the insider

summer 2018

CICRA at 40!

how it all began and the difference our supporters have made

the search for a cure

By Dr Richard Hansen, **CICRA** Medical Director

BSPGHAN President on improvements in treating IBD

advances in IBD support and awareness thanks to patient organisations

cicra

better lives for children with crohns and colitis

inside > your invitation to our 40th anniversary IBD family day and how you can fundraise for our special research fund better lives for children with crohns and colitis

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message from the Chair

I have to mention it again – the 40th Anniversary – yes, it is a milestone in the charity but one that we hoped wouldn't be necessary. Unfortunately the number of children being diagnosed with IBD is still increasing. The one thing that will really give children and their families hope is research but we can't do this without financial support. If you are able, please help us mark this special year by giving that little extra.

We are reprinting on page 8 the first story ever written in the newsletter – a little part of the journey of my son Graham, now a CICRA trustee. His childhood was a traumatic time for us as a family but he ended up one of the lucky ones as you can see from the photo, some of you having met him at meetings. We wish all children with IBD the same outcome as he has had.

CICRA, through its research and support programme, has had a real impact on helping all children with IBD. In the 70s Professor John Walker-Smith's primary ambition was to have paediatric gastroenterology recognised as a clinical and academic speciality. We were fortunate to be able to help him achieve this by funding the early work of Professor Alan Phillips, Professor Tom MacDonald, Professor Ian Sanderson and of course all those who have come through the CICRA fellowship training. To do this we have obviously had an enormous amount of financial help from many sources, including the families and friends of those affected, and we thank them sincerely for this.

The CICRA board of trustees has changed over the years but they have all been dedicated to helping families affected by this complex condition. Trustees do not receive any remuneration for their work and I would like to take this opportunity to thank them all, both past and present, for their very valuable contribution, each bringing different skills to the table. As well as good governance, we also have very much appreciated practical help.

> **Unfortunately, the numbers of children being diagnosed with IBD is still increasing.**

We are looking forward to 2018 being a great year under the direction of our CEO Nick Posford who is busy putting in place many ways of taking CICRA forward to further success. Our honorary Medical Director, Dr Richard Hansen, has a real understanding of the needs of children with IBD as you will see from his article on page 4. Also, a great article on page 12 from our former medical director, Professor Nick Croft. We have been lucky to have had the support of so many great medics. With this sort of help there is great optimism for the future of CICRA and for the children and families who we are here to help.

Best wishes

Margaret Lee,
Chair of the Trustees

our bold strategy and new look

Nick Posford,
Chief Executive, CICRA

This year, we have been supporting children with Crohn's and colitis, and their families, for forty years. In that time, we have seen a dramatic increase in the number of children being diagnosed with inflammatory bowel disease. At the same time, through our research programme, CICRA supporters have funded many paediatricians to specialise in gastroenterology and although not yet sufficient to ensure every child can be seen by an expert, this has helped medical care try and keep pace with the growing prevalence of the conditions in children. Our supporters have also funded research that has led to a greater knowledge of how IBD affects young people's lives physically and emotionally, and the ongoing impact into adulthood. We have developed better treatments such as enteral nutrition and projects we are currently funding are looking at the opportunities for personalised medicine in the future.

> **We have been working on a new website, a revamp of our information and a new look to ensure we make things easy for young people to understand.**

Last year, we surveyed children and families to understand what mattered most to them. Although the dream of a cure featured highly, it was the impact of IBD on childhood that was their greatest concern, so achieving remission was more important in the here and now than a future cure. We know that the disruption of a serious illness can drag down educational achievement and physical and mental development, causing problems for children when they become adults. The survey also told us that there were considerable difficulties in getting schools, teachers and friends to understand IBD and how it affects children. Information was crucial in countering this lack of understanding, and children and families also needed supporting.

We have been working on a new and much improved website, a complete revamp of our information and a new look to ensure we make things easy to understand for young people and families. If you haven't already visited our new website, pop over and have a look: cicra.org

We are delighted that Global's Make Some Noise has chosen us as one of their charities for 2018. This will really help boost the support we can offer. We have already increased the number of information days we hold, to try and reach more children and families. We also have work under way to help teachers with key facts about how IBD impacts children and young people, and we are developing some more support for those about to move from paediatric to adult services.

As has been the case since we started, research is fundamental to our plans. Through the projects we fund, we want to get to as good as a cure, where symptoms are well controlled with limited side effects from the drugs many need.

Our strategy is to overcome each challenge faced by children and families. To achieve our ambition in ten years will take a lot of hard work, and will depend on the invaluable contribution of healthcare professionals, researchers and fundraisers. But we've done so much already, and we are all committed to the same goal of giving children a childhood unlimited by Crohn's and colitis.

a childhood unlimited by inflammatory bowel disease?

Dr Richard Hansen, CICRA Medical Director
(Consultant Paediatric Gastroenterologist and
Honorary Clinical Associate Professor, Glasgow
Children's Hospital)

I've recently been thinking a lot about the idea of a 'cure' for inflammatory bowel disease (IBD) - what do we mean by this word when thinking about IBD? What does it mean for Crohn's disease, for Ulcerative colitis, and for the other forms of IBD we sometimes describe, like IBD type unclassified? The Oxford English Dictionary helps a lot here: 'eliminate (a disease or condition) with medical treatment.' The sad news is we're here at the beginning of 2018 and we're not really any closer to that definition of cure than we were when CICRA was founded 40 years ago. There is however plenty of room for optimism, but we might first need to rebalance our idea of 'cure' and maybe rethink our aspirations about what we should be aiming for in IBD.

One of the other definitions of cure set out in the Oxford English Dictionary is 'relieve (a person or animal) of the symptoms of a disease or condition.' Now this happens all the time in IBD practice in the UK. I'm happy to say this is a regular occurrence in almost every clinic in the country. This is also something that's definitely improved in the last four decades. It's important to say though that it's still not the only outcome we see, and we have to remain mindful of those with difficult journeys in IBD, particularly those who fail to respond to multiple treatments and those who need multiple operations. For those people, even this definition of cure seems fanciful. This is however a target we can aspire to, often meet, and can aim to improve on in 2018 and beyond. Whether it's really

a ‘cure’ is up for debate - I think not, but who am I to argue with the dictionary? So, let’s make 2018 the year where we aspire to relieve the symptoms of IBD as much as we possibly can. And can we do this more than in previous years? I believe so.

