serious side effects. At Chelsea and Westminster Hospital in the Department of Paediatric Gastroenterology (1) we are trialling a new diet for children with Crohn's disease which is showing promise to prolong remission, reduce relapse and may offer children the chance to minimise medication use.

Our collaborative group (Professor Kroll and Dr Epstein) has previously shown that the gut microbiota is accurately represented by non-invasive sampling methods and that an invasive gut biopsy is not required (2).

We have recruited to date over 20 children with newly diagnosed Crohn's disease and have characterised their faecal microbiota through next generation sequencing at serial time points in their treatment. We are correlating the microbiota with (a) diet; (b) disease activity and (c) IBD-specific quality of life scores.

The information generated will shed new light on our understanding of the role of the gut microbiota in Crohn's disease, and specifically as it relates to diet. This will contribute to our understanding of how the disease develops and why diet is relevant to disease progress. It may allow us to predict in future which individuals are more likely to respond to dietary therapies at the outset.

Organoids? What are they?

We are delighted to report that Judith Kraiczy, funded under the CICRA PhD Studentship scheme, passed her PhD with flying colours.

Studying under the direction of Dr Matt Zillbauer at Addenbrookes Hospital, Cambridge Judith has done extremely well and we will be reporting more about her work in the next newsletter. In the meantime here is Judith's report on a meeting that she attended in Heidelberg, Germany.

Thanks to the support of the CICRA Educational bursary, I was able to attend the international conference "Organoids – Modelling Development and Disease in 3D culture", organized by the European Molecular Biology Organization (EMBO) in Heidelberg, Germany. Given the title of this conference, you may now wonder: What are organoids?

Organoids are self-organizing, complex structures of cells that essentially

News from Scotland

An important contribution by CICRA to finding the answers to Inflammatory Bowel Disease are their small educational/travel bursary grants to help medical students, young scientists and other members of the medical profession attend important meetings. In the case of Ross Porter, medical student from Aberdeen, it helped to enable him to spend time in a laboratory in the USA and below is his report.

Prior to my intercalating 4th year as a medical student at The University of Aberdeen, I undertook a summer internship at The National Cancer Institute (NCI), which is part of The National Institutes of Health, in Frederick, Maryland, USA. I worked in Dr. Scott Durum's laboratory, within The Cancer and Inflammation Program, with Dr. Caroline Andrews (Fellow in Comparative Molecular Pathology and Veterinary Pathologist) who is investigating interleukin (IL)-27 as a potential treatment for inflammatory bowel disease (IBD).

IL-27 is a type 1 cytokine (soluble mediator of inflammation) that has recently been identified as a potential therapy for IBD. Only recently discovered, research has still to uncover IL-27's full potential and determine whether it promotes or ameliorates inflammation. The group's previous work supports the latter. During my studentship, we were looking for expression of IL-27's heterodimeric receptor (gp130/IL-27Rα) in intestinal epithelial cells, in mice. While IL-27 is an effective therapy for experimentally-induced colitis in mice, its mechanism of action is not fully characterised. Studies such as the one I contributed to this summer are helping us understand how this therapy works in mice, and hopefully, how it may be an effective treatment for human patients with IBD.

Scientific research normally starts off with a sound hypothesis, followed by systematic experiments on cell cultures and animal models, and then clinical trials in human patients. During my time at NCI, I was trained in organoid culture. Colonoids (from the colon) and enteroids (from the small intestine) are complex, 3D, mucosal structures that resemble the tissue they are taken from. These novel "mini-guts" are grown in Petri dishes in a laboratory and offer an exciting adjunct to cell cultures and mouse models. The unique similarity of these organoids to the tissue which it was taken from (e.g. a biopsy) also offer great promise in the fields of translational and personalised medicine.

This summer studentship was generously supported by CICRA's small bursary grant which has helped advance our global effort to find novel therapies for IBD. Moreover, it has allowed me to become proficient in culturing murine colonoids and enteroids. Dr. Mairi McLean, (Senior Clinical Lecturer and Consultant in Gastroenterology) at The University of Aberdeen, has a longstanding collaboration with NCI and an interest in mucosal immunology and anti-inflammatory cytokines as treatments for IBD. Therefore, translating murine organoid culture techniques back to the Aberdeen Gastrointestinal Research Group will offer a great potential for the study of human gastrointestinal pathology and development of IBD therapies.

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form part of a "mini- organ" in a dish. Scientist can keep these mini- organs in culture over long periods of time and use them as models to perform experiments. These culture models have many advantages; for example that they are a three-dimensional system and that they can be derived from human cells.

Our research group is growing the so-called intestinal organoid model, or "mini- guts". This means we culture the inner lining of the gut (the gut epithelium) in a dish. We are able to generate these mini-guts from just a tiny piece of intestinal tissue (i.e. a biopsy) from children that had an endoscopy in our unit. In a current project, we characterized these mini-guts on a molecular level by looking at the molecular switches in a cell that can turn genes on or off. We call these switches "epigenetic mechanisms". Interestingly, we found out that the switches in mini-guts nicely reflect their state in the human body. This means we now can make mini-guts from children with IBD and use them to find out what is different in the gut lining in IBD.

I was selected to present our findings on a poster at this conference, and got great feedback from other researchers working on related questions. Furthermore, I had the opportunity to talk to top scientists in the field, including the ones who invented the mini-gut model. The talks at this conference made clear how "mini-organs" can provide exciting new opportunities for research into human diseases. Therefore, I am very grateful to CICRA for their support that allowed me to be a part of this by attending this conference.

Aaron: brave and resilient

Having a very young child diagnosed with IBD (VEOIBD) has a big impact on family life and here we have the thoughts of a Mum whose son Aaron (pictured) was diagnosed with Crohn's disease at 2 and is now 6. We feel sure that many Mums and Dads will be able to relate to this.

We initially noticed bleeding in Aaron's nappy and then it was a long process of testing ending in a diagnosis of Crohn's disease. Initially the stress was all about the appointments to get diagnosed, culminating in a colonoscopy etc. Not only do you have the ill child to take care of during this time but also their siblings, so childcare is a big issue.

When we received the results, Aaron began with 6 weeks of EEN via a nasogastric (ng) tube. Eating as a family became difficult and we arranged it around his nap times or ate in shifts. This was even harder when socialising with the wider family or friends, you just don't realise how much we eat socially, as a society, until you can't! Special events are often based around food, cakes, treats and meals, so we had to be creative and rethink this. There was a lot of secret eating during this time!

There were blood tests, new medications and ng tube replacements to get our heads around. Being so young the tube came out a lot! Aaron's joints and stomach hurt and he needed the toilet a lot due to the amount of liquid he took in, so we were up in the night, just like having a new-born again. This resulted in very tired parents who could be short tempered with each other and with his brothers. At one point I was so tired I couldn't actually remember if I had a boy or girl child upstairs and thought he was a baby!

Our middle child also had medical problems so it was hard to find the energy to do it all again. Little things became impossible like having friends round for tea, 'after school clubs' or even getting his brothers to school on time. Then there was the nappy changing and the smell in the house! As a sibling, he was too tired to play with his brothers which they missed and they had the worry of all the treatments, medicines and bleeding etc. For us he is the baby of the family so we were already giving him more attention due to his age, now he was taking even more time and energy up and away from his brothers. It was also hard to relate to other parents e.g. at toddler groups, as our world was very different on a day-to-day basis. There has been lots of jealousy of the attention he gets.

