

“Cure for IBD” – unfortunately not just yet

Over the years there have been many headlines of “Cure for Crohn’s” or “Cure for IBD” but that is what they are, just headlines – the cause still eludes the scientists.

Countries all over the world are, like us, funding a huge amount of research but as yet no breakthrough. Until we have scientific proof of the CAUSE there cannot be a cure or prevention, but research does produce better treatments. It is therefore essential that we continue to fund good quality peer-reviewed scientific research into all aspects of IBD. You can be sure that whenever and wherever the cause is scientifically proven we will all know about it very quickly.

Although we don’t boast about it, perhaps not as much as we should, CICRA has done an enormous amount over 38 years to find some of the answers to IBD and the problems associated with it, particularly in the young.

Gone for most is waiting, sometimes years, for a proper diagnosis, as was

the situation for the early cases of young people with IBD. This was not caused by queueing, just that until the 1970s, IBD hadn’t been seen in children and therefore we didn’t have the experts to recognise, diagnose or manage it.

Whilst waiting for the answers to this very complex condition we continue to improve the lives of all sufferers through better knowledge. We have, through our research programme over the past 38 years, funded:

- Specialist training for **22 paediatric gastroenterology consultants**, most of whom now treat children and young people in IBD centres around the UK.
- **27 PhD students** interested in completing a three-year scientific study into IBD. These students are our future leaders in scientific research and by starting their career researching IBD they will generally continue in this line of research.
- **60 basic scientific projects** to understand more of what goes wrong when an otherwise healthy child or adult develops IBD.

Three courageous young people at our meeting in Cambridge gave us an insight into ‘life with IBD’. Whilst waiting for the cure we aim to improve the quality of life for them and all others with IBD.

We obviously can’t do this without the invaluable help of our fundraisers and supporters though and there are several ways you can help us in our mission. Even if you don’t like to fundraise on your own there are other ways – even the smallest donations, collectively, make a big difference. You can:

- Ask your company if they have a ‘Charity of the Year/Week’ scheme
- Organise a fundraising event with friends and family
- Text CICR01 £5 or CICR01 £10 to 70070
- Set up a standing order
- Give a one-off donation
- Join the 200+ club

Little by little all scientists involved in IBD are gaining better knowledge of this complex condition. One day there will be answers and we will be proud to have played our part in research.



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Trustees Report

Letter from the Chair

Dear Friends

Well, what a year this is turning out to be. Quite suddenly, after Christmas, we realised that we would have to leave Motspur Park with all the upheaval that this would cause. However now that the worst is over, we can look forward, and continue with supporting families affected by IBD.

To add to the ever increasing number of children (usually over the age of 6) being diagnosed with Crohn's or Colitis, the last couple of years has seen, as we have reported in an earlier newsletter, many diagnosed with very early onset IBD (VEOIBD). Often the parents of these very young children (some just months old) experience problems that CICRA may not have met before, so, being able to support these families has been a challenge.

However, as with other problems, we have learnt from some of the families themselves and apart from being able to ring the office for support, parents can now, if they wish, join a small network of other parents of the very young, to keep in touch and support each other. IBD can have a devastating effect on the lives of the young, and their families, so it is rewarding that we have been able to give help and hope to these families. We are currently working with the team at Great Ormond Street Hospital to continue to find ways to support them.

With the help of Oyster Healthcare, 2017 should be a very exciting year for CICRA as we see the early stages of upgrading the website and literature coming to fruition. Alongside this you will see on page 3 that we have provisional plans for three family day meetings in Edinburgh, Surrey and Bristol.

Enclosed with this newsletter is our Christmas card brochure and we hope you will want to support us by placing an order, and encouraging others to do the same. This year, for the first time, we are also able to offer children's packs and wrapping paper so we look forward to receiving your orders.

In sending Seasons Greetings from all at CICRA we also wish you a healthy and happy 2017.

Margaret Lee

Chair

Congratulations Kay

In our Spring 2015 newsletter we printed an article from specialist IBD nurse, Kay Greveson, from the Royal Free Hospital London, on 'Top tips for holiday travel' giving details of the website Kay has set up for people with IBD: www.ibdpassport.com

We are delighted to tell you that Kay was named as Gastroenterology/IBD Nurse of the year at the 2016 British

Journal of Nursing Awards in London.

Kay has done a great deal for people with IBD and has always been a great supporter of CICRA.



It is good to see her rewarded for her endeavours.



CICRA is moving

After almost 30 years at Parkgate House, CICRA is moving to a new office.

As in so many other cases, the Parkgate office block has been sold for residential development. Our lease was due to finish in September this year so we had no choice other than to look for a new office. Small, reasonably priced, offices are hard to come by but, following many disappointments, we were fortunate enough to be on the telephone to a commercial agent at the exact time a new instruction was received by them.

Not waiting for a full description, we made a visit to the office and knew straight away that this was what we had been hoping for. We will now be working on the ground floor of the Sutton Housing Society offices which are conveniently situated for local transport/buses and trains.

It has been a worrying time not knowing where we would end up – always thinking that if we couldn't find anything local we could end up with staff and no office or office and no staff!

Our move will take place during September and we are looking

forward to this very much. The change of location will not affect our staff and volunteers as much as we had feared at one time and we are hoping to settle in quickly and have a great new start, especially as, with the help of Oyster Healthcare, we have already started on the upgrade of our website and literature.

More volunteers

We can always use more volunteers, so if you live in the Sutton, Surrey area and would like to help in the office on an ad hoc basis we would be very pleased to hear from you.

In the 38 years that CICRA has been around we have, of course, collected much that we are reluctant to part with so, although we are taking the opportunity to 'thin out', for the sake of the historians we have selectively kept something from each year. These items will be securely archived. To find again all the handwritten letters has been a joy (no emails in our early days!) and we are pleased to say that writers of some of those letters are still supporting CICRA today. Thank you all.

Margaret Lee

Dates for your diary

The next popular IBD Family Information Day will be held in Cambridge on **Saturday 12th November 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**.

25th March 2017 in **Edinburgh** will be our first stop for an IBD Family Information Day followed on **1st July** by a **Surrey/London** meeting and then **Bristol** on **14th October**. These days are still in the planning stages, and may be subject to change but if you would be interested in joining us and would like to register now please email support@cicra.org or ring Jayne on **020 8949 6209**.

Prestigious award for CICRA Trustee

Congratulations to CICRA Trustee, Dr Philip Smith, who has been named Young Gastroenterologist of the Year award after being identified as a potential emerging leader by the British Society of Gastroenterology.

Philip said: "I am delighted to receive the British Society of Gastroenterology 2016 Young Gastroenterologist of the Year award. It is a great honour to receive an award from the national society representing UK Gastroenterologists and I am as delighted in winning this as I was when I was awarded the BSG Presidents' Medal in 2014.

I love working as a SpR in Gastroenterology – not just in my job looking after patients (which is my first and main priority always) but also because it has allowed me to develop many educational initiatives for other UK trainees, as well as be involved



Picture: Professor Matthew Brookes, Professor Nicholas Talley, Dr Philip Smith and Professor Emad El-Omar

in the development of UK national Gastroenterology guidelines in IBD and Adolescent Medicine.

I am very grateful to all those who have supported me – my junior doctor

colleagues and consultants, nursing and other professional colleagues and finally (and most importantly) my family and long suffering wife Beverley and my beautiful daughters Genevieve and Gabrielle."

Support group for Welsh families

We met Sian Jenkins and her family at the CICRA IBD Family Information Day in Cardiff earlier in the year. Sian's 10 year old son Cameron had recently been diagnosed with Crohn's Disease and the family were keen to find out as much as possible about the condition.