For decades now, we’ve understood that the immune system is causing damage in IBD, so our earliest medical treatments have aimed at trying to suppress this. I often talk about IBD drugs turning the volume down on the immune system - this is a reasonable parallel, if a little crude. As we’ve understood more about the immune system and have made discoveries about the genetic basis of IBD though, we’ve learned to focus more on what’s happening. Our newest generation of drugs, starting with infliximab, don’t just turn the volume down, but target one particular part of the music and turn this down whilst potentially leaving the rest of the music playing.

> **“For decades now, we’ve understood that the immune system is causing damage in IBD”**

Say, for instance, you wanted to focus on the rhythm of a band so wanted to listen to them playing without lead vocals. This is sort of what infliximab does to the immune system, it takes the lead vocals out. The music is still discernible and as loud as before, but its fundamentally changed. Since infliximab, two other major drugs have arrived in adult IBD care and are starting to be introduced on an individual case basis in paediatric practice - vedolizumab and ustekinumab. Extending my analogy, we could say that vedolizumab removes drums only and ustekinumab removes bass guitar. So, great you might think, this will transform things, and all will be better. Well, not exactly yet. We don’t have good tools yet to identify which patient will respond best to which drug, and certainly some types of IBD seem to respond differently to different approaches. Plus, we’ve decades of experience in using other ‘volume reducing’ drugs, just over a decade of experience of using infliximab, and even less experience with the newer drugs, so the reasons for not jumping straight to newer drugs don’t just relate to cost (though this is of course a factor), but to our familiarity with older drugs – how they work, what to expect from them, what side-effects to look for, how to monitor dosing and bloods, etc… all experience built and refined over decades and not easily or quickly replicated.

So just like our tastes and styles of music evolve over time, our approach to the medical management of IBD is changing too. More drug options with narrower and more specific effects, offering more options for treating these difficult, and yes, still incurable, diseases. But we have more and more to offer the difficult cases and we’ll hopefully see more and more of the ‘relief of symptoms’ version of cure in the coming years.

we've come a long way since 1978

In the year that gave the world the mobile phone system, the first IVF baby and Saturday Night Fever, CICRA was born, established by a small group of parents who wanted to improve outcomes for their children. Here Margaret, co-founder of the charity, remembers the history of CICRA.

Margaret Lee MBE,
Chair and Co-founder, CICRA

In CICRA's 40th anniversary year I have had my memory jogged as to what it was like to have a child with Crohn's disease in 1978.

As a small group of parents with young children being treated for Crohn's by Professor John Walker-Smith at St. Bartholomew's Hospital, London, we desperately wanted to find out why our children had been affected by a condition which, until then, had only been seen in adults. Steroids and surgery were the only options available but we couldn't fault the care our children were receiving, so the only practical way we could help was by raising funds. With advice from Professor Walker-Smith, Dr Colin Campbell and the Dean at Bart's Hospital, we set up the Crohn's in Childhood Research Appeal.

The setting up of CICRA

To understand all the legalities of setting up a charity I read library reference books and was fortunate that my local library allowed me to take these out at closing time, as long as I promised to get them back before the library opened the following morning. They realised that the only time I had to read was during the night!

It is hard to remember those early days, travelling to the Charity Commission offices in London and looking through dusty old books to see whether there was anything already set up for Crohn's. Having found nothing, we decided to put Crohn's on the map. A year or so later the National Association for Colitis and Crohn's Disease (now Crohn's and Colitis UK) was set up. We liaised closely with them, and still do, but stayed independent fearing that children's special needs might be lost amongst the thousands of adults with IBD.

We later realised that 'Appeal' in our name was not relevant because unfortunately we couldn't see an end date for CICRA's need. Reaching out and giving support became very much part of what we did when there was a dramatic increase in children being diagnosed with either Crohn's or Ulcerative colitis and the name was changed from 'Appeal' to 'Association'.

CICRA funded specialist training for young qualified doctors

Taking good advice from our mentor and now Life President, Professor Walker-Smith, the trustees set up a research fellowship training scheme, our aim being to help reach a time when all children diagnosed with IBD would be able to see a specialist. Most of the leading specialists treating children with IBD today have come through this scheme and many are now training a future generation of specialists, again with funding from CICRA. How could we have imagined that just a handful of children with a rare condition could increase so much that we now have 27 very busy IBD specialist centres in the UK. Unfortunately, the incidence in children is still increasing, some being diagnosed as babies or toddlers. The need to continue and expand our research programme is vital.

40
years
1978 2018
research & support

As a comparatively small national charity we are able to give personal support and understanding to all members of the family - my original thought in 1978 being that if I could prevent just one family going through what we had gone through I would be happy. Our family information days around the UK, supported so well by members of the medical profession, are definitely days when we go home knowing that we have helped.

Opening of the first laboratory in the UK for childhood IBD

In 1982 CICRA set up the first paediatric gastroenterology laboratory in the UK under the guidance of Professor John Walker-Smith. Precious laboratory space had become available in one of the disused office blocks at St. Bartholomew's Hospital so, with very little funds available, CICRA furnished the lab with second hand equipment bought cheaply from wealthier charities. With CICRA offering what was probably a very small salary for a scientist with such expertise, Professor John Walker-Smith persuaded Professor Tom MacDonald to return to London from America to head up this laboratory. Within the year, Professor McDonald applied for, and was awarded, a prestigious Wellcome Trust fellowship, releasing CICRA's money for other research. The laboratory became world recognised and major sponsorship from other sources has taken this from strength to strength. It later moved to the Blizard centre in London.

Modulen

As a very early research fellow, Professor Ian Sanderson carried out research that led, nine years later, to Modulen. We know that many children will shudder at the thought of taking this but it has proven to be a very good first line of treatment for children.

Those who have met Professor Walker-Smith, Professor Sanderson and Professor MacDonald will know how dedicated they are and with their help, CICRA trustees have made some very wise investments. We thank them all, and other members of the medical profession who have helped over the years, not forgetting the numerous people who have given practical and financial support.