Long term it has been all the above, plus several flares, sessions of EEN or the extra challenges of prednisolone steroids!! The medication he takes just keeps getting stronger and more worrying. There have been too many appointments to count which involve trekking to London for re-scopes, infusions, fortnightly injections or weekly methotrexate with associated nausea. We have had to change our meals and frequently use our creative thinking to keep everyone happy. Then there is the cost of diet and the equipment involved, and not being able to forward plan. The chronic nature really takes its toll.

There have been many challenges for him at nursery, and now school. Not eating at all whilst being tube fed or eating different meals sets him apart especially on special occasions, parties etc. Whilst waiting to get ng training in place I had to attend school daily with him. He has also done shorter hours or needed significant amounts of time off. Even when well enough to be at school he can be feeling blah, and 'different'. This probably has more of an impact on him socially than we can measure. It is hard to fit in 'after school' activities, playdates and homework when he is tired from the normal school day. He is open to catching bugs due to the immune-suppressing effect of his medication – a constant worry at this age. All this not only impacts his wellbeing and the social side of life, but also has an educational impact, and as there is no prior data or baseline due to the age he became ill. It is hard to assess.

Toilet facilities at school can be an issue, he can be clingy if not feeling 100%, the invasive treatments, tests and side effects of medication can leave him not quite 'there' in the moment at school. It must all be quite scary for him. However, he likes the rewards he receives for being brave from stickers to sweets to little toys. He is more resilient than the average child his age and he really enjoyed the girls looking after him when he had his feeding tube

Helping shape the future of IBD care with the IBD Registry

Collecting information on Inflammatory Bowel Disease (IBD) goes a long way to helping us all understand how it affects people's lives. The more information collected, the greater the potential insight. This is the theory behind the IBD Registry, which has been set up to help IBD teams use real data about their patients to make better decisions about their IBD care.

IBD teams in hospitals across the UK collect data about ulcerative colitis and Crohn's disease and how they're treated, and submit the information to the IBD Registry via an official NHS data processing service, which for England and Wales is NHS Digital. The information can be collected in the course of a normal consultation, either on the phone or when your child visits his or her doctor or nurse. Patient information is sent to the Registry in a coded form to safeguard your child's identity and make sure that all details are properly protected.

The beauty of the IBD Registry is that it continues to grow each time more data is added, making it increasingly useful over time. By including data from children, the Registry provides a unique resource to track the evolution of IBD as the children grow up, and importantly, help to ensure consistent care and support as children with IBD transition from paediatric to adult care.

The data in the Registry will be analysed by clinicians and statisticians to show how IBD affects different people and what treatments and services they receive – both in child and adult care. This information will help improve understanding of IBD and will help the NHS shape its IBD services both locally and nationally. Information from the Registry can also be used to help essential research into IBD treatment and care and the safety of medicines. Approved researchers may be allowed to analyse the data under strict conditions, but no-one who has access to Registry data can identify the patients.

When your hospital participates in the IBD Registry project, you have the right to choose whether you or your child want your information to be sent to the IBD Registry and, if you wish to opt out immediately, you can do so by talking to your IBD nurse or doctor. During this year, your IBD team will be asking you to confirm in writing whether you consent. They will send or give you a patient information leaflet to read with a consent form for you to sign. The leaflet and form will give you more information about how the data will be used to improve care for people with IBD.

Over 25,000 people with ulcerative colitis or Crohn's disease from 25 hospitals in England and Wales have had their data entered into the IBD Registry so far, but another 75 hospitals will soon begin to submit information about their patients. The Registry will be extended to Scotland and Northern Ireland later this year.

In your child's next consultation with their doctor or nurse, you may be asked if you would consent to allowing their data to be included in the IBD Registry. It is vital that the Registry collects data from as many UK hospitals as possible, so by allowing your child's data to be collected and sent to the Registry, you will be helping to improve the care of people with IBD, now and in the future.

If you have any queries or concerns you can speak to your child's IBD nurse or doctor, or look at the patient section of the IBD Registry website http://ibdregistry.org.uk/information-for-patients/.

New research

At a recent meeting of the Medical Advisory Panel, following our usual call for applications for funding, a PhD studentship for Dr Matt Zillbauer of Addenbrookes in Cambridge was recommended to the Trustees.

The student has yet to be appointed but will take as their three year project: *Validation and use of human intestinal epithelial organoids as models to study paediatric IBD pathogenesis*. This will be a continuation of the three-year study by Judith Kraiczy (pages 4-5). We will update readers in the next newsletter.

Young people’s stories

If anybody wants to understand what it is like to have Inflammatory Bowel Disease as a child they only need to read the stories from the young people that we reproduce in the newsletters. They are a lesson in not giving up on your dreams whether that be a future career, sport, music or dance. We wish them all well.

CLAIRE-MARIE’S STO

Hello my name is Claire-Marie I am 13 years old and live in Norfolk.

Two years ago, my mum and dad where worried about me feeling sick, sitting on the toilet for ages, and not wanting to eat my dinner. I was very thin and small and always feeling tired.

I suffered with an under active thyroid so we saw our doctor to see if the medication needed changing. We then went to the hospital and I had build-up drinks and iron, which didn’t work. Intolerance to certain foods was ruled out yet I was still losing weight, feeling tired and sick. I cried at dinner time as I was hungry but it got stuck, made me sick or I ran to the toilet.

I was sent to Addenbrookes for a scan. Our consultant showed us pictures of my inside and explained my intestines should be a 4-lane motorway but mine was blocked so only a 1 lane motorway and they confirmed I had Crohns.

We then met my lovely nurse who spoke firm but fair and explained everything to me with mum and dad listening. She asked lots of questions – some I knew; some mum answered; some embarrassing. I was put on modulen and was unable to eat for 9 weeks which included Christmas. I had no chocolates or sweets but modulen didn’t really work. Steroids didn’t work – they made me look like a chipmunk and dad called me Alvin.

SCOTT’S STORY

I am Scott. I am 16 and I have Ulcerative Colitis which is a condition that causes inflammation of the inner lining of the rectum and colon.

Yes, I know that sounds very sciencey but it basically means tiny ulcers develop on the surface of the lining of the colon and these can bleed. In my case, these ulcers did bleed when going to the toilet. In 2012, I started to find blood when I went to the toilet. At first I didn’t think anything of it but then I got concerned. Obviously, it isn’t normal to find blood in the toilet so I went to the GP to find out what the matter was. My GP did some tests on me. He told me that I had “piles” and gave me some cream. What a lot of help that did me … not!

I then went back to the GP and they referred me to a children’s clinic at Addenbrooke’s. I had further appointments and tests but we still didn’t know what the matter was. During this time, I had stomach pains that hurt more than they should. I also felt very weak and lethargic.

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Because I wasn't getting better I had another scope, and woke up with a tube up my nose which stayed in for 24 hrs so I could have an MRI which is weird but not scary.