Sian was dismayed to learn that there were no support groups for families in Wales that had a child with IBD and decided, with our help, to do

something positive and start a group of her own. With families living long distances apart and often in remote areas we decided that a 'WhatsApp' group would be a very easy way for Sian to start the group, make contact with other families and start an all-important Welsh support group.

We received a great response from families in Wales and the group is now up and running. We've had some lovely comments from the parents involved:

"Thank you for setting up this group."

"I wish I'd had something like this 6 years ago as I did feel very alone."

"...I am finding this group therapeutic."

If you live in Wales and would like to join Sian and her group or if you are interested in setting up a group of your own, please call Jayne at the CICRA office on **020 8949 6209**.

Spring Family Day heads into Cardiff

For the first Family Day of 2016 on the 5th March, we headed into Wales where members and supporters met up in the very pleasant surroundings of the Marriott Hotel. For our first ever visit to Wales it was great to welcome some 140 people to this informal and informative day.

The Welcome was given by CICRA's Medical Director Dr Nick Croft and Dr Ieuan Davies (Consultant Paediatric Gastroenterologist – Cardiff). Dr Davies then gave a very interesting explanation of paediatric IBD services and treatments provided in South Wales.

17 year old George Haines is a young man with Crohn's who treated us to a very entertaining talk about his life since being diagnosed some 3 year previously. This was followed by something quite different, as Dr Jackie Doyle who is a Clinical Psychologist had the audience listening intently as she explained all about 'Mindfulness interventions for young people with IBD', a project being funded by CICRA at University College Hospital, London. This really different approach to IBD treatments was initially greeted with scepticism by some attendees but it was fascinating to see how many of those people soon became engrossed in and convinced by Jackie's approach.

Before we took a brief coffee break, we had the pleasure of listening to Harry Johnson, age 13. Harry was diagnosed with Ulcerative Colitis age 5 and gave a very eloquent account of how his condition had affected his childhood.

After the break, our younger members were given the opportunity to join a creative writing workshop organised by Oyster Healthcare.

Professor Tom MacDonald, Dean of Research at Bart's & The London, gave us another of his fascinating talks outlining all the happening in the research world, focusing particularly on 'New treatments for IBD'. This was followed by a brief video presentation which gave a clear explanation into the purpose and benefits of the IBD Register.

Dr Barney Hawthorne (Consultant Gastroenterologist) gave an interesting talk on a subject that is of great

concern to many parents – "Transition". Dr Hawthorne explained how the system for transitioning in Wales operates, and what parents and patients should expect.

CICRA funded Dr Protima Amon, followed on with a fascinating and highly amusing talk entitled 'It's a bug's life'. Accompanied by a slide presentation to explain just how bugs influence our IBD. She revealed that she is also known as 'Dr Poo'.

The final 'star turns' for the morning session were Mick Cullen & Rachel Russell, Paediatric IBD Specialist Nurses from Southampton, whose talk was entitled 'Top to Bottom'. The title needs little explanation! But as we always expect from our wonderful IBD nurses, their talk was delivered with much humour, which took us nicely up to lunch.

With everyone well refuelled, a brief talk was given outlining all the work the CICRA do and the services that we provide, along with some useful information about fundraising.

The remainder of the afternoon was taken up with our ever popular rotating discussions groups covering a variety of subjects in the field of IBD with the groups being chaired by a variety of well qualified medical experts. While these took place, there were other groups for the 12 to 17 years olds and the 18 to 25 year olds which resulted in the sharing of views and ideas and the formation of many new friendships. The under 12's were not forgotten as they were entertained by our resident professional entertainer Ian Davis.

Tea and coffee was on offer as the sessions concluded, which gave the opportunity for many of those attending to exchange phone numbers or facebook details as many new friendships were formed.

Our grateful thanks to all who contributed to the success of the Cardiff event, especially the Doctors and Nurses who gave so freely of their time.



Without doubt the highlight of our 'Family days' is hearing our young people tell their own, very personal stories of coping with living with IBD, bringing a tear to the eye of many in the audience.

ABBI'S STORY

Abbi Ashcroft spoke very eloquently at our Family Day in Manchester.

“ I am Abbi. I am 16 years old and from Liverpool. I was diagnosed with Crohn's Disease when I was 9. I had severe eczema around my mouth and I was only 3st but went two years before being diagnosed. I couldn't eat and my parents thought I was just a fussy eater. I also vomited frequently so what I did eat I couldn't keep down.

As my weight declined my mum noticed that my sister, who is two years younger, was going past me in weight and height. Doctors were confused about my symptoms so I was put on general health supplements to maintain my weight and nutrient levels. I was then referred to Alder Hey Hospital under the care of the gastro team led by Dr Auth. He took one look at my thumbs and practically diagnosed me there and then. I had an endoscopy which proved I had Crohn's Disease and when I woke from the anaesthesia I had a nasogastric tube in which fed me directly for the next eight weeks.

I really enjoyed not having to eat during those eight weeks because during the years of not being able to eat, my parents were desperate to try and get me to eat. I used to sit in the kitchen with a plate full of food that haunted me because I knew I couldn't eat it but my parents didn't know this. I also used to sneak my lunch box to the kitchen to hide the fact that I never ate in school. I was then put on Azathioprine but six months later my

symptoms came back so I was put on the nasogastric tube again.

In 2010 I was vomiting again and losing weight so I was put on a new intravenous drug called Infiximab. I had to go to Alder Hey every eight weeks for infusions. It was incredible, I felt I could eat anything and run miles without getting tired but I felt lethargic and unable to eat when close to needing another infusion.

Hairline fracture

At the end of 2014 I had a weird pain in my foot and a hairline fracture was diagnosed. A few weeks later another X-ray showed that where my fifth metatarsal bone should have been it was black instead of white and there was nothing there. A biopsy was taken of my foot but no one knows what bacteria took away my bone. What they did know is that it was an infection and as Infiximab is an immune depressant drug I had to be taken off it.

A few weeks later my symptoms came back worse and I was taken to A&E several times for pain relief – it was excruciating. This carried on until March of this year when I had surgery after Dr Auth found two narrowings of my small bowel. Dr Baillie and Dr Emmy removed 3ft of diseased bowel but luckily I didn't need a colostomy bag. The surgery gave me a whole new lease of life. I am eternally grateful for what Dr Baillie and his team did for me.

During the aftermath of my foot surgery and the A&E visits I was in a very dark place and I was no longer



happy with my life and couldn't see a way out of what I was going through. It seemed to be one thing after another.

The only advice I can give you today is to have a support system in place with people who love you. Something that helped me last year and still today is that I listen to the music of the singer Sia. I found that I related to her lyrics and it really helped me to be distracted from my pain and sink into a world of lyrics which inspired me to keep going. Pick something that you truly love.

Unfortunately, there will be times when you will feel alone and that no one understands you but what I realised was that I wouldn't change me having this illness because I believe that I am the person I am because of it and I feel that I have come out stronger on the other side. Don't forget to be proud of yourself and who you are. ”

WILLIAM'S STORY

William Butcher was another of our speakers at the Manchester Family Day. Will had attended a meetings in 2008 and was so inspired by what he heard, that he has stayed in touch with CICRA and was keen to update members on how his life (and health) have progressed over the past eight years.

“ Hi I'm Will and I'm a 23 year old with Crohns disease. Diagnosed from a young age such as 6. I had no idea what was wrong and neither did my parents. By 8 years old I was 2 stone and that's scary for any patient or parent to see. Things developed from there and I had to have special feeding through a nasal face tube which some of you know is horrible.

Feeds got easier later on when I got a Micky button fitted to help feed me and even going to school having bolus feeds and a feeding pump overnight. It was un-enjoyable feeling like I was so different to the other kids not being able to eat like normal but sometimes there was an upside coming into hospital for check-ups. I would ask my mum to go to the canteen so I could smell the food which she thought was torture, yet I



saw it as a release like things weren't that bad and food was still real.

