

the insider



spring 2020

ten tips for parents
of children newly
diagnosed with
IBD

**FUTURE
LEADER**

cicra

better lives for children with crohns and colitis

inside >

developments in medications for IBD
report from our biggest ever family day
Imogen and William's inspiring stories

CONTENTS

message from the Chair	2
impact of diagnosis	3
Imogen Tickner personal story	6
report from our London family day	8
William Parson personal story	9
IBD drug research update	10
meetups for children and families	12
BSI Congress	14
Digestive Diseases Week	15
John Earnshaw Award	16
new resources to help	17
our amazing supporters	18
raffle & 200+ Club winners page	23

With thanks to Vicki Sharp Photography
www.vickisharpphotography.com

Life President Professor J Walker-Smith	Hon. Awards Advisory Panel Professor I Sanderson (Chair) Professor S Ennis Dr J Epstein Dr R Heuschkel Professor T T MacDonald Dr S Protheroe Dr N Thapar Prof. H Uhlig Prof. D Wilson
Trustees Mrs M Lee MBE (Chair) Mr G Lee (Vice-Chair) Ms A Bollen Ms C Malloy Mr S Coleman Mr P Cooper Mr N Gooding Mrs N Pitney-Hall Dr P Smith	Staff N Posford (CEO) J Boyd-Bell P Justice-Hay L Palmer
Hon. Clinical Director Dr R Hansen	

The views and opinions expressed by the contributors are not necessarily those of the Association or the editor. This publication provides information only. Unless otherwise stated, the authors have no medical qualifications whatsoever. CICRA and its officers can accept no responsibility for any errors or omissions. Medical advice should always be sought on any specific matter.

CICRA is the operating name of Crohn's in Childhood Research Association, a registered charity in England & Wales, number 278212, and in Scotland, number SC040700 | the insider is published by CICRA | Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey SM2 6AQ 020 8949 6209 | support@cicra.org | cicra.org



message from the Chair

Dear Friends

Unfortunately our income in 2019 wasn't as good as we had hoped but because, over many years, the Trustees have kept a very close check on our finances, and reserves, the good news is that we were still in a position to put out a call for new research. These applications are currently going through a rigorous peer review process and our Medical Advisory Panel will make recommendations at the end of March. We are very grateful to our Medical Advisors and the reviewers for their help in ensuring that CICRA's funds are spent wisely. Whatever grants are awarded the research will help in the understanding of IBD and hopefully bring about better treatments and an eventual cure for this complex condition.

As you probably know we don't receive any government funding so we are constantly aware that if we are to help children with IBD, we need to make sure that the pace never slackens on fundraising. We are therefore very grateful for the fundraising events organised by members, their families and friends and equally so for the regular donations. Some members, whose children are now adults, have supported the work of the charity for many years and we are very grateful for their loyalty. Jayne Boyd Bell continues to raise funds from Trusts, companies and charitable organizations so if you know of a Charitable Trust that would be sympathetic to our cause please let the office know and we will make an official appeal. If your employer has a 'Charity of the Year' perhaps you can nominate CICRA or again please let us know and, if necessary, we will do the asking.

Apart from the fundraising and research we were pleased to welcome many people to the Family Days this year. They were all well attended and very much part of the support offered to families. The average attendance for a meeting is around 150 so to double that at the London meeting was a challenge in itself but, as those of you who joined us agreed, it was really worthwhile. Our thanks to Trustee Paul Cooper and Jayne for all the work they put into making these meeting a success.

If you have any queries or questions about the condition, research, or the work of the charity please do get in touch – we will try and help.

I wish you all a very happy and healthy 2020

Margaret Lee
Chair of Trustees



dealing with diagnosis

Being told your child has IBD is a very challenging time. Here we look at results from a CICRA survey exploring the impact of diagnosis and how you can find a way forward.

Our survey exploring the impact of diagnosis found that parents experienced a wide range of emotions, with fear of the unknown, anxiety, being frightened, disbelief and shock being among the most commonly experienced.

Most parents responding to the survey were not aware at the time of diagnosis that their child may have IBD. Wondering 'what does this mean?' and 'why' were frequent reactions to the news. Uncertainty about what would happen next or what the future may hold were commonly experienced. There is a lot to take in, as parents learn about their child's condition and come to terms with the reality that it is lifelong.

"It hit home hours later that we had very little idea what Crohn's was and what it meant for our daughter's future. We went to pieces."

As part of the survey, we also asked parents what advice they would give to other parents on coping with diagnosis. Here's what they told us.

get informed

A common piece of advice is to read as much information as possible about your child's condition: *"Go away, read what you've been given, take time to process."*

Several parents advised against Googling (*"there are some scary stories out there"*) and only using reputable sources of information such as CICRA's literature.

A number of parents made the point that what works for one child may not for another:

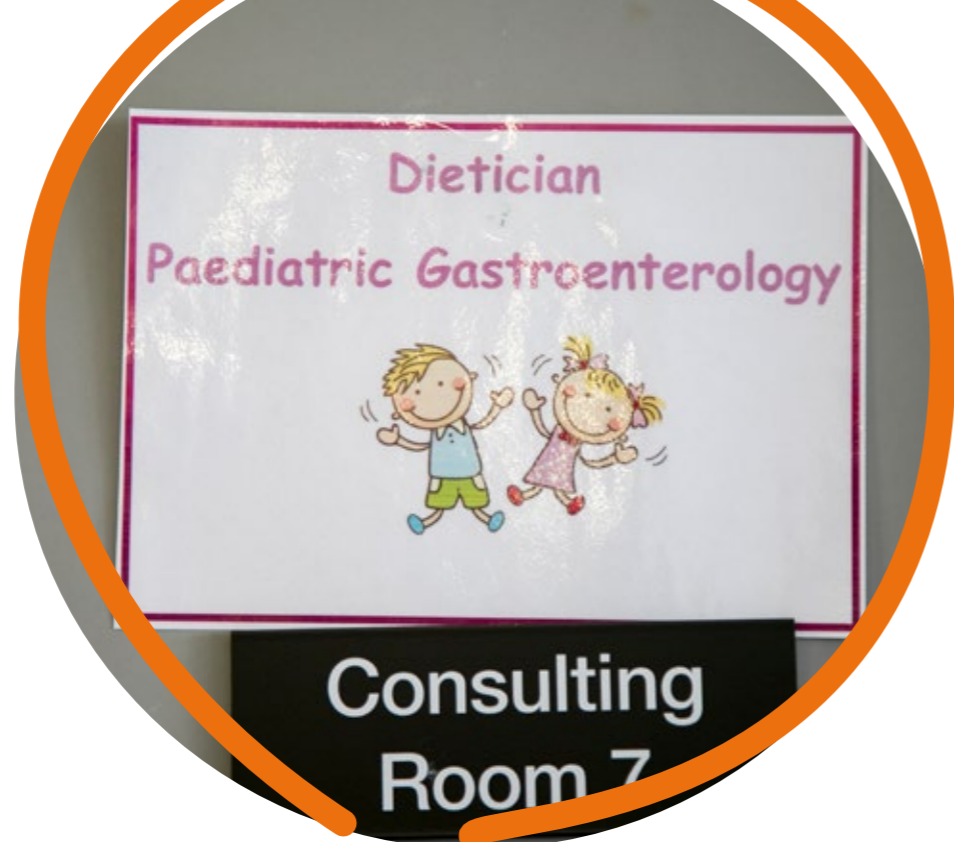
"Take a deep breath, try and get as much information as possible, but remember everyone is different and responds differently to the treatment."

ask questions

Asking questions can help parents get to grips with the unknown and better understand their child's condition, as well as potential treatments. One tip is to write down questions ahead of appointments *"as it's sometimes hard to think of questions off the top of your head at the time."*

more overleaf →





Don't do it all alone. And give time to yourself to rejuvenate. You got to look after yourself to be able to look after your children.



involve your child

Several parents responding to the survey said it was important to involve the child in how their condition is managed and talked about: *"They will have it for the rest of their lives. As parents we cannot and must not make all the decisions for them."*

For older children, letting them ask questions and make decisions was suggested. For younger children, being *"open as early as possible about all the things that would normally be embarrassing"* was recommended.

get support

This was a key piece of advice given by parents responding to the survey. Parents described the benefits of support – to feel less alone, to help deal with their fears and also a way to learn more about their child's condition.