On New Year's Eve 2015, I had an infusion with infliximab which went in my arm over a couple of hours. I even got a present. Mum stayed with me and we played games, listened to music and watched TV. By the third one it was starting to work, I had energy and was wanting to do things. I now have them every 8 weeks. On the first day I feel a little yuck, then I feel great but I know when I am due again as I start to get tired about a week before.

The hardest part with Crohn's is that friends do not understand as you don't look ill. I struggled at school and could only do half days as I was falling asleep and needed the toilet or felt sick. I would lay on the sofa feeling sorry for myself but mum would make me get up and walk the dogs or practice dancing and although this helped, I never let mum know.

I am a keen dancer and this has kept me going and my teachers have been amazing supporting me and encouraging me even when I was tired.

My nurse is amazingly funny, firm and full of knowledge which has helped with my mad family. A typical conversation always ends up about toilet habits and who spends the longest time in there; me or my brothers on their phones. This has helped me to go out and not worry. If I need the toilet in a restaurant and we are ready to go, my family laugh, take coats off and sit down again.

I have learned about the drugs I take and explain to friends but sometimes they think I am just trying to get out of school and am making it up. My few close friends have asked for more information but sometimes they say you look OK but inside I feel yuck.

Last weekend I competed in the amateur medallist grand final ballroom and Latin grand final where I reached the semi-final which places me in the top 12 nationally.

I am also helping with a research project. When the doctors take blood or tissue samples they take a little extra for research. My brother also did a study trial to help understand and treat Crohn's better in the future.

In 2013, I had an endoscopy which is a camera down my throat and a colonoscopy which is a camera up my bottom. After all that time, we finally knew what was wrong with me and I got diagnosed after the operation. Being diagnosed was good but we needed to get some medicine that worked for me. Another thing that was a problem was that I was losing a lot of blood. I had a round of steroids but they didn't do anything for me. As I was losing blood, I became very weak and tired. This meant that I needed to have a couple of iron infusions.

Whilst all this was happening I had to move schools. During this time, I was very ill but my high school didn't know. I spent a lot of time in medical. After a couple of weeks of this happening, I got introduced to a student support teacher. I could go to her room if I needed to get away from classes or if I felt anxious or ill. After all that time spent experimenting with different medicines, we finally found the correct medicine that would stop me bleeding. Suddenly everything was much better. The stomach aches stopped and I became more energetic.

Then something amazing happened. I got invited to go on Dreamflight. Dreamflight is a charity which takes 192 seriously ill or disabled children to Orlando in Florida. We went to all the different theme parks there. We also got to swim with dolphins, which was amazing. We spent 10 days there.

Since I got back, I became much more confident. At my school, there were auditions for the school's musical, I auditioned and didn't think I would get a big part. I was so happy because I got the lead male role. Afterwards I was so much more confident and now I am addicted to musical theatre and performing arts.

The last thing I have to say is, I learned NOT to let the illness control me…I control the illness.

KATY'S STORY

Hi, I'm Katy. For the first years of my life we lived in Switzerland and all was well.

Then aged 6, we moved to Boston, Massachusetts, which is when I first got sick. I don't remember much about it but my parents noticed I was always complaining of stomach ache and often had an upset tummy and was losing weight. We were soon referred to Boston Children's Hospital and it took about 4 months to diagnose me with Crohn's.

When I was first diagnosed, I had very active disease from my stomach all the way to the other end. I was put on anti-inflammatories and high doses of steroids. I went from a severely underweight child to a severely overweight child in a matter of weeks! So much so that people didn't recognise me when I returned to school at the end of the summer!

Every time my doctors tried to reduce my steroids I got symptoms so I ended up being on different doses of steroids for the next 7 years. During this time, I've tried every combination of meds there are. I did not enjoy methotrexate injections so my parents always did them before my early morning riding lessons. That way the focus of the day was riding and not injections. I then tried infliximab for 1 year.

In the beginning, it worked really well but within 6 months I was on extremely high doses and the gap between treatments was getting shorter and shorter. So my doctors moved me onto adalimumab, more commonly known as Humira injections which is a med in the infliximab family which suits me and I have been on it ever since. When my doctors were trying to reduce my steroids, I met a surgeon to talk about removing my large intestine but my parents wanted me to be old enough to make the decision for myself so we waited and kept going with steroids on low doses.

The fun part of having Crohn's in America was Camp Oasis. This was a camp for kids all with Crohn's and UC. Even the leaders had IBD and it was run by doctors and nurses. It was a few days where we had a lot of fun and everyone understood each other, very much like the CICRA days.

Despite being ill, I still had many hobbies. As well as horse riding, I also enjoyed ballet, playing the viola and skiing. When I was 13, my family and I moved back to Bern, Switzerland. My new hospital was excellent. Dr Schibli and her team were lovely. They soon got me off steroids and, for a while, things calmed down.

But then I started to get abscesses and fistulas in the – to put it politely – very end of my colon. My Swiss doctors love the use of liquid diets for bowel rest to help with the infections and fistulas. Modulen was their go-to solution. However, I couldn't stand the taste...the only way I could get it down was to use a nose tube. But I didn't want people at my school to know I was unwell so I learned to put the tube in myself every day after school, was on Modulen all night and then removed the tube every morning – for 6 weeks.

Unfortunately, nothing was stopping the infections and I now had stenosis at the end of my colon. Every 4 weeks I needed to go into hospital for a dilation procedure. This happened

15 times and I was barely attending school. So in November 2013, I decided that I needed to focus on my schooling and chose to give my colon a break and had a colostomy. In case you didn't know, one of the rules of a colostomy, or any stoma for that matter, is that you have to name it. I named mine Joy, because she was going to bring joy back to my life, although in hindsight, that may not have been the best idea...especially at Christmas! Joy to the world indeed! This decision has definitely been life changing. It meant that I could attend school and enjoy life again.

We then moved to the UK and I went back a school year to catch up. I've had a lot of support from my family and friends, those close to me as well as those I've met through CICRA. Because of that, I recently finished my GCSEs and am at sixth form studying maths, further maths, French and German at A level.

I have yet to reach the elusive remission people talk about. Over the years this disease has affected my kidneys, my liver and my joints and is most active in my colon right now. I am hoping that one day we can reverse the stoma but for now I just want to focus on my studies and enjoy being young!

80th birthday celebration

This was a celebration with a difference and one that I was honoured to attend.

L-R: Prof. Alan Walker, Boston, Dr. Mario Vieira and daughter, Brazil, Prof. Walker-Smith, Prof. Jacques Schmitz, Paris, Dr. Paolo Lionetti, Florence and Dr. Jorge Dias from Oporto

In December last year John Walker-Smith, Emeritus Professor of Paediatric Gastroenterology at the University of London and Life President of CICRA, celebrated his birthday at Apothecaries Hall in London with a Research Forum in the afternoon entitled "Chronic Inflammatory Bowel Disease and History of Medicine" followed in the evening with a dinner for his family and friends.

The afternoon meeting, arranged by Professor Alan Phillips and Dr Rob Heuschkel was attended by friends and colleagues from many parts of the world.

In the first session, chaired by Professor Allan Walker from Boston USA, Dr Rob Heuschkel (former CICRA Fellow), Professor Ian Sanderson (former CICRA Fellow) and Professor Paolo Lionetti from Florence gave presentations on IBD in childhood (present and future), Enteral Nutrition and Microflora.