Unfortunately, things got worse after many months of feeding and having to go back to hospital. I was told it was vital to my health and that having a colostomy was the only way I would get better. It was so scary not knowing the unknown. I had no clue what was going to happen. I thought that, as a 13 year old, my life would be put on hold for a few years but there was a ray of hope, I was out of hospital within a week.

I thought having a colostomy would stop me living, going out with friends, working in a kitchen or even working to my full potential. I also thought relationships would be difficult. But I later told myself that if they cannot accept my past then I have no future with them.

Later things got better. I had my Micky feeding tube taken out. I guess you could say I had the micky taken out of me or if some call it a peg I guess I got taken down a peg. What I want to say now is that things will get better. I am now a 23-year-old with Crohns disease, who has travelled so much. I have been to America, France, Australia and Amsterdam soon. I have my friends who I love so much and also a relationship which I am very happy in. Don't think you can't do it because you can. If you believe you can do it, you can do it. You just have to believe.

In closing, my name is Will and I have Crohn's disease but I don't lay down, I stand up.



JOSH'S STORY

Completing our 'Fab Three' young speakers in Manchester was Josh Chambers. At just 12 years old he has already been through some tough times, but was very keen to share his experiences.

“Hi everybody, I'm Josh and I live in Leeds! I'm 12 years old and I have been recently diagnosed with ulcerative colitis or UC for short. Today I'm here to give a speech on my journey so far.

In the January of 2015 I began to experience the symptoms of UC. To start with I thought I just had bad diarrhoea but when the symptoms worsened I realised that something wasn't quite right. I was very worried and tried to hide the symptoms from everybody (even my parents).

I stopped eating and began to get pains in my stomach and lose weight but believed this to be from my lack of food. My symptoms worsened by the day, to the point where getting to the toilet on time was practically impossible. Accidents became a common occurrence and I was embarrassed to admit it. Unaware to me, my parents had begun to notice something was up. It's surprising how well a mother knows!

We sat down and had a chat about what was going on and I explained everything. This was to be the first of many visits to the doctors. We were sent home and told to return three weeks later if no better but the symptoms worsened yet further and caused me to stop doing the things I love most.

I'm a very active person and love to play football and cricket for my local teams. I also love playing out with my friends and walking my two dogs Archie and Dora but I had to stop due to the lack of energy and needing to go to the toilet all the time. I felt as though somebody had snatched this pleasure from me. I was going to the toilet up to ten times a day.

Three weeks had passed by now and we returned to the doctors hoping for answers. I was advised to try a dairy-free diet and was sent home with a sense of hope. This didn't work so I also tried a wheat free and gluten free diet but without success.

After many months I had my bloods taken and got an appointment at the hospital. I was really worried. After many tests such as ultrasounds, blood tests and a camera in some very awkward places the results were in. I had been diagnosed with UC. I was placed on steroids, mesalazine and anti-acid tablets. I was taking up to 12 tablets a day! On the plus side the steroids have worked wonders for my asthma. We slowly reduced the tablets but the symptoms came back.

My friends know about my condition as I have been very open about it and I believe that this is the right thing to do. It makes playing out and sleep overs a lot easier as I take my tablets with me. They have been very supportive and don't see me as any different to anyone else.

UC will always be a part of my life but I'm not going to let it get me down any more. My condition isn't fully



under control yet but I'm not going to worry because there are many more treatments available and I have a brilliant UC nurse and doctor who I know will always support me. I'm still on mesalazine and steroids but I am starting to reduce the amount again. Fingers crossed I will be able to stop taking steroids altogether.

I started playing my favourite sports again and my energy and appetite is back. Recently we went camping for the first time in a long while and the worry of rushing to the toilet just wasn't there. Without my medication, going camping would be impossible but with the treatments I receive we had a fantastic time.

Recently I have been invited to go to Greece for a school trip to play football. This is the most excited I've been since I was diagnosed. Without my medication I would be unable to go so this will be the first thing I'll pack!

I'm not an expert on UC and can only tell you my story but if you have any questions feel free to ask me. Thank you for listening, Josh!



If you would like to tell your story at a future CICRA Family day, then please do get in touch. We would love to hear from you, and we can then arrange for you to speak at a venue close to where you live.



CICRA WORDSEARCH

Congratulations to all those who submitted the correct answer of 'airport' in the last Wordsearch. Quite an achievement considering that a line of letters had been missed off during the printing process!! Congratulations to the lucky winner who was **Dylan Vashi**.

In the puzzle opposite are hidden different words relating to the human body. 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@bicra.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 7th October**, and the winning entry will be drawn and the lucky winner notified on Monday 17th October. **GOOD LUCK!**

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| EYE | LIVER | SPINE |
| FEET | LUNG | SHOULDER |
| FINGER | MUSCLE | TEETH |



E-Pals



Would you like to chat to someone of a similar age by e-mail who understands what it's like to have Crohn's Disease or Ulcerative Colitis?

Join in with the CICRA E-Pals, a great way to chat and make new friends with people who understand what you are going through. To find out more, contact Jayne at the CICRA office by e-mail: groups@bicra.org

New Treatments for Inflammatory Disease

What's on the Horizon?



Your feedback is always very useful in guiding what sort of information we should provide to our friends and supporters at CICRA and this time we are bringing you news from the biotechnology and pharmaceutical world of any new or ongoing developments of potential new treatments for IBD.

Mongerson as a new Crohn's therapy

We previously highlighted data from phase 2 clinical studies (see panel opposite for an explanation of the various phases) of Celgene's candidate Crohn's therapy, Mongerson (GED-0301), an oral antisense oligonucleotide targeting Smad7 that was shown to induce clinical remission in about 60% of patients with active Crohn's disease. At that time, Celgene had not committed to any paediatric development. On the basis of the data from their initial phase 2 studies there have been a few positive developments for this potential new therapy, namely:

- Last summer the US Food & Drug Administration (FDA) granted orphan status for Mongerson for paediatric Crohn's. Orphan status can be granted to new treatments (even during development) that address significantly unmet conditions and/or conditions that are very rare. Orphan status provides incentives for drug companies during the development process and after marketing where treatments may otherwise not be commercially viable.

- Note: Orphan drugs are fast tracked and don't follow the "traditional" path as above. Paediatric development plans for testing drugs children are also set out with the authorities on a case by case basis and if already "tried and tested" in adults, circumvent some of the steps above and are more "bridging" to confirm safety and efficacy and appropriate doses in youngsters in case something specific to children that wasn't seen in tests in older subjects.

- Ad hoc analysis of the initial phase 2 adult Crohn's study from 2014 showed that patients with the highest Crohn's Disease Activity Index scores were the most likely to experience remission with the highest dose of Mongersen.

- Celgene are now active in pre-registration (phase 3) studies in adults to enable them and their co-development partners, Nogra Pharma, to apply for a licence to market this drug.

All in all, although Mongerson is not quite "there" yet, it's very good news that momentum continues a-pace with this potential new treatment and that there is at least some commitment from Celgene and Nogra to its future development for use in children. Remember that CICRA funded some of the early work on the role of SMAD7 in inflammatory bowel disease. . .

Biological therapies



Other biological therapies for IBD with alternative targets to TNF-a may be on the horizon. Janssen presented phase 3 data clinical data on Stelara at Digestive Disease Week in the US recently. Stelara (Ustekinumab) is a novel biologic therapy targeting interleukin (IL)-12 and IL-23 cytokines, which are believed to play a role in a number of immune-mediated diseases, including Crohn's disease and it is already approved for the treatment of certain types of psoriasis.