Parents recommended four sources of support:

- Health professionals, particularly gastro/IBD nurses (*"ring your gastro nurse at any time if you are worried or need reassurance or need help"*).
- CICRA and other charities. CICRA's family days were recommended as *"these benefit parents and children."*
- Support groups for parents (one parent said these *"help immensely"*).
- Friends and family (*"helps you get through it"*).

One parent advised seeking support *"straight away."*

Another related how they felt *"alone, uneducated and isolated and wouldn't get through the days ahead"* until they found a support group: *"to know you're not alone is fantastic."*

give yourself time to adjust and grieve

Several of the parents responding to our survey felt that it was important to give yourself time to come to terms with the diagnosis and adjust to what one parent described as *"a new 'normal' in life."* Parents should also allow themselves the time to grieve:

Not thinking too far ahead can make it easier to deal with difficult and uncertain times

"Give it time, grieve, get support, contact organisations, take it slow/ one step at a time, there is a lot of info and stories which can be overwhelming too soon."

"Take a breath. Take time to grieve the idea of what you thought things would be like then pick yourself up and start your new journey."

At the same time, it is important not to blame yourself:

"It's nothing you have done to cause it. I had to tell myself that as I kept thinking there must be something."

take things one day at a time

Not thinking too far ahead can make it easier to deal with difficult and uncertain times:

"Take each day as it comes and don't get overwhelmed by thinking too far into the future."

look after yourself

Parents responding to the survey stressed the importance of looking after yourself, as well as getting support:

"Don't do it all alone. And give time to yourself to rejuvenate. You got to look after yourself to be able to look after your children".

"You will go through many emotions like a grief process, it's ok to cry and be angry. Make sure you have support from friends and family and make time for yourself, it's important to look after yourself so you can take care of your sick child."

get psychological support if you or your child needs it

As well as looking after yourself, a few parents highlighted the need to get appropriate psychological help for children and/or parents who need it.

"If your child is traumatised by what is going on, get clinical psychology involved asap - they were awesome."

"Ask for psychological help for your child if you feel that would help (and maybe for yourselves too. After all, you have to be strong enough to care for them!)."

look forward

Finally, although it can be devastating to get the diagnosis, many parents also felt a sense of relief that they finally knew why their child was ill and could now focus on their treatment:

"This is the child you love, this is part of them and you will find a path to make them better with the support of those around you."

help and support from CICRA for parents, carers and young people

- IBD Family Information Days
- Information about IBD for young people, for primary and secondary schools
- Local meet ups
- Email support groups

For more information, please visit our website (www.cicra.org).

Laura, CICRA's family support worker, can provide practical and emotional support. You can contact Laura by email (laurapalmer@cicra.org) and she is also available to talk from 7-9pm on Mondays and Thursdays on 020 8949 6209.



Imogen's story

Imogen recently spoke at our London family information day. Here's what she had to say.



Hi,

Today I will be doing a speech about Ulcerative Colitis and how it has affected me, I will now take you back to when it all started, 2018. Well, it might well have started a bit before then; my mum has ulcerative colitis and my brother has Crohns but first, this is a little of my back story.

2013: Whilst I was about 6, I kept getting really bad tummy aches. So bad that I sometimes got sent home from school. My mum was worried that it might be IBD. They did some tests which ruled out IBD, I had a few breath tests to check for lactose and fructose intolerances. They were both off the scale so my Mum had to rethink my diet a bit more, but we soon adapted. The tummy aches went away and everything settled down.

2018: By now I was in year 5, my symptoms returned – more tummy ache but this time a lot worse. Now I was having diarrhoea which also contained blood and mucus. A couple of days after we had first seen it, we went to the hospital and they did a scope. I felt quite panicky because I had never had one before and I started crying, I wanted to go home but no-one would let me. During the procedure they found I had Ulcerative Proctitis and gave me some medicine to take. Suppositories. (Yippee!!)

During the Summer (June) it got worse, I was going to the toilet a lot, sometimes I would be ok for a few hours but I spent a lot of time on the toilet.

Early one Sunday morning I had been sitting on the toilet for ages. I didn't realise it, but it was a rectal prolapse. My dad called the ambulance, they said call 111 who then said I needed an ambulance, my mum came and read me a book and brought with her my favourite teddy, then when the ambulance came I was frightened of getting off the toilet but the paramedic gave me a glove elephant balloon that calmed me down, then we went to A & E they did a blood test and said not to go to school for a while and sent me, my mum and dad back home. Then the next day it all happened again and we went back about 4 o'clock in the morning to be admitted into hospital. I stayed in my own room for about a week.

I had IV medication and when I was starting to get better I was sent home again. I went back to school but things got steadily worse and worse. I lost a lot of weight and was spending more and more time on the toilet and less and less time doing fun things. I was tired all of the time, I didn't want to eat.

I had more and more trips to the hospital and tried lots of different types of medication. One of which was Azathioprine, my mum wasn't keen on this one – but we tried it because anything had to be better than having all of my symptoms.

However, it seemed to make me worse, I was getting headaches and being sick. After a holiday in France, with a broken-down car I was admitted back into hospital via A&E I was so dehydrated I felt dizzy every time I stood up. I was either sleeping, pooing or being sick.

I was treated with IV antibiotics and steroids, and was no longer eating any food. I had another scope which showed that the disease had spread and become much more severe. I now had ulcerative colitis, my large colon was affected. I was put onto Modulen, which I found very difficult at the beginning but have got used to it now (although it still isn't my favourite thing to drink) The medications I was given did not stop my symptoms so it was decided I should start on infliximab and mercaptopurine. It was like a miracle, after my first infusion I had the first blood free poo for months. It didn't last so I had another dose ten days later. My symptoms then started to improve. After two and half weeks I was eventually allowed home.

I was told about CICRA and started to use their e-pal scheme; this has really helped me as I know other children are also happily living with IBD.

I go to the hospital every six weeks for my infliximab. I take lots of different medicines every day. Modulen was reduced then increased, but it's ok. I am pretty much symptom free. I do get a few tummy aches and headaches and sometimes feel dizzy but most of the time I feel like I am just me.

I now play netball at school – I'm getting better at it. I go to Guides, which is fun. I help at Brownies, which I love. I walk to school every day – which I am not so keen on, but I walk with my friends so that is good. I love watching Strictly – Amy is my favourite, and when I found out that she has IBD she was even more my favourite!

IBD has affected me in a lot of ways, it's made me lose weight and put on a bit of weight and then lose it again! I have had a lot of mood swings. I've had my fair share of moon faces- I do know that it will go once I have finished the steroids.

It's also taught me a lot, that just because you might look different to everyone else you don't need to hide it. As I have said I go to the hospital every six weeks for treatment, It can take all day or just a few hours so I pack for the worst, depending on how busy it is. Sometimes my treatment goes without a hitch but sometimes I freak out when I have to have my cannula put in. But I take pride in having UC, no matter how hard it gets I will always triumph. Showing people, you can still live a normal life even if you have medical issues, you can do anything, no matter how different you are.

When I grow up, I would like to write books. I have written a couple where the main character has had UC, this has also helped me. If I become an author, I will write books about lots of different things, I may even include a character with IBD.