The second session chaired by Professor Alan Phillips saw an interesting talk by historian Professor Tilli Tansey followed by Dr Bill Dinning from Oxford posing the question "Did Biaise Pascal (1662-1662) have Crohn's disease?" Professor Walker-Smith then presented 'Special Places – a Photographic Reflection" with Dr Rob Heuschkel giving a concluding tribute to John Walker-Smith. A long-lasting standing ovation followed, showing the high esteem in which CICRA's President is held by his colleagues in the medical profession from all parts of the world.

Margaret Lee

CICRA funding reaps rewards

One thing that CICRA has always been aware of is that, because we don't have huge funds, all monies raised must be used wisely.

In the very early days, on the advice of Professor Walker-Smith, CICRA set up a Research Fellowship Training Scheme and a little later, on the advice of Professor Tom MacDonald, a PhD studentship scheme. These are fine examples of money well spent. Many of the leading paediatric gastroenterologists treating children today have had their specialist training through this scheme – something we are very proud of. That these doctors have gone on to great things is undeniable and this time we offer congratulations to Dr Mark Beattie *(pictured)* from Southampton Hospital who has recently become a Professor. Mark went from his specialist training under the direction of Professor Walker-Smith, to Peterborough to work as a Consultant Gastroenterologist and then moved to Southampton with Professor Tom McDonald to set up the unit at Southampton. You will see from the front page what good work this unit is doing and once again it can be seen what a wise investment CICRA made in funding the specialist training of Mark who, since he moved to Southampton, has, with funding from CICRA, overseen the training for Dr Ronald Bremner, now Consultant Gastroenterologist at Birmingham Children's Hospital and Dr Tracy Coelho, who has just finished his three years and is staying on at Southampton.

Support is the key

Mick McCormick tell us about his experiences looking after his daughter Eleanor

This is our daughter Eleanor who was diagnosed with Crohn's Disease in December 2015. Our talk to CICRA members in Cambridge offered a brief history. However, our main messages were about what helped us in this process. Here is a summary of our talk:

This is a picture of Eleanor on holiday in Rhodes in July 2015 and it was at this time that we began to see a change in her – frequent trips to the toilet, vomiting, listlessness, off food, losing weight. On returning from holiday we visited our GP and began investigations focussing on viral infections etc.

After what seemed to be endless false starts, stool samples and a deteriorating daughter – we were eventually referred to Addenbrooke's Hospital and a diagnosis of Crohn's Disease was made on 23rd December 2015 – Merry Christmas!

The following year was just as difficult – although we had a diagnosis, we had to get to know the Disease and work our way through a bewildering array of facts and an even greater stack of misinformation and ignorance.

In a nutshell, Eleanor had: Modulen (not a treatment of any great efficacy at Christmas); Prednisolone; chickenpox (so off prednisolone and inpatient treatment); Prednisolone; Azathioprine; Mercaptopurine. All led to some short term improvement, but not sustained. Back to Addenbrooke's for MRI scan, colonoscopy, endoscopy and prescription of combination of Infliximab and Mercaptopurine. IMMEDIATE improvement (we're talking two days) and sustained now with regular trips back to hospital for Infliximab infusion.

I believe we've been fortunate and are eternally grateful for the expert help and support we've received from Franco Torrente, Mary Brennan and all of the team. Presenting our story to CICRA in Cambridge has also caused us to reflect on what helped (or didn't help) to support and sustain us through the year after diagnosis which we'd like to share this with you:

- RELATIONSHIPS and SUPPORT – key to getting through
- CICRA family days –a vital source of support and information for parents and carers
- Knowledge and information – from a variety of sources. Mary Brennan, a wonderful IBD nurse specialist is top of our list here.
- Of course, we all look at Google, but searches should come with a health warning – simply searching can bring up misinformation, false hope and fake news.
- School – Eleanor has missed considerable chunks of schooling – either being absent or too unwell and weak when present to benefit from schooling. The first thing we had from Mary Brennan following diagnosis was a really helpful letter for school informing them of Eleanor's diagnosis and offering advice on how school could support her. This was invaluable in helping us develop excellent relationships and support from the school.
- Similarly, the idea of 'shared care' and our relationship with our GP surgery – for example, surgery now arrange appointments and blood tests before school so that Eleanor's time off school is minimised.
- Openness with the team is vital – it's not really about us, it's about how best we can support our child to live with her ongoing health condition
- Don't lose your sense of humour and don't 'blame'.
- Be prepared to accept that relationships will change and not everyone will want to be supportive (people can get impatient with chronic/lifelong conditions – so they'll offer magic cures and advice based on Google/ignorance/misinformation). Be prepared to give up on unhelpful relationships. Focus on looking after yourself and your child.
- Find strategies that work for you – and more importantly for your child. For example, the more prepared and informed Eleanor is the better – she wants all detail and all likely outcomes before any procedure etc.
- As difficult as it might seem – wherever possible, do allow your child to make decisions. Our view – it is Eleanor's 'condition' and she will be managing this for the rest of her life – better that she engages with the process as early as possible and feels in control where at all possible.
- We would welcome some CICRA research focus on the social, psychological and educational impact of Crohn's Disease – this would be of great benefit to CICRA families.

CICRA WORDSEARCH

Congratulations to all those who submitted the correct answer of 'stomach' in the last Wordsearch and to the winner: Imogen Bryant.

In the puzzle opposite are hidden different words relating to Harry Potter. You will find them all listed below the grid – just cross them off the list as you find them. One of those words **can't** be found in the puzzle and that is the prize answer.

Simply send us the missing word, along with your name, age and contact details, either by email to: **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 12th May**, and the winning entry will be drawn and the lucky winner notified on **Monday 15th May**. **GOOD LUCK!**

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

RAVENCLAW
ALBUS
HIPPOGRIFF
HERMIONE
HAGRID
POTTER

HEDWIG
DARK ARTS
HUFFLEPUFF
GRANGER
WEASLEY
HARRY

SCAR
JK ROWLING
DUMBLEDORE
RONALD

A return to Cambridge

With our former Medical Director, Dr Rob Heuschkel, chairing this meeting there was plenty to interest everybody – the young people being able to join their different age group activities while their parents and the older youngsters listened to the talks during the morning and joined the breakout sessions in the afternoon.

We thank Claire, Scott and Katy for telling us how they cope with IBD and on pages 8-10 you will find their stories. We also thank Mick McCormick for giving a Dad's thoughts on his daughter Eleanor's Crohn's disease. On these special days, we rely on the medical professionals to help and they never fail. Research, new treatments, investigations, psychological problems, etc. were all covered by talks from Dr Matt Zillbauer, Professor Ian Sanderson, Dr Jenny Epstein, Dr Jackie Doyle and Dr Rob Heuschkel. Professor John Walker-Smith spoke of the good work that CICRA has done and was pleased to see four former CICRA Research Fellows at the meeting. We thank all the speakers and the other members of the medical profession who took the afternoon discussion groups.

E-Pals

If you have Crohn's Disease, Ulcerative Colitis or Indeterminate Colitis why not join the friendly CICRA E-Pals and make new friends. Share stories and chat by e-mail to other children who understand what it's like to have IBD and who know what you are going through.