Janssens data showed that a significantly greater proportion of adult patients with moderate to severe Crohn's receiving Stelara as subcutaneous maintenance therapy were in clinical remission at one year. This trial evaluated 388 patients who achieved clinical response eight weeks after a single remission inducing intravenous infusion of Stelara and demonstrated that 53% of patients receiving a 90 mg subcutaneous injection of the drug every eight weeks



Stem cell transplantation

and 49% of patients receiving a 90 mg injection every 12 weeks were in clinical remission at week 44, the study's primary endpoint. This compared to 36% percent of patients receiving placebo. Janssen are currently in the process of filing applications for approvals of Stelara/Ustekinumab for the treatment of moderately to severely active Crohn's disease in adults in the US and Europe.

Possible therapy for perianal fistulas TiGenix also recently presented data on its candidate therapy, Cx601, for complex perianal fistulas in Crohn's disease in patients with inadequate response to previous therapies, including anti-TNFs. A single injection of Cx601 was statistically superior to placebo in achieving combined remission at week 52 in TiGenix's phase III ADMIRE-CD clinical trial (212 patients) and confirmed the favourable safety and tolerability profile of Cx601 previously reported at week 24 of the study.

These new biological therapies contain highly complex and potentially very potent molecules but might seem relatively straightforward compared to work on stem cell transplantation as an intervention for Crohn's disease.

Results from the Autologous Stem Cell Transplantation International Crohn's Disease (ASTIC) trial published late last year were not as positive as those recently reported for biological therapies in that autologous Haematopoietic stem cell (i.e. cells obtained from the same patient into which they will be transplanted) transplantation (HSCT) was not significantly better than conventional therapy at inducing sustained disease remission at one year in patients with Crohn's disease that was not responding to conventional therapies.

Further analysis of the data from this trial however show other benefits of HSCT over conventional treatment that the investigators say warrant further study.

Significantly more HSCT patients were able to withdraw all immunosuppressive therapy for the three months prior to the 12 month endpoint compared to controls and although not statistically significant, more patients undergoing HSCT had been in clinical remission for 3 months and were free of disease on endoscopic / radiological assessment compared (p= 0.054) at the 12 month endpoint.

Message:

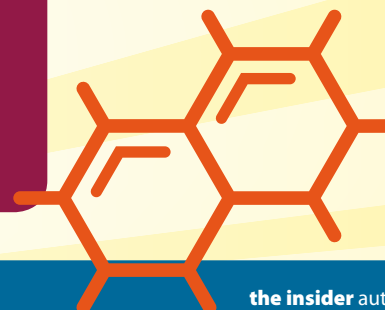
Activity from the industry continues/ picking up even more and some there are novel approaches to tackling IBD – some drugs potentially very close to approvals for adults and frustrating that bit more of a wait to get into children but no reason why development for paediatric development cannot begin very soon for those that are successful in obtaining marketing approvals.

Watch this space...

We hope that this and future round-ups of inflammatory bowel disease drug discovery activity within the pharmaceutical and biotechnology sectors is/are useful and at least provide a positive message of the chance of new, more targeted and effective medicines for the future for children and young adults with Crohn's and colitis.

Dr Deborah O'Neil

Trustee and Medical Advisor



Clinical trials explained

Phase 1 clinical trials are to assess safety and tolerability and are generally conducted in healthy volunteers.

Phase 2a clinical trials are conducted in the target patient population and are to confirm/assess safety, tolerability, pharmacokinetics and potentially generate the first evidence of efficacy (i.e. drug effectiveness).

Phase 2b clinical trials are to further confirm data from 2a, narrowing down optimal dose levels for the best chance of efficacy. "Blinded" studies (patient and investigator don't know what the patient is taking) so can compare drug against placebo to check effects are "real".

Phase 3 clinical trials are known as confirmatory/registration/pivotal studies as these provide the efficacy data – design of the study based on findings from Phase 1 and 2 trials – on which regulatory agencies decide to approve a drug or otherwise. Placebo controlled, double blind trials as for P2b.

Phase 4 "post marketing" clinical studies can and sometimes have to be undertaken once a drug is approved to look at comparative efficacy against other drugs, interactions with other drugs and/ or food etc and potentially to continually monitor for side effects.

For your convenience...

Grace signs up access f

Grace Warnock is a determined young lady who is keen to make life easier for her fellow IBD sufferers, and her voice has already been heard in high places. Grace's Mum Judith tells the story...

“ During diagnosis Grace sometimes needed me in beside her as her toilet trips could take a long period of time. When you're young and in a lot of pain and bleeding sometimes having me with her helped.

I always say that “normal cubicles” are not built for two so most of the time we would use the disabled toilet. I became aware of people looking at us but it wasn't until Grace got talking to a lovely volunteer from CCUK about the challenges that are faced that Grace became more aware of the reactions of others.

Grace decided that she would try to change the way people reacted to those who used a disabled toilet and

the best way she thought was to change the sign. She wanted others to be kind and understand that you don't have to be in a wheelchair, and that some disabilities are not visible.

Grace designed a sign and asked where she could send the sign that would maybe get someone to help raise awareness. The sign and A4 page letter written by Grace were sent to Iain Gray MSP at the Scottish Parliament. At no point in my wildest dreams did I ever think that anyone would respond, but Iain did. He put us in touch with a couple of agencies and Grace had her story published in the *Big Issue*.

A couple of visits to the parliament and a message from Gemma at a design company called Teviot Creative in



Grace with one of her new signs

'Can't Wait' card

The CICRA 'Can't Wait' card, which bears the name of the young Crohn's or Colitis sufferer and their photograph, is available free of charge to members to help explain their medical condition and can be invaluable when urgent toilet facilities are required.

However, as you can see from one of our member's comments below it can have other potential advantages as well.

Heidi's daughter Francesca has IBD, and when, along with the rest of the family, they embarked on a recent trip abroad, they presented Heidi's 'Can't Wait' card to the British Airways check in staff. Here are Heidi's comments:

"BA kindly allowed my daughter and my family to use the special assistance check in line queue, on presentation of her CICRA



card, to avoid waiting in line for hours. Good advice for other CICRA passengers."

Obviously, we can't guarantee that staff will always be so kind but it is well worth asking.

or IBD sufferers

Edinburgh who helped take the design from a drawing to art work and we had "Grace's Sign".

At around this time it was decided to try to get people to change the way they spoke about the toilets using the word accessible rather than disabled toilets. The love heart on the sign is for two reasons, the first is to symbolise invisible illnesses and the second reason is for others to have a heart, to not judge a person using an accessible toilet. We also added Braille to ensure that this sign would benefit all.

World Toilet Day

A motion was raised in the Scottish Parliament just after World Toilet Day and Grace was invited to the Scottish Parliament to watch Iain Gray gain cross party support for her campaign.

Then the call we were waiting for that the Scottish Parliament had decided to place "Grace's Sign" on their

accessible toilet doors. This coincided with Disabled Access Day and what a fantastic way for the Scottish Parliament to raise awareness than by launching the first sign.

The heading in the *Big Issue* was "Can changing a door change an attitude". This was exactly what Grace was trying to achieve. She doesn't want people to tut or shake their head or worse.

Shortly after launching this campaign it became very apparent that this is needed not just for IBD but various other illnesses. It's not also not just in Scotland, we have had messages of support and people who have shared stories from the UK, Ireland and as far away as America, Canada and Australia.

Grace would love to see it all over the world and maybe one day it could become the globally recognised sign for accessible toilets.

It looks like Grace's message with regards to disabled toilets is already spreading, as we were very pleased to see a recent press release from Asda:

New signs make toilets accessible to those with "hidden" disabilities

"We understand that not all disabilities are visible which is why we're rolling out new signs for our disabled toilets in more than 400 of our stores.

We want to make sure all our customers feel comfortable using our facilities – including those with disabilities that aren't always obvious such as autism, Crohn's disease and Ulcerative Colitis (IBD).

