the Spring 2016 Spring 2016 Children and young adults with crohns and colitis

CICRA committed to £1 million research funding

February is the time of year when decisions are made on funding for the coming years and we are delighted to report that once again we are using funds where they are really needed – supporting good quality research. We have added a further £450,000 to the current commitment making a total commitment over the next three years to just under a £1 million.

Peer review is the essential element of ensuring that funds are well spent and we are fortunate to have an excellent panel of experts to advise us. The process of peer review is carried out over several months culminating in a one-day meeting of the panel at which the recommendations are put to the Trustees. We are very grateful to our experts (listed on page 2).

Last June, applications were invited in four funding streams and grants were eventually given in three of those. Since the very early days of the charity a Research Fellowship scheme to fund young doctors wishing to specialise in Paediatric Gastroenterology has been our priority. To add to the two Fellowships already being funded, the Trustees offered a three-year Dave Casson Fellowship to Dr Marco



Gasperetto *(pictured left)*. Dr Gasperetto, who will be supervised for the next three years by Dr Matt

Zillbauer and Dr Rob Heusckhkel at Addenbrookes Hospital in Cambridge will, in addition to his clinical duties, be working on a research project, the aim of which is to validate identified paediatric biomarkers in a second patient cohort and adjust it to be detectable in whole blood samples. This should bring them closer to using it in clinical practice to personalise/ tailor treatment.



A three-year PhD Studentship was awarded to Dr Mairi McLean (*pictured left*) at the University of

Aberdeen. The student has yet to be appointed but the research study will

Continues on page 3 🔿

Dates for your diary

The next popular **IBD Family Information Day** will be held in the North West at the Doubletree Hotel, **Manchester** on **Saturday 25 June 2016**. If you would like to join us please complete and return your invitation slip. If you have not received an invite yet, please email support@cicra.org or call Jayne on 020 8949 6209.

East Anglia is our next stop and an **IBD Family Information Day** will be held in this area on **Saturday 12 November 2016**. This is still in the planning stages but if you would be interested in joining us there and would like to register now please email support@cicra.org or ring Jayne on 020 8949 6209.

CCRA

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Crohn's in Childhood Research Association

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Trustees Report

Letter from the Chair

Dear Friends

Firstly, I would like to thank you for your support over the last few months. Young people, parents, families and friends have been busy raising funds to help maintain and expand our Research and Support Programmes and we are very grateful.

As you will see from the front page we have committed a further £450,000 to our Research Programme, but if we are to continue to fund good quality research we do need to raise as much as possible. All applications for research funding undergo a very strict Peer Review process so you can be sure that any funds raised for CICRA, whether large or small, are spent wisely.

Last year we were able to organise four Family Information Days. We zigzagged across the UK covering Newcastle, London, Aberdeen and Southampton in the hope of giving as many families as possible an opportunity to learn more from the experts about Inflammatory Bowel Disease, research, new treatments etc and, most importantly, provide an opportunity for children, young adults and their families to meet others in a similar situation.

In March of this year we held a very successful day in Cardiff and on 25 June we will be going to the north west of England. On 12 November it will be East Anglia, so please let us know if you would like further information.

We had a very good response to the Oyster Healthcare survey. All answers are now being collated and this will help us provide the information you and the young people need, and in the way you and the young people would like to receive it. Meeting the children has helped no end and below is a very descriptive poem from 15-year-old Olivia O'Toole who won the first prize in a creative writing workshop at our Cardiff meeting.

Comments from children at the meetings, some quite young, whose thoughts and fears were expressed so clearly, make us realise why we are here and needed – to try to give a better quality of life to children with IBD and maybe, one day, take away the fears that they have for their future.

We wish you all a healthy and happy summer.

Margaret Lee

Chair

Having a chronic illness is like the weather.

One day there could be a horrendous storm, wind howling, causing waves to crash against the cliffs. Another day it may be sunshine beaming down onto the sea, reflecting off the sparkling surface. The only thing you never know is what the forecast will be. When it is stormy you do not know when the sun will shine again. When everything goes back to sunshine, a storm will hit suddenly without any warning. You just have to deal with it and accept you have to go through the storms to find the sunshine.

Olivia O'Toole, age 15

News

Update on vaccines and immunosuppressant drugs



It is almost eight years since the Insider ran a piece on the risk of chicken pox infection in children (and adults) with IBD who are taking immunosuppressive medications so we take this opportunity to print an updated article. We are very grateful to Dr Rob Heuschkel, Consultant Paediatric Gastroenterologist at Addenbrookes Hospital, Cambridge for compiling these important facts. If you have any queries or doubts please look at the lists overleaf or ask your GP or a member of the Gastro team treating you or your child.

Despite several reviews, working groups and eminent position statements, the advice for children with IBD has changed very little since then. Although having IBD itself does not weaken the immune system, this does happen with certain doses of steroid and types of medication (see list in Table 1 overleaf).

It is still important to remind everyone looking after children with IBD

that the majority of treatments we prescribe affect the immune system, and therefore do increase the risk of otherwise 'quite' harmless infections – although this risk is a lot lower in children than in adults and the elderly.

Conditions such as severe malnutrition, major surgery and the need for longer-term intravenous nutrition (PN) do increase the risk

Continues on page 4 🔿

Continued from page 1

CICRA commits to £1 million research funding

assess the impact of interleukin-27 on expression of inflammatory genes, change in function in individual types of immune cells and healing of the cell barrier that lines the gut. Overall interleukin-27 represents a potential new treatment for IBD.

A very different but equally important area of research is the project for which a two-year



grant has been awarded to Professor Deborah Christie *(pictured above)* at UCLH London. Mindfulness Based Stress Management (MBSM) is the most well-known programme for the management of stress and chronic illness and Professor Christie, and her team, will be looking at how effective intervention with MBSM is for young people with IBD.

Professor Christie, and her team, will be running a large trial of 87 young people with IBD. They will look at Crohn's Disease and Ulcerative Colitis activity, psychological stress, anxiety, pain and mindfulness skills, before and after the course. They will also look at aspects of the immune system that relate to inflammation using blood samples regularly collected in clinic.

In future newsletters we will be reporting on all CICRA-funded research.

AMRC audit

The Trustees are pleased to report that CICRA, as a member of the Association of Medical Research



Charities, has received its Certificate of Good Practice following the 2011 AMRC Audit.

Apart from the certificate it also allows us to use the AMRC audit logo to show that our process for granting awards for research is of a high standard.

News

Continued from page 3



of 'opportunistic infections' (these are usually harmless infections that can become more severe under certain circumstances). Although one immunosuppressant medication only really increases the risk of infection between 2-3 times normal, taking two or more immunosuppressants at the same time can increase this risk to 14 times normal.

The European Crohns and Colitis Organisation (ECCO) released a detailed statement in 2014, which included advice and recommendations relevant to children and young adults with IBD. This publication provided a useful checklist for patients who are newly diagnosed with IBD, which helps document previous infections (incl. chicken pox, tuberculosis, pneumococcus, hepatitis, measles and glandular fever (EBV)).