Being diagnosed with IBD in 2018

Hearing that your child has Crohn's disease or Ulcerative colitis is exactly the same for families today as it was in the seventies - the initial shock, perhaps relief at somebody putting a name to it, but then fear for the future. Fortunately, we have come a long way since 1978. Specialists are able to diagnose IBD earlier and much improved treatments allow better management. However, we still need to do more. If the elusive 'cure' still evades the researchers then we hope for a time where long lasting remission is the norm and children can experience all the usual childhood activities, education and social life unimpeded by IBD.

40 years
1978 2018
research & support

Graham's story

This was the first 'story' written for an early CICRA newsletter (1987 to be exact) to give hope to other anxious parents faced with a Crohn's child not growing, as well as the other problems of medication, surgery and trying to cope with a debilitating illness. The follow-up is at the bottom of the article.

At the age of nine Graham shocked both his family and school by saying that he no longer wanted to play in the school football team as he felt too tired and too cold. Although quickly followed by a rapid weight loss this was thought, at first, to have been caused by some sort of viral or emotional upset. As more symptoms appeared, numerous tests were carried out requiring varying lengths of hospitalisation. Over two years later Crohn's disease was diagnosed. To his family this brought great relief – at least somebody had put a name to an illness that had turned a normal healthy boy into a near skeleton – and now there was HOPE.

Various drug regimes brought about remissions during the following three years but also relapses, requiring further periods in hospital. During this time, with schooling badly affected, came the realisation that hopes of achieving his early scientific ambitions were fading fast. Having given up active sport he concentrated on chess, many games being played in hospital but also managing to represent school and county on occasions.

Lethargy and a feeling of never really being well continued with growth retardation becoming a serious problem. Surgery was carried out but unfortunately complications followed (not from the surgery or the disease, but from him as an individual) which meant another long spell in hospital. During this time he needed total parenteral feeding (nothing by mouth at all). Although he tried he was not well enough to concentrate on school work in hospital but once home, having missed another complete term, he again set himself the task of borrowing books and trying to catch up (with much help from teachers at his state grammar school). Feeling better helped, but lethargy was still a problem and there was very little improvement in his growth. Socially, problems were increasing for although he had many friends, continuing to have the looks and size of a ten year old brought many embarrassing, frustrating but sometimes amusing situations. At this stage, however, he did learn to accept that it wasn't other people being awkward – he did look young – and realised that if he was to have any sort of social life he would have to accept the situation and face up to each problem as it arose. To try and avoid being thrown out of cinema queues etc., he went out armed with his birth certificate and joined his friends on as many social events as he felt well enough for.

Hopes of being able to follow his chosen career were uppermost in his mind with 'O' levels coming up but at the start of revision less than three months before the exams, a

Lethargy and a feeling of never really being well continued with growth retardation becoming a serious problem.

weekend of continuous pain and sickness meant another trip to hospital and further surgery. Fortunately, this time there were no complications and recovery was quite normal. He managed to gain passes in his ‘O’ levels and although not the high grades normally required of students wishing to pursue a science course, to his delight the school did, after much considerations, accept him on three science subjects at ‘A’ level.

The next two years brought about better health but despite various diets, tests etc., still no growth and very little weight gain. When ‘A’ levels results arrived there were three passes but, like the ‘O’ levels, were low grades and not good enough to be accepted for a science degree. After much heart searching he decided that he would not give up, but resit ‘A’ levels whilst continuing his part-time job with a chemist. This year of study and work proved very hard and at 18 lack of growth was very evident – even wanting to join friends for a social drink presented obvious problems. However, support from family and friends helped him keep a sense of humour and when the question arose as to how he could learn to drive when even with blocks he was too small for a Mini, he was first to laugh at the suggestion that perhaps a periscope would help.

The second try at ‘A’ levels produced better results but it was not until after his 19th birthday that the long awaited signs of growth appeared. The months that followed were of great excitement – the elusive 5ft had been passed and acceptance on an Honours Degree course confirmed. During the next year growth was rapid and, beyond the expectations of everybody, he grew to almost 6ft.

Fortunately, he is still well but always aware that problems could recur. Whilst studying he is sharing a house with other students, joining in a hectic social life, taking part in sport and well on course to receive a good degree – something which seemed impossible just a few years ago.

Graham grew to over 6ft, got the degree he hoped for and followed a career in computer science. He is happily married with three healthy children and a few years ago set up his own IT consultancy business in which he is very busy but coping with the stress remarkably well. As a trustee, many will have met him at the CICRA meetings.

the growth and development of Crohn's and colitis patient organisations

by Rod Mitchell, CICRA Trustee and former Chair of the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA)

While it has been 50 years since the birth of the first foundations in North America representing patients with inflammatory bowel diseases (IBD), the movement in Europe is about 10 years younger.

In 1967 the Crohn's and Colitis Foundation of America (CCFA) was founded to research IBD and assist the rising number of patients. Increasingly adult gastroenterologists, surgeons and other health professionals, especially those attending congresses and working on secondment in the USA and Canada, were hearing about growing numbers of Regional Ileitis/ Crohn's and colitis patients being diagnosed across North America. Colleagues in developed countries, where IBD was also rising, began to see the value of patient groups.

Some 40 years ago and through talking to their patients and families, the gastroenterologists and other specialists began to work with small groups of like-minded families and patients diagnosed with IBD to help them cope better with their often long-term conditions. This was when, with limited knowledge and treatments, the more severe Crohn's and colitis patients often needed surgery and long spells in hospital.

With encouragement and support from medical professionals, national groups set up and often mirrored the structure of the growing numbers of major disease specific patient organisations. Crohn's and colitis patient groups began to appear in Western European countries from about 1975 onwards, often with an informal structure and a few dedicated helpers providing basic phone contact. Over the next decade more than 12 country associations across Europe, including the UK and others around the world, were formed.

Children in the UK were first diagnosed with IBD in the late 70's. As there was no organization for IBD a group of families launched the Crohn's in Childhood Research Association (CICRA). CICRA has gradually adapted over the years to provide not only the funding for research but also a range of information and support for children, young people and their families, some members now well into adulthood. In 1979 the National Association for Colitis and Crohn's disease (NACC), today known as Crohn's and Colitis UK, was formed and until around ten years ago focused mainly on adults with the condition. The numbers diagnosed around the world have risen sharply over those 40 years and continue to do so especially in younger people, children and toddlers.