But for now, I am happy being a preteen and living my life like every other preteen!

Thank you for listening.

➔ If you'd like to attend a CICRA Family IBD Information Day, see the back cover or email support@cicra.org



London family information day



CICRA trustee Paul Cooper writes about our most recent family day at the Oval cricket ground in London. It was our busiest one ever, with well over 250 children and family members attending.



It really was a solid performance at the famous 'Kennington Oval' on Saturday 16th November as around 300 members, family, friends and esteemed medical professionals joined together for our first Family Day in London for five years.

Trustees, staff and volunteers arrived early to set up CICRA stalls and make ready for the days programme and to welcome the record crowd of attendees.

After a warming cup of coffee, everyone took their seats in the 'England Suite' and were welcomed by CICRA Trustee Graham Lee, Dr. Richard Hansen our Medical Director, & Nick Posford our CEO.

Dr Protima Amon, a Consultant Paediatric Gastroenterologist from the Royal London Hospital at Whitechapel was the first speaker and gave a very extensive overview of Paediatric IBD services in the capital.

The stars of our Family Days are always the young people who tell us their stories, and this time we had two special youngsters. First was the amazing Imogen Tickner, who at just 11 years old gave us a first hand insight into the ups and downs for her of living with Ulcerative Colitis. Imogen was followed by the equally awesome William Parsons. At 14 years old, William has been through some really

tough times, and gave the assembled audience a very interesting account of his 'Crohn's Journey'.

At this point in the meeting a number of parents and youngsters left the meeting for a short while to join the pre arranged tours of the 'Oval' ground. They were split into two groups with each being escorted by guides who were members of the Club and took great pride as we were taken pitch side and then around places like the famous Long Room, Members Pavillion and Trophy Room. The highlight for many people though was to visit the dressing rooms, and read all the graffiti on the walls which had been written by so many famous names from the cricket world both past and present.

revolutionary treatment

Back in the England Suite, our Medical Director Dr Richard Hansen gave a fascinating talk about 'CD Treat'. This revolutionary treatment which has been developed by the team in Glasgow offers new effective diet therapies that are more acceptable and tolerable for people with Crohns Disease than current liquid diets. This new therapy works as well as the liquid diet, but does not involve stopping all normal foods, so it is thereby more appealing and socially acceptable to most CD patients.

The psychological impacts for children living with IBD is a subject that is without doubt not discussed enough, and in her usual calm and interesting manner, Consultant Clinical Psychologist Dr. Kate Blakeley gave an amazing insight which resulted in many questions from the audience.

The final speaker of the first morning session was Professor Tom Macdonald. As a professor of Immunology, Tom is a fountain of knowledge when it comes to talking about all the latest research that is taking place in the field of IBD. A subject which the assembled audience were clearly very interested in hearing all about, and without doubt very reassuring to learn from Tom that there is still so much important Research taking place.

A short break allowed everyone to stretch their legs and have a coffee, whilst the youngsters went off to another part of the Stadium to enjoy a fun team building activity session hosted by our friends from 'Wise-Up'.

the elusive 'cure'

The second session of the morning opened with Professor Nick Croft. Whilst we are all keen to hear about Research and the elusive 'cure', much research simply cannot take place without the involvement of young IBD patients and their families, and Nick gave a really interesting talk explaining

just how critical this interaction is and what research does involve for our young people.

One of the most frightening statistics in recent years has been the large increase in the diagnosis of IBD in younger and younger children, and Dr. Jochen Kammermeir from the Evelina Children's Hospital in London, is an expert in this particular field. Jochen gave a fascinating talk with an insight into the ever increasing number being diagnosed with Early Onset & 'Very' Early Onset IBD.

Many of the communications into the CICRA office and our support worker Laura relate to the problems that children have at school with their IBD. Our next speaker was Steve Green, who enlightened parents as to what their options and entitlements are when dealing with their child's school, and also offering many useful nuggets of information to help ensure that youngsters get the support they need from their teachers.

Biologics have been much at the top of the agenda in the world of IBD for some years now, and last, but not least, in the morning session, Dr Sandhia Naik took to the floor to give a most informative presentation about the 'good' and 'bad' qualities of Biologic treatments which was of great interest to our many young people currently undergoing these therapies.

After a morning filled with such an amazing 'menu' of highly qualified speakers, many peoples heads were doubtless full of questions, and it was therefore the perfect opportunity for those questions to be asked of the assembled medical panel which comprised Dr Richard Hansen, Dr Kate Blakeley, Dr Sally Mitton, Dr Jenny Epstein, Professor Tom MacDonald, Ms Lauren Reed and Dr Marco Gasparetto (all kept in order by chairman Professor Ian Sanderson!).

The meeting then adjourned for lunch where everyone had the chance to visit the various stalls and sponsors, and of course chat with other families.

remarkable personal stories

As we reconvened in the main room, Nick Posford introduced Prue Ruback. Prue's grandson Max has Crohns disease and, keen to help find a cure for him, Prue and her husband have been on a mission to raise more money to fund our research programme. She was full of ideas and suggestion as to how you can all help CICRA and was happy to help people get onboard with fundraising efforts.

This was the first time that Prue & David had attended a CICRA Family Day, and after the event, Prue sent the most amazing message to the office, some of which we have included here:

"The sight of so many families, from all over the South of England, gathered in one huge conference room, was truly amazing to behold. There were refreshments on arrival, there were displays and CICRA merchandise and a splendid buffet lunch, all of which were provided free of charge. Of course contributions to the costs of the day were requested and much appreciated; but I was so heartened to see that families with young IBD children, many of whom had travelled some distance to attend, were not deterred from attending because of financial considerations".

"I was so impressed by the clarity of the presentations, for a non-medical audience. Later, parents were encouraged to ask questions during a panel session just before lunch. All questions were answered with tact, sensitivity and honesty. Of particular poignancy were some remarkable personal stories from a little girl of 10 and another young man who spoke of their struggles firstly to get a correct diagnosis of IBD and then their ongoing quest to find appropriate medication to get their symptoms into remission. They explained the effects of IBD on their education, schooling, their social lives and their whole families".





“During the lunch break I was particularly impressed to see the consultants circulating round the tables, talking freely to children and their families, trying to offer reassurance and support. I have attended many academic conferences in my own field, but have never seen professionals giving so generously of their time and expertise to what can be termed a “non-medical” client group”.

“For the kids of all ages there was no pressure to join in and participate in any of the activities on offer, they could sit and watch, or just listen. This allowed the youngsters some personal autonomy, so vital when so many of their life choices are outside their own control”.

“I came away from the meeting at 5.00pm reflecting that good will, reassurance and being part of an IBD community like CICRA is hugely beneficial for all concerned. It makes the burden of living with IBD easier to deal with. However we are still many years away from finding any cure”.

“But raising money to fund new research is currently the optimum way forward to help IBD children face the future with confidence.”

“We need to reassure these children with the lifelong chronic conditions of IBD that the adults around them are doing everything possible to enable them to grow up as well as possible and lead fulfilling adult lives.”

Prue Ruback

These kind words from Prue really do say so much about CICRA and how it is so very important that we all work together to raise money and ‘Find the cure’.

Our CEO Nick Posford then continued on the fund raising trail giving those present an explanation of how your money is spent along with some great ideas of how members can set up their own fund raising event be they large or small.

The final ‘innings’ of the afternoon came as the Group Discussion Sessions were introduced. Parents came together in a number of different break-out groups of their choosing. Topics covered a range of subjects such as Living and Coping with IBD, Research, Diet & Nutrition, Medication & Surgery, Early Onset IBD and School. While the parents were moving around their various group discussions the teenagers and young adults took part in their own groups and were joined by Dr Protima Amon, Sara Sider, Natasha Burgess, Arthur Leech, Kay Crook, Bukky Kukoyi Laura Palmer, Sophie Austin. These groups of young people getting together are really important, as it means they can discuss any subject that they wish, especially in relation to their IBD, and its effects on school, relationships etc.