This sort of screening does allow children to be vaccinated against pneumococcus and chicken pox (if they are not yet immune) before they need treatment with immunsuppressants. Otherwise live vaccines should be delayed for at least 3-6 months after stopping immunosuppression.

Over 70% of children with IBD will eventually require treatment with an immunosuppressant; these should not be started for at least three weeks after a vaccination.

If children on immunosuppressants are not immune to chicken pox and develop the rash of chicken pox or shingles, they should stop their immunosuppressants immediately and seek medical advice. Significant contact (play or direct contact for at least 15 minutes) with chicken pox or measles (without being immune) may need protective antibody treatment (e.g. VZIG).

Routine vaccination with the flu vaccine should be given – every year – to all children taking an immunosuppressant for their IBD. The HPV vaccine should also be given routinely – even if a girl is on immunosuppressants.

Table 1

Immunosuppression is likely if the following have been taken within the last 3 months:

- Corticosteroids (20mg or more for >1 week; or 2mg/kg if <10kg)
- Azathioprine
- 6-Mercaptopurine (6-MP)
- Methotrexate
- Cyclosporin
- Tacrolimus
- Mycophenolate Mofetil
- (MMF)
- Infliximab (Remicade, Inflectra)
- Adalimumab (Humira)

Table 2

Live vaccines – to be avoided while immunosuppressed

- Oral Polio
- Flumist Influenza vaccine (nasal spray only – injectable version should be given as inactive)
- Measles, mumps and rubella (MMR)
- Chickenpox/ Shingles (Herpes Zoster)
- BCG (Tuberculosis Vaccination)
- Rotavirus (used in infants only)
- Yellow Fever
- Cholera (oral version also available as inactive)
- Oral Typhoid (injectable version is inactive)
- Adenovirus
- Smallpox / Anthrax

BSPGHAN and SSPGHAN meetings: a must for CICRA

The CICRA Trustees are invited to many meetings during the year and if it is relevant to the work that CICRA is doing they try to cover as many as possible, two of which are a 'must'.

These are the annual meetings of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and the Scottish Society of Paediatric Gastroenterology, Hepatology and Nutrition (SSPGHAN).

Last November Rod and Margaret attended the SSPGHAN meeting in Stirling, where Rod was given the opportunity to say a few words about the work of CICRA and the research being funded in Scotland.

These meetings are an ideal time to meet up with members of the

medical profession and to introduce CICRA to the younger members just embarking on a career in paediatric gastroenterology. It is also a time to



Dr Nick Croft

meet up and share experiences with other charities, similar to our own, who in many ways are faced with the same day-to-day problems.

This year the BSPGHAN meeting was held at the Marriott Hotel in Bristol so, as it was within reasonable travelling distance, Rod, Margaret and Paul shared the three-day cover. This year was even more special in that our Medical Director Dr Nick Croft, who many will know from our Family Day meetings, took over from Dr Alistair Baker as President of BSPGHAN for the next three years.

Congratulations Nick we know you will do a good job and on behalf of all the CICRA Trustees, staff and families of children and young people with IBD, we thank you for all the support you give CICRA.

Data from Dr Protima Amon

CICRA awarded a Bursary Grant to medical student Greg Williams to present data, collected by a current CICRA Research Fellow, Dr Protima Amon, at the annual winter meeting of the British Society of Paediatric Gastroenterology and Hepatology in Bristol. Here are a few words from Greg.

Whilst undertaking a studentselected module at the Royal London Hospital, I had the opportunity to complete a piece of research examining the clinical outcomes and use of exclusive enteral feeding as an initial therapy following the diagnosis of Crohn's disease in children. The data was compiled using patient notes collected between March 2014 and October 2015 with the help of my supervisor, Dr Protima Amon. The results showed that exclusive enteral feeding is a well-tolerated, safe and effective method of inducing clinical remission.

Excellent opportunity

To be able to present these findings at the British Society of Paediatric Gastroenterology, Hepatology and Nutrition annual meeting was an excellent opportunity that was made possible due to the support I received from CICRA. I consider myself very lucky to have been able to attend the conference as a medical student, and it has provided me with not only a greater insight into the world of paediatric gastroenterology but also into the world of research itself.

I think being able to present findings to senior clinicians and professionals is a great learning experience in my final year of medical school.

After attending the conference, I now hope to complete a further elective placement in paediatrics at the Royal London Hospital with the potential of a final career inside the speciality.



Modulen

Mick's Modulen March

Some of our members, especially those whose children are attending Southampton Hospital, will have heard of Mick's Modulen March and maybe followed his journey on YouTube. For those who don't know, Mick Cullen is an IBD nurse at Southampton. Mick decided that during March he would do what so many of his young patients have to do and that is give up food completely and survive on Modulen, an enteral feed. The idea was that he would better understand how his young patients feel on this treatment. He sums up his experience below. Well done Mick.

Modulen March has just come to an end and reflecting on it I feel it was a very worthwhile challenge and I have learnt lots that will enhance my practice. It allowed me to gain insight into what it's like to be on the treatment. It was hard going at times and not having Crohn's meant I didn't get that "feel better kick" that patients experience which I suppose is what keeps them on it.

But in saying that I didn't feel bad on it. I was able to remain upbeat and cheerful. With the help of our dietitian here, we worked out my dietary requirement and energy expenditure to come to a daily amount of 2.5 litres. I didn't feel hungry at all. That's not to



The 'tools of the trade' for Mick



Brave Mick with his Modulen

say I didn't miss food!! Bacon frying in the morning was a killer – I mean, that can even turn vegetarians!

The things that I learnt:

- 1 Much harder at weekends.
- It's a pain to make up every evening – sometimes I would forget and have to get back out of bed and make it up late at night. So respect to all the mums and dads that do it for 8 weeks.
- 3 The logistics of getting a rightsized kettle and transporting the finished drink takes some working out. I spilt some in my bike panniers on the first day – I can still smell it now.
- You get used to the taste I am not a big milk drinker (black tea and coffee) so I thought I would struggle but after day 3 I was flying. So for those struggling keep at it, if it's a good medicine for you – it is a great medicine for you.

- It is hard for family members they feel guilty about eating so they don't enjoy their food as they should. There is a tendency to want to skip family days out for fear of upsetting the person on Modulen. The person on Modulen will want to do those things – include them – talk about ways of adapting the day.
- 6 I can now understand why children might not want to do a second course of exclusive Modulen. It is hard.

So as it comes to an end I must thank CICRA for their support – without which I couldn't have done it.

Making videos on YouTube proved a great distraction and helped alleviate the urge to pick at food. They have been well received and hope that in a humorous way they have highlighted important issues.

If you haven't seen them search "Modulen Mick".

Youngsters

GET INVOLVET

If you are under 18 years of age, this page is for you - join in and get involved!

Many young people with Crohn's Disease or Ulcerative Colitis find it useful to chat and share experiences with others who understand what they are going through.