A European Federation of Crohn's and Colitis Associations (EFFCA) was formed as an umbrella organisation in 1990. A global IBD group for professionals was launched and in 2001 a similar European group (ECCO) was born which has been invaluable, expanding our knowledge and research, assisted by pharmaceutical investment in new studies.

Around the world there has been much progress over the 4 decades with the development of information technology and e-Health systems, leading in many cases to, earlier diagnosis, less invasive tests, the availability of better drugs with reduced side effects, fewer hospital visits and an improved quality of life. However Crohn's and colitis are still complex diseases and much is still unknown about them so we continue to work together to solve the missing pieces of the jigsaw puzzle. CICRA will continue to be there for you and those who may need us in the future. The support of all continues to be necessary and we look forward to the day when we can say that we know "why" and we can "prevent".

Vicki Sharp Photography

40 years 1978 2018 research & support

There has been much progress over those four decades with the development of information technology and e-health systems, earlier diagnosis, less invasive tests, the availability of better drugs with reduced side effects, together with fewer hospital visits and an improved quality of life.

achievements in treating IBD over the past 40 years

by Professor Nick Croft, Professor of Clinical Paediatric Gastroenterology, Royal London Hospital, and former CICRA Medical Director. President - British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN)

Development of the speciality of paediatric gastroenterology hepatology and nutrition, and in particular IBD

When CICRA started there was no established specialty of paediatric gastroenterology hepatology and nutrition (PGHN) and children with IBD were largely managed by general paediatricians in some cases supported by adult gastroenterologists. Now the sub-speciality has really become a well-established core for all specialist children's hospitals and many of the larger children's services based alongside adult hospitals. Much of the work in these units are to look after patients with IBD. By providing research funding CICRA has been central to supporting the development of many of these specialists during their junior doctor training (most doctors take 10 or more years after leaving medical school to become fully trained as a consultant) and this in turn has really helped build the speciality in the NHS (in addition to the benefit of the new knowledge from the research undertaken).

Multidisciplinary teams

As part of the development of the speciality the importance of the multidisciplinary team (MDT) has become much better recognised and supported. This includes all areas such as clinical nurse specialists, dieticians, pharmacists, surgeons, stoma nurse, psychologist, play therapist etc. IBD nurse specialists have had some of the biggest impact on the care of our patients by providing rapid and excellent access to support. Following the recent publication of the BSPGHAN and RCPCH (Royal College of Paediatric and Child Health) quality standards in 2017 we aim to increase and strengthen clinical networks across the UK to ensure all children have the best quality specialist care delivered through MDTs as close to home as is possible.

New treatments

One of the biggest changes over the last 20 years was the introduction of biologics, the first being infliximab. When introduced this was the first new treatment for IBD for many years and showed quite good efficacy including in those with quite severe disease who had failed all the previous treatments. There are currently a lot of new drugs in development internationally including new oral medications. The treatments are tested first in adults and so, before coming into children, we do have some evidence of benefit and safety. The studies in children are then aimed mainly at examining issues specific to children (such as the correct dose).

For the future – how patients can help drive research forward

At the moment there is not an obvious direction that would lead to us finding a single cause and so to the holy grail of either preventing or at least curing the disease - although one never knows what may suddenly appear in the journals. However, the multiple new medicines and other treatments on the way will in coming years at least offer more options in the clinic, especially for those with the most difficult disease. A lot of research will need to focus on how to use these drugs best for individual patients and trying to be better at fitting the best treatment options to each individual. Some patients really have relatively mild and easy to control disease, others do not and there is a lot of research being undertaken to understand better how to predict the future for each patient. This is so called ‘personalised medicine’ and requires better understanding of why people get the disease (including any genetic influences), what happens to make it active in the individual (for example immune activation) and so what the best treatment options are.

To advance knowledge like this requires research in the laboratories, in large populations but also in individual patients in our clinics. To be able to undertake this research needs funding (hence the crucial role that CICRA and their incredible supporters play) but also for patients and their families to participate. Without patients we cannot ‘translate’ findings in the laboratories into real patients. What this involves can range from almost nothing (for example using anonymised clinical information from routine clinical visits) to quite a lot (drug trials testing novel treatments).

All studies have to have approvals and what is required when actively participating will be fully explained. Consent from both children and family will be gained. For those who cannot or prefer not to participate, ongoing care in the clinic will not change. All I suggest is do seriously consider if asked and make sure you ask questions about anything you are not clear about before deciding.

Of course, another way many people help is by raising funds for charities such as CICRA, without which many ideas simply cannot get off the ground. So please keep on encouraging friends, families and colleagues to cycle hundreds of miles, run marathons, bake cakes and having sponsored silences!

>>> To support CICRA’s 40th anniversary research fund go to - bit.ly/cicra40

my mountain


Jack

If you would like to share your story, please email **marketing@cicra.org**

Why do people write blogs? Why did I write mine? There will be lots of answers to the first question but I can tell you why I started mine.

I'm Jack, I'm 13 and ¾ and in October 2017 after months of feeling unwell, I wasn't growing, I was very pale and hadn't gained any weight in over 18 months, I was admitted to Southampton Children's Hospital. While I was in there I began to write notes in a notebook about how I felt and what had happened to me so far. There was a lot to remember and think about and there were lots of things that I wanted to make sense of.

When I was told what my diagnosis was likely to be, I searched the internet trying to find a young person's view on Crohn's disease. I really wanted to know how they felt and how they coped with things. We didn't find very many online blogs or personal experiences from a child's point of view so we started talking about using the notes in my notebook to start my own blog. Mum talked to me about internet safety, she does this in the school where she works but normally gives the talk to 6 & 7 year olds and helped me set up my website and blog. When we started adding bits I didn't know if anyone else would read it but I hoped they would. I wanted people to be able to read my story and see that it's OK to have Crohn's and that although it's sometimes like a rollercoaster ride you can live with it and its ups and downs.