The new signs were inspired by a conversation between our Newark store manager Abby Robinson, mum Tonya Glennester and her five-year-old daughter Evalynn after a recent visit to the store.

Evalynn, who has ADHD and autism, used the disabled toilet but she and her mum became upset when they were questioned by another customer who told them "You don't look disabled."

Abby, who has just taken over as manager at the store, spoke to colleagues at Asda's Head Office and it was agreed that new signs will go up in 421 stores over the next few weeks to make them more accessible."

Our congratulations and thanks to Asda on this great initiative, and for recognising that not all disabilities are visible.

RADAR – NKS

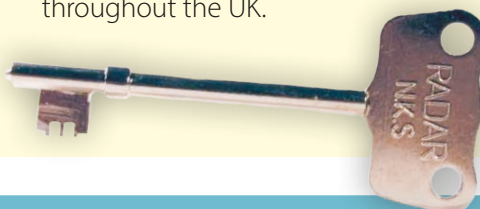
You will have read above about the use of disabled toilets. Whilst these are often unlocked in some shops and public places, generally they are only accessible with a special key.

The RADAR NKS Key gives independent access to locked public toilets around the country. The key opens almost 9,000 locked public accessible toilets around the UK.

RADAR is now part of Disability Rights UK who administer and manage the National Key Scheme. RADAR Keys are only sold to

people who require the use of toilet facilities due to a disability or a health condition. You will be required to sign a declaration form to confirm that you are eligible for a key prior to use.

Keys can be purchased for £4.50 from Disability Rights UK directly, please phone **020 7250 8181** or visit **www.disabilityrightsuk.org**. Disability Rights UK also publish a guide which lists all the NKS toilets throughout the UK.



Marathon efforts



Described as the “toughest footrace on earth”, **Marathon des Sables** is not for the faint-hearted. New CICRA member **Simon Dunn** and his friend, **Rory Connor**, took part in this six-day multi-stage challenge in April.

With the exception of tents and water, participants were expected to be self-sufficient and carry all their own food and equipment for the week on their back.

Rory and Simon completed the 156-mile course and raised an incredible combined total of £11,879.72. Rory

and Simon have received a certain amount of press coverage for this commendable effort, and I'm sure you'll agree that they deserve a pat on the back... or two!

We were lucky enough to have two participants in the London Marathon in April this year: **Ruth Turner** ran in the charity place allocated to CICRA, while **Piers Edwards** won his own place in the ballot and kindly chose CICRA to benefit from his sponsorship. Ruth and Piers both ran personal bests and raised an incredible £4,246 and £1,591.67, respectively. Long-time CICRA member and supporter **Madeleine Brent** donated a very generous £1,000 to be split between the two runners.

In addition to our London Marathon runners, we had marathon runners raising money for CICRA all over Europe in the first half of this year: former CICRA Trustee **Simon Owen** completed the Hamburg Marathon and raised £595; **Tom Cooke** ran the Paris Marathon, bringing his online fundraising to £1,646.25; and **Inga Judge** took part in the Seville Marathon, adding to her fundraising total of £1,430, which has been raised in memory of her friend, Zul.

Simon & Rory



Piers



Inga



Tom



Ruth



Simon



British 10k Run

Amidst days of variable and unsettled weather, the cloudy and mild but dry conditions were not unwelcome for our runners on July 10.

Starting on Piccadilly outside The Cavalry & Guards Club on Hyde Park corner, runners made their way

past huge crowds and landmarks, including the London Eye, Big Ben and the Houses of Parliament. All the runners assure us they enjoyed the day, with around £5,000 raised. Well done to everyone (listed below with finishing times).

George



Deborah



Lisa



Janice



Dee and Abigail



Chloe & Joseph



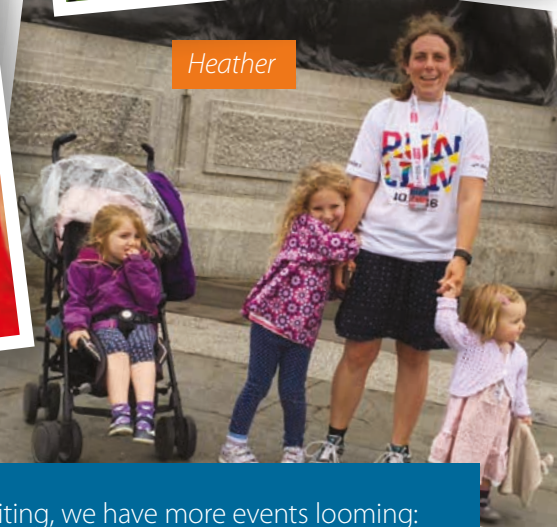
Tom



Neil



Heather



Name	Time
Tom Draper	39 min 49 sec
Phil Woodgate	44 min 11 sec
Neil Gooding	44 min 51 sec
Mark Slater	49 min 19 sec
Joseph Reeder	52 min 54 sec
Rajat Kapoor	54 min 36 sec
Heather Heath	58 min 16 sec
Lisa Vernon	1 hr 16 sec
Yvonne Slater	1 hr 4 min 17 sec
Deborah Whitlock	1 hr 6 min 58 sec
George Millington	1 hr 7 min 15 sec
Davina Embery	1 hr 18 min 5 sec
Abigail Bareham	1 hr 18 min 5 sec
Chloe Reeder	1 hr 38 min 42 sec

Upcoming events: At the time of writing, we have more events looming: participants are training for Prudential RideLondon and the Great North Run in September, as well as other individual challenges. Look out for those in the next newsletter!

Running, walking, cycling



In addition to the CICRA places in organised running events, we have seen a number of members participate in a variety of runs of their own choice this summer.

Natalie Pook ran a half marathon in Plymouth and raised sponsorship of £413.75, **Barbara Daughters** ran the Reading Half Marathon, raising £360, while **Craig Allington** ran 10k in Bristol (raising £645) and **Alison Fox-Fitzgerald** participated in the Great Manchester Run (raising £390). **Sarah Chambers** took on The Osprey Sprint and raised a wonderful amount of £637.74, inspired by her daughter's fundraising earlier in the year: **Charlie** held a successful cake sale at her school, raising £132.70.

Steve Ellis took part in the Robin Hood Half Marathon last September to raise funds for CICRA. Despite suffering with a cough and cold on the day, and previously having had reconstructive surgery on an ankle, Steve finished in good time and was humbled by the amount that family and friends sponsored him for, a total of £1,931.

Belated thanks also go to **Tony Seath**, who raised an incredible £1,186.25 when he ran in the British 10k last summer.

Graeme Wintle, Chris Handy, Roland Bodlovic, Dunstan Power and **Mike Proctor** came together to form a **ByteSnap team** and take part in the Wolf Run. They raised £860.

Vicky Allmey and Hannah Golderska got a team together for the Tough



Michael Banks and friends tackle the Yorkshire Peaks for CICRA

Mudder London West. The day was muddy, exhausting and fun-filled, with a combined total of £2,374.25 raised for CICRA.

Thank you very much to all those who put on their running shoes for CICRA!



Michael Banks and several friends took on the Yorkshire Peaks and raised sponsorship of £971 for CICRA. The weather wasn't especially kind, with Michael describing the day as "tough but enjoyable". Thank you to all involved. (see photo above)

In aid of her niece, Olivia, **Michelle Brereton** raised sponsorship for

completing the Basingstoke Canal Walk in April of this year. Michelle raised an excellent £703.75. Thank you, Michelle!



After experiencing first-hand the care and expertise that Great Ormond Street Hospital provide, when his daughter Willow was unwell, **Neil Pickett** decided to take on a challenge suggested by a friend: he cycled the South Downs Way – 100 miles!

As well as fundraising for GOSH, Neil donated a wonderful amount of £300 to CICRA. Well done Neil, and thank you!