• Do you have any **tips**, **suggestions** or advice (amusing or serious) on how to cope with school, exams, friends, outings and family?

- Share your story, you never know when your experiences could help other young people.
- Do you have any **questions** about Crohn's or Colitis that you would like answered?
- If you would like to **chat** to someone of a similar age who understands what you are going through, join in with the CICRA E-Pals. A great way to make new friends; everyone taking part has Crohn's or Colitis and is between 9 and 17 years old.
- Would you like to receive a copy of the CICRA newsletter, information about **E-Pals** or competitions directly to your smart phone or tablet?

Contact: Jayne at the CICRA office. Many of you may have met Jayne at the CICRA Family Days or through the E-Pals and she'd love to hear from you with your stories, tips, suggestions, advice and questions. Contact her by e-mail: groups@cicra.org

CICRA word search

As the nice weather arrives, (hopefully!) here is the chance for one lucky young member to win a £10 voucher of their choice from either iTunes, Toys-R-Us or Amazon.

In the puzzle are hidden different words relating to holidays and travel.

You will find them all listed below the grid. Just cross them off the list as you find them. But 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, Parkgate House, 356 West Barnes Lane, Motspur Park, Surrey KT3 6NB.

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

All entries must be received by Friday 20 May, and the winning entry will be drawn and the lucky winner notified on Monday 23 May. GOOD LUCK!

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Medical article

Autophagy and Crohn's disease: A role for current IBD medicines?

Working on a collaborative project led by Dr Craig Stevens (Edinburgh Napier University) and Dr Paul Henderson (Royal Hospital for Sick Children, Edinburgh), CICRA-funded PhD student Kirsty Hooper is aiming to determine any potential changes in the autophagy process by current IBD medicines.

To date, the most significant progress made towards understanding what causes Crohn's disease (CD) has come from studies of people's genes. Major interesting areas identified through these studies include the body's immediate response to disease (innate immunity) and autophagy (a process that breaks down and recycles substances within individual cells).

The innate immune system is our body's first line of defence and is very important for the detection of unwanted pathogens (bacteria, viruses, fungi), while autophagy can deliver pathogens to specialised structures called lysosomes to be destroyed. This theme of an abnormal immune response to microorganisms that arises from recent genetic discoveries is in line with the long-standing interest in the role of bacteria in CD.

The process of autophagy is now receiving increasing attention in the context of inflammatory bowel disease (IBD) mostly due to the association of three autophagy-related genes (ATG16L1, IRGM and LRRK2) and recent work demonstrating that these genes play a key role in the protection against bacterial infection.

With research studies suggesting that autophagy is not functioning properly in some IBD patients, and that increasing autophagy levels may be of therapeutic benefit, a better



CICRA-funded PhD student Kirsty Hooper

understanding of how some drugs can alter autophagy is an important area of future research.

Results of Kirsty's initial work suggest that several of the most commonly used medications (azathioprine, 6-mercaptopurine, methotrexate and infliximab) may have their effect in part through stimulation of the autophagy pathway.

Kirsty's focus now is to characterise the mechanism of action of these drugs in

the context of autophagy, assess their effect on the survival of CD-associated bacteria, and investigate their effect on autophagy pathway activity directly in primary cells from paediatric IBD patients.

Kirsty is currently using the excellent facilities available at Edinburgh Napier University where she is able to look at cells in real-time and assess their response to different drugs. She hopes that some new results will be ready to present early next year.

An inspiring talk from a 13-year-old

Harry tackles tricky subjects at Family Day

Thirteen-year-old Harry Johnson (below left) recently gave a very interesting and inspiring talk at a CICRA Family Day meeting. He touched on subjects that are not often talked about including how he dealt with bullying.

During the talk he asked a member of the audience to screw up a piece of paper on which he had listed all the bad things about having IBD. He then threw the piece of screwed up paper over his shoulder to demonstrate how he deals with the bad things in life by discarding them and concentrating on the good things.

Once again, we had a very inspirational talk from a young person on how not to let IBD take over your life. Below is a short summary of his journey with UC since he was 5 years old.

"Hello I'm Harry, I'm 13 years old and have ulcerative colitis. I was diagnosed when I was 5 years old. So I have had to go through primary and part of secondary school with the disease. I can't really remember much about when I was diagnosed. It was all really a blur. But I do remember my hospital room with the TV and I'd watch in the night garden before I went to bed. I was put on steroids, had blood transfusions and gradually went into remission. I had a period in my life when I was in remission, quite a long period actually. About 4 years. But then I had a flare in year 6 and that wasn't very nice with SATS. But I did the tests. The flare carried on into year 7 and 8. Not nice to go through the start of secondary school with. However, I haven't let it stop me.

I have been on a few trips, one to Paris and one to Wales. I'm going on a water sports trip in the summer which will be a nice experience I hope. Also, I have a London Academy Of Music And Dramatic Art (LAMDA) exam at school in May. Wish me luck when my pieces get marked! It will be my first ever LAMDA exam at my school so I hope everything goes well.

Friends at school have been very very supportive of me, we are always laughing and whenever I'm not at my best they always keep me up and running. Although, sometimes it gets in the way of PE, but that's no problem as I don't like it anyway!"

helping childen and Young adust

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Southampton

Guests are bowled over

Last November a visit was made by CICRA Trustees and staff to The Aegis Bowl, the home of the Hampshire cricket team, not to watch cricket but to hold one of their popular Family Information Days and a packed day it was.

We were happy to have a representative from Dr Falk Pharmaceuticals join us as well as Amanda and Annabel from Oyster Healthcare who were 'information gathering' to help CICRA with an update of their literature.

CICRA's medical director, Dr Nick Croft, welcomed all to the meeting and introduced Dr Mark Beattie who gave an overview of Paediatric IBD in the Wessex region with current CICRA Fellow Tracy Coelho and Senior Research Nurse, Rachel Haggerty talking about the current research in Southampton.

Romana Rai, aged 18, gave a very enlightening talk about her hopes and fears for the future whilst living with Crohn's disease and Nera Cornell, aged 16, assisted by her mum Doina, talked about life with Ulcerative Colitis. An interesting presentation on surgery was given by Mr Mike Stanton and Dr Nadeem Afzal recalled his 10 years experience in managing children with IBD. Our regular and popular speaker, Dr Kate Blakeley spoke about the psychological issues she sees in young people with IBD attending her clinic at the Royal London Hospital. We were fortunate to have two specialists from Cambridge join us for the day – Dr Matt Zillbauer gave an interesting talk on current research at Cambridge and Dr Rob Heuschkel talked about immunosuppressant drugs and immunisations. This was an interesting topic for many and on pages 3-4 you will see an article written by Dr Heuschkel on this subject.

To close the morning we had a double act from IBD nurses Mick Cullen and Rachel Russell on progress to diagnosis and transition. On page 6 you will see an article on Mick Cullen's 'Modulen March' – undertaking a month of having Modulen in order for him to understand how some of the youngsters cope when this is prescribed.