During this time, the younger children were separately entertained by a young lady doing circus skills, arts & crafts and balloon modelling.

As the sessions finished, everyone assembled back in the ‘England Suite’ where our CEO Nick, drew the winning raffle tickets, and then thanked everyone for coming and especially the medical professionals who so kindly gave up their free time to attend.

This was a record breaking attendance at a CICRA Family Day, and on a personal note, I would like to add my sincere thanks to our loyal health professionals for giving so generously of their time, including those who headed up the group sessions during the afternoon. Thanks also to the volunteers who helped us – your support is much appreciated. Finally, my thanks to Jayne who works so hard in putting the programme for these events together and chasing all the Doctors, and putting up with me!

On behalf of all ‘Team CICRA’ we look forward to seeing you at one of our Family Days in 2020.

Paul Cooper, Trustee

SEE BACK COVER FOR
DETAILS OF 2020 FAMILY
DAYS AND HOW TO
BOOK PLACES

William’s story

William was diagnosed with Crohn’s on his 12th birthday. He’s now 15 and here he tells us his story.

My name is William Parsons. I am now nearly 15 and I was diagnosed with Crohn’s on my 12th birthday. For ages before this, mum and dad had been noticing that I was really pale. They took me to the GP but they didn’t know what was causing it. Then I started complaining about belly aches, and not always finishing my meals. I was really tired all the time, and would randomly be sick. Eventually I went to a different GP. She referred me to see the Paediatrician and he told me I might have IBD and referred me to the Gastroenterologist. I was scoped a couple of weeks later and they were able to confirm that I have Crohn’s.

The first treatment I tried was Modulen, I really found it difficult not being able to eat and only able to drink sweet shakes. After only a couple of weeks, every time I drank some it made me feel sick, and after a while I just wasn’t able to keep it down. One evening around then, I mentioned to Mum that my legs really hurt. A friend of ours who is a doctor arrived with his medical textbook, took one look at the red blotches on my shins and said I had erythema nodosum. By the next day it was too painful to walk, and I was sick every time I tried to drink some modulen so Mum and Dad took me to hospital in pretty bad shape!

The next medication I tried was Steroids. I was on a nine-week course. After the first two weeks or so it made me feel so hungry and much better than I had felt for ages. But, as the steroids were coming to an end, I started saying to Mum and Dad that I had a really sore back. After a series of scans, I was told that I had really weak bones, and this led to finding out I had compression fractures in my spine, hence the back pain.

The good news is that by then my back didn’t really hurt much, it only hurts occasionally now. But I need to have an infusion every six months to try and strengthen my bones, and I see an endocrinologist to check my back is healing.

After I finished taking steroids, my Crohn’s symptoms started to return. This is when we decided to try the

Specific Carbohydrate Diet. Mum had found out about it through a friend and done a lot of reading, and she was keen to give it a try. At first it was really difficult. There are lots of ‘normal’ foods that I can’t eat, and I really missed things like

bread and pasta and junk food! We decided to try it for three months and see if it helped at all. We all noticed a huge improvement. I was no longer giving up halfway through a meal and I started to feel really normal again.

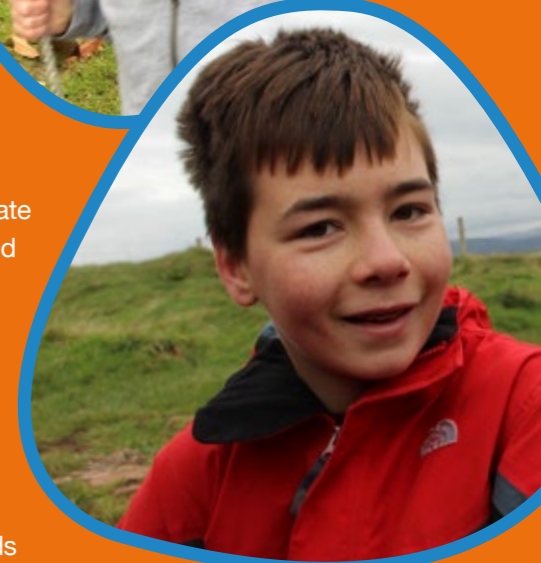
That was all more than two years ago. Being on such a strict diet is not always easy. When my friends want to go out and eat somewhere, I always will have to check the menu beforehand, And often bring my own food which makes me self-conscious. But I have felt really well & so it seems worth it.

At the beginning of the summer, my doctors decided I needed more treatment to try and fix a fistula and to help me grow. In September I started having infliximab infusions. This means spending half a day in hospital every few weeks. I feel like I am getting to know the nurses on the Snow Fox ward at the Evelina pretty well now!

I feel different from other people having Crohns. Most of my friends don’t have a chronic illness that won’t go away. I feel like I have got mentally stronger because I have had to go through things that most people my age don’t know anything about. I don’t know what the future holds, but I am well at the moment, and I have lots of people in my life – friends and family, who are always there for me.



pre-diagnosis October 2016



Post-diagnosis October 2019





research into IBD treatments



At our family information day in London late last year, Tom MacDonald - Professor of Immunology at Barts and the London School of Medicine and Dentistry, Queen Mary, University of London - spoke about the latest research into treatments for IBD. This is what he said.

I'm an immunologist, and the reason I work in IBD is because the cause of IBD is inflammation, and inflammation is caused by excessive activity of immune cells. The gut is a very interesting organ, because when it's healthy it is packed with immune cells, but these are controlled and do not cause disease. Because the gut is one of the main sites where infections can occur, the gut is richly endowed with immune cells and tissues. In fact, 70% of the body's immune cells are in the gut.

As I said, the healthy gut is full of immune cells without disease. This is called physiological inflammation, and there's no damage done. But something happens in IBD that flips the immune system into a hyperactive state. I'll be honest - we don't know what causes this. Once you get gut damage, it keeps on going because inflammation is essentially white blood

cells leaving the blood and moving into the tissues. In fact this is the basis for many of the diseases of the world in many different organs and tissues.

new therapies

Inflammation is very important in terms of new therapies for IBD. I would say that probably 99% of the effort involved in developing new therapies for IBD involve controlling inflammation. It's an exciting time because there are so many therapies coming through. Recent studies have worked out a lot of the immune mechanisms that cause tissue damage. We know by studying samples from patients that inflammation is complex, but if we can identify those cells and molecules that are important, we can then find ways to combat their damaging activities.

The main way to combat inflammation up to now has been with antibodies.

But things have moved on, and instead of using just antibodies like infliximab, there are now pills that look as though they are quite effective. And of course, taking a pill is much easier than having an injection under the skin or an intravenous infusion.

new research

So what is driving all this research? Well, it is industry - it is big pharma. A recent report showed that the size of the IBD market worldwide is enormous and increasing, as incidence of IBD also increases in developing economies. The biggest selling drug in the world is an anti-TNF antibody that is used in IBD, psoriasis, and rheumatoid arthritis. It has \$20 billion of sales a year.