SNIPPETS

Special mentions also go to the following for the support they have given the charity via various sales, work and school events, and collections and raffles:

From a variety of collections and raffles, **Alison Johnston** has raised a brilliant £359.64 for CICRA this year. We remain grateful for Alison's continued support.

Member **Ella Mayhew** chose CICRA as her school's House Charity of the Year. A variety of fundraising efforts have resulted in an impressive £707.30 funds raised for CICRA. Ella was presented with her certificate at the end of term. Thank you Ella, and all the best for next year! (see photo below)



The Senior Gents at **Adrian Bowling Club** collected £85 to donate to CICRA, nominated by CICRA member **Catherine Walls**. Our thanks go to all who donated.

A wonderful £500 was raised and donated by the **Northants and Hunts Masonic Bowling Association**. Thanks go to all involved and in particular **Eric Preece**, who nominated CICRA as the charity to benefit from the donation.

Lisa Ward held a collection at Slimming World and raised £112 for CICRA.

Tracey Frost and the **Castelan Group** raised an impressive £166.50 by holding a raffle at work.

EA Jarvis collected 'pennies' at the Potter Street Garden Club, raising £20 for CICRA. This is something that the club has done for many years and even though the club has disbanded, former members still pass on their pennies to donate. Thank you – we are touched.

Amelie Simpson was diagnosed with Crohn's Disease last summer. Since then, she has been fundraising for CICRA – including by helping in Grandad's hair salon and selling raffle tickets and refreshments at a local craft and produce fair. **Amelie** and her mum, **Sophie**, have raised and donated £400. We really appreciate your efforts, Amelie!

Meg Brazier participated in a neighbourhood sale and chose to donate the £20 she raised to CICRA. Thank you, Meg!

Amy James decided to hold a stall at a local fete. Amy sold CICRA merchandise and raised donations amounting to £52.25. Thank you, Amy.

Longstanding members **Paula and Martin Abel** raised £100 selling handmade rag dolls: what a lovely way to raise funds for CICRA!

Karen Reid kindly chose CICRA to be the recipient of £60 from her 'Bank of Stars' at the company she works for, Murgitroyd & Co Ltd.

Freya Ambrey was another thoughtful 10-year-old selling her preloved toys to raise £190.14 for CICRA. What lovely young people to give so generously to others. Thank you, Freya.

Janine Whitlow raised £202 as a result of a wonderful coffee morning at the school where she works. Thank you Janine for suggesting CICRA as the charity to benefit from your school's generosity.

The Romsey School, attended by CICRA member **Harry Johnson**, allowed pupils to come to school in their own clothes in exchange for donations. Harry himself and his friend proudly wore CICRA t-shirts. The school raised a total of £515.89, which is an incredible amount.

Tutor Group 9RS at St Bedes School organised a basketball competition and donated the £98 raised to CICRA, after one of the class members was diagnosed with Crohn's Disease. A good time was had by all and CICRA is grateful for the time and efforts of those involved.

Eleven-year-old **Aidan Saunders** sold toys he no longer uses and donated the proceeds – £230 – to CICRA. What a kind thing to do – thank you Aidan (photo below).



We regularly receive donations, either as a single donation, a standing order or sent with draw tickets or Christmas card orders and would like to thank everybody, too numerous to list, who have contributed in this way. You can be very sure that your generosity is very much appreciated.

Fundraising



St Oswaldtwistle Boys Brigade



Romsey School



Steve Ellis



Sarah Chambers



Holly & Robert



Alfie

Sharon Philips Dance School



Lindsay Wallace



Neil Pickett



Bytesnap team



Craig Allington

SNIPPETS

Sue Slater donated the proceeds of the Billborough Village monthly coffee morning in March. Thank you to all involved for the £100!

Tracy and Lani Philip held a cake sale in their house and have reported that the house was absolutely wall-to-wall with hungry cake lovers! They sold over 420 cakes and raised £440, which was split between CICRA and Crohn's and Colitis UK. (see photo below)



Joanne Chilcott continues to raise funds for CICRA, this time organising a hog roast, which raised another £250 for CICRA. We are ever so grateful for her continued fundraising efforts.

Margaret Battrick and the St Oswaldtwistle Boys Brigade held a quiz and pancake evening for local families, raising £160 for CICRA. Thanks to all those involved.

Thanks go to all who were involved in the monthly coffee morning held at Farnhill Methodist Church in February. CICRA was selected to receive the £80 raised by **Steve Clayton**.

We have been told about two young fundraisers who received sponsorship from family and friends for taking their Modulen: **Natasha Owen** raised £100 and **Robert Gold** raised £124. What a great idea! Robert's sister, **Holly**, also held a cake sale at her school, boosting the total raised to £135.20. Great work guys!

Alfie is an inspiring young boy with autism. With the help of his loved ones, Alfie decided to set himself and his horse, Poppy, a challenge and fundraise for three charities: Cancer Research UK, The National Autistic Society, and CICRA. Alfie and Poppy have covered over 100 miles together in their fundraising challenge.

Five-year-old **Dhruv** was almost two when his mummy, Meena, passed away from Fulminant Colitis at the age of 34. Dhruv set himself a fundraising challenge and



completed a mini triathlon – running, cycling and swimming – and raised £1,657.89. Dhruv and his father, **Mukesh**, chose three charities to benefit from Dhruv's efforts, and CICRA was one of those. Thank you to Dhruv and Mukesh.

We were very lucky to have been chosen by the **Sharon Philips Dance School** to be the recipient of money raised from the end-of-year production. Some of you may have noticed our current Facebook photo – these are just a few of the children who put on a brilliant production and raised an inspiring sum of £4,000. Absolutely amazing.

When **Andrew Sheaf** embarked on retirement last year, he very graciously asked to forego the retirement party and requested the money instead be donated to CICRA. We think this was a wonderfully original and selfless gesture. His company, **Schroders plc**, were so delighted by the idea that they donated an additional sum. When combined with the amount of £1,150 from Schroders, CICRA received a fabulous donation of £2,650. When making this donation, Andrew wished it to be in honour of Professor Ian Sanderson's work with young Crohn's and Colitis patients. Thank you very much indeed, Andrew and Schroders,

and we all sincerely hope you are enjoying your retirement!

Readers may recall from the spring newsletter that **Trish Walker** gave a talk to the Quilters Association and nominated CICRA as a Charity of the Year. The exhibition will be held in August and we plan to update you in the next edition of *The Insider*. Trish also continues to show her support by very kindly donating money raised from her sewing club. £597 was donated in March, and another £581 donated in July – wonderful amounts for which we are very grateful. Thanks to Trish for her kind efforts.



A hugely successful rugby match was organised by **Stanningley Rugby League Club** in memory of Crohn's sufferers, Josh Sanderson and Darryl Peacock (see photo above). On Saturday 26 March, Leeds Rhinos legend Jamie Peacock put on the Stanningley shirt for one last time for a special charity match. The sell-out day raised £14,000, which was split between two charities, with CICRA and Wheatfields Hospice receiving £7,000 each! Josh's Dad and Uncle, Jason and Mark, hope to raise more funds for CICRA, with more fundraising events planned for later this year. We are ever so grateful for their efforts.

Rebecca Parkin suggested CICRA as the recipient of the proceeds of a sponsored swim undertaken by students attending **Hummersknott Academy**. The students, aged between 11 and 15, took part in the sponsored swim over a three-week period, both before and after school. The amount raised – £1,292.14

Long-time supporter and member **Jax Martin-Betts** held a successful tennis tournament with all funds raised going to CICRA. £1,220 was raised – this is the seventh tennis tournament to be held and we are extremely grateful for the continued support.

David Stone chose CICRA as the charity to benefit from a work charity event that he organised. The event was a great success and raised £402.07, which was doubled to £904.14 due to matched funding by Barclays PLC.