Lunch was followed by short presentations on the work of CICRA and current fundraising and an introduction to the afternoon discussion groups. As usual, the teenagers and the young adults had their own groups and the younger children were entertained by professional entertainers 'Jingles & Sparkles'.

We would like to thank everybody involved in making this a great day especially the health professionals for giving up their Saturday to join us. Our thanks also to the Pye Charitable Trust and Sobell Trust for their donations towards the cost of this meeting.

We hear some amazing comments from children about our Family Information Days. Here are some of them...

l an 15 and the day made me vealise l am not alone.

I felt really positive after the day and couldn't believe how similar other people's experiences were to mine.

It was a very good day, being able to talk and joke with others who understood. Despite not wanting initially to go to the group session for the teenagers. I really enjoyed it! I met two ginls and hopefully we will keep in contact as none of my close friends understand what it's like to have IBD.

I was blown away by not being alone and that lots of other completely normal kids are in the same or a worse position as me. It was good to share experiences with people going through the same thing.

Aberdeen

Something for everyone

Last October a CICRA team of staff and Trustees travelled to Aberdeen to meet members and their families at a CICRA Family Information Day held at the Hilton Aberdeen Treetops Hotel.

These days, organised by CICRA, gives families affected by IBD the opportunity to hear talks from clinical and scientific specialists in paediatric IBD, learn more about the condition in a relaxed setting and meet other families in a similar situation. A varied programme was organised and something arranged for all ages.

Trustee Deborah O'Neil, from Aberdeen, opened the meeting by welcoming everybody and gave an overview into what had been arranged for the day which started with talks from Dr Michael Bissett, Dr Richard Hansen and IBD nurse Carol Cameron covering diagnosis, research and video consultations.

Following a break for coffee and entertainment for the children, past

CICRA Fellow Dr Fiona Cameron gave some very interesting data on 'IBD in Scotland' and Dr Anna Clancy, Kathleen Ross and Dr Shyla Kishore continued with talks on 'How psychology can help', 'Diet – Fact or Fiction' and 'Treatments – What's on the horizon?'

James Cooper gave a young person's talk and showed with great slides how despite having Ulcerative Colitis he has managed to continue with his sporting activities including climbing, cliff jumping, skiing. He ended his talk with a slide titled 'Seal the Deal' which was of his wonderful wedding day. Thanks James.

Following an opportunity to chat during lunch, CICRA's medical director Dr Nick Croft introduced a video made by Chloe, a 14-year-old with Crohn's – a very moving insight into the problems

I loved everything about the teenager's group session! Despite being really tired and feeling unwell the day left me feeling on a high! Excellent to be given opportunity to meet others, share experiences and make friends.

> Meeting other teenagers and talking openly about our illness excellent!

I really enjoyed the day. It was interesting to find out more about Crohns and hear of other people's experiences with the illness. The group discussion in the afternoon was a great as I was able to talk about my experience and answer some questions that other people had.



experienced by young people with IBD. We are happy to say that Chloe is currently very well.

Asking questions

The very popular discussion groups had been arranged for the afternoon and gave an opportunity to ask questions of the experts whilst the young people met in a group of their own and the very young were kept well entertained by the 'Great Hootini'. From the laughter coming from their room it was evident that they had been well catered for.

We would like to thank all our medical professionals for giving up their Saturday to help families affected by IBD and everybody who helped in any way to make this a special day for many families. We would also like to thank the AMW Charitable Trust for their donation towards this meeting to support families in Scotland who have a child with IBD.

As a footnote, the CICRA team thought that they may have to sleep in Aberdeen Airport when their flight, the last of the day, was cancelled. However, with a great rush they were all able to scramble on to the earlier flight – so apologies if everybody seemed to disappear in a hurry.

Meetings

Oyster Healthcare

Following the Southampton meeting in November Amanda Burrell from Oyster Healthcare put out a blog. This is a shortened version.

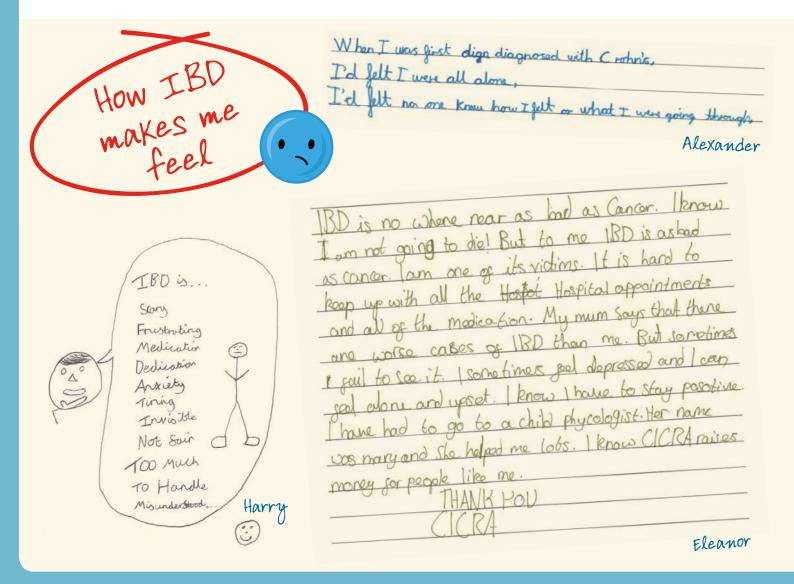
Growing up with a chronic bowel condition

The number of children being told they have inflammatory bowel disease is on the rise: one in four people newly diagnosed with Crohn's or ulcerative colitis is under 16. While there are many unproven theories on why this is, no one really knows the answer. What is certain is that these diseases throw childhoods into disarray.

The event at Southampton was an opportunity for the children and young people to spend time with each other, a chance for the younger ones to have some fun, and for the older ones and parents to learn more about IBD. It was inspirational and heart breaking in equal measure.

As well as the talks from doctors on research, treatment and surgery, a number of teenagers spoke about their own experiences of living with IBD.

The embarrassment of school trips with shared bathrooms, the impact



of exam stress on flares and how IBD shouldn't stop you getting involved in first-year university shenanigans were among the topics of discussion.

These speakers really stuck a chord with us, and would with everyone who has been through adolescence. Growing up is hard enough, without having each and every right of passage coloured by a chronic disease you can't talk to anyone about.

Everyone we spoke to was united by one thing – they were just happy to have the opportunity to talk about it.

We asked youngsters to draw on our feelings wall, which they did with relish and to greater and lesser degrees of artistic flair. We played some rounds of "label the bowel", which gave them a chance to learn a little bit about the inside of the bellies, and we asked young people to write us poems on how having IBD made them feel.

To read the words of children as young as nine talking with maturity and grace about a disease they know they will have to live with for the rest of their live was humbling beyond words.