The CICRA E-Pals has been a great success over many years (originally 'penpals') and we sometimes print a list of new youngsters joining the scheme. This time we thought that we would bring you some thoughts from the young people (aged 6 to 18) who have found understanding, confidence and, most importantly, new friends by joining E-Pals.

Connor – age 8

I was 6yrs old when I was diagnosed. I was very poorly. I didn't like the blood tests etc. I've had help dealing with this from a psychologist. It has been hard for my family. I like getting emails from other children, especially jokes to cheer me up. I am going to be 9 years old at the beginning of April! Mum also has found it good talking to other parents

Katy – age 18

Being diagnosed with Ulcerative Colitis is a step into the unknown, and being such a debilitating illness, it has the ability to make any sufferer feel frightened and lonely. When I was first diagnosed at age 7, I felt isolated because I didn't know anybody else that was going through the same thing as me. Nobody seemed to understand the daily pain that I was making part of my regular routine. Would anybody ever understand what I was going through? Would anybody ever be able to relate to the crippling stomach cramps and constant visits to the toilet?

This is where CICRA E-Pals came in. For the first time, it allowed me to connect with people my own age who knew exactly what I was going through. Sharing experiences and relating to people is what enabled me to stay strong throughout my IBD. Knowing that I am not alone in this meant that I could accept my IBD for what it is and learn to deal with it as best as I can. Now, at the age of 18, I have met some amazing people who have inspired me to keep going with my life.

Amy – age 14

When we first knew something was wrong I was seen at hospital quite quickly as I was bleeding badly. I had an endoscopy at Bristol Children's Hospital. The team was really nice and kind which helped a lot as I was really nervous. When I was put under anaesthetic they made a joke that the anaesthetic was penguin milk because it was white and cold when it went up your arm! My operation took half an hour and when I woke up I was given something to eat (I couldn't eat for 2 days before, except lolly pops!) and then I was told that I had Crohn's Disease. It has been hard for me to get to grips with this. I have been on steroids, Azathioprine and now Infliximab. I have an amazing consultant who has been here for me a lot and has helped me hugely. I am very thankful for all the help that I have received from him. However, I felt very alone for a while as I felt different and the odd one out from all my friends. I was told about CICRA by my consultant and I had a look and signed up to E-Pals! It has helped me enormously and I have made some amazing friends (Lucy and Brooke) and I am very thankful for all their support. A big thank you to CICRA for being here and helping me through the tough times.

Rosanna – age 12

Before I was diagnosed with Ulcerative Colitis I felt so unwell that it was a relief to finally find out what was wrong with me. Although my medications have had side effects, my colitis is now in remission, and I can attend school full-time and participate in sports. I am really happy to be an E-Pal because I can make friends with other children who understand what I am going through. We support each other but also chat about general things.

For your child's safety, parents are urged to follow government advice and sensible practise with regards to the use of the internet, and to carefully monitor any correspondence made through emails or IM services. Please note that CICRA and its Trustees cannot accept any responsibility for any undesirable or unsuitable contacts made through this column and our website. Ed.

Tami – age 13

I was diagnosed with Crohn's Disease on the 10th June 2016, through a colonoscopy at Bristol Children's Hospital. The year before, I became ill and was struggling to go to school. I started a dairy-free diet which I still follow which eased my symptoms for a while, but they came back. After being diagnosed I was put onto Modulen (a milkshake type drink) which was substituted for food for 6 weeks. This worked a miracle the first time but once I had finished the course my symptoms came back and I was put on a second course but finished it early because I was so poorly. After this I started Azathioprine which once again worked brilliantly for a few months until I started to have a relapse. Since the 16th March I have been on a drug called Humira, it comes in a pen also most like an epi-pen and I self-inject every two weeks. The CICRA E-Pals programme has given me more confidence in knowing I am not alone in having this illness and I can talk to people who have had or are going through the same experience as I am. It sometimes feels like your friends don't understand what people with Crohn's go through on a day-to-day basis and the CICRA E-Pals has helped me learn about other people's experiences and tell people about mine.

Madeline – age 12

I was ill for quite a while before the doctors realised what was wrong with me and I was diagnosed with Ulcerative Colitis. I was so poorly I missed quite a lot of school and wasn't able to do very much. When I was poorly my mum found CICRA and now I chat to people who are going through the same as me. It makes me feel great because I feel like I am not the only one that is different, and there are other people like me. I would suggest joining the E-Pals because it makes you take your mind off things and you can find new friends!

Sam – age 6

I have made two friends through CICRA E-Pals. I like to be able to write to someone who understands what I am going through. I also write to them about football and other things we both like. It has helped me to know what to do about things like talking to my friends about ulcerative colitis. It's nice to know I am not the only one.

Lydia – age 17

When I was diagnosed with Ulcerative Colitis in 2014 all of my confidence was knocked out of me. Having to cope with taking medication every day had a huge impact on my life and provided a new sense of responsibility. My consultant provided me with information on CICRA and I immediately signed up to the E-Pals scheme. As soon as I got in touch with a variety of people who are around the same age as me I started to realise how similar my illness was to others, this therefore allowed my confidence with UC to increase. I still maintain contact with my E-Pals and we talk to eachother about our illnesses if we have any queries. Overall, I think it is important that young individuals who are newly diagnosed with IBD use CICRA E-Pals as it can really allow you to open up and to not feel alone as there are loads of people like you in the UK who are coping with IBD.

Amy – age 10

I was diagnosed with Ulcerative Colitis in January. When they explained what I had, I felt like I was being torn apart and that I wouldn't be able to do many things ever again! I thought that I will never be able to start a family of my own! But then my Mum found this website where you could choose people to be your E-Pals, and you could add your name to the main page so other people can ask you to be their E-Pal! Having E-Pals makes me feel a lot happier because you can talk to people that are going through the same things as you, so they will understand more, as my school friends don't really understand how hard it can sometimes be. For one of my E-Pals, we have each other's phone number, so we just text. We talk about what's going on in our lives and ask questions. Like: What's your favourite movie?. When we go to a hospital we sometimes talk about that as well.

If you would like to join, just email **support@cicra.org** and we will send you the necessary forms.

12 days and 1,000 miles

My nephew Jake was diagnosed with Crohn's disease aged 10 and watching him going in and out of hospital on a regular basis and the support he needed, I decided I would do something to help, *writes Mark Coulter.*

Having taken up cycling the year before, it seemed obvious to me to cycle the iconic Land's End to John o' Groats route.

This is how I found myself at Land's End on an overcast Tuesday morning at the end of August with 57 like-minded cyclists aiming to cycle 80–100 miles for the next 12 days. The first 2 days took us through Devon and Cornwall, over Dartmoor and into Somerset, crossing the Severn Bridge into Wales at the end of day 3. By now we had split into smaller groups and my group was averaging a very healthy 16mph. Day 4 was spent cycling through the beautiful Wye valley and back into England.

Up until now the weather had been kind, day 5 changed that and the entire 92 miles were spent cycling in heavy rain, eventually finishing in Preston beyond soaking!

Day 6 saw us cycle through the Lake District and a few hills and on day 7 we passed into Scotland and took the obligatory photos. The roads got better and the traffic less.