Some of you may know members **Jasmine Ellis** and her mum, **Emma**. Jasmine's uncle, **David Wright**, recently took place in an event called the Fan Dance and raised over £1,395, which is absolutely fantastic. The Fan Dance is a gruelling 24km non-navigational race over two sides of Pen Y Fan, the highest mountain in the Brecon Beacons. Jasmine must be very proud of her uncle! Jasmine has also raised £250 from various cake sales, so should indeed be very proud of herself too!

With the involvement of **Lindsay Wallace** and family **The Brethren of Heortnesse Lodge** organised a very successful cycle ride. CICRA was one of three charities chosen to receive £600, for which we are very grateful.

Rather belatedly we thank **The Volkswagen Group, Wardray Premises, Rosalyn & Philip Phillips, Mrs S Robertson, Mrs H Passmore, Joanne Chilcott and Colin & Linda Vesty** for their donations from various Christmas activities which raised over £2,200.

We also thank **Heather Reid** from the **Aboyne Loch Caravan Park, HSBC staff**, the **Whirlowdale Park Ladies Coffee Group Sheffield** and the **Northants and Hunts Masonic Bowling Association** who, in total raised a further £800 and **Rebecca Parkin's Nana** who celebrated her 80th birthday by raising £130 to help fund research. Thank you all.

Ask the doctor

Here at CICRA, we are always happy to hear from youngsters and parents alike who may have medical questions or queries in relation to their IBD.

At one time or another we have all had a consultation with a doctor who has said something we didn't understand, or we have gone to a hospital appointment with lots of questions in our heads and then not had the chance to ask the doctor any of them!

Well this column gives you the chance to ask those questions easily and anonymously, and you will get an answer that's not full of 'medical jargon'.

So whatever your age, and whatever your questions, please write to us (or email us) at the usual address and we will hopefully publish your question along with the answer from one of our team of respected medics.

Q I would like to know if there's any advance in medication that just targets the bowel instead of suppressing the whole immune system, and if so when is it likely to be available?

Dr replies: A new drug – called Vedolizumab (not licensed for children yet) is targeting alpha4beta7 integrins. These molecules are involved in the process of inflammatory cells leaving the blood stream (called extravasation). Hence, this process is thought to reduce inflammation in a specific tissue. Vedolizumab is thought to work primarily in the GI tract, hence making it a potentially "GI selective" treatment.

Q My daughter is 16 years old and has Ulcerative Colitis.

Is there a specific diet or foods that are helpful to boost the immune system?

Are probiotics such as VSL3 beneficial to teenagers with UC?

Dr replies: Really the best advice to boost the immune system is ensuring

that the diet is sufficiently varied and includes all food groups to ensure recommended daily allowances of all vitamins and minerals are met, usually assessed by diet history and growth.

In terms of probiotics this is a big area of research at the moment, therefore no clear cut answer yet but watch this space. There is evidence that VSL3 helps in pouchitis specifically but for patients who don't have this, there is no evidence

yet to say it is beneficial. However taking probiotics is not harmful.

Q My daughter is 10 years old and has Ulcerative Colitis, after a flare last year she has developed a general food phobia and struggles to eat. Do you have any general advice or strategies to help at meal times and with food in general?

Dr replies: I have seen a few children with IBD who have developed a food aversion. What seems to happen is they associate pain from the IBD with a particular food or eating and their range of foods decreases as they think that by controlling their food they can control the pain. The problem then becomes one of anxiety about food and eating.

There are various strategies around desensitisation to food but they are quite hard to do without professional support as parents are understandably stressed and worried and tend to inadvertently put pressure on the child to move faster than the child can manage. A good dietitian or even psychologist will be able to work with the family to find the best strategies for the child.





Can you please give us some information on maintenance drugs – does everyone go

on them and once on them, we presume you cannot stop? Also information on Modulen and its remission rates on young people. Our son is 16 years old, once off Modulen do young folk go straight onto maintenance drugs?

Dr replies: Maintenance medications are medicines that work in the background to act as a buffer to manage symptoms and prevent flare-ups long term.

The majority of IBD patients will be on some form of maintenance therapy-whether its 5asa or indeed immunosuppressants. Are they forever? Not necessarily so. In paediatrics two main focuses of care are growth and education and we aim to maximise the potential for both so we would be reluctant to stop medicines that we presume are keeping you well at these important times. But outside this, if you've been well for 3 years or more you can discuss with your clinician a trial without.

With Modulen we have experienced up to 80% of patients going into remission. Once the course of Modulen is finished the majority of patients go on some form of maintenance medication for the reasons mentioned above.

We find it difficult to get patients to do a full second course of exclusive Modulen but may recommend a retry for a couple of weeks or using the Modulen as a supplement to diet.

Once diagnosis and initial first line treatment has got the patient well, maintenance medications have a role in keeping patients well long term. They are not guarantees of relapse free disease.

Every child with IBD deserves to have an IBD Nurse

IBD nurses can be instrumental in improving the quality of life for youngsters with IBD and are often families' first point of contact with the hospital; they provide expert care often during distressing times.

Many families describe their IBD nurse as a 'lifeline', we'd love to hear about your experiences; Jo-Ann (pictured) is a young CICRA member and recently wrote to tell us about her IBD nurses, Carol and Brenda.

“ My name is Jo-Ann, I am 12 years old and live in Aberdeenshire. Last summer I was diagnosed with IBD. My older brother James also has IBD so I already knew what it was. Before he was diagnosed the doctors didn't know what it was so he had to have scopes done to see what was wrong, nobody we know or in our family had anything like IBD so it was a very worrying time for my family.

One thing that helped were the gastro nurses at the hospital, they told my mum and dad everything they needed to know and explained what was going to happen to my brother in a friendly way. Even though I was only 8 years old at the time I could tell that it calmed them down and made them less anxious.

Of course, when I was diagnosed 2 years later we had gotten to know the gastro team not just as nurses but like friends from appointments, e-mails and phone calls. My brother started a new medication which he does himself by an injection, the



nurses (Carol and Brenda) showed him how to do it. I know my brother was really anxious about it but they knew exactly what to say and within only five minutes of talking to them he felt like he was ready, could you do that? I know I couldn't!

Recently I had to go to hospital as I was having a serious flare, I had to go on IV steroids, over the course of the 10 whole days I was in hospital my mum and I literally counted the hours until we got to talk to Carol or Brenda.

Before I got to go home I had to start a non-oral medication, I was really scared. I had no idea what was going to happen to me but again here to save the day were the gastro nurses. They told me something that not all my doctors have, THE TRUTH, yes, it was going to hurt for a bit but then I would feel better for ages.

So in conclusion as much as I like the doctors and other staff, they don't offer what the gastro nurses do. I go to hospital so much, I don't think of them as nurses, I think of them as my friends who understand. I feel as if the gastro nurses aren't something children with IBD want – it is something they all seriously NEED. Every child with IBD deserves to have an IBD nurse.



Families and friends unite in Manchester

Saturday 25 June 2016 saw another successful Family IBD Information Day, providing an opportunity for families of children and young people, affected by IBD, to come together. Held in the DoubleTree Hotel in the Piccadilly area of Manchester, families heard wide-ranging and informative presentations, and also took part in breakout sessions.

The small, hard-working, team of CICRA Trustees and staff, augmented by family volunteers, helped to make the day a success with Trustee, Mr Neil Gooding, getting the meeting off to a good start, as part of the AGM, with a presentation on the work of CICRA during 2015.

We were grateful to have such an eminent team of doctors and medical professionals join us for the day to give families and young people a better understanding of IBD. From Alder Hey Hospital Liverpool, Dr Christos Tzivnikos gave an overview of **paediatric IBD services** in the north-west while Professor Steve Allen's talk covered **'What's new in research?'** Dr John Puntis from Leeds General Infirmary then took as his subject **'The importance of diet & Nutrition in IBD'**.