One told us she felt left out at school because she was too tired to play hockey with her friends, and a nineyear-old asked us if the drugs she was on would stop her having children when she grew up. To hear such a young person worrying about such things was soul destroying and it was all we could do to stop ourselves reaching out for a hug. Parents told us of the difficulties they faced getting their children diagnosed and trying to get schools to understand their children needed special dispensations: extra toilet breaks, help to catch up when their disease flared and left them hospitalised for weeks on end.

They spoke about the pain they went through watching their children having to deal with a disease that impacted on every aspect of their young lives, from family activities to social lives. They told us how tough it was trying to get their child to accept they had a chronic medical condition, while they themselves were cracking from the strain.

But this was not a depressing day – it was uplifting and inspirational. There

I've got crohn's disease would feel sad if i'm quele And it wouldn't be very nice Joshua whose big sister has Crohn's Disease anding Jasmine

Meetings

were high fives and high jinks; laughter and mischief. These children were not about to give up, and, even if they were, their parents had no intention of letting them do so.

The subject matter was heavy and these children were dealing with what many of their peers would find unimaginable, but there was a buzz about the place. Being able to hang out with other people who knew what they were going through was the one thing they all said they wanted – to know they were not alone, that they were normal kids.

While their classmates were worrying about computer games or their latest crush, these youngsters were attempting to stick to strict medication regimes, juggle hospital appointments and work out which of their favourite foods make them feel worse.

While all parents have to come to terms with their children growing up, these parents have to learn how to hand a normal hormone-fuelled teenager's responsibility for their own health.

A diagnosis of IBD is a knockout punch for parents and their children, as well as siblings, grandparents and the whole family. All too often it's a disease they know nothing about and, in many cases, had never heard of. A quick Google search will confront them with thousands of pages of information, mainly scary, mainly inaccurate.

That's why organisations like CICRA are so important: it provides

trusted information and a reliable source of support that many described as a lifeline.

CICRA wants to do more, though, which is why we are carrying out a review of its current information offer. Over the next few months we will be carrying out surveys, running workshops and interviewing specialist nurses to make sure everything we do has these incredible young people and their parents at its centre.

Oyster will be donating its time and expertise to the project, and instead of sending Christmas cards last year, we made a donation to CICRA to help it continue to support the increasing number of young people affected by IBD.

•••	I teel, sick. I feel,
	sick sick sick.
	Lan Hungry, Lan very very Hungry. I Have IBD.
	Lydia
	How have the part?
	Statutor Conso

Sometimes my FBO ... By Horry Sometimes my IBD ... Well to be porest it weakens me, Changes my lise, For the better and worse, Always Seeling tired, Yet is I didn't have it, I wouldn't be who I am row ... A sinter, Awarrior, What people don't upder start, Never giving up Is what we do best!

Harry

Fundraising

28003

British 10k London Run

On a sunny day back in July last year CICRA had a great team of runners in the British 10K which is staged on one of the world's greatest road routes through the heart of central London.

The team of 13 runners included three members of the same family, Michael, Carolyn and Simon Tetlow and one of our own Research Fellows,

Dr Protima Amon who also encouraged her friend in the lab Shezan Elahi to join her. Nicola Read, Chris Ward, Matthew Foord, Katina Punia, Inga Judge, Tammy Woodrow, Alice Sweeney and Veronique Skinner completed the line-up and we are delighted to report that they raised a magnificent £9,842. Well done to you all – we really appreciate your support.







28004

28005

Great North Run 2015

Congratulations and a big thank you to all the CICRA runners who completed the Great North Run and raised a splendid £4,300.

We also thank the Walker family for kindly meeting the runners at the

finish. Spurred on by the supportive crowd CICRA's team of Justin Kisielewicz, Martin Marchant, Richard Sutton, Darren Middleton, Giles Harper, Estelle Murray, Helen Atkins, Tracy Tomlinson, Michael Jones and Sara

Kerr achieved impressive times and, although Philip Stimpson at the last minute was unable to run, he raised a considerable amount for CICRA. The day was a great success and thoroughly enjoyed by all in the beautiful sun and scenery of South Shields.



Fundraising

Bikes galore



Bikers gather at the Cmwdu Annual Motorcycle Charity Show

Guests arriving at the Cmwdu Annual Motorcycle Charity Show were greeted with line upon line of wonderful machines glinting in the sunshine.

The sight of so many types of bikes, and the sound of engines throbbing, must have been a joy to the enthusiast, not forgetting a choir singing, stalls buzzing, the smell of burgers braising, children playing on the bouncy slide and all the other things that go with a great day out. The stories about past bikes, biking histories and escapades must have been a treat to hear.

At the end of the day, CICRA was able to add a further £2,430 to its research programme thanks to Julie Fletcher and son George (who you may have read about in earlier copies of the newsletter) who nominated CICRA to receive funds from the show organised by Carol and Paul Bond.

Thank you Julie, George, Carol and Paul.

2015 Rose Queen

Janine and Mark Whitlow have had a busy year fundraising and we are grateful to the Thomas Ashton School and the Alderley Edge May Fair for their support.



Daughter **Eleanor** was selected as the 2015 Rose Queen for Alderley Edge (*pictured*) and nominated CICRA as her chosen charity. Proceeds of the 5 a-side football, Crown Green Bowls match and donkey derby were donated to CICRA. Grandparents, **Gillian and Tony Battersby** have also been actively fundraising throughout the year and we are very grateful to them.

A challenging summer

Last year an inspirational 9-yearold, Oscar Lewis set himself some sporting challenges for the summer to raise funds for CICRA.

In August, he cycled 15 miles along the Tarka Trail from Torrington & Barnstaple and, not content with that, he then went kayaking on the Tamar Lake. This was followed on a sunny day in September by Oscar completing a three-mile run around Tamar Lake together with his little brother Fergus.

The final challenge was the hardest of all them all, a 1-mile-swim, and to show their admiration for his wonderful stamina and courage, family and friends sponsored Oscar for the wonderful amount of £583.75.

Oscar says about the fundraising: "I enjoyed the cycling on the Tarka Trail and running at Tamar. The kayaking was fun and felt my muscles aching. The swim was the hardest of the challenges and took me 90 minutes. I would like to raise money for CICRA again and choose some different challenges next time like abseiling!"

Many thanks Oscar – you did a magnificent job and we wish you well.



Biking Oscar

Alternative holiday en France?

Steve Worsnip, our long time fundraiser, got into the saddle again last September to cycle from Paris to Nice in 7 days to raise funds for three charities close to his heart, one of which is CICRA as his son Martin has Crohn's.

Beginning at the Eiffel Tower, Steve and 16 friends, cycled for 7 hours in 34 degrees of heat. Events of the day included a member of the team landing on an innocent shopper and squashing her bread – not sure she was impressed – and skilfully avoiding a 20 mile detour using great escape skills. The reward for such a long day was an F1 hotel, a tiny bed, no towel, 34 degrees heat, no air conditioning, shared showers and loos – oh such luxury – but compensated for by the



Steve began his ride at the Eiffel Tower

incredible cathedral light show in Sens Square.