I spend a lot of time traveling around talking to pharma companies about new therapies. I was in San Antonio, Texas, three weeks ago talking to a

company that has a new drug they think might work in IBD. We were discussing the ways in which we might do some studies to justify the huge investment they need to get that drug into IBD patients. Making drugs is very expensive. It costs \$1 billion to get a drug on the market. Because the market is so big and there is potential to make money, lots of very big and small pharmaceutical companies have IBD research programmes

There are literally hundreds of small pharmaceutical companies that are targeting IBD for new therapies with really creative and revolutionary drugs and better delivery systems (i.e. pills instead of injections).

research hub

There is also quite a lot of activity in the UK. Recently Crohn's and Colitis UK announced a £5million grant for a unique IBD research hub because we are now generating so much data from patients with IBD. We have their genetic profiles. We have the genes IBD patients have in common. We have their microbiome. We have the therapies to which they responded. We have their disease course and clinical history. Nowadays we have tens of millions of pieces of data on patients with IBD. This hub will gather all the data together and use artificial intelligence to identify new targets. We also have the Wellcome Trust IBD Case Consortium here in the UK and they are very active in research on IBD mechanisms and also on clinical trials.

However, it's very unlikely that we'll be able to find an inflammatory pathway that's common in all patients. That's just not going to happen because Crohn's disease is a very diverse disease, probably more so than ulcerative colitis. The immune system is incredibly resourceful. It has been developed to protect against cancer and infections. If one pathway doesn't get rid of the infection, the immune system develops another pathway and another pathway and another pathway. Someone who

is given a very successful anti-TNF, such as infliximab, may find that it will stop working after two years. Why is that? It's because the treatment is changing the inflammation. What we need to try and figure out is the best treatments for individual patients.

the 15 year gap

In 1997, we discovered that infliximab was highly effective in IBD. Something that CICRA can be proud of because it funded the research in my lab that showed that TNF was a key factor in driving gut inflammation. Then there was no new drug licensed until 2012. Since 2012 however, we've had a whole range of things coming along such as more anti-TNFs and antibodies to IL-12 which are useful in patients who do not respond to anti-TNFs. I work with a company that is giving an oral anti-TNF - a pill. There's been a clinical trial, a Phase 2a study, at St Thomas' Hospital, that showed that this drug induced mucosal healing in colitis patients.

We've also got a new class of drugs called kinase inhibitors. These are drugs that target the molecules inside cells that drive inflammation. We've got Tofacitinib, Filgotinib and Persitinnib. These drugs can be delivered via a pill, but there have been some problems with side effects - for example the dose of Tofacitinib had to be dropped.

There's another whole new class of antibodies ready to be patented. These are called the cell migration inhibitors. These work on the very simple idea that inflammation is when white blood cells leave the blood and go into tissues. If you can stop them leaving the blood, you don't get inflammation. The one that everyone uses now is Vedolizumab. There is another drug in development, an anti-MAdCAM which stops cells moving into the gut. A drug which should be licensed this summer is called Ozanimod, which is a pill that also stops cells from moving into tissues. The latest activity in this area is in what are called anti-IL12/23 inhibitors.

A potentially exciting area is to make antibodies which neutralise a cytokine called IL-23. There are five different antibodies being made by 5 different companies and clinical trials are starting to appear which show they have some efficacy in IBD.

so many options

However, one of the issues gastroenterologists face now is which one do you use? That's a big question, and the answer is, at the moment nobody knows. The challenges ahead are very patient-oriented. Essentially, the question we want to ask at diagnosis is - which patients will have mild disease versus severe disease? How can we identify people who won't respond to anti-TNFs? At the moment, we give an anti-TNF to 100 people and only 50 will respond. So what's going on with these patients? The answer is we don't really know.

Finally, with a lot of new therapies around, can we determine the best therapy for each patient ie, can we use personalized medicine? In other words, can we say that the signature of this individual's Crohn's disease is such that an anti-TNF wouldn't work, but maybe vedolizumab might do it?

Something else people are thinking about; Is combination therapy better than monotherapy? One drug company wants to do a study with two of their antibodies. They want to use infliximab (an anti-TNF) and combine it with an anti-IL 23.

So, this is a very, very active area worldwide. There are literally billions going into developing new treatments for IBD. We've got all these choices now. Instead of having one option, soon we will have twenty different drugs for IBD. I believe the situation is very bright. I'm an optimist.

I think that human beings are unbelievably clever and we can do all sorts of things. We can put a man on the moon without modern computing. We can cure IBD.



find your support network

Many of our members are busy setting up local groups to support other families in their area who have a child affected by IBD.

Over the past few months we been contacted by families expressing interest in attending or setting up a social/support group in their local area as a way of meeting other families going through similar experiences. To date 4 groups have been established in Stockport, Sheffield, Birmingham and Gosport with several more on the horizon.

The groups are not run by or affiliated to CICRA, but we are very happy to offer advice and support as well as advertise the groups (via our social media channels as well as through targeted e-mails to families on our database who live within a locality). Advice on setting up an independent group can be found on our website. Don't hesitate to get in touch with our family support worker if you want to discuss this further laurapalmer@cicra.org

Cheadle Hulme, Stockport


Karen set up a social group for families in Cheadle Hulme, near Stockport

"Through a contact at work I found out about a church with a room that they like to offer out to external users as it gets people to know about the church and what it is providing to the local community, they were also keen to make use of a room they recently had built. They let me have the room for free, it has a self-contained kitchen and toilets close by. One of the church Elders is present as he covers the insurance and health and safety side of things. I got my brother to do flyers and posters and found a name that would relate to young people but not have bowel or anything like that in it. We came up with 'Crohn's and Colitis Youth Group' but abbreviate it to CCYG. We thought we'd start off with a monthly group, over the weekend and for a couple of hours each time. I had no idea who would turn up or how the group would go. We advertised

on Facebook, via CICRA and through our Local hospital. The group is really informal, I provide light refreshments and for the first one I invited a friend along to do a sewing activity, so that people had something to focus on and didn't feel too awkward about not knowing what to say, this worked well. The numbers have started small but those who have come along seem to have got a lot out of it, including me. It was great support for all of us. I have had a lot of interest and now that we have agreed a regular day each month and more people find out about us, I think things will progress!"

Venue: Cheadle Hulme United Reformed Church, 65, Swann lane, Cheadle Hulme, SK8 7HU

When: This group takes place on the last Saturday of every month, 13.30-15.30

 www.facebook.com/TAYIBD/

 ccyg19@gmail.com

Birmingham / Midlands

This group is aimed at parents of children with IBD, informal coffee and chat.

Venue: Village Hotel Birmingham/ Dudley DY1 4TB

When: Dates to be confirmed

 scrampo@outlook.com


Gosport, Hampshire


Abi's Got Guts - Crohns & Colitis Youth Support Group supported by Pegs YC for young people which is a new informal social support group for members to have fun, play games, arts and crafts, kick back, relax and socialise. Siblings very welcome, and parents also welcome to stay.


Venue: Studio Two, Gosport, Hampshire

When: Dates to be confirmed

More info: Please book in advance, so that we have an idea of numbers.

 02392 175627

 Search for Abi's Got Guts - Youth Support Group

 abisgotguts@outlook.com


Sheffield

This group is aimed at helping children and teenagers to meet others with IBD in Sheffield, but there will also be an opportunity for parents/carers to stay and chat too if they want. Tea and coffee, drinks and snacks available!

Venue: St Timothy's Church, 138 Slinn St, Sheffield, S10 1NZ

When: This group will take place on Sunday March 22nd, May 3rd, June 14th, all from 3-5pm

 Ring or text Lorna 07886324629

 oliverfamily33@gmail.com

Sheffield support group

We started a support group for parents and children in Sheffield at the end of 2019. My daughter Emma age 13 was really struggling to cope emotionally with everything that has happened to her since being diagnosed with UC at age 9. Her IBD has totally changed her life and since being diagnosed she has had three severe flares all which resulted in her being admitted to hospital for over a week. She has also had Pancreatitis and Nutropenia as a result of the medication she is on. One year she had a blood test every week of the year, sometimes two! She has missed a lot of school and even though her school have generally been supportive she struggles with feeling like she is on her own and that everyone is judging her about having to go to the toilet so much. She has missed out on fun stuff with friends due to anxiety or fatigue.