Today my blog is filled with entries about infusion days, things we have done as family days, my eight-week Modulen IBD diary and I share how I am feeling. When I read it back it's amazing how much has happened in such a short time and it reminds me that you have to 'go for it' on the days when you feel well. There is a brilliant support team around me which includes my family, my consultant Professor Beattie, the IBD nurses and the dietitians at the hospital. They have always discussed my treatment with me and have always made me feel like I was part of the decision making when it comes to any treatment. They treat every patient the same and always make time to explain things.

So this is my blog, thank you to everyone who reads it.
mymountainbyjack.weebly.com

Leicester IBD family information day

7 July 2018

- watch presentations from specialists who treat children with IBD
- ask questions of consultants from leading UK children's hospitals
- meet and chat with families in a similar situation
- listen to young people talk about living with crohns and colitis

"Wow, an informative, interesting and supportive day. Both my daughter and I came away feeling more positive."

"My son got a chance to talk to the other young people his age. I think he was reassured that he's not alone."

"Brilliant day, better than I could have imagined."

FREE to attend, comfortable venues, accessible city centre location
To book or find out more, contact Jayne:
email: **support@cicra.org** | phone: **020 8949 6209**

Book your place now!

John Earnshaw Award

One important part of CICRA's support for researchers and other healthcare professionals is to help fund the costs of attending meetings to present their work on IBD. As a university lecturer the late John Earnshaw knew how important this was, and with the agreement of his family the legacy he left CICRA is being used for this purpose. We were pleased to be able to help Specialist Nurse Sibo Chadokufa of the Evelina Hospital, London attend the Paediatric IBD 2017 meeting in Barcelona. A short report follows:

"Included in the hot topics at the meeting were Early Onset IBD, diet in IBD and psychological support. I took away a lot of things that I am excited to implement at our Centre. I also had the opportunity to present four pieces of work that I have been working on together with the team at our centre. I presented the outcomes of a quality improvement project we have been part of for seven years. Since joining the ImproveCareNow, (the quality improvement tool) results show that from 2010 to present day we have seen our overall remission rate increase from 60% to 72%; Steroid free remission rates from 50% to 71%; patients off steroids from 60% to 98%; satisfactory growth status from 92% to 93%; patients in nutritional failure from 9% to 0%. ICN has proven to be an excellent tool for improving quality of care in PIBD, managing treatments and improving outcomes.

To be able to present these findings at the prestigious international meeting was an excellent opportunity that was made possible due to the support I received from CICRA. After attending the conference, I have been able to share the information I learnt with my fellow nurses at our trust."

BSPGHAN meeting in Leeds

CICRA Research Fellow Dr Marco Gasparetto, Addenbrooks Hosptial, Cambridge, specialist nurses, Rulla Al-Araji, Birmingham Children's Hospital and Natalie Burgess, Royal London Hospital were also given bursary grants to attend the BSPGHAN meeting in Leeds in January. Joining them at this three day meeting were CICRA Trustees, Paul Cooper & Margaret Lee and CEO Nick Posford. This annual meeting, specifically for anybody involved in paediatric gastroenterology, is a great time for CICRA to be represented. It was an opportunity to network amongst those caring for children with IBD.

Further small grants to attend the European Crohn's and Colitis Organisation (ECCO) meeting in Vienna were awarded to Vaios Svolos, a PhD student at Glasgow Children's Hospital and Dr Rebecca Tresman a Paediatric ST3 Trainee at Evelina Children's Hospital whose report is below.

"I was lucky enough to have an abstract accepted at the 13th annual meeting of the European Crohn's and Colitis Organisation (ECCO) which was held this year in Vienna, Austria. I worked with the consultants in the paediatric gastroenterology department at Evelina London Children's Hospital to develop the project that led to this poster, which aimed to assess association between azathioprine (AZA) weight-based dosing, thiopurine metabolites and disease activity in a cohort of paediatric inflammatory bowel disease patients. Current recommended AZA dosing is 2 – 2.5mg/kg/dose in the presence of normal thiopurine methyl-transferase (TPMT) level. Elevated levels of the AZA metabolites 6-TGN and 6-MMP have been associated with increased risk of myelotoxicity and hepatotoxicity, however evidence suggests that monitoring metabolites can help optimise effectiveness and safety of thiopurines.

I conducted a retrospective review of our paediatric patients with IBD who were taking AZA and had regular thiopurine metabolite measurements (total number of patients 41). Disease activity was assessed by use of the 'paediatric ulcerative colitis activity index' (PUCAI) and 'paediatric Crohn's disease activity index' (PCDAI) scoring systems.

We found that in this cohort of children with IBD, thiopurine metabolites were therapeutic and clinical remission was achieved with low dose azathioprine (mean dose 1.3mg/kg), and we suggest that not all children with IBD require the current recommended dose of azathioprine to maintain clinical remission. Though our sample size was relatively small, we are hoping that our findings can contribute to the current discussions surrounding treatment and monitoring in paediatric IBD.

I presented this abstract in the form of a poster, and was in the company of over 800 other accepted abstracts. It was exciting to be at such a well-established conference with attendees from all over the world, and hear the fascinating talks on current research and updates on studies in both adult and paediatric IBD and I am extremely grateful for the support from CICRA which helped make it possible."