Dr Anna Piggot joined us from Stoke on Trent Hospital and spoke interestingly about **'The importance of early diagnosis and the team approach in IBD'** with Dr Andrew Fagbemi from Manchester Children's Hospital looking at **'New treatments on the horizon'**.

Dr Kate Blakeley, our regular consultant psychologist from London, spoke about the **psychological issues faced by young people with IBD** and, to complete our superb line up of speakers, Professor Mike Thompson from Sheffield Children's Hospital, gave a serious but entertaining talk about his speciality – **colonoscopies**. Professor Thompson is the absolute expert on this form of diagnosis having set up and now, overseeing the training of young paediatric gastroenterologists, in the art of 'Endoscopy'.

.....
"The day exceeded my expectations, the meetings should be funded by the NHS as a critical part of care!"

A comment from a medical professional

.....
Interspersed among the much-appreciated medical presentations were those from **Abbi** and **Josh**, two young patients and **William** a 23 year old, remembering his time as a child with IBD (their stories are on pages 6, 7, and 8). Parent, **Mark Whitlow**, described his experiences when his daughter **Eleanor** was diagnosed. It was emotive and empowering to hear how, they had overcome the many challenges in their lives.

A special mention here to Mr Colin Baillie, Dr Yvonne Humphreys, dietitians Sharon Watters and Helen Garrett



and IBD nurses Valda Forbes, Sally Grange and Janis Maginnis, who along with the morning session speakers, ensured that the small afternoon discussion groups were once again a wonderful opportunity for parents and youngsters to join others and have some of their questions answered.

Lastly thanks to Ian Davies, our children's entertainer who, as usual, had his young audience enthralled with his antics.

CICRA Summer Draw 2016

At the Manchester meeting on 25th June the CICRA Summer Draw took place.

Below are the prize winners:

Prize	Ticket No.	Name
1st	34418	Mrs A Kelly, Worcester
2nd	12672	Mrs Hooper, Carmarthenshire
3rd	11227	Mrs Grover, Surrey

Thank you very much for your support.

Margaret Lee (promoter)

CICRA project summary

Below is the first report from Dr Neil McCarthy, a post-doctoral research scientist at The Blizard Institute London who was awarded a CICRA grant to study: *Human colonic T-cell responses in Crohn's disease: modulation by phosphoantigen products of the gut microbiota*

"Gut bacteria produce many different types of chemical that can activate the immune system in different ways to cause intestinal inflammation in Crohn's disease (CD) and ulcerative colitis (UC).

Most of the drugs used to treat these conditions target immune responses to the 'peptides' that gut bacteria are made of, but there are also many other types of bacterial chemical that can trigger intestinal immune responses, and we have specialized immune cells that are dedicated to recognizing these. Importantly, not all of these specialized immune cells are present in mice, so it is not possible to study how they work in the rodent models – often used to study inflammatory bowel disease (IBD).

In humans, the immune system recognizes a class of bacterial chemical called 'PAG' which activates a cell type called 'delta2', not found in mice, therefore little is known about their role in gut inflammation or how they might be working differently in human IBD.

Dr McCarthy recently found that PAG-activated delta2 cells in human blood can travel to the intestine and increase the inflammatory activity of other major immune cells in gut tissue and, with colleagues Drs Andy Stagg, James Lindsay and Ed Giles, has been investigating how this process is controlled and what effects this might have on inflammatory activity in the intestine. Working also with leading delta2 cell scientists at Cardiff University (Dr Matthias Eberl,

Prof. Bernhard Moser and Dr Chris Tyler), they found that when delta2 cells are exposed to bacterial PAG they become able to activate other intestinal immune cells to produce a chemical messenger called IL-22. This chemical is important for protecting the gut barrier against infections because it causes the release of anti-bacterial factors such as 'calprotectin', which is now being routinely measured in the clinic as a way of assessing inflammatory activity in the gut. Importantly, delta2 cells were able to boost the levels of IL-22 produced in intestinal tissue without causing any increase in a major disease-associated chemical called IL-17. A key player in this pathway was the immune cell-regulating signal TNF α , which is also the target of several current 'biological' therapies for IBD, including infliximab (Remicade) and adalimumab (Humira).

Having identified some of the most important components of this new pathway, Dr McCarthy and colleagues are now preparing a report of their findings for submission to a leading medical journal and are assessing whether IL-22 production via this route can still work properly in patients with active gut inflammation.

Future work will aim to establish whether this newly identified way of boosting levels of protective IL-22 in human intestinal tissue can be exploited to develop new types of therapy for patients with IBD".

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:

- **Brian Corkett** – A Crohn's sufferer for many years, he will be remembered with love by all the family and friends.
- **Anthony Pullen** – Fondly remembered by family and friends.
- **John Humphreys** – A gentleman who suffered from Crohn's and its effects for many years. Fantastic father, son, brother and partner. Loved and missed. Rest in peace.
- **Mary McInally Holmes** – Wife/mother of a Crohn's sufferer. Will be remembered with love by all family and friends. Always in our hearts.
- **Liz Arthur** – Mother of a Crohn's sufferer. Loved and remembered by all her family and friends.
- **Margaret F B Smith** – Treasured Great Grandma of Alexandra, 5 years, a Crohn's sufferer. Lovingly remembered by all the family.
- **Audrey Fossey** – Remembered with love and sadly missed. Laura, Patrick family and friends.
- **Edith Marjorie Hindle** – Fondly remembered by family and friends.



Larger prizes in CICRA 200+ Draw

A big 'thank you' to all members who have participated in the 200 Club which, in addition to raising funds for the CICRA research and support programme, also gives members a chance of winning a cash prize. We

are grateful to CICRA's Vice Chair, Rod Mitchell, who is now administering this fundraising initiative and therefore it continues to be done on a voluntary basis. We still have a few numbers

free so if you would like to join please contact the office on **020 8949 6209** or email support@bicra.org and we will send you a form. The cost is £26 per year, paid quarterly if preferred.

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 **£817.78** has been put towards research. Our thanks go to:



Mr Chan, (Home)

A Cobbett, (Dalesway Public House)

Mrs Ann M Donohoe, (Home)

Robin & Karran Eames, (Home)

Mrs Julie Jones (Ye Olde Murenger House)

Mrs M McGowan, (Home)

Mrs Sandra Miles, (Home)

John Nugent, (Home)

Gill & Tony O'Neill, (Home)

A Pittman, (Automobile Engineering Co. Ltd)

Mr J Seal, (A & J Seal Family Butchers)

Jane Tweedie, (Craigellachie Filling Station)

Janet Warren, (Home)

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

WINNERS 2016...WINNERS 2016...WINNERS 2016...

Jan	114	A Northridge, N.Ireland	£50	Apr	109	L Browning, Dumfries	£50
	208	P Manby, Suffolk	£50		91	I Pell, Sussex	£50
Feb	7	S. Clyne, Manchester	£50	May	194	J Rai, Hampshire	£50
	106	P Cooper, Kent	£50		111	D Menarry, Lancs	£50
Mar	135	R Brandon, Kent	£250	Jun	183	C Shaw, Manchester	£250
	89	D Williams, London	£75		163	J Cotterell, Newport	£75
	207	N World, Cambridge	£75		90	R. Jones, Essex	£75

CORPORATE DONATIONS

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

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- M L Weinstein Charitable Trust
- NEXT PLC
- Michael & Anna Wix Charitable Trust
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- Generations Foundation



children and young adults
with crohns and colitis

The *insider* is published by

Crohn's in Childhood Research Association

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

Tel: **020 8949 6209** Email: support@bicra.org www.bicra.org

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