We wanted her to understand that she is not alone and that there are other children going through the same things as her. We set up the support group in the hope that she would make friends with other kids who have IBD. So far we have had two

meetings so it is still early days. We hire a church hall which has a pool table and table tennis table and we provide drinks and biscuits and just let the kids and parents chat and play. As parents it has been invaluable to talk to other parents who 'get it' and we are hoping that as time goes on the children will become friends. So far we have only had a few families at each one but we hope this will increase. The Sheffield childrens hospital gastro nurses and our amazing consultant Dr Nurula have helped in advertising the group and have been really supportive. Val - our gastro nurse actually came along to the first group to chat with us all which was brilliant. CICRA have supported us too - Laura the family support worker has kept in touch to see how it is going and has put us in touch with other parents who are setting up groups in other parts of the country.

If you are thinking about setting a group up or going to a group in your local area - go for it. Even if it only makes a difference to one family it is worth it.

Lorna Oliver

We have some other areas where someone is interested in setting up a group and welcomes contact with other families:

South Wales | Kent | Surrey
Highlands (Scotland) | East Anglia

If you are interested in setting up a group in your local area and would like to have a chat, contact Laura via e-mail: laurapalmer@cicra.org or phone: 020 8949 6209



BSI Annual Congress



The BSI Annual Congress took place in December in Liverpool. Here Daniel Brice talks about the knowledge sharing opportunities available at such a large event.

As a CICRA-funded PhD student I attended the British Society for Immunology (BSI) annual congress in Liverpool, bringing together over 1,500 researchers and clinicians from 43 countries with the aim of promoting excellence in research and clinical practice for the benefit of human health and welfare.

As a PhD student coming to the end of my research in the lab of Dr Mairi McLean at the University of Aberdeen attending this congress was a fantastic opportunity for me to present my research poster and network with experts in the field of immunology and IBD. During the congress I was able to learn about the latest research into IBD whilst gaining feedback on my own research and make connections which are indispensable to early career researchers.

My research in Aberdeen looking at potential new treatments for IBD and their effects upon the mucosal barrier was well received with much interest expressed in the models that we have developed in our lab to replicate the human mucosal barrier.

The opportunity to present my research at the BSI congress as well as my entire research has only been possible thanks to the generosity of CICRA, its members and supporters. CICRA has in the last three years funded my research project and my attendance at the conferences of two world-leading scientific societies, I am thankful to CICRA and all those who work to enable research into Crohn's and colitis and look forward to continuing to contribute to this field.

Congratulations!

We are absolutely delighted to report that Dr Marco Gasparetto, who many CICRA members will have met at CICRA Family Days, has been awarded the Cambridge University Ralph Noble Prize in recognition of the very high quality of his MD dissertation. We offer our sincere congratulations to Marco for being awarded this prize and our thanks for being a very special doctor to children with IBD.

Dr Gasparetto received his specialist training at Addenbrookes Hospital under the CICRA Fellowship scheme. Dr Rob Heuschkel, himself a former CICRA Fellow, kept a watchful eye and direction on the clinical care training and Dr Matt Zilbauer on the science based childhood IBD project, resulting in some interesting findings.

CICRA 3 year Fellowships have been the mainstay of CICRA's funding over the last 40 years and helped to ensure that children with IBD are cared for and treated by someone who has received specialist training in this area of medicine. We are really pleased that there is an obvious sign that CICRA's funds have, and will continue to be, well spent.



learning at Digestive Disease Week



Digestive Disease Week (DDW) is the largest gastroenterology conference in the world, with over 14,000 attendees. Dr James Ashton looks back at how attending this conference last May helped inform his research.

Whilst the conference is not only for childhood-onset inflammatory bowel disease (IBD) there were multiple sessions on both basic scientific and clinical aspects of paediatric IBD, presenting some ground-breaking research to impact on future care.

As a doctor training to be a paediatric IBD specialist at Southampton Children's Hospital, and also a current PhD student at the University of Southampton, researching genetics and environmental interaction in PIBD, it is of huge benefit to attend these conferences. The sessions and discussions provide the ability to hear about the best, most-to-date research and pick up new ideas. At Southampton we had the prestigious honour of having work on single-gene causes of IBD accepted for an oral presentation. This represents a direct application of research into a clinical setting.

In addition to our study, which was

well received, there was lots to learn and engage with at DDW. This year we heard about big international collaborative studies, advances in genetic research in young children with IBD, personalised medicine, optimising current treatments and new medicines (including new biological therapies) that are currently in development. Attending a conference such as DDW focuses our clinical and research teams to understand what causes Crohn's disease and ulcerative colitis and move towards personalised, precision therapy for children and young people with these conditions, based on the genetic research we do in Southampton. The presence of over 14,000 delegates is a fantastic catalyst to provide the basis for improving care in children and young people with Crohn's and colitis.

Our work in Southampton, led by Professor Sarah Ennis and Professor Mark Beattie is run from

Southampton Children's Hospital and University of Southampton. To date we have over 500 children recruited into our study, which has received past support from CiCRA. We continue to recruit and sequence the genomes of patients in order to move this research into the care of children. Over the years we have made several important discoveries and we are now on the cusp of translating genetic findings into clinically applicable actions. Without the involvement of children, and families, we would not be able to make progress to advance paediatric IBD care forward - a huge thank you from the team at Southampton.



extending medical knowledge thanks to CICRA



Dr Nurulamin Noor
Academic Clinical Fellow in Medicine,
University of Cambridge

The John Earnshaw Award is a bursary of £1000 which is granted to a trainee paediatric gastroenterologist towards travel to an international medical meeting.

I am a Clinical Research Fellow currently undertaking a PhD examining ways to improve the efficiency and impact of clinical trials, particularly those taking a more personalised approach to patient care. Alongside this role, I am a member of the research team leading the PROFILE trial (PRedicting Outcomes For Crohn's disease using a moLecular biomarkEr), a personalised medicine trial taking place across 40 hospitals around the United Kingdom, where we hope to show that individualising therapy from diagnosis leads to better outcomes and quality of life for patients.

I am extremely grateful and feel privileged to receive partial financial support to attend the recent United European Gastroenterology Week (UEGW) meeting from Crohn's in Childhood Research Association.

UEGW is currently the largest gastroenterology research meeting in Europe, and arguably the largest and most important gastroenterology conference worldwide. Whilst the meeting had the latest research presented from across the whole breadth of gastroenterology, the fantastic progress being made in IBD research was highlighted by the award of the best abstract prize to a research study for children with Crohn's disease.

The TISkids study was co-ordinated by the paediatric gastroenterology team from Rotterdam, Netherlands and the results presented for the first time by Professor Lissy de Ridder. This study was performed in children aged between 3 and 17 years old with a new diagnosis of Crohn's disease. A conventional "step-up" approach of escalating treatment if symptoms are not controlled, was compared to a more "top-down" approach where the children received infliximab biologic medication from diagnosis.