ECCO European Crohn's and Colitis Organisation

BSPGHAN

PIBD 13-16 September 2017 Barcelona

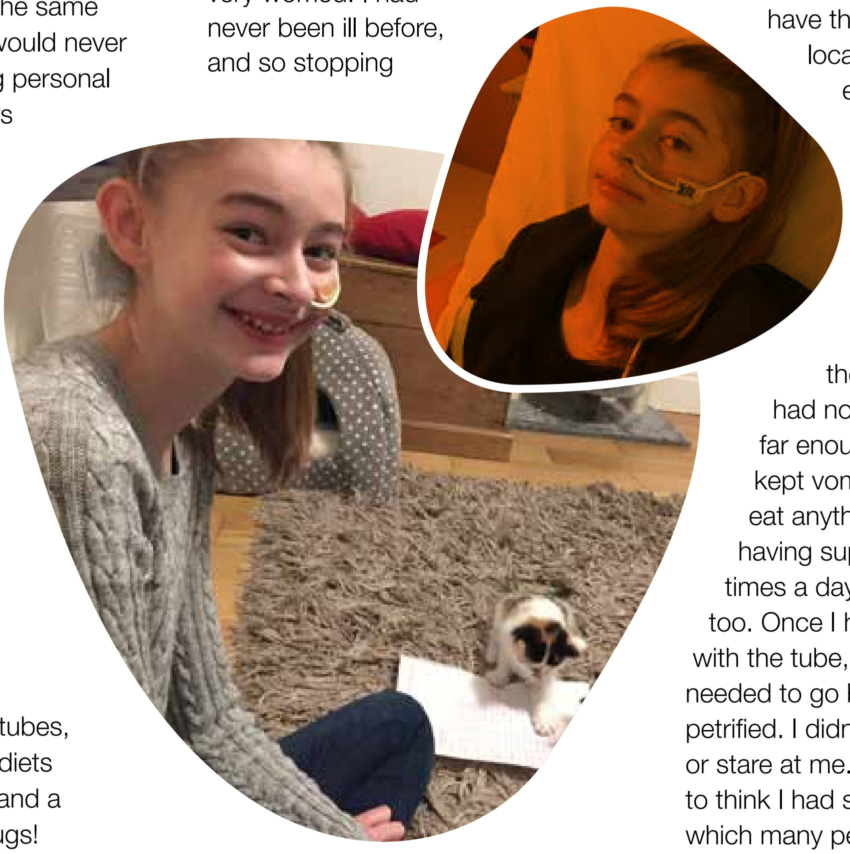
Orlaith Oates

Orlaith's story

Hello, my name is Orlaith, and in January 2017, I was diagnosed with Crohn's disease and Oral facial Gramulomatosis. I had spent the previous year going back and forward to various doctors with a small lump on my lip. It seemed to come and go then it gradually got worse.

> **"When I was finally diagnosed, I had ulcers on the inside of my mouth, hugely swollen lips and inflammation and ulcers all through my digestive system."**

When I was finally seen by the paediatric consultant he asked a gastric doctor to have a look at me. This was the first time Crohn's was mentioned. When I was finally diagnosed, I had ulcers on the inside of my mouth, hugely swollen lips and inflammation and ulcers all through my digestive system. It was pretty much everywhere except for the stomach. It was a big shock to me and my family. It was good to know what was actually wrong but quite a lot to take in at the same time. Two years ago, I would never have dreamed of having personal discussions with doctors I have never met. I did not know what Crohn's was, or that there is no cure. Since diagnosis I have put on over 10 kilograms, had twenty one lip injections, I have had gum biopsies, regular blood tests, regular IV fluids, two colonoscopies, two endoscopies, several emergency overnight hospital stays, four NG tubes, 14 weeks of liquid only diets and two cuddly kittens and a rabbit for therapeutic hugs!



Not only has having Crohn's affected me emotionally, it has also affected me physically. I used to do Irish dancing training several nights a week and competed regularly. I was thirteen when I had to stop, as my doctors told me I could have a heart attack while training so hard with such a low BMI. I didn't understand the significance the dancing was having on my body as I had no idea what was going on inside at the time. My weight became so low that everyone suddenly became very worried. I had never been ill before, and so stopping something I had been doing since I was four was very odd. Within weeks I was admitted into hospital for an endoscopy and colonoscopy. I tried eating lots to put on weight but nothing seemed to help.

My first colonoscopy and endoscopy were a disaster, after taking the repulsive Picolax, and spending the night before crying with pain, the procedures were cancelled when I arrived in the hospital at 7am. In a way I was anxious, but I was also relieved. After another failed attempt to have the procedures done locally we eventually got an emergency appointment to have them done at King's College Hospital. A few days before Christmas 2016, I had an NG tube inserted. It was horrendous! I was there for ten hours as it had not been pushed down far enough into my stomach. I kept vomiting and I struggled to eat anything. At that time I was having supplement drinks four times a day and eating normally too. Once I had come to terms with the tube, I was then told that I needed to go back to school. I was petrified. I didn't want people to point or stare at me. I didn't want people to think I had something contagious, which many people did. At the time

it seemed impossible to start living a normal life but my parents and siblings helped me build up the confidence and once I went back to school it wasn't as bad as I'd imagined. People did stare at first but it was easier in a way because the tube showed them there was something wrong and I didn't just have weird swollen lips for no reason.

Once I was diagnosed with Crohn's disease, I went on the liquid only diet and spent 6 weeks having just the Modulen. My friends couldn't understand at all what this meant. I did try to explain but I'm not sure anyone really understood. The first time, I reminded a friend every day, and by the end I would finally get to eat a jacket potato! The next morning, I ran to her and said "I had a potato last night!" And she looked at me as if I was insane! I then reminded her again that it was my first solid food for six weeks. Then she said "Wait. You had no food for six weeks?" I wasn't angry at all, but I felt upset that people didn't understand it, despite multiple explanations.

> **My fatigue can be overwhelming sometimes so school is often difficult, as I am currently preparing for my GCSE's.**

Recently, I have been feeling particularly nauseous throughout the day. This has been ongoing for quite a few weeks now. My weight is constantly fluctuating and is often very low. My fatigue can be overwhelming sometimes so school is often difficult, as I am currently preparing for my GCSE's. I constantly worry about the threat of the tube being put in again. After spending two Christmases on the feeding tube I am determined to do anything I can for it not to happen again.

My school and all the teachers have been fantastic. They allow me to do work at home when I'm struggling with fatigue or nausea. They allow me to come in late and go to hospital appointments whenever I need to which is fairly often. They never make a fuss about my attendance and I try to do my best so they know how much I appreciate their support. It has been rollercoaster of a journey so far but am hoping that one day my medication and determination will get me through so I can fulfil all my ambitions. I am even hoping to get back to dancing sometime this year even it has to be a little less frequent and intense. I can't wait!

I now want to tell people about Crohn's. I'm not embarrassed and I want to raise awareness, so that people can feel like they can talk to others. In the UK, there are around 300,000 people with Crohn's and colitis. Someone is diagnosed every thirty minutes. It is becoming more and more common in young people, so it is important to raise awareness.