Each day was littered with small and special moments too numerous to mention so skipping to day 6, christened "the gorge of scaryness" they were faced with a 60 mile uphill climb. In addition to the rapid descents, the challenge of the afternoon was getting to the hotel ahead of the mandatory restaurant dinner of no later than 9pm. The hotel were so caring they forced everyone to bed at 10.30pm with mandatory lights out. As Steve said: "Victorian Britain is alive and well in Digne."

Despite having a sore rear, bruised ribs and hip and a very visible black eye, from a fall on day 4, Steve said that he truly believes that it was all in a great cause.

Well done Steve – we appreciate your support over the years and the funds you have raised to support our research programme.

Ieuan Man Wales goes the distance

In addition to looking after our children with IBD many paediatricians do much to raise funds to help good causes. One of those is Dr leuan Davies, Consultant Paediatrician at the University of Wales Hospital, Cardiff. In his own words:

"Just after 10.30 pm on Sunday 13 September 2015, I completed the "Iron Man Wales" in Tenby.

The event started at 7am with the Welsh National Anthem and a 2.4 mile sea swim which I completed in 1:30. There followed a 1km run to transition before the 112 mile cycle through Pembrokeshire. I managed this stage in 8:07 including over 2,000m of climbing. I concluded with a rather sedate (hilly) marathon (26.2 miles).



The whole event took 15.5 hours but I was safely within all the cut-offs, had an hour and a half in reserve at the end and most importantly, I thoroughly enjoyed what became a very emotional day for me and my family.

I am really grateful for the support from my friends, family and colleagues swimming, running and cycling for CICRA during at 15.5 hour challenge

throughout the 6 months of training. I also appreciate the generosity of those who gave towards the 2 charities I chose and this allowed me to raise over £1,000 for CICRA."

 We are very grateful to Dr Davies for his support and for caring so well for many children with IBD.

Fundraise for CICRA

Here are some interesting and fun ideas for fundraising our supporters have thought up. Each issue of The Insider mentions the innovative ways people fundraise for CICRA. Perhaps you have an unusual way, contact us, we are only too pleased to support you. Thank you and well done everyone – your continuing support is greatly appreciated.

INDIVIDUAL FUNDRAISING

Two of our most regular fundraisers have been busy again. Joanna Chilcott sent £842 from selling tasty bacon butties at the Portbury Community Café, a BBQ at The Portbury Beer & Cider Festival and selling Christmas wreaths. Maxine Armitage raised an impressive £1,707 from a summer fair, line dance, sponsored walk and Christmas Cake sales. Maxine also received a £200 donation from the Wessex Highlanders Band to add to her incredible total.

Margaret Passmore raised £200 by selling handmade knitted goods and cards and also sent us £56 from a raffle at a line dance club. We thank her for this and for continuing her good work.

Alison Johnson continues to send the proceeds from the raffle at her monthly line dance raising £174 for the CICRA coffers.

Eleonor Wright, whose young daughter is a Crohn's sufferer, raised £202.50 from a curry night and the sale of Christmas Cards.

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There was a great turn-out for **Kirstie Harland's** coffee morning. We don't know how much coffee was drunk but they raised an amazing £433.52 for CICRA.

'Stay Sober for October 2015' was what **Nicola Grundy** decided to do for a

Nicola Grundy decided to do for a charity fundraising idea and raised £140. Well done.

Emma Mills participated in the Carbonated Drinks Challenge, raising £97.71.

The Gibson Wyer family are

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regular supporters and Peter Gibson Wyer kindly raised £51.17 from donations for coffee on the Casualty TV set. Not to be outdone, their daughter Jemima offered refreshing elderflower or blackcurrant cordial for a donation to CICRA at their local Open Gardens Day. Well done Jemima and Peter.

A Sunday stroll for CICRA

Vicky Dawson's husband Dave had been her childhood sweetheart. Sadly he passed away in October 2007 just after their 38th wedding anniversary.

One of Dave's last wishes was that Vicky would continue to raise funds for children with diseases and this is what she has done – the most memorable being organised near their wedding anniversary. As Vicky's niece Olivia has been diagnosed with Crohn's disease, CICRA was the charity to benefit by £608 from this anniversary 10k walk around Alice Holt Woodland in Hampshire. Thank you Vicky.



Out and about with Vicky in Hampshire

Ormerod House, Archbishop Sancroft School, Harleston voted CICRA to be their Charity of the Year. Students and teachers raised £368.10 from cake sales and other fundraising events and are continuing their fundraising.

Sam Cates, who two years ago ran the London 10K for CICRA, is a member of the Redhill Bowling Club and nominated CICRA to receive the funds from a charity day. A total of £224.50 was raised from the day and a further £217.85 collected in the collection buckets. Thanks Sam.

One of the students at the **Ready to Rock School** suggested CICRA to benefit from the Christmas Charity Gig held in the Wedgewood Rooms, Southsea and we are so grateful that they agreed because an impressive £972.96 was raised. It sounded as if those who attended had a great night.

The CICRA office staff have helped swell the CICRA coffers. **Jayne's** daughter and her husband-to-be decided that rather than buy 'wedding favours' for their guests they would give a £150 donation to CICRA. We know it was a great day for all and we send our thanks and best wishes to Jessica and Ellis. **Linda** kindly organised a raffle at her local choirs Christmas Party (Eclipse Choirs) raising £229. The evening was enjoyed by all dancing to 'The 60's Allstars'.

The Marc Bolan Fan Club have been bopping once again and, due to their generosity, a further £560 has been donated to CICRA.

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Sophie Simpson and young daughter **Amelia** were able to send us a cheque for £101 thanks to the generosity of Europa Hair, Simon Nash and a kind friend.

Thanks to **Ruth Mullineux** who competed in the Great Manchester Swim, CICRA benefitted by a magnificent £112.50.

Dorrie Mottram has been organising the West Sussex Group for almost as many years as the charity has existed and, although not doing as much as they did, we still benefit greatly from their fundraising and particularly the public awareness created by her events in the county.

We have received £1,850 recently. Dorrie's next event is a concert on 17 June in Hassocks. If you are interesting in going, please ring the office.

HALLOWE'EN FUNDRAISING

Loyal supporters, Verity and Mark

Batchelor held three weekends and a number of half term days of 'pumpkin picking' at their farm in Kent as well as making pumpkin soup, cakes and chutney for donations. The visitors raised a generous £885.60 and Mark's business, Riverside Farmers, made a donation of £1,000 to CICRA.

Several fundraisers held Halloween parties, raising much needed funds for CICRA – Vikki May's daughter, Astrid May-Tipler raised £70 and Member Jane Corbett raised £265.55. Thank you and we hope everyone enjoyed the parties.

GROUP FUNDRAISING

The residents of Largs have been busy again raising funds for CICRA, a

Continues on page 20 🔿

Exeter quilters

Over several years Trish Walker has kindly donated fees from her sewing course in Exeter and we are grateful once again for her sending a further £533 at the beginning of this year.