The next few days we continued up the west coast before finally turning inland at Fort Augustus, stopping at the Commando Memorial at Spean Bridge and alongside Loch Ness – no sighting of the monster though.

The final day was just a short 30 miles ride from Thurso to John o' Groats in glorious weather. There was a large group of friends and relatives to greet us; tears were shed, hands shook, and photos taken before jumping on a coach to Inverness for a celebratory meal.

Once everything was counted, I raised over £4,400 for CICRA which I am sure will go to help other children like Jake and make things just a little easier for them.

Cook, curry and cabaret

£21K raised

Jane and **Alexander Tweedie** held another hugely successful Cooker, Curry & Cabaret Night with a popular auction, offering sought-after whiskies, raising over **£10,000** on the evening. This was then matched by The Robertson Trust's matched funding scheme at Edrington. Along with collection boxes and various other donations from work colleagues, the total CICRA has received from the Tweedie family's efforts in 2016 alone was over **£21,000**.

Jane and Alexander have been raising large sums of money for CICRA each year in memory of their son, Callum Tweedie, who very sadly passed away in January 2010.

(left to right) Jane Tweedie, Kathleen Ross, Dr Gamal Mahdi and Alexander Tweedie. Kathleen is Lead Paediatric Dietitian at Royal Aberdeen Children's Hospital and Dr Mahdi was Callum's Consultant Gastroenterologist

Quids for quilts

I've fundraised for CICRA since my teenage daughter was diagnosed with Crohn's disease 7 years ago.

I'm a member of Exeter Quilters and this lovely group of ladies chose CICRA to receive a donation from their quilt exhibition in August of last year, recently sending CICRA £2,250. The quilters additionally made donations to 2 other charities and all received their cheques at their Christmas party. As you can see from the photo below, Jim Hart, a Consultant Paediatrician from the Royal Devon and Exeter Hospital, kindly accepted the cheque on behalf of CICRA.

The three day exhibition, held every three years in the heart of Exeter, showcased some of the many quilts made by the 85 members since their last exhibition. The proceeds came from a small entry charge, sales table, raffle quilt and from refreshments.

The event takes loads of organisation but all the members helped in its preparation, selling raffle quilt tickets or attending sew-in days to make cushions, cards, Christmas decorations, bags etc for the sales table, together with kitchen duties, refreshments, door duties and sales during the show itself. They were delighted that Exeter's Lord Mayor Cynthia Thomson supported the show and took great interest in all the quilts, including CICRA's own quilt (which you may have seen on family days).

Exeter Quilters have been quilting together for over 30 years. They meet monthly in a church hall and enjoy speakers, slide shows, etc as well as sharing their work and skills. They alsomeet in their own homes to sew, chat and enjoy tea and cake!

'Insider' also asked me to mention the little weekly sewing group which I have run now for several years. Back in the day, I studied City and Guilds Soft Furnishing and always fancied passing on the skills I learned. So I put a small ad in the village magazine and 6 or 7 ladies have been coming ever since bringing their projects to make cushions, blinds, curtains and quilts.

The ladies write a cheque to CICRA for the skills they learn. The mornings are a joy to me as I now have some really good friends. There's much tea and laughter and we've shared many of life's ups and downs over the years.

Trish Walker

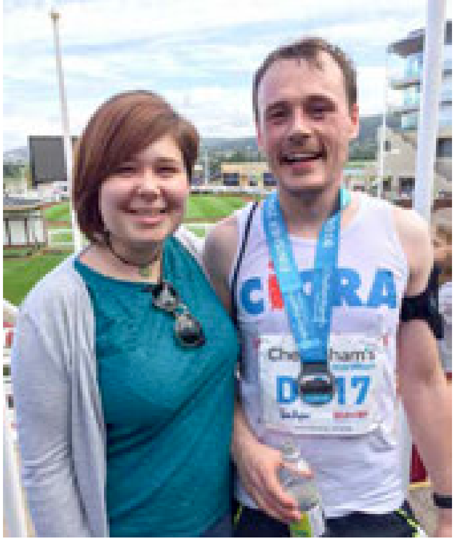
Creative fundraising

Our thanks to artist Adrian Medina-Lueerssen for kindly raising money for CICRA through sales of his creations. You can see more of his beautiful work such as 'Water drop leaf' (pictured right) at: https://adrilumedina.wixsite.com/adrian

Our amazing fundraisers

RUNNING

Paul Graham (*pictured below with sister Joanne*), raised **£405** by running the Cheltenham Half Marathon in September.



CICRA member **Joanne Chilcott**, ran the Bristol Half Marathon in September with Jess and Katherine (*pictured below*), raising **£975.50**.

Not content with running in the Paris Marathon for CICRA earlier in 2016, **Tom Cooke** also completed the London Triathlon and Nottingham Marathon, raising a total of **£2,316.25**.

Long-time supporter **Oli Monks** took part in another event for CICRA in September – the Great South Run, keeping his campaign for CICRA going.

WALKING

Dave Bentley and **Mike Stradling** (*pictured below*) walked the full 102 miles of the Cotswold Way, Chipping Camden to Bath, across 4 days (25th to 28th August 2016) to raise **£1,677.50** for CICRA on August bank holiday. Having seen their close friend suffer with Crohn's for much of his life, David and Mike decided to raise money for CICRA – and we are very grateful.

Member **Colin Vesty** participated in the 100 Miles Race Walk 2016 in August, raising **£5,143.05** for CICRA. Here's what he had to say after the event:

"Omg – what a weekend – the dream came true. More than two years of relentless training, studious planning and preparation has paid off – BIG TIME!

100 miles completed in 20:39:44, 2nd place overall, 1st new Centurion, 1st Brit – National champion to boot!

I don't think that there was any point in the race when I even doubted that I would finish, I was a man on a mission and nothing was going to stop me. Not only did I have a sound race plan to stick to, I had a whole host of counter plans for every eventuality I could think of. As it turned out over-prepared was best-prepared.

Oh, I have to go – Charlie has just brought me his lead and a pair of trainers. looks like it's time for a long walk!"

Colin Vesty, Centurion: C1167

Swim Serpentine

We have places for the new ½ and 1 mile Swim Serpentine in September. Please email **fundraising@cicra.org** or ring the office for more details.

CYCLING

Prudential London-Surrey 100

CICRA is grateful to the four entrants (three pictured below) who completed the Prudential London-Surrey 100 last summer, raising a combined total of **£3,945**.

As if a 100-mile cycle was not set to be challenging enough, various collisions and detours through the day meant the day, quite literally, had its fair share of twists and turns.

Chris Jacobs, **Nick Stevenson** and **Jonathan Snelgrove** cycled around 330 miles from Ipswich to Dorset and raised an impressive **£1,420.98**. From Nick's JustGiving page: 4 days, 330 miles, 17,400 feet of climbing, top speed 46.5mph, and 2 punctures – and memories that will last a lifetime.

Andrew Stockdale raised **£255** for CICRA undertaking various cycling challenges in 2016.

Steve Worsnip

John Walker with son James

David Betts with daughter Lucy

In memory of Josh Sanderson

Dedicated family and friends raised an astounding £16,985.25 in memory of Josh Sanderson in 2016, from a range of auctions and events, including:

Ste Kirkstall and five friends *(pictured right)*, who make up most of the Bramley Blasters, raised **£371.25** when they completed an Ultra Marathon trail.