If you would like
to share your story, please
email **marketing@cicra.org**

my marathon effort

Joanne Chilcott

"My eldest child, Hamish, was diagnosed 7 years ago after two years of symptoms; and my youngest, Connie, was diagnosed 18 months ago after 4 months of feeling ill. We were given CICRA booklets in hospital to give to the school and we attended a Bristol Family Day, where Hamish met his penfriend.

I have been raising money for them ever since.

For years, we have been sending small regular amounts from the bacon buttie sales at our monthly village community café, feeding the drinkers at the annual village cider festival, and participated in various runs, including London 10k, Bristol Half Marathons and, in 2017, the Brighton Marathon.

Having been chosen for CICRA's 40th year place in the London Marathon, I wanted to offer fun events, not just rely on sponsorship. And so a plan was made, with the hope of exceeding £5,000.

With the help of friends and family, I organised two gin festivals – in October 2017 and April 2018, each one raising in excess of £2,000. Although a few days of hard work, it was easy to organise and run. There were 40 gins to choose from, some donated by gin companies after I wrote to them. All were served with the correct garnish by my lovely sisters and their husbands.

At Christmas, I held two wreath-making workshops: 120 doors or tables were adorned with much holly and greenery! The tickets were a very reasonable £15 each and CICRA received £1,000.

I keep running for Hamish, Connie and a cure.

As the race approached, and after my 20-mile training run in horizontal snow, the running got a bit easier! Fewer miles but with a bit of variation. My friend Sharon got me out to do hills and husband Stefan helped me get the pace up a bit.

The race was amazing – hot and busy, with so many runners and supporters. When I was getting ready in the starting pen, the rhinos arrived, music playing – the atmosphere was indescribable. The race was hard, one of the hardest things I have done. Everything hurt and it was so hot, but there were loads of showers and water.

My supporters surprised me at miles 8, 14, 18 and 25. I loved them being there and I'm sure it's what got me through. I apparently went past Buckingham Palace but I didn't see it – I was in the zone to get over that finish line!

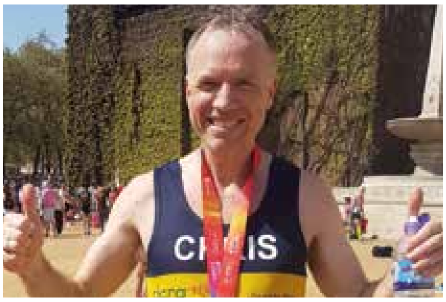
Thank you CICRA for feeling I was worthy of the place. I just wished you had one for next year. I have applied for 2019 so fingers crossed!

I keep running for Hamish, Connie, and a cure."

At the time of going to print, Joanne's fundraising total was over £7,200. Thanks so much Joanne!

Raised £7,200!!

the 26.2 mile club



In addition to our CICRA place, we were very lucky to have three other supporters running in the London Marathon for us this year: Chris Dowden, Helen Cooper and Liz Worrall all did fantastically – both on the day and by fundraising a combined total of £6,500.

Raised £6,500!!

Not many weeks before, CICRA member Sarah Jones ran the Greater Manchester Marathon and raised a whopping £4,898. Huge thanks to Sarah – and to her family for encouraging her!

Raised £4,898!!

Simeon Jenkins

Raised £1,180!!

At the top of Pen Y Fan. From left to right:
Rear - Mark Ayling, Gareth Bateman, Jordan Adderley, Simeon Jenkins, Chris Vaughn, Jason Davies, Lukasz Perczak. Middle - Owain Evans, Michelle Thomas, Gary Slack, Haydn Ralph. Front - Gareth Davies.

“We are a very lucky bunch of 12 recruits that recently completed 14 weeks of arduous mental and physical training as wholetime firefighters.

As part of our course, we were asked to raise money for the Firefighter Charity and one other worthy cause. As our son, Cameron, suffers with Crohn’s, this was at the forefront of my mind. The rest of the recruits were happy to raise money for CICRA and the wheels were set in motion.

The challenge was decided: to climb Pen Y Fan in the Brecon Beacons, in full firefighter kit and carrying breathing apparatus on our backs!

We took on the challenge on the 23rd of November and the weather was great!

We raised money by bag packing in supermarkets and via general collections.
One recruit, Hayden Ralph, raised over £300 by cycling 100 miles on a static bike in Tesco. The final total raised was £1,180 for each charity.

We hope this helps!”
Simeon Jenkins and the whole squad of 01/17 firefighters.

other amazing challenges

Raised £1,545!!

Stuart Hardy set himself the challenge to run **three Tough Mudder courses in one weekend!** Stuart completed his challenge successfully and raised £1,545. We are very grateful – and also in awe!

See www.cicra.org for more fantastic fundraisers and get your story featured

Raised £2,850!!

Organised by London Marathon Events, Swim Serpentine is a festival of **open water swimming** staged in the heart of London. It took place on 16th September 2017 and CICRA had three eager entrants, Tess, Amy and Tom, who raised a combined total of £2,850. Very impressive effort from all!

Steve Mann and two friends, Jim and Andy, completed **“The Loch Ness Monster”** challenge, a **60 mile cycle** around the great Loch Ness, a **canoe paddle the full 25 mile length of the Loch** (further than crossing the channel) and then **climb to the summit of Ben Nevis.** Their fundraising went towards the incredible effort by Steve’s mum, **Carol, Lady Captain at Southport Old Links Golf Course for 2017.** Carol has worked with children all her life and has Crohn’s herself, **so chose CICRA to benefit from a year of fundraising – a grand total of £5,926.89.** CICRA volunteer and member Julie Buchanan travelled to the club for a cheque presentation, for which we are very grateful. Thank you to Carol, Steve and all involved.

Raised £1,178!!

doggy treats!

❝ Our spaniel had puppies and instead of selling them, we carefully chose friends who would give them fantastic homes and asked for a donation that they could afford to give. We split the money between CICRA and another charity - Spaniel Aid UK and were able to give £500 to each charity.

We didn't make any profit and we felt passionately that they needed to go to the correct homes: people who understood and love spaniels as much as we do; with a view to helping our two favourite charities along the way. ❞

Julie Fletcher

pumpkintastic!