In addition, Trish gave a talk to the Quilters Association and nominated CICRA as a Charity of the Year. We are pleased to say that we are one of two chosen charities. Thank you Trish. The exhibition at which Trish and her group will be participating will be held in August. For further details please ring the office.



Holly flies high

Holly Rideout took to the sky to raise funds for CICRA and paid for the jump herself to ensure that CICRA received all the sponsorship money of £394.



Continued from page 19

donation of £50 from the Ladies of the Guild, Clark Memorial Church, £20 from **Helen Hannah** raised by her local shoe shop, **Nealy's** and £100 from **The Rotary Club of Largs**.

Joanna Raven kindly sent a donation of £50 from Latchingdon Spiritulist Church in Essex and Jennifer Illsley's Fellowship Group raised £36 from a 'Bring & Buy' stall.

Member Jax Martin-Betts helped the Year 8 children at Cumnor House School make their leavers' quilt and then raffled it to make £900. She didn't stop there though and raised a further £1,075 from the annual Horsted Keynes Tennis Tournament.

A golf Day held at the Knighton Health Golf Club, organised by **Julie and Darren Cox and son Isaac** together with **Terry Doe** and **Martin Collins**, raised a grand total of £752.

Tulloch Homes Ltd celebrated their 90th anniversary and generously gave all employees £90 to donate to a charity of their choice. Employee lan McMillan kindly chose CICRA to receive his donation.

Dale Power Solutions Ltd,

Scarborough participated in the September Dress Down Friday raising £90.80 for CICRA.

THE BIG '0's

Some of our supporters when reaching their 70s, 80s and 90s decided to ask for donations to CICRA instead of receiving presents and, thanks to the generosity of their friends and families, CICRA was able to put a splendid £1,596 towards research. Congratulations to **Verity Batchelor's** mother-in-Law on her 70th birthday, **Mr P Reeder's** friend on his 80th, **Mrs E Winston** and **Mrs Beryl Rudd** on their 90th and **Eve Flowers** (not sure which birthday).

For her 70th birthday **Joan Waldron** organised a line dance and country partner dancing evening. She raised an impressive £1,000 which was split between CICRA and her local hospice.

CYCLE RIDES

Two cyclists joined in the London to Brighton ride last year. **Jayesh Patel** rode for the third time to raise funds for CICRA and raised £1,845. **Ian Fullbrook** also completed the ride in memory of his father Peter and raised a further £250.

_RUNS & WALKS

Colin Vesty along with members of Leicester Walking Club raised £109.85 on their Smile Mile Walk and this August Colin is running 100 miles in 24 hours! Thank you Colin.

Gerry Gallagher ran in the Men's 10k race in Glasgow, raising £182.50.

Brian Hoskins completed the Milton Keynes Marathon, raising £853.75.

Sarah Davies ran the Tenby Marathon in July raising £918.60 and then, with her husband **Huw**, ran the Dublin Marathon raising a further £572.97.

Katie Morrison and Alasdair Seivwright participated in the Loch Ness 10k Run and raised an amazing £1,282.50.

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Ruth Needham raised £338.75 (*photo on page 15*) and **David Matty** raised £587.50 in the Great Birmingham Run.

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The **Moore family** have been busy fundraising for CICRA. **Jay** Moore raised £353.73 from a Blacklight Torchlight Run & Parish Run and mum **Lorraine** raised £200 from commission on a Candle Party and raffle donations.



Tom and Sophia at the finish line

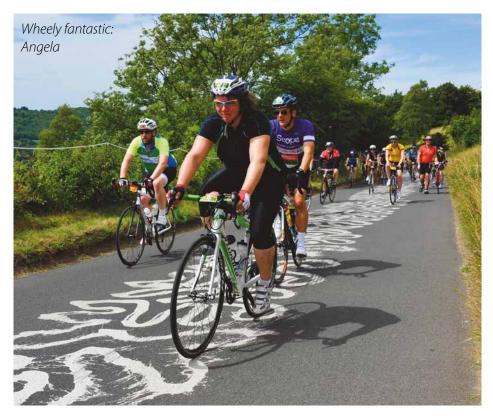
Tom's trio

Those of you who know Tom Kent may also know that his oldest daughter Sophia spent last summer holiday on a very restrictive liquid diet. She had nothing solid for nearly eight weeks and did amazingly well.

Tom says: "Generally she is very well and this is mainly due to her great attitude, medication and an excellent NHS." To say well done for sticking to her restricted diet, Tom said he would raise some money for a charity that helps to try to find a cure. He chose CICRA and one of the tougher sponsored events – the Eaton Dorney triathlon – a 750m swim, a 19km cycle and a 5k run. Well done Tom and thanks for the wonderful £1,275 for research.

Wonders on wheels

The Prudential RideLondon begins in the new Queen Elizabeth Olympic Park, follows a 100-mile route on closed roads through the capital into Surrey's stunning countryside and finishes on The Mall in central London. Last year, CICRA members **Angela Basit** and **Andrew Hewitt** took up the CICRA places but unfortunately **Ian Head** who had planned to ride sustained an injury. We were delighted that **Darren Creely** who had his own ticket decided to raise



funds for CICRA. They were three wellearned medals.

The 20,000+ riders started in the traffic free roads of London then travelled through Kingston and on to Surrey with leg-testing climbs and a route made famous by the world's best cyclists at the London 2012 Olympics. Support at the local towns and villages was wonderful. The Box Hill villagers even made them a 'tea' tent.

Angela wrote: "The support was great and it was something special to cycle over Putney Bridge, down the Embankment, past Parliament and Downing Street and into the Mall with Buckingham Palace as the finish."

Our thanks to Angela, Andrew and Darren for raising, together with a large donation from Ian Head, a fantastic total of £2,308.

Not to be outdone, **Christie Creely** took part in the only UK cycling event especially for women – the New Forest Cycletta 150K and raised a wonderful £295.

Dancing raises £1,000 for CICRA

In his year as President of The Vale of Itchen Masonic Lodge, Harry Punia chose CICRA as his Charity of the Year.

The lodge's two main fundraising events were a Burns Night and a Ladies Dinner and Dance Evening. A Whisky Raffle helped to swell the funds and Harry was able to present a cheque for £1,000 at the Southampton Meeting.

Harry is pictured presenting a cheque to Graham Lee



Give more for research without cost to you

Gift Aid

Gift Aid is an income tax relief designed to benefit charities such as CICRA. If you're a UK taxpayer, Gift Aid increases the value of your charity donations by 25% because CICRA can reclaim the basic rate of tax on your gift at no extra cost to you.

How does Gift Aid work?

The process is really simple: if you have a standing order, all you need to do is fill out a Gift Aid Declaration form and CICRA will be able to claim 25% on every donation until you ask us to stop. If you want CICRA to claim Gift Aid on just a single donation you can put that in writing, either when sending the donation or later, remembering to add your name and address as this is needed to identify you as a current UK taxpayer. These details will be confidential to CICRA and not shared with, or sold to, any other organisation.