I am extremely grateful and feel privileged to receive partial financial support to attend the recent United European Gastroenterology Week

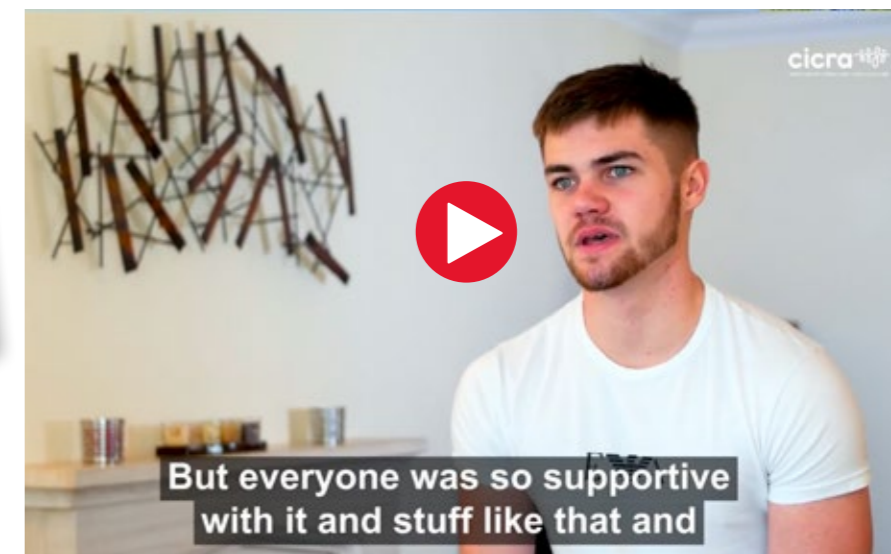
In adults, long-term outcomes can be variable and a personalised approach is likely necessary, as is currently being investigated in the PROFILE trial. Whereas, in paediatric IBD, there is a skew towards having more severe disease, so using a more "top-down" approach right from diagnosis was thought may lead to much improved outcomes. Indeed, the findings from the TISkids study did show that children had significantly better clinical symptoms after one year of "top-down" therapy rather than conventional "step-up" therapy. Whilst, these results will need to be examined in more detail when published, this could represent a step-change in management of children with Crohn's disease and encourage earlier use of biologic treatment as part of a "top-down" approach.

I was also humbled to be asked to co-chair two sessions on IBD advances, as a young and rising talent in the field. A particular highlight of the abstracts I chaired, was a presentation by Dr Philip Jenkinson from Edinburgh, UK who presented about a decrease in surgical colectomy rates since the introduction of biologic medication as maintenance therapy for patients with ulcerative colitis. The data was compelling and the same group have shown similar findings for patients with Crohn's disease, helping dispel some of the conflicting information reported about biologics and surgery.

In summary, I am very grateful to financial support from CICRA to attend this meeting, which has highlighted the breadth and quality of research being undertaken across adult and paediatric IBD, all resulting in improved care and quality of life for patients with IBD.

resources to help

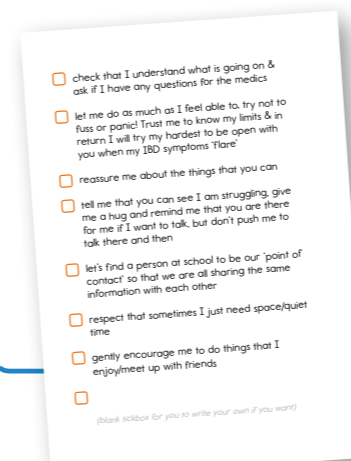
Living with IBD can be tough enough at any age, and if you're a child or young person it helps to have extra resources to help you deal with it. Here are some we think might help.



support cards

Sometimes when you are ill, it can be hard to know what support we would like and for others to know how to be helpful. Sometimes other people want to be supportive but feel embarrassed, don't know what to say or are worried about upsetting us. We've put together some cards for young people with IBD to give to people, with ideas about how they can help and with room for your own suggestions, too. The cards are to share with your friends, teachers or parent or carer. You tick the ideas that could help you at the moment.

→ Order your cards today by emailing laurapalmer@cicra.org



share our videos, help others understand

Late last year, a group of very impressive young people agreed to be filmed talking about their experience of living with inflammatory bowel disease. We now have a whole section on our website dedicated to videos about paediatric IBD, including sections on:

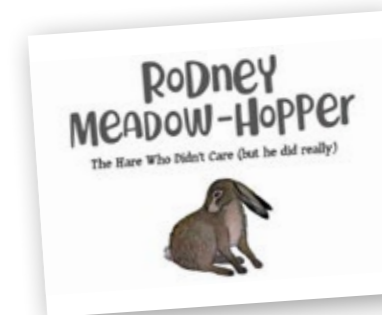
- about IBD
- living with IBD
- diet and nutrition
- emotional wellbeing
- school
- how CICRA can help
- symptoms and tests
- treatments and medications
- research
- healthcare

→ Watch them all direct from our website: cicra.org/videos

book for little ones

Rodney Meadow-Hopper tells the story in gentle rhyme about a hare who seems grumpy and doesn't want to play. The truth is that Rodney has a hidden illness and he is too frightened to tell his friends. The story, written by CICRA supporter Gail Crampton, encourages children to be honest about what they are feeling from a young age. Inspired by her daughter's chronic illness (she has Crohn's disease), Gail wanted to spread the word that it's OK not to be OK.

→ Search online for 'Rodney Meadow-Hopper' to get your own copy.



our amazing supporters!

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

Positivity rules!

Emma was diagnosed at the age of 10 with undetermined IBD in July 2019. She has been hospitalised twice and whilst recovering specialists have been trying to find the right medication to keep her stable.

In 2019, Emma suffered a particularly challenging episode of poor health; such was this prolonged period of illness Emma could have been forgiven for feeling as though life had served her a harsh hand; instead Emma did what many adults find it so difficult to do, she turned the situation on its head and thought, how may I help others? Whilst Emma's body was in her hospital bed her mind was elevated to thinking of ideas of how she might be able to raise funds to help others.

One of Emma's ideas was to run a stall at her school's Christmas fair. Having considered this achievable, Emma set to work with her brother Archie, aged 9, and her friend Ella, aged 8, making keyrings and jewellery. These items together with plenty of sweets were used as prizes for their tombola-style game.

Emma's school were so impressed with her initiative, the stall hire was waived and after much planning, mainly by Emma, the Christmas fair was a roaring success – manned by Emma, Ella and Archie. According to mum, Jackie, 'the children especially loved the 'Pick a Card' game and the home-made prizes went down a storm!' On the day, team Emma raised nearly £100 and after posting the event on Facebook, at least a further £100. Mum reported that, after putting such an awful lot of time and thought into the stall, this project had given Emma a positive focus at a difficult time. Emma was really pleased with the result. And so are CICRA; we should like to thank Emma and her team for their great enterprising and marketing skills to raise over £200 for others.



Raised £200!!

it's a family affair

Bina Jesani organised a great family get-together at Christmas and raised £200.

Raised £200!!

flower power

Lucas, with aid of his parent's handywork, ran a kerbside sale for 12 months selling a variety of items such as the beautiful plants featured in the picture. He raised a healthy sum of £200. Well done Lucas!

Raised £200!!



cake sales

Massive thank you to Sam Tickner, who had two cake sales at her local school before Christmas.



Raised £152!!



we're jammin'

Despite being busy with maternity leave preparations Patrina Law found the time to produce and sell delicious preserves raising a sweet £143 for CICRA. Here's one of her work colleagues picking up some marmalade.

Raised £143!!



Raised £755!!

starstruck

Oli and mum Tor Forster raised £755 from a quiz and sale of raffle ticket prizes including a designer Mulberry item.

Ollie, Tor's son, is pictured with the owner and president of Bristol Rovers Football Club, Wael Al Qadi. He was helping to raise the profile of CICRA that might help a future fundraising initiative. The owner was so taken aback by Ollie, who had been a match mascot, that Ollie and mum were invited to watch the match from the owner's box. On this day, Ollie was 'the cat that got the cream'!



Raised £700!!

raffle and quiz

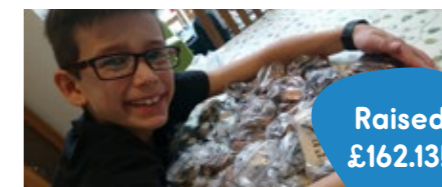
Iolo's Christmas Quiz raised £700. "We had a number of raffle prizes including, wines, chocolates, books, cuddly toys, breakfast vouchers, salon treatments, tattoo sitting, etc. along with 2 main prizes of a weekend cottage B&B break in West Wales and a weeks accommodation in a 4 star villa with private pool on a golf course near Mar Menor."