Ian Popplewell and friends *(pictured below)* completed a Saddle and Paddle Challenge, raising **£2,237.50** in memory of Josh.

Glynn Bell raised **£566.75** when he ran the Leeds Abbey Dash in November.

Thank you so much to the Sanderson family and everyone who pulled together to raise so much money for CICRA in Josh's memory.

Fundraising

SNIPPETS

Special mentions also go to the following for the support they have given the charity:

Some close friends and family of **Lenny Minton** organised a football match between Year 10 North Walsham Boys and Year 11 North Walsham Boys, selling tickets to spectators to raise **£249.71** for CICRA. Special thanks go to Tyler, Nathan, Alfie and Andrew for their organisation of the teams and refereeing, as well as Lenny's sister, Faye, and her friend Rosie for baking and selling cakes to spectators.

Ste, **Steve** and **Paul McCready** took on a skydive together in October. Friends and family sponsored the trio and raised a generous **£1,773.75**.

As well as her running efforts, **Joanne Chilcott** also donated **£500** at Christmas: money raised from a wreath-making event *(pictured right)* – a lovely original idea!

For a few weeks a year, **Verity** and **Mark Batchelor** of Riverside Farmers open their farm, Beluncle Farm in Hoo, to the public to enable visitors to pick and buy their own pumpkins. It is reported that around 40,000 people visit the 40-acre farm and the experience is a wonderful family day out. The total donated to CICRA from this fantastic event was **£2,105.58**: £1,000 of that comes directly from Riverside Farmers, £25 from Verity's parents 50th wedding anniversary (congratulations!), and the rest from the generous visitors, family and friends in exchange for pumpkin tasters.

Jemima Gibson Wyer sold refreshments at a get-together and raised **£57.38**.

Many of us have a vice, and for **Emma Mills** this is carbonated drinks. She decided to tackle a 'carbonated drinks challenge' – giving up fizzy drinks for a year – and raised money for CICRA.

MH Passmore donated three times in recent months with funds totalling **£265** raised from selling her knitted items and other crafts.

Joy Baskerville organised an afternoon tea and raised **£63.90** for CICRA.

Katie and Andrew Coe very kindly donated **£80** from the proceeds from selling their baby items.

Rachel Cartmell held a community Hallowe'en event raising **£632.50**. It was such a success that Rachel is planning an Easter Eggstravaganza!

Sue Garnock and the Marc Bolan fan club raised **£360** at a London bop.

Paul Maya Denman raised **£375.50** by holding a Bingo Night.

Izaac Coverley organised a Christmas shopping event and raised **£276.25**.

Joyce Holder and friends held a school reunion and donated **£120**.

The Right Illustrious Knight Bob Hancock of the **Surrey Division, Red Cross of Constantine**, visited the CICRA office in November to present a cheque for **£1,000**. Our thanks go to

the Grand Imperial Conclave for this generous donation.

Summerfields chapel collection chose to donate **£112.70** to CICRA.

Islington Townswomen's Guild donated **£80**.

Amelie Simpson's nanny and friends had a collection and raised **£120**.

The Downs Flying Club donated **£70**. CICRA members Verity and Mark Chapman offer their farm to the club for the event and pass on this donation.

Our thanks go to the following schools for thinking of CICRA for their fundraising efforts:

Cumnor House School, known to longstanding member **Jax Martin-Betts**, donated a generous **£593.01**.

Bitterne Park has donated twice in recent months, having raised **£177.93** via their skills centre.

Shireland Collegiate Academy donated **£51.55** following a school fundraiser.

Member **Harry Johnson** helped to organise an open mic night at **The Romsey School** in Hampshire, raising over **£100**.

Our thanks go to the following workplaces for thinking of CICRA for their fundraising efforts:

Keeley Daley organised a Christmas jumper day at her work, Volz Filters UK, and raised **£100**.

Danielle Grimley took on an unusual physical challenge in November by climbing the O2. Thanks to Danielle for raising **£469.50** for CICRA.

CICRA member **Toby Broome** and a team of colleagues at **EMC** *(pictured above)* focused on CICRA for their charitable donations last summer, raising **£530**.

Maxine Armitage, together with **daughter Poppy** and sister **Amanda Warnock**, took on a zip wire challenge – the longest zip wire in Europe – to raise close to **£900** for CICRA. The video is posted on our Facebook page: have a look, it may inspire you!

Another of our long-term supporters, **Alison Johnston**, continues to donate from raffles and collections. Alison donated **£380** since the last edition of *The Insider*.

Olivia Chappell and her work colleagues had a dress-up day at work and raised **£160**. They took some great pictures too!

Nearly 40 years of giving!

We feature as many fundraising events as possible in our newsletter but we don't forget that there are many members/supporters who give regular donations either by cheque or bank standing order – some of these going back nearly 40 years! We thank all donors/fundraisers for their very valuable support.

Dorrie tunes up

When Dorrie Mottram *(picured right)*, an accomplished pianist, agreed in 1977 to play for a 'one-off' variety concert as a celebration of the Queen's Silver Anniversary in her village of Hassocks, West Sussex, she probably never thought that she would still be playing for them 40 years later but that's exactly what she is doing.

The group called themselves Friends and Neighbours and as Dorrie says 'our loyal community kept supporting us so we kept on doing what we enjoy doing.'

In 1989 when Dorrie's son Kevin was diagnosed with Crohn's, she decided to fundraise for CICRA and formed the West Sussex Group. Not sure where to start, she had a coffee morning which led to fundraising events of various kinds, one of which was the proceeds from the annual Summer Variety Concert by 'Friends and Neighbours'.

To date Dorrie, her family, friends and supporters have raised over £80,000 and we are very grateful to them all, and for the support given to them by 'Friends and Neighbours' and the village of Hassocks.

The next Variety Concert is on **Friday 16th June at the Adastra Hall, Hassocks starting at 7.30pm**. If you would like tickets (very reasonably priced) please contact CICRA.

Christmas cards

Last Spring, when we were due to arrange the choice and ordering of Christmas Cards, we realised that as we hadn't found a suitable office to move to from Parkgate House, and didn't know where we would be in June when the cards were due to be delivered, we had to make a decision.

Fortunately, one of our suppliers, Dash UK Ltd, offered a part, or full, fulfilment service. We are very grateful to Dash for being so flexible in their arrangements in which we were still able to be part of the service but not have to worry about storing the cards and packing the orders.

Unfortunately, there were a few cases of orders taking longer than normal but that was mainly due to the much longer process of administering the orders and payments before being able to let Dash know where to send the cards to. We apologise if you were affected but we did not want to stop selling cards nor spend too much of the profit paying others to do something that had always been done on a voluntary basis.

CICRA Christmas Draw

Our thanks as always go to all who purchased and sold tickets for the Christmas Draw. Your generosity resulted in a total profit of £3,478 towards our ongoing research and support programmes.

The draw took place on Tuesday 13 December at our offices in Pat Shaw House with Glynis Gatenby, the Director of Operations from Sutton Housing Society drawing the winners. Some of the prize money was returned as donations and we would like to thank the supporters concerned for their very generous gesture.