Am I eligible for Gift Aid?

For a charity to claim Gift Aid on your donation you must first have paid UK Income or Capital Gains Tax in the current tax year and understand that if you pay less tax in the current year than the amount of Gift Aid claimed on all your donations it is your responsibility to pay any difference.

Results of the CICRA 2015 Christmas Draw

As always, our thanks to all who purchased or sold tickets for the Christmas Draw. Your generosity resulted in a total profit of some £3,533 towards our ongoing research programme. The draw took place on Tuesday 9 December at our offices at Parkgate House.

Prize	Ticket No.	Name
1st Prize	14886	Mrs M Dinwoodie, Shetlands
2nd Prize	28494	Mr A Perera
3rd Prize	25724	Mrs Fairbrother, Derby
4th Prize	05396	Ms Clarke, Hertfordshire
5th Prize	08694	E Kyle, Cambridge** donated back
6th Prize	26750	K Walker** donated back
7th Prize	29372	K Ross, Aberdeen
8th Prize	17490	D Howlett, Essex
9th Prize	35771	K Telford, Co. Durham
10th Prize	08386	J Steele, Devon
11th Prize	08241	S Flanagan, Essex
12th Prize	20494	S Laing, Fife
13th Prize	26315	B Kerr, Chesterfield

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What if I pay higher rate tax?

If you're a higher rate taxpayer, you can claim additional tax benefits for the donations you make to charity, which you can keep or pass on to CICRA. Simply indicate how much you've donated when completing your tax self-assessment form.

Notes:

- a. You can cancel a Gift Aid declaration at any time by notifying the CICRA office.
- b. It is essential that you notify the CICRA office if you change your name or address while the declaration is still in force.
- c. Remember to notify the CICRA office if you no longer pay an amount of income tax and/or capital gains tax at least equal to the tax that CICRA reclaims on your donation in the tax year (currently 25p).
- d. If you are unsure whether your donations qualify for Gift Aid tax relief, please ask your local tax office for leaflet IR113 Gift Aid.



Giving

Wills and legacies

- Please remember CICRA in your will -

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 that is distributed to charities by the Executors/Trustees of the will using use 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 your will

Making a will is very simple and 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.

All bequests to charities are taken from the estate before tax and therefore help to reduce the amount of tax payable. We invite you to consider including CICRA among those you wish to benefit from your estate. All you need to do is to include the words:

"I give and bequeath the residue of my estate to the Crohn's in Childhood Research Association of Parkgate House, 356 West Barnes Lane, Motspur Park, Surrey, KT3 6NB and direct that the receipt from a Trustee of CICRA shall be a good discharge to my Executors."

This means that CICRA will receive the remainder of your estate, after other specific bequests have been settled.

Alternatively, if you wish to give a particular sum to CICRA, the wording should be:

"I give and bequeath the sum of £.....to the Crohn's in Childhood Research Association, Parkgate House, 356 West Barnes Lane, Motspur Park, Surrey, KT3 6NB and direct that the receipt from a Trustee of CICRA shall be a good discharge to my Executors."

You may have already made your will and now wish to include a bequest to CICRA, in which case, you should execute a codicil to your will.

In all cases, of course, the document must be correctly witnessed.

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:

- Mr Peter Thomas – Treasured Grandfather to Thomas, a Crohn's sufferer, remembered every day with much love and affection by all his family.
- Mr Alwyn Millar Grandad of Katie McSweeney (Crohn's sufferer) – Loved him lots and will be missed a lot.
- Mrs Mary Paton Beloved Granny of an Ulcerative Colitis sufferer, lovingly remembered by all the family.

Annual donations made in memory of:

- Richard Groombridge by his sister Mrs Sheila Foord
- David Allen by his parents Joan and John

Bequests:

- Mr David B Simpson
- Mrs Ida Savage



CICRA 200 club: larger prizes in draws

Thank you very much to those of you who responded to our invite to join the 200 Club. As we said in the last newsletter we have gone over the 200 mark. This has enabled us to give larger prizes in the quarterly draw and prizes will continue to increase as we get new members. Some of you now have numbers over 200 but this makes no difference – your number will be in there with an equal chance. The name '200 Club' has no legal

Collection boxes

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Grateful thanks to our members who organise collection boxes in their homes and various, shops, pubs, leisure centres etc. A further **£508.42** has been put towards research and our thanks go to:



Melanie Beaver (The Country Kitchen) Mr & Mrs Eames (Home) Raymond Fisher (Laurie Café) Mrs S Howden (Kip Marina) Brian McKinney (Village Inn, Exchange Bar, Tower Bar) Gill & Tony O'Neill (Home) Keren Piatt (Home)

Linda Rimen (Home)

A & J Tweedie (Craigellachie Filling Station)

Eunice Vickers (Mini market) Mr & Mrs Gibson Wyer (Desk at BBC Casualty Set)

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

bearing and we may change this in time as we get more members. More members mean higher prizes and more for research as the funds are split evenly between the two.

Thank you so much for supporting us in this way and, should you wish to contact us, please phone the office on 020 8949 6209 or e-mail: support@cicra.org

I Pell, Pevensey, E. Sussex

C Stanley, Newport, Gwent

N Thornton, London

C Thomas, Faversham

C Thomas Faversham

K Griffiths, Cheltenham

R Jones, Essex

122 A Govey, Broxbourne

S Anderson, Woking

127 A Wall, Staffs

£50

£50

£50

£50

£200

£75

£75

£50

£50

£50

S 2015....WINNERS 2015....

Julv 91

Aug 4

Sep 90

0ct

Nov

101

53

53

98

25

		WINNERS 2015	WINNE
Jan	180	G Lee, West Sussex	£50
	176	S Golding, South Wales	£50
Feb	60	L Leveson, Richmond	£50
	32	J Harris, Leeds	£50
Mar	68	J Hibberd, Wiltshire	£150
	25	S Anderson, Surrey	£50
	157	A Hodson, Gloucestershire	£50
Apr	104	P O'Neil, Wigan	£50
	50	L Rimen, Gloucestershire	£50
May	75	M Cave, Northants	£50
	171	T Paul, Norfolk	£50
Jun	94	P Herman, Worcestershire	£200
	42	V Carter, West Sussex	£75
	15	B Morrison, Derby	£75

118 A Veitch, Edinburgh £50 92 C Hougham, Aldershot £200 Dec 106 P Cooper, Maidstone £75 **B** Forsdick, Wymondham £75 80 CICRA is grateful to the following

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- AMW Charitable Trust
- Astor Foundation
- BP Exploration
- C Brewer & Sons
- Clara E Burgess Charity
- Forest Friendly Society
- The Freemasons' Grand Charity
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companies and trusts who have so very kindly made donations.

- Homelands Charitable Trust
- Hospital Saturday Fund
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The **insider** is published by

Crohn's in Childhood Research Association

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