Raised £85!!

piece of cake

Emma Gardiner raised £85 from a cake sale held at home – great CICRA coordination!! Emma and her mother Liz also decorated the Mason Jars for the event.



Raised £162.13!!

it all adds up!

Simeon raised £162.13 from a year long collection of pennies campaign.

keep on running

A family of four (Daniel, Paul, Martyn and Andrea) ran for CICRA in the Great North Run 2019, raising a staggering £1810. Daniel was diagnosed with Crohn's on his 13th birthday and, seven years on, has taken up marathons! Andrea says whilst nervous about their first half-marathons, the team were excited too; all the practice paid off as they all managed to finish in good time and Daniel is running again later this year. This superb effort was also in honour of Daniel's late grandfather, Mr Walter Kelly, who was a great supporter of CICRA for many years.

Shirley Hennessy committed herself to run 75km for CICRA, an increase of 60km from the previous year. In December alone, Shirley ran: 5 Park Runs; 3 Santa Dashes; a local night run, Betwys Coed/Llandegla forest 10km, Chester Walls Run and one Moel Famau route run. Thank you, Shirley, for your dedication!

Raised £1810!!



Raised £771!!





whatever it takes

Thank you to Cathryn Jones, whose son was diagnosed with Crohns who ran the Cardiff half Marathon and is still collecting funds.

"It went well. Unfortunately we had to walk all the way as my friend had a chest infection but we did it and have the medal to prove it lol. Aching a little today but hopefully be back to normal soon."



more amazing supporters!

CICRA do not receive a government grant but we are humbled to have received over £7000 through a combination of donations and collection tins during the last quarter. We are so very grateful to all the CICRA benefactors; here are a few highlights. Thanks to:

Sarah and Daisy Pitt (£100.00) from a person inspired by Daisy's bravery

Bronwyn Feather (£703.00) raised from their work's Christmas Hamper auction.

Gill Morgan (£750.00) Inspired The Old Lodge Fellows (North Gloucestershire District Lodge) donation.

Mrs Snelling donated (£100.00) and Regular donors Mrs Passmore donated £200.00 and Alison Johnson (£376.00) through running her line dancing classes.

Mr Bill Wiltshire (£100.00)

Cathy Owens (£40.00) encouraged donations instead of Christmas cards.

Gail Crampton (£250.00) was match funded by her employer when she took part in a 5Km walk.

Sophia Simpson donated £54.00

The Leatherhead Revive Shop that sells preloved furniture presented a donation to CICRA to the value of £1774.75. Thank you to the person who nominated CICRA, if you have a shop by you why not visit and nominate CICRA too.

Eunice Vickers donated £18.30

Gwilym Treharn inspired the £200.00 donation from Creignu Golf Vetran's Society.

The Christmas Cake fundraising was promoted at the recent London Family Day event and resulted in at least ten separate events. Thank you to all the organisers and those who took part. The next Cake Bake is due on World IBD Day, 19th May 2020. Fundraising packs are available from Patricia at the CICRA office.

ho ho ho

Carla Burrows and her two sons Ben (younger, has IBD) and Oliver (older brother) ran the Newcastle Santa Fun Run. Carla and Ben were novices to such runs but completed feeling exhilarated. Oliver completed in 22 mins but ran back to escort his mother and brother to the finish line.

"It was so lovely & Ben was so thrilled to have done it... I think you can tell that by his face."

Many thanks to all supporters, limited space prohibits us from featuring everyone, but we are hugely grateful for every penny raised.

Would you like to help raise money for children with IBD? Contact us for top tips

Email fundraising@CICRA.org
Tel: 020 8949 6209

If we're not there we'll get back to you as soon as possible

200+ club winner list 2019

Welcome to those of you who joined the 200+ Club recently. Your support is very much appreciated. All funds are split 50/50 between prizes and research - a real 'win-win' situation. If you are not a member yet but would like to help us raise funds by this method please ring the office on 020 8949 6209 or email margaretlee@cicra.org and we will send you the forms.

July

5 C Lazenby, Leeds £50
253 J Chilcott, N Somerset £50

Aug

152 B Govey, Middlesex £50
79 M Bines, Kent £50

Sep

133 J Patten, Kent £250
198 T Wagstaff, Essex £75
234 M Ukereghe, Surrey £75

Oct

94 P Herman, Worcestershire £50
153 L.Sanderson, Liverpool £50

Nov

179 C Tetlow, Gt.Missenden £50
83 M Coupe, Preston £50

Dec

204 L Baker, Derby £250
223 A.Cooper, Berkshire £75
39 D. Chapple, Bristol £75



Raised £500!!

music for the soul

Professor Ian Sanderson, chair of our medical advisory panel, is a member of the Chelsea Chamber Choir (CCC) and took part in a concert at Christ Church Chelsea on Sunday 24 November. CCC is a non-profit organisation with a mission to support charities through its concerts. The retiring collection at the concert was in aid of CICRA and raised £500

in memory

At a time of bereavement, families often suggest that instead of flowers, relatives and friends may like to make a donation to charity.

CICRA is very grateful for donations in memory of:

Mr Walter Meddes

much loved grandfather of Daniel Meddes

Eva Storm

much loved great grandmother of a 10 year old Crohn's sufferer

CICRA Winter Draw 2019

Results of the CICRA Christmas Draw which took place on Thursday 11th December 2019

Below are the winners

Prize	Ticket No.	Name
1st Prize	51871	L Morrison, Derby
2nd Prize	24441	H. Hall, Middlesex
3rd Prize	07583	D Kemp, Essex
4th Prize	27933	D. Cheyne, London
5th Prize	49238	J Jackson, Carlisle
6th Prize	45431	W Zwart, Edinburgh
7th Prize	04156	L Moore, Isle of Man
8th Prize	07107	H Nally, Essex
9th Prize	10143	M Ross, Dorset
10th Prize	40504	G Gill, Aberdeen
11th Prize	32554	S Durman, Guernsey
12th Prize	27644	J Weider, Middlesex
13th Prize	33318	P Vertannes, Surrey

Many thanks to members who either bought tickets themselves or sold tickets to support this draw. 100% of the funds raised will go towards the funding of new research into inflammatory bowel disease.

We don't send tickets to those who do not, for whatever reason, wish to receive them, so if you do have to return unsold tickets, please enclose your name and address so that we can make a note not to send again.

Nick Posford, Promoter





CICRA family IBD information days

CICRA family IBD information days are friendly and supportive meetings for families who have a child or young adult with Crohn's disease, Ulcerative colitis or IBDU

Meet and chat to other families in a similar situation. These are a great opportunity to share experiences and connect with others. At each family day, specialists in paediatric IBD join us from leading children's hospitals across the UK.

Book for our 2020 information days:

- Cardiff, 25th April
- Liverpool, 11th July
- Glasgow, September TBC
- Belfast, 17th October
- Milton Keynes, November TBC

**BOOK NOW
FOR OUR 2020
INFO DAYS**

What to expect

Adults can listen to talks and join discussion groups on topics that include:

- living & coping with IBD
- the importance of diet & nutrition
- the latest in research
- new treatments and medication
- supporting children with IBD in school

For children and teenagers, friendly and fun activities include:

- activity session, the Hub Challenge
- discussion groups to chat, share experiences and find out more about the condition
- children's entertainer for younger children

Book or register interest

www.cicra.org/familydays

020 8949 6209 | support@cicra.org

CICRA family IBD info days are suitable for families who have a child up to 21 years of age with IBD