Prize	Ticket	Winner
1st	06010	P Carver, Derbyshire
2nd	24530	E Strowger, Aberdeen
3rd	25938	M Green, Lincolnshire
4th	21519	H Richardson, Surrey
5th	26905	A London, Orpington, Kent
6th	19366	C Lazenby, Leeds
7th	10590	M Hill, Norwich
8th	22564	E Verney, Edenbridge
9th	01730	L Powell, Gloucester
10th	30745	P Herman, Worcester
11th	02756	R McCaffey, Lancashire
12th	00750	K Holmes, Billingham
13th	31840	R Jones, Hockley

We try not to send to those of you who do not, for whatever reason, wish to receive these tickets, so if you do have to return them to us unsold please do put your name and address on them so that we can make a note on our database not to send them again.

Glynis Gatenby and Margaret Lee

Professor Delphine Parrott

Just after Christmas 2016 we were sad to learn of the death of Professor Delphine Parrott, a pioneering scientist who over the course of her career made many outstanding contributions to Immunology.

In 1973 she was given a personal chair at Glasgow, the first female professor in the 473 year history of the university. Delphine was a founder of the science of T-cell immunology, which has led to clinical advances including organ transplantation.

Although teaching was not necessarily always at the forefront of her duties, it is here, that her contribution equals that of her excellent science. In the late-1970s Delphine and others negotiated the setting-up of a BSc devoted to Immunology; the first of its kind in the UK. This course has produced many excellent immunologists.

Professor Delphine Parrott

Delphine was very supportive of research into IBD and a good friend of CICRA. We are grateful for all that she contributed to science and for the generous bequest she left towards the continuing work of CICRA.

Wills and legacies

Legacies are an extremely valuable source of income for all charities and CICRA is extremely grateful for any that we receive – whether large or small.

Some donations come as a direct bequest and others as part of the residue of a will which is distributed to charities by the Executors/Trustees of the will using their own discretion as to the wishes and desires of the deceased.

Unexpected income such as this is a great asset to CICRA and has helped to provide the funds to maintain and expand the research programme. CICRA will always respect the wishes of the legatee or his/her family if there are certain wishes as to the way the funds are used and will ensure that it is properly administered and acknowledged.

Making a will is very simple. You can do it yourself but it may save problems arising later if it is done by a solicitor or with the help of the Citizens' Advice Bureau.

Making a will is often spoken about but is something that we all tend to put off but if you die without making a will your estate will be distributed according to the law of intestacy and this might not be in accordance with your wishes.

If you are considering leaving something to CICRA in your will and would like the correct wording please contact the office.

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:

- **Mary Townsend** – Remembered with fondest love by daughter Annette, family and friends.
- **Frank Staff** – Will always be in our hearts. With love Muriel and family. Grandson Aiden is a Crohn's sufferer.
- **Diana Joy Kew** – Much loved and sadly missed by daughters Leanna (Colitis sufferer) and Kayleigh (Crohn's sufferer) and husband Malcolm.
- **Kathleen Humphries** – Fantastic nanny to grandson William suffering from Crohn's. Much loved and missed by us all.
- **James William Beaney** – Grandfather of a Crohn's sufferer, Jono Wake. Loved and missed so much by all his family.
- **Horace Owen** – Much loved dad and grandad. Remembered and missed by all.
- **Arthur Leighton Carey** – Fondest memories from his son Steven, family and friends.

Bequests

We are grateful to have received a bequest from the estate of the late B J Coveney and a very generous bequest from Professor Delphine Parrott.

Larger prizes in CICRA 200+ Draw

A big ‘thank you’ to all members who have participated in the 200 Club, and to the new members who joined in 2016. Thanks also to Vice Chair Rod Mitchell for administering this fundraising initiative on a voluntary capacity so that all money raised can be split on a 50/50 basis for monthly prizes and the CICRA Research and Support programmes. If you would like to join please contact the office on **020 8949 6209** or email **support@cicra.org** and we will send you a form. The cost is £26 per year, paid quarterly by standing order if preferred.

CICRA 200 CLUB WINNERS LIST 2016

Jan	114	A Northridge, N. Ireland	£50
	208	P Manby, Suffolk	£50
Feb	7	S Clyne, Manchester	£50
	106	P Cooper, Maidstone	£50
Mar	135	R Brandon, Longfield	£250
	89	D Williams, London	£75
	207	N World, Manea	£75
Apr	109	L Browning, Dumfries	£50
	91	I Pell, Pevensey	£50
May	194	J Rai, Lee on the Solent	£50
	111	D Menarry, Tarleton	£50
Jun	183	C Shaw, Manchester	£250
	163	J Cotterell, Newport	£75
	90	Rita Jones, Essex	£75
July	23	J Campbell, Dumbartonshire	£50
	102	D Neill, Leicester	£50
Aug	197	A Basit, Watford	£50
	83	I Pell, Pevensey	£50
Sep	2	K Wentworth, Surrey	£250
	57	C Prosser, Cardiff	£75
	102	D Neill, Leicester	£75
Oct	2	K Wentworth, Surrey	£50
	200	L Mills, Tunbridge Wells	£50
Nov	27	H Alton, Bedfordshire	£50
	31	J Tweedie, Aberdeenshire	£50
Dec	66	C Shipp, West Sussex	£250
	195	P McQuade, Lincolnshire	£75
	169	T Lack, Dorset	£75

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 **£1,155.88** has been put towards research. Our thanks go to:

Mr Melanie Beaver
(The Country Kitchen)
C Chan *(Home)*
Alyson Chapman *(Shop)*
Ann Donohoe *(Home)*
Robin Eames *(Home)*
K Harland
M McGowan *(Home)*
B McKinney *(Pub)*
Gill O’Neill *(Home)*
Linda Rimen *(Home)*
Jenny Steer
Carolyn Stimpson *(Home)*
Jane Tweedie
(Craigellachie Filling Station)
Mr Varu *(Mini Store, Sutton)*
Eunice Vickers *(Mini Market)*

If you would like a collection box for your home or local shop, pub etc, please contact **fundraising@cicra.org**.

CORPORATE DONATIONS

CICRA is grateful to the following companies and trusts who have so very kindly made donations.

- Andor Charitable Trust
- Andrew Patons Charitable Trust
- C. Brewer & Sons Ltd
- Chapman Charitable Trust
- Charles Littlewood Hill Charitable Trust
- Clover Trust
- Dr Falk Pharma
- Edwin Henry Tutty Charitable Trust
- G C Gibson Charitable Settlement
- Graham & Mary Stacy Trust
- Homelands Charitable Trust
- Kite & Co
- Leiper & Summers
- Lord Belstead Charitable Trust
- Lynn Foundation
- Mackintosh Foundation
- Muir Construction Ltd
- Nancie Massey Charitable Trust
- Naomi Joels Charitable Trust
- NEXT PLC
- Paul Bassham Charitable Trust
- Reuben Foundation
- Rio Tinto
- Sandra Charitable Trust
- Sobell Trust
- Tay Charitable Trust
- Thomas Tunnock Ltd
- Wessex Water
- Wilkin & Son

CICRA
children and young adults
with crohns and colitis

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