Each October, longstanding members the Batchelor family donate to the charity following their annual pick-your-own pumpkin event. The event is a huge crowd-pleaser and this year was no exception, with £2016 raised from on-the-day support as well as a large donation directly from Beluncle Farm.

young supporters

It is so touching to see pupils and staff in school get behind CICRA and organise a fundraiser. Most recently we have received cheques from Stockport Grammar School and Sir Alexander Fleming Primary School. Thank you to all involved and we hope you had loads of fun too!

charity of the year

Thorntons Investment Ltd employee Shirley Robertson nominated CICRA as her workplace charity of the year, because her daughter was diagnosed with Crohn's disease aged 9. Staff members enjoyed a bake-off, an Urban Challenge event, and a quiz. Trustee Deborah O'Neil visited the office for a cheque presentation and to thank them for their donation of £1,200.

For more fundraising stories and inspiration, please visit our 'new look' website: www.cicra.org

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

sharing and learning together

Here is a selection of photos from our Birmingham and Bristol family information days. Both days saw impressive talks from young people living with Crohn’s and colitis as well as expert contributions from specialists.

Professor Tom MacDonald spoke at Bristol about the potential hope of new drugs

Group hug at Birmingham for some young people

Young people at Birmingham information day

Mansi told our Bristol family day about her experience of coping with the psychological impact of IBD

Dr Rafeeq Mohammed from Birmingham Children’s Hospital spoke at our family day

Birmingham team activity for children and young people

Bekah Stonelake presented a cheque to our CEO at Birmgham after having her hair cut in support of her sister

In Birmingham, we were presented with a cheque for £85 from Rebekah (‘Bekah’) Stonelake, for cutting her hair.

Bekah donated her chopped hair to the Little Princess Trust to make wigs for poorly children, and then through sponsorship raised £170.00, giving £85.00 to CICRA and £85.00 to Birmingham Children’s Hospital to help patients with IBD. Bekah’s sister Lydia is a patient at Birmingham and Bekah was keen to help her and other young people with IBD.

Such a kind gesture; we are honoured to have your support, Bekah, and we’re glad your beautiful hair also went to a good cause! Thank you!

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:

Claire Louise Golby
Remembered with fondest love by Mum, partner Brian, sister, niece, nephews, aunties, uncles and friends.
Always in our thoughts.

Mrs Betty Judd
Treasured Great-Nanny to Emily (16) a recently diagnosed ulcerative colitis sufferer. Much missed and lovingly remembered by all her family.

Mr William F Holder
Grandfather of two Crohn's sufferers.
Remembered with love by all the family.

Mrs Barbara Ricketts
Grandmother of a Crohn's sufferer, Charles Wintour, remembered with love by all family and friends

Mr George Simmonds
Adored Grandfather of a Crohn's suffering Grandaughter missed and remembered by all his family and friends

Mrs Joan Spandler
Joan was Grandmother to Kieran who has had Crohn's since 9 years of age and was a great supporter of CICRA

bequests

We are very grateful to have received bequests from the wills of the late:

Albert Francis Harris
Hazel Pauline Darrington
Pamela Clark
William Marshall

wills and legacies

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

Unexpected income such as this has helped to provide the funds to maintain and expand the research programme, improving the lives of children with Crohn's and colitis.

We will always respect the wishes of the legatee or their family if there are certain wishes as to the way the funds are used and will ensure that it is properly administered and acknowledged.

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

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

CICRA 200+ club winner list 2017

The 200+ club is split on a 50/50 basis for monthly prizes and CICRA's research and support programmes. If you would like to join, please email support@cicra.org or call us on 020 8949 6209. The cost is £26 per annum, paid quarterly if preferred.

January		
39	D Chapple, Bristol	£50
62	A Walls, Falkirk	£50
February		
62	A Walls, Falkirk	£50
127	A Wall, Litchfield	£50
March		
56	R Thornton, London	£250
47	J Gooding, Surrey	£75
41	L Tomlinson, Warrington	£75
April		
172	C Allen, Suffolk	£50
195	P McQuade, Lincolnshire	£50
May		
167	M Khuraijam, Cheshire	£50
168	H Arthur, Derbyshire	£50
June		
208	P Manby, Suffolk	£250
128	G Pritchard, London	£75
95	J Campbell, Dumbarton	£75
July		
67	C Stanley, Gwent	£50
95	J Campbell, Dumbarton	£50
August		
134	J Coles, Surrey	£50
23	J Campbell, Dumbarton	£50
September		
125	R A Pritchard, London	£250
169	T Lack, Poole	£75
215	S A Pearce, Nailsea	£75
October		
145	J Gregory, Middlesex	£50
68	J Davey, Wiltshire	£50
November		
120	C Ram, London	£50
70	P Smith, Enfield	£50
December		
183	C Shaw, Manchester	£250
135	R Brandon, Longfield	£75
210	J Beever, Isle of Sheppey	£75

2017 winter prize draw results

The draw took place on Tuesday 14th December at our offices in Pat Shaw House with Glynis Gatenby, Director of Operations, Sutton Housing Society, drawing the winners. Many thanks to members who either bought tickets themselves or sold tickets to help raise funds to maintain and expand our research programme into inflammatory bowel disease.

1st prize	01949	K Bargh, Chesterfield
2nd prize	15378	K Gill, Aberdeen
3rd prize	24700	J World, Cambridge
4th prize	16933	J Gregory, Middlesex,
5th prize	28461	N Herbert, Peterborough
6th prize	05174	P Plumb, Durham
7th prize	39571	A Sharp, Surrey
8th prize	07117	T Lack, Poole
9th prize	03290	S Farnham, Wiltshire
10th prize	03391	J Doran, S Lanarkshire
11th prize	06139	W Bullivant, Leicester
12th prize	40886	L Saunders, Surrey
13th prize	01416	A Battersby, Gwynedd

1978 **40** 2018

years

research & support

Help us continue our ground-breaking research

With 4000 children diagnosed every year with IBD, there is an urgent need for more specialists and better treatments. This has been CICRA's focus for 40 years but we can only continue making advances and training new specialists with your support.

To support our 40th anniversary special research fund and give better lives for children with crohns and colitis:

- fill in the **form inside**
- go to **bit.ly/cicra40**
- call us on **020 8949 6209**

100%

of your donation will fund new research